Exploring the lived experience of both the provider and the receivers of an Intentional Compassionate Communication Intervention (ICCI) for older people in an Accident and Emergency Department

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Abstract

Background

Attending an Accident and Emergency (A&E) hospital department can be a stressful experience for older people. In 2016, to try and improve older people's experience in A&E, an Intentional Compassionate Communication Intervention (ICCI) was developed by a hospital in Southern England to enhance the delivery of compassionate care. The ICCI comprised proactive communication-focused support targeted at older people, particularly those who were alone. Little is known about this intervention and about the experience of those receiving and providing it.

Aim

The purpose of this study was to explore the lived experience of older patients who received the ICCI in A&E and the lived experience of the member of staff who delivered the ICCI.

Method

Interpretative Phenomenological Analysis (IPA) was used to carry out one-to-one, semi-structured, in-person interviews with eight individuals over 65 years old who were admitted for any reason to the hospital via A&E, presented either alone or confused or with a diagnosis of dementia, received the ICCI while in A&E, were referred to the Dementia Care Team and were able to give informed consent. Four online IPA semi-structured interviews were carried out with the ICCI practitioner. Interviews were audio recorded and transcribed verbatim. The data were analysed thematically following IPA guidelines.

Findings

There were four main themes from the older person interviews in their experience of A&E: Helplessness, Uncertainty, Unpleasant Sensations, and a Sense of Safety. There were three main themes from the interviews with the ICCI practitioner: Navigating the Unknown, Bringing Together/Connect, and A Values-Based Practice.

When bringing together the two sets of findings, three important concepts emerged: The Unknown (and the fear of it), Disconnection (and the sense of general lack of safety it prompted) and The Importance of Effective Communication. These concepts represented the threads weaving the two sets of findings together, allowing for new meaning to be made, and new knowledge to emerge.

Conclusion

Exploring the lived experience of older people in A&E and the ICCI practitioner has shown how this intervention can humanise the experience of being in A&E (i.e. allowing people to feel seen, connected, safer).

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Acknowledgments

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A PhD is a solitary journey, particularly in the midst of a pandemic and the impact that COVID-19 had upon clinical research. I had the immense luck and pleasure to meet other PhD students who have been my friends sharing this incredible journey with me, I will never forget how we supported each other: thank you to: Raysa El Zein, Giulia Levi and Charlotte Clayton.

I would have never had the courage even to start this journey without the caring, validating and loving support of my husband. To him goes all my love and gratitude: you held me when I was so vulnerable, whispered “follow me” through a song and here I am. Here we are. Thank you from the bottom of my heart. I love you.

During the last year of writing, my dad became very unwell with a particularly cruel form of dementia. It was excruciating to write about the same things that you were experiencing dad, and especially whilst trying to source the best care and support for you from another country. The memories of these last few months of writing, though, are mixed with special memories of long video calls with you, while you were losing your capacity for language, at the same time -for some reasons- you were showing me much more love and willingness to connect than in our past father/ daughter relationships. One day, when I had returned to Italy we visited your doctor, you started “showing off” my academic achievements, and although totally “inappropriate”, that unfiltered, disinhibited expression of pride, melted my heart, and gave me the most important reason to keep on writing. More than ever, I need to write about those seldom heard voices, honouring their lived experiences, and fighting stigma, assumptions and prejudices.

Thank you, dad, for having been so vulnerable with me.

Partnership

This Doctoral study was match-funded between Bournemouth University and [redacted] Hospital NHS trust. The project was part of a programme of academic work between the University and the Hospital trust to enhance fusion and link education to practice.

Chapter 1 - Introduction and background

1.1 Outline of the chapter

In this chapter, I will present an overview, from both a personal and professional point of view, of the journey which brought me to Bournemouth University and to the commitment of undertaking this clinical PhD study. I will outline the specific interests, experience and reasons which brought me to refine the focus of the research, drawing both on the literature and on my experience at the hospital site of the study. Finally, I will give a summary of how the whole process has been impacted, and therefore has evolved, since the emergence of the COVID-19 pandemic in England in March 2020.

1.2 Background to the researcher and to the research

I am an Italian woman in her forties who moved to England in 2014 to qualify as a dramatherapist. I have been a registered dramatherapist in practice since 2016 and last year I also began a part-time role as a senior lecturer for the nursing department of the Faculty of Health and Wellbeing at the University of Winchester. My main focus is to embed creative and embodied forms of learning in the teaching of Annexe A (Communication and therapeutic approaches) of the Nursing and Midwifery Council (NMC), Future Nurse Standards of Proficiency for Registered Nurses (2018). In addition to this, I am working on the implementation of Schwartz Rounds - a regular forum for students to come together and share the emotional impact of caring for patients (The Point of Care 2022) - for all healthcare students across the faculty.

Dramatherapy is a unique form of psychotherapy which makes intentional use of drama and theatre to bring about psychological and social changes for clients (British Association of Dramatherapists 2022). Dramatherapists are both artists and clinicians and they are trained at master’s level, their profession is protected and ruled by the Health and Care Professions Council (HCPC) and represented by the British Association of Dramatherapists (BADth).

My approach to clinical practice is deeply influenced by Psychoanalysis, Humanistic Psychology, Person-centred Psychotherapy, Existentialism and

Buddhist philosophy. My approach to research, and my more general approach to life stem from those influences too.

Back in Italy, while studying for my bachelor's degree in Performing Arts, I was a drama practitioner (actress, facilitator and director) for 15 years, particularly interested in the possibilities of applied and social theatre. Applied theatre is an umbrella term for the use of theatrical practices and creativity in an educational, community or therapeutic context (Rossi Ghiglione and Pagliarino 2007). Social theatre is, more specifically, the use of creative processes and dramaturgic forms to respond to the needs of communities and individuals to express themselves, feel empowered and strengthen their connections (Rossi Ghiglione and Pagliarino 2007).

My work experience ranged from leading drama groups for children with and without learning disabilities and autism, facilitating the experimental and dissemination phases of "Glottodrama" (Nofri 2009), a new method for teaching a second language through drama, facilitating the drama-based self-development workshop for young people, "Il Ruolo, la Maschera, la Vita" (Role, Masks, Life) in collaboration with the Faculty of Humanities of University of Tor Vergata in Rome (Di Santo et al. 2009), to running creative drama groups for older citizens in council community centres.

My interest in various forms of compassionate communication and humanising practices started when I discovered the para-theatrical work of Jerzy Grotowski, a learning which I deepened during my training as a dramatherapist. Towards the end of his career, Grotowski, one of the most important directors of 1900's European theatre, made a series of creative experimentations after his realisation that theatre and drama could be used for humans to experience a *true encounter* with each other through the process of *disarming* (Grotowski 1973; 2002). Disarming for him meant to take away the everyday masks and armours we wear to bring our attention to one another in full presence to be able to simply be a human being in front of another human being deeply seeing each other (Pollastrelli 2006).

The MA training in dramatherapy allowed me not only to deepen this subject on a theoretical level but to experience it myself both through experiential learning and through personal psychotherapy (which is a compulsory part of the training).

Both during the training and later on, in professional practice (with children on the autistic spectrum, adults with schizophrenia and personality disorders, young women with eating disorders) I experienced more and more how the therapeutic relationship for me is mainly about empathy and compassion and how the most important work I can do, both as a human being and as a therapist, is to create the conditions in myself to empathise with another person's suffering, experience compassion and remain resilient.

When Bournemouth University advertised the studentship for this NHS match-funded clinical PhD, the title of the research study was: *A study exploring the impact on older people's health and wellbeing from compassionate communication during their admission and in-hospital stay*. I immediately felt that it could be a fantastic opportunity for me to put together my interest in compassionate and humanising care and my wish to support vulnerable people at a different level, through research, bringing my previous skills and expertise into this new role.

My time during the initial year of this PhD studentship - which entailed a mix of academic work and clinical work at the hospital trust site of the study - was divided between delving into the literature to dig deeper into the areas relevant to the key terms of the initial research proposal and working at the hospital, providing emotional support to older people at the bedside and to staff, through the delivery of Schwartz Rounds. At the same time, I was observing or shadowing the work in various departments, included the A&E, while meeting older people and their families, and several gatekeepers, discussing issues related to older people in hospital with them. These parallel processes eventually brought me to the decision of narrowing the focus of my research to a specific compassionate communication intervention - mainly targeted to older people - which was taking place in the Accident and Emergency (A&E) Department of the hospital and which, for this study, I named Intentional Compassionate Communication Intervention (ICCI). In the following sections, I will present a background overview of the key aspects which informed the rationale for this research. These are: the awareness that we are an increasingly older population, the often very complex presentation and experience of older people in hospitals' Accident and Emergency Departments, compassion, its role in the UK National Healthcare System (NHS), the importance it can have when caring for older people in A&E, and, finally, how this has been addressed by the ICCI at the NHS hospital trust where I run this study.

1.3 An increasingly older population

At the biological level, the process of ageing can be defined as the result of an accumulation of a variety of molecular and cellular damage over time. This process entails a gradual decrease in physical and mental capacity, a growing vulnerability of the organism to disease, and eventually death (Viña et al. 2007). However, these processes of change are not always linear or consistent, and they are only loosely correlated with individuals' biological age (World Health Organisation -WHO- 2022). At the same time, the diversity that one can appreciate in old age is not random: beyond biological changes, ageing is associated with major life transitions such as retirement, relocation to more appropriate housing and the death of friends and partners (WHO 2022) and can be affected by a variety of factors such as: nutrition, exercise, education, social network, financial status and more (Abud et al. 2022).

Human beings, particularly in the West, are living longer than ever before. The Office for National Statistics (2018a) predicted that over the next 30 years the global population of people aged over 60 years will more than double to the point of reaching 2 billion by 2050 and, although the COVID-19 pandemic contributed to lowered life expectancy for both men and women (Centre for Ageing Better 2022), we are still an ageing population. In England alone, over the next 25 years the number of people older than 85 years is expected to double to 2.6 million (Raymond et al. 2021). Such data, which would appear to be a reason for celebration, represents a harsh reality: although some older people are healthy and live an independent life, evidence suggests that the proportion of life in good health has remained broadly constant, implying that the additional years are mostly spent in poor health (WHO 2022). Older people often live with complex comorbidities, including hearing loss, back and neck pain, osteoarthritis, chronic obstructive pulmonary disease, diabetes, depression, urinary incontinence, pressure ulcers, cognitive decline, problems related to polypharmacy and frailty, as evidenced by the Global Burden of Disease -GBD- tool (Institute for Health Metrics and Evaluation -IHME- 2019). Dementia or other forms of cognitive decline (although not synonymous with ageing, the risk increases with age) can often be part of the picture, with dementia affecting 55.2 million people worldwide and 944.000 individuals in England, of which 65 per cent are aged 65 years or over (Alzheimer's Research UK 2022). The number of people with dementia in the UK is predicted to rise to 1.1 million by 2030, 1.4 by 2040 and will reach 1.6 million by 2050 (Alzheimer's Research UK 2022).

These data evidence a greater vulnerability in older people: many of them can feel (and be) at risk both in the community - particularly if living alone - and inside the NHS, where they might receive poor care due to a system which has shown to struggle and even to fail to meet their needs (Abdi et al. 2019).

Adding to the scenario of an aging population living with co-morbidities, there also appears to be the risk that older people might be forgotten or neglected by decision makers in the Government, especially if they are the 'oldest old'. They are often categorised by politicians and the media as a homogenous and costly mass addressed as 'the elderly'. This engrained attitude towards old age entails that not only the contribution that older citizens could bring to our society is overlooked but also that their needs and their intimate lived experience might be neglected (Ayalon and Tesch-Romer 2018).

1.3.1 Older people and Accident and Emergency departments

NHS Accident and Emergency departments (A&E, sometimes called Emergency Departments) in England are intended to deal with life-threatening medical emergencies. They are located in hospitals and offer access 24 hours a day, 365 days a year. A&E staff includes nurses, radiographers, healthcare assistants, physiotherapists, doctors, reception staff, porters, and others.

The waiting time target for patients in A&E is currently set to four hours from arrival to admission, transfer, or discharge, following the "Reforming Emergency

Care” policy document (Department of Health 2001) which, between other changes in emergency care, required that nobody should wait for more than four hours in A&E (with a few exceptions: people with minor injuries may have a longer wait -NHS 2022-). In certain cases, patients may be sent home and asked to arrange for a GP visit, or they may be given a prescription and sent home.

Before the first wave of the COVID-19 pandemic in the UK, in March 2020, the number of hospital emergency admissions had already substantially increased in England, by 42% over the previous 12 years. Older people (those aged 65 years or older) represented the demographic group whose emergency admissions had seen a particularly sharp rise, especially patients aged 85 years or older (Steventon et al. 2018). Although the number of presentations to A&E dropped for all age groups during the COVID-19 pandemic, older people in the UK still represented nearly a quarter of the people arriving at A&E (Howley et al. 2021). In addition to the co-morbidities already mentioned above, older patients are more prone to feeling disorientated in A&E. This can be due to a high percentage having dementia, delirium, delirium superimposed on dementia or other CSD - Cognitive Spectrum Disorders - (McCabe and Kennelly 2015), and older people are also at a higher risk of developing delirium while in A&E (Reynish et al. 2017).

Delirium is a common medical problem that is characterised by changes in cognitive function. When delirium occurs, people are confused. Its onset is quite sudden, but it usually lasts only for a few days (National Institute of Care Excellence -NICE- 2023). However, if not addressed delirium can become a serious complication which can lead to a longer length of stay in hospital and higher mortality (Witlox et al. 2010). Stress is one of the common triggers for delirium and there is also some evidence that longer and particularly stressful A&E experiences are associated with the risk of older patients developing delirium over the following hours (Bo et al. 2016). This entails hospital staff having to manage patients in the emergency environment presenting with much more complex needs associated with co-morbidities and often with less external support than younger people (Sorrel 2010), and at the same time trying to manage the pressure of waiting time targets. The A&E four hours target has been a contentious one in the NHS. There have been concerns over the lack of consultation, planning and communication before implementation (Mortimore and Cooper 2007), and suggestions that this required change has been often managed sub optimally (Hayes 2002). Furthermore, the focus on measurable time targets, as opposed to a focus on improving the quality of emergency care overall, has been harshly criticised (Campbell and Higginson 2017). It has been said that patients are often rushed out of departments in the last 20 minutes of the four-hour period (Locker and Mason 2005), which can negatively affect other hospital teams. For these reasons, it has been claimed that Accidents and Emergency Departments have become *a queue processing machine* (Hughes 2006) and it has been claimed that a focus on the target has a negative impact on the quality and safety of the care delivered (Campbell and Higginson 2017).

Studies have explored the experiences of A&E from the specific point of view of older patients, reporting that most participants believed that their symptoms posed a serious threat to the control they exerted over their lives (Kihlgren et al. 2004) and that the attitudes of nurses in A&E were often perceived as indifferent and inattentive, thus causing a feeling of exclusion and disappointment (Olofson et al. 2012). Empathy and compassion were perceived by patients to be the most significant elements of good care in A&E (Kihlgren et al. 2005).

However, it is not always easy for A&E staff to be able to convey kindness and compassion: emergency department healthcare workers have had one of the highest incidences of burnout even prior to the pandemic (Li et al. 2018; Zhang et al. 2020) with literature uncovering high levels of staff turnover, clinician burnout, and post-traumatic stress (Johnston et al. 2016). These factors have intensified with additional stressors arising from the pandemic (Chor et al. 2021) and from the combination of ongoing pressure on healthcare services, backlog of care after the ease of restrictions and chronic staff shortages which led to record peaks of patients' waiting times in A&E (British Medical Association 2022) with ambulances sometimes having to wait for lengthy periods outside hospitals (The Health Foundation 2022).

1.4 Compassion and compassionate care

There is no general agreement on what compassion is and which components exactly constitute compassion (Gilbert, 2017). The word *compassion* comes from the Latin term *cum-patire* which means: *to suffer with*, or *to bear with* (Collins Dictionary 2017). However, there are a variety of current definitions of this term, some of which only partially overlap. Is compassion an emotion? The literature does not agree on this. Goetz et al. (2010), in a review of some evolutionary and historical origins of compassion, put feeling at the core of it: “We define compassion as the feeling that arises in witnessing another’s suffering and motivates a subsequent desire to help” (p.351). Like them, several authors define compassion as an ‘emotion’ experienced when one feels concern for the suffering of another and has the desire to increase that person’s wellbeing (Hofmann et al. 2011; Shih et al. 2013).

Kirby et al. (2017), however, suggest a different category for the term compassion: they see it as a complex multidimensional construct, rather than ‘just’ an emotion or feeling. They refer, for example, to Thupten Jinpa, who developed the Stanford Compassion Cultivation Training program where he defined compassion as being made up of key components from the cognitive and the affective to the motivational domain (Kirby et al. 2017), and to Strauss and colleagues who, after having carried out a review of definitions and measures for compassion, also suggested that compassion includes a variety of domains of human experience (Strauss et al. 2016).

Perez-Bret et al. (2019), in their systematic literature review which aimed to investigate definitions of compassion and analyse the concepts encompassed by the term, concluded that compassion is:

> “a process that emerges from the interaction of a number of somatic, affective, cognitive, attentional and embodied processes”
>
> (Perez-Bret et al. 2019, p.602).

They identify the following steps in what they define as the *compassion process*:

> "- Reaction to suffering;
> - Acknowledgement of this situation of empathy with the sufferer;
> - Rational process (understanding, evaluating and weighing up a difficult situation);
> - Seek ethical assistance for the sufferer;
> - Perform the action aimed at providing the solution, with the hope that it is effective and alleviates this situation;
> - Personal satisfaction and maturity"
>
> (Perez-Bret et al. 2019, p.602).

Their process seems to build on the analyses from Jinpa and Weis (2013) and Strauss et al. (2016) adding to them an ethical dimension ("seek ethical assistance for the sufferer"), the word *hope* ("…with the hope that it is effective and alleviates the situation") and a final stage, where the person who has gone through the compassion process - from a first reaction to someone else's suffering to the performing of an action aimed at providing a way out of that suffering - gains "personal satisfaction and maturity". There is a clear 'movement forward' in the process they describe; it looks like a process of growth or maturation.

It is also useful to separate compassion from other terms which are often used interchangeably, like sympathy, or empathy. Sympathy, as Schantz points out (2007) relates to the feelings we have of a person regardless of what exactly produces those feelings. Compassion on the other hand, relates specifically to the pain or distress of the other person.

Empathy is defined by Dymond as:

> "The imaginative transposing of oneself into the thinking, feeling, and acting of another and so structuring the world as he does"
>
> (1949, p.127)

or, more simply, as the vicarious experience of another's emotions (Goetz et al. 2010). It can be noticed that while empathy denotes only an emotion, compassion adds to that emotion (or substitutes it with) a motivation or an attitude to act to relieve the suffering (Gilbert 2010).

In the current study, I embraced the definitions of compassion proffered by Jinpa and Weiss (2013), Strauss et al. (2016) and Perez-Bret et al. (2019), and I looked at compassion as a multidimensional construct where body, cognition, feelings and values/motivations are all involved, as I feel it better reflects the complexity of such a uniquely human experience. For the purposes of this study, here is my definition of compassion:

A feeling of resonance and participation with the suffering of another (emotional component) which immediately translates into an embodied experience (physical/emotional component) of wanting to relieve that suffering (intentional and cognitive component) through action (motivational component) and is accompanied by the belief that it is the right thing to do (value component).

1.4.1 Compassionate care in the UK NHS

Compassionate care is not a new concern for the NHS but following high profile failings highlighted from the Maidstone and Tunbridge Wells' Healthcare Commission report (Healthcare Commission 2007), the Parliamentary and Health Service Ombudsman's report (Health Service Commissioner for England 2011), the Care Quality Commission report (2011), and the Mid Staffordshire report – also known as the Francis Inquiry report - (2013), new strategies and policies such as Compassion in Practice (National Health Service Executive 2012), and Compassionate Care in the NHS 2010-2015 (Department of Health 2015) have been introduced, further emphasising the importance of compassionate care, and formalising of the 6Cs (care, compassion, courage, communication, competence and commitment) as a set of values for practice (National Health Service Executive 2012) leading to a new, values-based recruitment strategy for all students recruited to NHS funded training programmes to ensure they match the values of the NHS Constitution (Health Education England 2014).

Literature has explored different perspectives, from the poor experiences of care by older people living with frailty which has been uncovered by the Francis

Report (2013), to the challenges experienced by nurses expected to deliver compassionate care, who often struggle to align the reality of practice to their ideals (Curtis et al. 2012).

Cornwell and Goodrich, in a study exploring patients' experiences state:

> "The presence or absence of compassion often marks the lasting and vivid memories patients and family members retain about the overall experience of care in hospital".
> (2008 p.15)

This is equally valid for patients who are temporarily confused and/or live with dementia. Projects like the “Dementia diaries” show that some people may not only be aware of how they are treated and how they feel even in the middle of an extremely confused state, but they may also be able to recall this (Dementia Diaries 2018). Patient satisfaction and patients’ emotional and psychological safety should be considered a goal in itself; however, the literature also suggests that patients receiving clear and compassionate communication are more likely to disclose their symptoms enabling a greater understanding of their situation and more accurate diagnoses (Epstein et al. 2005; Cornwell and Goodrich 2008). Delirium-related complications are paramount to this: delirium is frequently missed in older A&E patients (Lee et al. 2020), while earlier identification could be vital. Acute delirium in older adults is associated with accelerated functional and cognitive decline, post-discharge depression and increased mortality - even when recognised in A&E (Han et al. 2010). However, when delirium is missed in A&E, the patient has an increased risk of dying (Han et al. 2010; Shi et al. 2021).

1.4.2 Compassionate care for older people in A&E: the Intentional Compassionate Communication Intervention (ICCI)

There appears to be an increased awareness, internationally, of the specific needs of older people in A&E, and of the needs of healthcare professionals who struggle to deliver effective care for them in this setting (Hayes 2000; Bula et al. 2012; Gasperini et al. 2016). This awareness has developed not only in the United States (Carpenter and Plattz-Mills 2013; Rosenberg and Rosenberg

2016) but also in England, which has seen the opening of its first OPED (Older People Emergency Department) in 2017, inside the Norfolk and Norwich University Hospital.

Anecdotally, it has been the awareness of the high incidence of stress for patients in emergency departments (Bo et al. 2016), and of the importance of compassionate care, particularly for older people, that has driven the development of a specific Intentional Compassionate Communication Intervention (ICCI) within the emergency department of the UK district hospital where I ran my study. The ICCI started in 2016 and comprises of proactive communication-focused support for older people. It involves a specific member of the support staff, a Patients Well-being Co-ordinator, identifying disorientated older patients in the emergency department and talking to them to help address their psychological needs and hopefully relieve their anxieties, sharing information and providing reassurance. The member of staff who delivers the ICCI had been a volunteer in the hospital for six years and is now a non-clinical member of the Dementia Care Team.

The delivery of the intervention is prioritised to support older people in the emergency department who present alone and to those who appear to be cognitively impaired. The Patients Wellbeing Coordinator demonstrates empathy and compassion through talking, gently re-orientating the older person if confused by asking simple questions while using a friendly and reassuring tone of voice, offering a glass of water or a cup of tea, maybe a blanket. The member of staff can also try to reassure patients by enquiring with other staff about the outcome of an examination or about the next step in the patient’s hospital stay when they are under too much pressure to be able to communicate with patients promptly and efficiently themselves. If words are not helpful (because the cognitive impairment is too severe, for example) she might play some music using a tablet computer or bring soft toys for patients to cuddle. The basis of this intervention is the meeting between two human beings whereby one of them is in pain (psychological and often also physical) and the other one somehow feels or recognises that pain and has a genuine wish to relieve it. The ICCI does not rely on any particular technique, rather it is exclusively based on a shared, deeply human drive.

The evidence from the sections of this chapter indicates that an investment in targeted compassionate communication for older people in A&E may make their care more effective, with the potential to reduce complications and make healthcare delivery more sustainable for the NHS, alongside giving patients and their families a better experience. This awareness represented the final prompt for me to take the decision to focus on the ICCI taking place in the Accident and Emergency Department rather than on the wider process of admission and in-hospital stay, particularly considering that while compassionate care had been explored directly in the more general hospital environment (Bloomberg et al. 2016) and, specifically, in other acute hospital settings (Dewar and Mackay 2010), there seemed to be very little written about interventions like the ICCI in A&E.

My aim was to carry out in-depth interviews with a number of older people who had received the intervention, in order to understand their lived experience by gathering rich and evocative accounts from them: this is how phase A of the study was born. Unfortunately, as will be further detailed in Chapter 4 (p.85), Chapter 6 (p. 159) and Chapter 7 (p. 187), the emergence of the COVID-19 pandemic changed the initial plans forcing me to stop interviews with older patients. This is how phase B of this study emerged. In striving to make sense of the ICCI phenomenon, I turned towards the lived experience of the practitioner who was running the intervention, and thanks to her engagement in the process, I carried out a number of in-depth interviews, which, when brought together with phase A, revealed a rich and detailed tapestry of human experiences, which now forms the core of this thesis as a whole.

1.5 Structure of the thesis

In this chapter I gave an overview of the processes that brought me to this research and of the rationale used (drawing from both literature and clinical experience) for defining its focus. I also gave a brief summary of how the COVID-19 pandemic impacted on the final shape of the research with the development of Phase B.

Chapter 2 (p.19) is where phase A of the study starts and will provide more details on the initial focus of the research and a detailed narrative review of the literature on the experience of older people in A&E up to July 2019 (when the data collection period was planned to start). Given that no formal clinical study exploring the lived experience of older people who received an intervention similar to the ICCI in A&E emerged, the gap in the literature was confirmed and with it my first research aim, which was to explore the lived experience of older people who received an ICCI in A&E.

In Chapter 3 (p.57) I will present the philosophical and methodological foundations for the study, explaining the rationale, relevance and application of phenomenology and, specifically, of Interpretative Phenomenological Analysis to the first aim of the study and my epistemological stand. I will conclude this chapter with a reflection on my positionality as a dramatherapist and on how this has informed my use of phenomenology in the study.

In Chapter 4 (p.85), I outline the details of the research design and the methods involved in phase A of the study, including an in-depth description of the analysis and the main ethical challenges involved in running the study with this specific participant group (older people, including people with dementia). At the end of the chapter, I present an in-depth reflection on the research process, and it is here that I reflect on the challenges posed by the emergence of COVID-19 pandemic, together with the decision to develop a second objective for the study.

Chapter 5 (p.129) reports the findings from phase A of the study, which are presented in a narrative form, rich in detail and evoking descriptions, together with direct quotes from participants.

Chapter 6 (p.159) opens phase B of the study, and it is here that I give an account of the processes and reasons which brought me to run a second literature review about the experience of staff or volunteers delivering care to older people in A&E. This narrative review includes records up to April 2021, which is when data collection for phase B of the study started. Despite this conspicuous body of knowledge, no formal study emerged about the experience of a member of staff or volunteer who delivers and intervention similar to the ICCI in A&E, therefore the second objective of the study was confirmed, which was to explore the lived experience of delivering an ICCI for older people in A&E.

Chapter 7 (p.187) presents an overview of the methods used for phase B of the study, reflecting upon the specific use of online interviews with the ICCI practitioner and the ethical challenges specific to this method. I then offer a self-reflection on my experience at this point of the research process, and I conclude with a section on quality and rigour.

Chapter 8 (p.207) presents the findings from phase B of the study and eventually brings together the two sets of findings (phase A and phase B). It is rich in evocative descriptions and quotes from the ICCI practitioner.

Chapter 9 (p.255), which is the concluding chapter of this thesis, discusses findings from both phases of the study alongside relevant updated literature. This chapter ends showing how this research adds new knowledge and perspective to our understanding of the experience of older people in A&E and to that of staff, and of the possible significance of a compassionate communication intervention for them. I then outline strengths and limitations of the study and the possible implications for both future research and clinical practice.

STUDY PHASE A

Experience of older patients

Chapter 2 - Literature Review - Study Phase A

2.1 Outline of the chapter

In this chapter, I will give an account of the processes and reasons which brought me to define the focus of the literature search for this study. I will then describe a) the process of screening of the articles (outlining inclusion and exclusion criteria), b) how the articles were appraised, c) how data were extracted and organised for synthesis and writing. I will then discuss the main themes and highlight the gap in the literature.

2.2 Defining the focus of the review

As mentioned in Chapter 1 , when I started working on this PhD project in September 2017 the research aims and objectives proposed by Bournemouth University and by the district hospital which co-funded this clinical studentship were still, intentionally, quite broad.

The initial overall aim of the original project was:

To explore how a compassionate communication intervention (CCI) at a NHS Hospital in the South of England can contribute to the health and wellbeing of older people during their admission and in-hospital stay.

This prompted an initial exploratory literature search on key terms such as: *compassion, communication, health, wellbeing,* and *older people* in *hospital* which then developed into a more structured search focused on *compassionate care* with *older patients* in *Accident and Emergency department*. But it was not until I took the decision to focus my study on the lived experience of older patients who received an ICCI while in the A&E that I defined and ran the literature review that I present in this chapter.

The decision to focus on the lived experience of individual patients was taken, moving away from the more general impact of the ICCI on the health and wellbeing of older patients as a group, because months of informal observations in A&E and emotional support at the bedside of older patients in the hospital's wards had made me realise the importance of their own individual lived experience of healthcare, and the powerful potential their own account of their experience could possibly have to influence both practice and future research. This new approach was the basis for the focus of the literature search and review which I present in the following sections.

The review question eventually was:

What is known about the experience of older people in Accident and Emergency Department as it is told from their own point of view?

2.3 Search strategy

To start with, I chose to engage in a narrative literature review as opposed to a systematic one, because I felt that a narrative approach - which rather than aiming to test a specific hypothesis, aims at presenting a broad overview of a topic subject (Noble 2018) - would better support my qualitative, inductive approach. My aim was, as Cronin (2013) points out, to provide the reader with a solid and comprehensive background - at the same time highlighting the need and significance of new research - rather than narrowing down the focus of the research as a systematic literature review would do. However, I strived to keep a rigorous approach in my literature search. In Table 1 (p.21) it is possible to see inclusion and exclusion criteria for the literature review.

Table 1 - First literature review - Phase A - Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion
Empirical peer reviewed research studies (only primary studies) - as I wanted to stay close to participants views.	Systematic reviews - relevant primary studies included in those reviews were extracted and included if they matched the inclusion criteria.
Exploring the experience of older patients	
In Accident and Emergency (A&E)	
From the patients' point of view	Studies which included the experience of older people only from the point of view of their carers or the hospital staff were excluded
Studies which explored the experience of older patients from multiple points of view (including those of older patients) or which explored both the experience of older patients from their point of view and the experience of other groups of people related to the patients, such as family members or nurses, were included, but only as long as the point of view of older people of their own experience still remained central.	
Written in English, because even if I can understand Italian language – it being my mother tongue- relevant Italian scientific studies are normally published in English.	
Up to July 2019 -the start of data collection for this phase of the study	

In order to answer my review question, I needed to formulate it as a PEO (Population, Exposure, Outcome) question, as I needed to find literature concerned with the outcome (experience) of the exposure to something (A&E stay) of a specific population (older people).

In order to create a research string with suitable key terms, I searched for synonyms with the help of a thesaurus, and I looked at MESH terms and alternative terms as I identified them from existing papers during the search. My key terms, including the appropriate Boolean operators and modifiers, can be seen in Table 2 below.

Table 2 - First literature string - Phase A

Framework	Key terms
P	“older patient*” OR “older user*” OR “older people” OR elderly OR geriatric OR “senior citizen*” OR “senior patient*” OR retired OR aged OR senior
E	“emergency department” OR “ED” OR “accident and emergency” OR “A and E” OR “A&E” OR “emergency room” OR “a&e” OR “ER” OR “emergency service”
O	experienc* OR feeling* OR attitud* OR perception* OR opinion* OR view* OR challenge

The search was carried out between July 2018 and July 2019 using the following databases: Scopus, Medline Complete, Science Direct, CINHAL complete; SocINDEX and PsycINFO. As Cronin (2013) states, there are numerous electronic databases and many of them focus on specific fields of information. Therefore, it is important to identify which databases are relevant to the topic of interest.

This specific choice of databases was made taking into consideration both the needs for sensitivity and specificity of my search topic and trying to balance them.

Scopus, being one of the largest international database of peer-reviewed literature existent (Elsevier 2022) would provide me with a broader base for my search Medline Complete - leading database of biomedical and health journals

(Ebsco 2022) and Science Direct - source for scientific, technical, and medical research, would represent valid sources for more medical orientated studies, and CINAHL, which provides indexing of the top nursing and allied health literature available, would let me access nursing literature.

SocINDEX, in turn, concerned with sociology research, and PsycINFO, focused on psychological and psychiatric studies - that are not found in other databases - would allow me to access literature more orientated towards a social sciences/ psychological approach.

I chose not to limit the search to a particular time frame of publication so that I could gather as much relevant evidence as possible. Both qualitative and quantitative studies have been included; this choice was made because even if my research question required a qualitative approach, I was still aware that some quantitative studies would certainly be able to inform the answer to the literature review question, offering some useful information on elements of the experience of older people in A&E through questionnaires or structured interviews.

A further category of articles came to my attention while running this search: these were service reports or descriptive articles, thus not articles based on primary research studies, not necessarily peer-reviewed, but of interest to me, as they described A&E services for older people which had many similarities to the ICCI, and could allow me to gather more knowledge about the subject, getting to know if other hospitals, perhaps, already had their own kind of ICCI (even if the experience of older people who had received such intervention had not yet been explored systematically). Therefore, I decided to complete a second practice-based review to investigate this further, running a second search on: CINHAL complete; PsycINFO; Science Direct; Medline Complete; SocINDEX and Scopus, not only concentrating on experiences and not limited to peer-reviewed articles using the key terms listed in Table 3 (p.24):

Table 3 - Second literature string - Phase A

“older patient*” OR “older user*” OR “older people” OR elderly OR geriatric OR “senior citizen*” OR “senior patient*” OR retired OR aged OR senior
AND
“emergency department” OR “ED” OR “accident and emergency” OR “A and E” OR “A&E” OR “emergency room” OR “a&e” OR “ER” OR “emergency
AND
compassion OR "compassionate care" OR "humanised care" OR "humanising care"
AND
project OR programme OR scheme OR service OR volunteer*

See inclusion/exclusion criteria in Table 4 below:

Table 4 - Second literature string - Phase A - inclusion and exclusion criteria

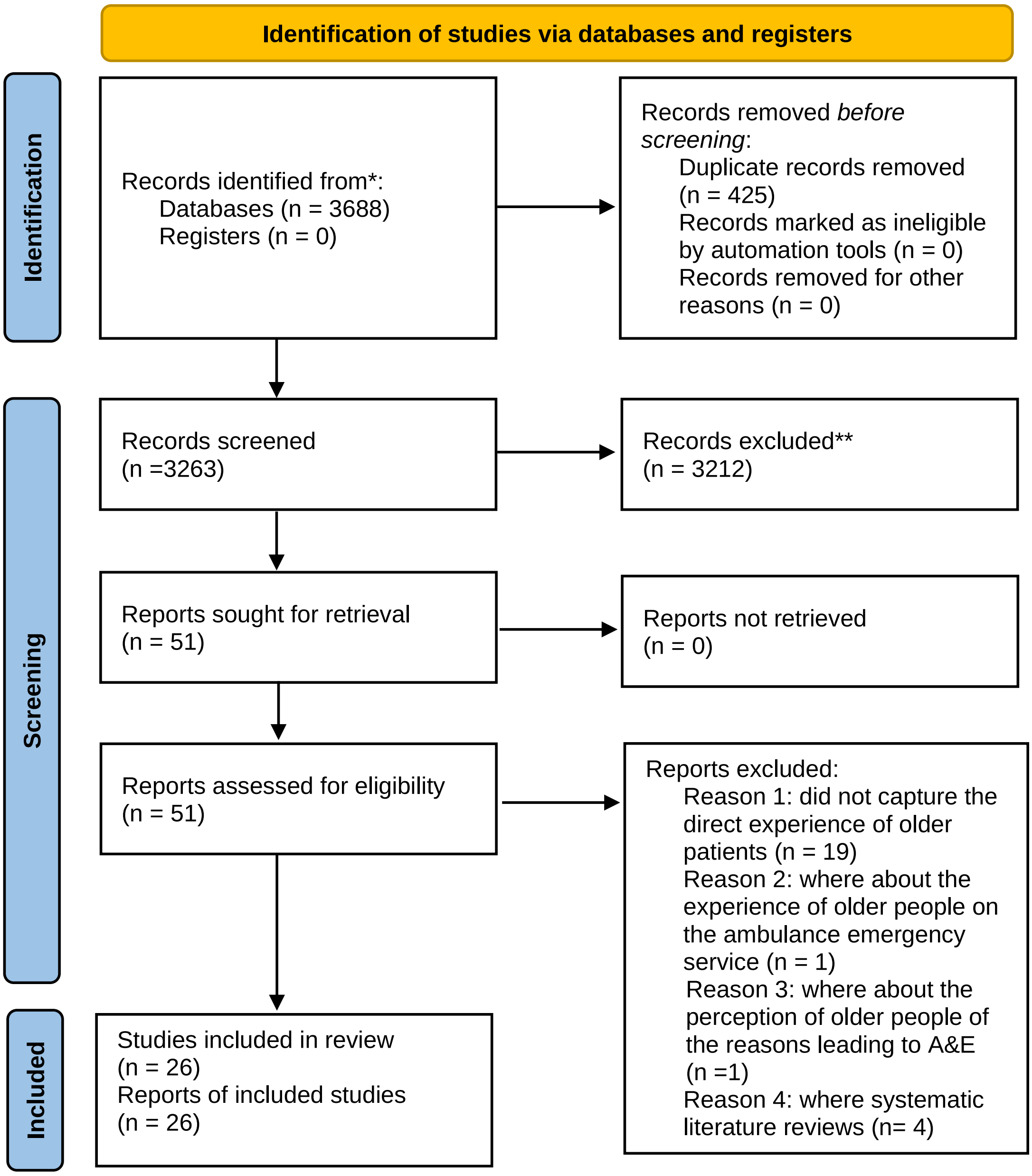
Inclusion criteria	**Exclusion**
Papers reporting A&E based interventions principally aimed at meeting older patients’ psychological and emotional needs	Papers describing interventions aimed at older people in A&E, but exclusively focused on their medical or physiological needs.
Papers reporting on interventions focused both on physiological and emotional needs	

Further literature searches were carried out for each of the themes which emerged from the findings of the study in phase A and the initial literature search carried on between 2018 and 2019 was repeated in July and August 2022 to ensure that any new data that would emerge since then would be included in the discussion.

2.4 Literature review diagrams Study Phase A

PRISMA 2020 flow diagram for new systematic reviews which included searches of databases only

PRISMA 2020 flow diagram for new systematic reviews which included searches of databases and registers only



From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

Figure 1 - Experiences of older people in A&E

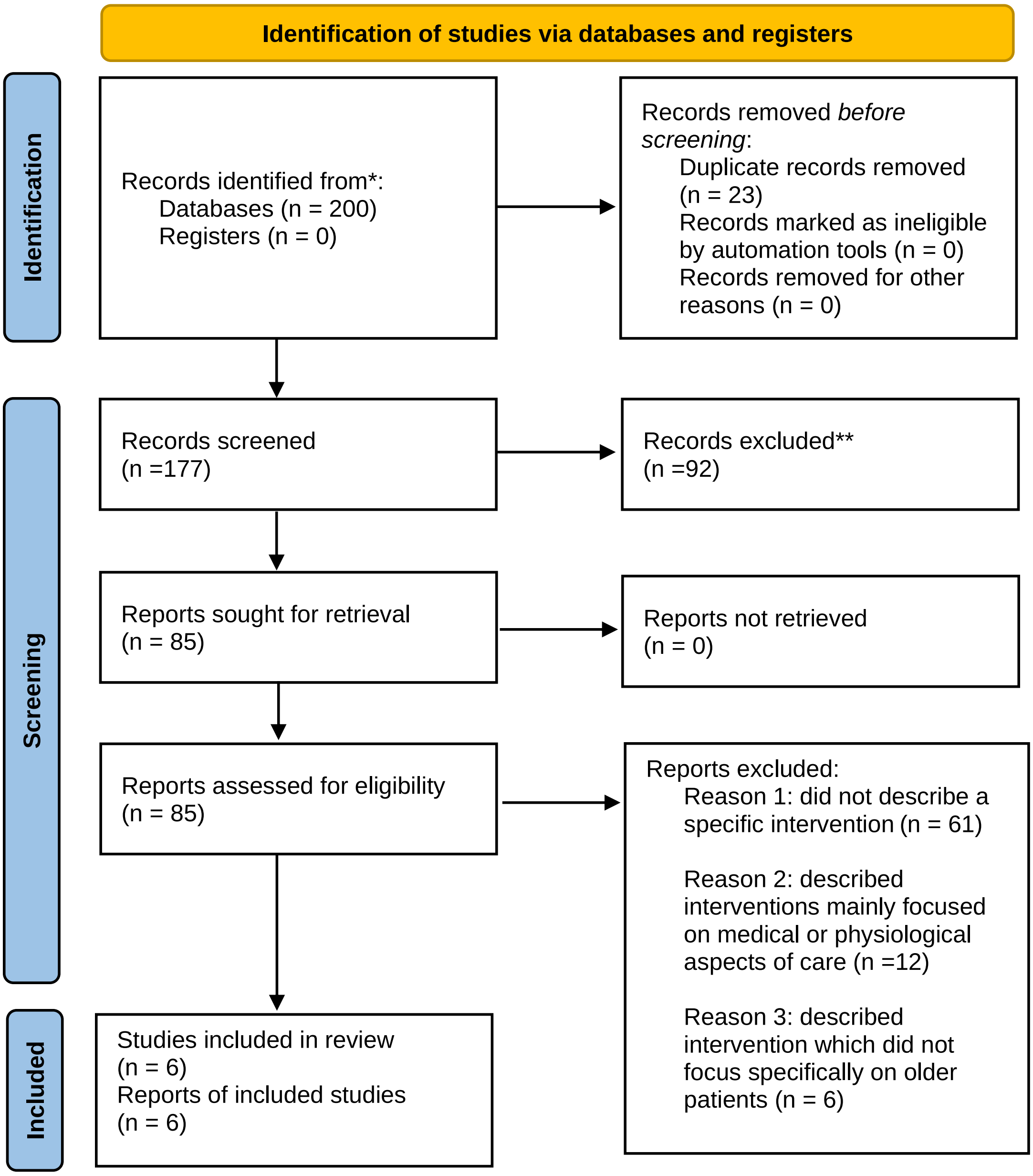
The first search, focusing on peer-reviewed primary studies, identified 3688 articles through a very sensitive database search.

After removal of duplicates, 3263 articles were left and screened via title and abstract of which 3212 were excluded because they were not relevant.

At this point I was left with 51 articles whose full-text I read and assessed for eligibility: 21 of those articles were excluded either because they did not capture the experiences of older patients from their point of view (19) or because they were about the experience of older patients in the ambulance emergency service (one) or because they were about the perception of the reasons that older people felt led them to A&E (one), and four of them were excluded because they consisted of systematic literature reviews which contained primary studies which I was already aiming to include.

Of the remaining articles,19 studies were included in the qualitative synthesis, six studies were included in the quantitative synthesis, and one was a mixed-method study.

PRISMA 2020 flow diagram for new systematic reviews which included searches of databases and registers only



From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

Figure 2 - Compassionate Interventions for older people in A&E

With regard to the second search, which I ran in order to find out possible reports or descriptive articles (not necessarily peer-reviewed) about services with a similar approach to the ICCI, I initially identified 200 articles which I screened by title and abstract. Of those, only 85 were assessed full-text for eligibility (as the other ones were not relevant to the research subject); of those screened full-text, 61 were excluded because they did not describe a specific intervention, 12 because they described interventions mainly focused on medical or physiological aspects of care, and six because they described intervention which did not focus specifically on older patients. Eventually, six of them were included.

2.4.1 Peer-reviewed primary research studies: critical review

All the studies included in the first review (only peer-reviewed primary research studies) were appraised using the Critical Appraisal Skills Programme (CASP) checklists for evaluating the quality of either qualitative or quantitative research (CASP 2006), with the exception of Hunold et al. (2016) and Liu et al. (2016), as there is not CASP checklist available for Cross-Sectional studies. For them, I therefore made use of an AXIS checklist (Downes et al. 2016). Critically appraising literature review articles is generally useful to make informed decisions about the quality of the research evidence. In this case, findings from these appraisals were not used to determine the inclusion or exclusion of papers, as there are no accepted methods to guide these decisions (Thomas and Harden 2008); however, engaging with the appraisal checklists helped me to acknowledge the strengths and weaknesses of each single study and to be able to consider them and the strength of the evidence when discussing the literature findings.

Overall, there was a range of different levels of quality within the articles, some of which were of good quality. In Table 5 (p.29) a summary of the appraisal is presented:

Table 5 - Literature appraisal summary - Phase A

Authors	**Was there a clear statement of the aims of the research?**	**Is a qualitative -or quantitative-methodology appropriate?**	**Was the research design appropriate to address the aims of the research?**	**Have ethical issues been taken into consideration?**	**Was the data analysis sufficiently rigorous?**	**Is there a clear statement of findings?**
Goodridge et al. 18	YES	YES	YES	YES	YES	YES
Han et al. 17	YES	YES	YES	YES	YES	YES
Blackwell et al. 17	YES	YES	YES	YES	YES	YES
Palonen et al. 16	YES	YES	YES	YES	YES	YES
Liu et al. 16	YES	??	??	YES	YES	YES
Hunold et al. 16	YES	YES	YES	YES	??	YES
Stein-Perbury et al 15	YES	YES	YES	YES	YES	YES
Goncalvez et al. 15	YES	YES	YES	YES	YES	YES
Parke et al. 13	YES	YES	YES	YES	YES	YES
Olofson et al. 12	YES	YES	YES	YES	YES	YES
Kelley et al. 11	YES	YES	YES	YES	YES	YES
Considine et al.10	YES	YES	YES	YES	YES	YES
Bridges and Nugus 09	YES	YES	YES	YES	YES	YES
Lyons and Paterson 09	YES	YES	YES	YES	YES	YES
Way et al. 08	YES	YES	YES	??	??	YES
Richardson et al. 07	YES	YES	YES	YES	YES	YES
McLeod And Ollson 06	??	??	??	YES	YES	YES
Kihlgren et al. 04	??	??	??	YES	YES	YES
Guttman et al. 04	YES	??	YES	YES	YES	YES
Nyden et al. 03	YES	??	YES	YES	YES	YES
Nerney et al. 01	YES	??	??	YES	YES	YES
Watson et al. 99	YES	YES	YES	??	??	YES
Spilsbury et al. 99	YES	YES	YES	YES	??	YES
Majerowitz et al. 97	YES	YES	??	??	??	YES
Hedges et al.92	YES	YES	??	YES	??	YES
Baraff et al. 92	YES	YES	YES	NO	??	YES

?? = cannot tell’

2.4.2 Peer-reviewed primary research studies: literature review tables

After the appraisal, primary, peer-reviewed research studies were analysed using literature review tables. These tables provided me with an easy-to-access overview of basic information (authors, year, country, aims, participants, settings and findings) about included articles, but they also provided information about the theoretical and conceptual frameworks and the methods used in each paper (Younes and Ali 2021), together with a summary of main limitations and strengths. These tables are provided in Appendix 2 - Literature review table phase A (p. 313).

2.4.3 Synthesis matrix chart

Findings were synthesized and organised with the help of a synthesis matrix chart, a table, which, when completed, provides a visual representation of the main ideas or categories found in the literature, easily revealing where there is overlap between authors (Clark and Buckley 2017). As it can be seen in page 31, a synthesis matrix (Table 6 – p. 31) can allow trends (categories or ideas that are repeated or shared) to be shown and gaps (ideas and categories about which sources seem to differ or which are simply not addressed) to emerge. Compiling a synthesis matrix chart has enabled me to see where these sources overlap or differ and how, therefore significantly facilitating both the analysis, the synthesis, and the writing-up process.

Table 6 - Synthesis Matrix Chart - Phase A

Categories	**Baraff et al. 92**	**Hedges et al.92**	**Majerowitz et al. 97**	**Spilsbury et al. 99**	**Watson et al. 99**	**Nerney et al. 01**	**Nyden et al.03**	**Guttman et al. 04**	**Kihlgren et al. 04**	**McLeod And Ollson 06**	**Richardson et al. 07**	**Way et al.08**	**Lyons and Paterson 09**	**Bridges and Nugus 09**	**Considine et al.10**	**Kelley et al. 11**	**Olofson et al. 12**	**Parke et al. 13**	**Goncalvez et al. 15**	**Stein-Perbury et al. 15**	**Hunold et al. 16**	**Liu et al. 16**	**Palonen et al. 16**	**Blackwell et al. 17**	**Han et al. 17**	**Goodridge et al. 18**
1 - Fear and Anxiety	x			x			x				x					x		x				x		x	x	
2 - Waiting Time	x	x			x	x			x						x			x	x		x			x		
3 – Communication	x		x	x	x	x	x	x	x	x	x	x	x			x	x		x	x	x	x	x	x		x
4 - Basic Physiological Needs	x	x		x	x		x		x				x			x		x	x		x	x			x	x
5 - Family/Friends Involvement	x											x	x			x			x				x			x
6 - Staff Too Busy																x				x						
7 - Personal Tolerance				x	x														x	x						
8 – Pain	x					x													x							
9 - Dignity/Significance/Self-Esteem			x			x	x		x		x	x	x	x	x	x		x						x		
10 – Deference			x				x		x		x															
11 - Safety/Trust						x	x		x		x		x				x		x					x	x	
12 - Isolation/Fear of Being Forgotten				x					x								x	x								
13 - Importance of Staff Kindness	x				x				x				x			x					x					x

2.4.4 Links to Lifeworld

Looking at the Synthesis Matrix Chart, I noticed that there were a large number of categories/ideas discussed by most papers, and I could potentially use them as they came out from the chart to craft the discussion of the literature in this chapter. However, I strived for further synthesis and felt the need to explore whether an already existing framework could be used to further shape it. My interest in phenomenology and in humanising practices, immediately brought me to consider the concept of the Lifeworld. In 1936, Husserl coined the term Lifeworld - in German: Lebenswelt –; with this word, he aimed at encapsulating the concept of the world as directly experienced by a subject from his (*sic*) own, unique, existential position, as neatly distinguished from the objective world of positivistic science (Husserl 1970).

Five elements/dimensions of our subjective Lifeworld have emerged from his body of work: Temporality - time as it is experienced subjectively rather than clock time - Spatiality - the meaning that places and spaces hold for the subject -Intersubjectivity - how the subject is in the world with others - Embodiment - the concrete here of the subject, his lived body - and Mood - how the subject's experience is coloured by his mood - (Husserl 1970).

More recently, in health and social sciences' research, practical applied work based on Husserl's Lifeworld has been developed. A new framework looking at how healthcare can develop and change towards a more humanising model, which takes into consideration what it means to be human from a philosophical point of view - Lifeworld dimensions - in a given healthcare situation, has been framed, called Humanisation of Healthcare Framework (Todres et al. 2009), and a number of studies have taken place, looking at patients' experiences in healthcare through the lenses of the Lifeworld and/or the Humanisation of Healthcare Framework (Pound and Jensen 2018; Hemingway et al. 2012).

Considering the Lifeworld as a possible lens for the analysis of the literature worked well: after the analysis of the 26 papers based on peer-reviewed primary research studies, looking at the particular categories emerging from the synthesis matrix through the lenses of the Lifeworld, I was able to present them under three of the Lifeworld aspects. These were: Temporality, Embodiment and Intersubjectivity. Each of the 13 categories I was able to identify in the literature could be linked back to one or more of the above three Lifeworld dimensions (see Table 7, p.34). These dimensions, however, are all perspectives of lived experience, therefore inseparable and intertwined. Even when Temporality and Embodiment seemed to take central place in the findings, what eventually emerged as the actual ‘container’ capable of shaping each of the other dimensions was Intersubjectivity. The perception, meaning and value of time (often waiting time), and Embodiment (discomfort or pain) varied with the variation of the qualities of the intersubjective dimension. Thus, in the literature, findings could oscillate anywhere between the two polarities of human connection and disconnection.

These themes/dimensions have been used as headings to structure the review. A discussion on the papers based on service reports or descriptive articles from A&E-based projects which I considered presenting many similarities of approach with the ICCI follows, providing further elements of reflection to support the identification of knowledge’s gap and the justification for the study.

Table 7 - Synthesis Matrix Chart showing Lifeworld Dimensions - Phase A

Lifeworld dimensions	**Categories**	**Baraff et al. 92**	**Hedges et al.92**	**Majerowitz et al. 97**	**Spilsbury et al. 99**	**Watson et al. 99**	**Nerney et al. 01**	**Nyden et al.03**	**Guttman et al. 04**	**Kihlgren et al. 04**	**McLeod And Ollson 06**	**Richardson et al. 07**	**Way et al.08**	**Lyons and Paterson 09**	**Bridges and Nugus 09**	**Considine et al.10**	**Kelley et al. 11**	**Olofson et al. 12**	**Parke et al. 13**	**Goncalvez et al. 15**	**Stein-Perbury et al. 15**	**Hunold et al. 16**	**Liu et al. 16**	**Palonen et al. 16**	**Blackwell et al. 17**	**Han et al17**	**Goodridge et al. 18**
Temporality, Embodiment, Intersubjectivity	1 - **Fear and Anxiety**	x			x			x				x					x		x				x		x	x	
Temporality, Intersubjectivity	2 - **Waiting Time**	x	x			x	x			x						x			x	x		x			x		
Temporality, Embodiment, Intersubjectivity	3 - **Communication**	x		x	x	x	x	x	x	x	x	x	x	x			x	x		x	x	x	x	x	x		x
Embodiment	4 - **Basic Physiological Needs**	x	x		x	x		x		x				x			x		x	x		x	x			x	x
Intersubjectivity	5 - **Family/Friends Involvement**	x											x	x			x			x				x			x
Intersubjectivity	6 - **Staff Too Busy**																x				x						
Intersubjectivity	7 - **Personal Tolerance**				x	x														x	x						
Embodiment	8 - **Pain**	x					x													x							
Temporality, Embodiment, Intersubjectivity	9 - **Dignity/Significance/Self-esteem**			x			x	x		x		x	x	x	x	x	x		x						x		
Embodiment, Intersubjectivity	10 - **Deference**			x				x		x		x															
Temporality, Embodiment, Intersubjectivity	11 - **Safety/Trust**						x	x		x		x		x				x		x					x	x	
Embodiment, Intersubjectivity	12 - **Isolation/Fear of Being Forgotten**				x					x								x	x								
Intersubjectivity	13 - **Importance of Staff Kindness**	x				x				x				x			x					x					x

2.5 Themes identified- The experience of older people in Accident and Emergency Departments

Three themes (or Lifeworld dimensions) were identified, stemming from the 13 categories of the synthesis matrix table: Temporality, Embodiment and Intersubjectivity. Having firstly described the nature of the literature reviewed, each theme will then be discussed in more depth.

2.5.1 Overview of sources

The analysis revealed the presence of papers covering a timeframe of approximately 26 years of research (between 1992 and 2018), in different - mainly western- countries: six studies were based in the UK, seven in U.S.A, three in Sweden, three in Australia, two in Canada, one was based both in the UK and in Sweden, one in Scotland, one in Finland, one in New Zealand, one in Brazil, and one in Taiwan.

The fact that most studies on the subject are quite recent is not surprising: a clear and institutional focus on patient-centred care and compassionate practice in healthcare is a fairly recent endeavour and, in the case of England -as already outlined in Chapter 1 - compassion, as a core value of the NHS, was formally introduced only in its constitution, which was not published until 2009 (Department of Health and Social Care 2009). As a result, *compassionate care* is a term that has entered the public consciousness only recently (Dewar & Nolan 2013), and with it, possibly, also the awareness of the importance of making older patients’ voices heard, exploring and telling their experiences. Moreover (as also already outlined in Chapter 1), compassionate care and the patients’ lived experience, in UK, have become more widely recognised as necessitating attention from practitioners, researchers and policymakers after the Francis Report (2013) was published, revealing a dramatic lack of compassion towards patients at Mid Staffordshire NHS Foundation Trust between 2005 and 2009.

It is also worth noticing that most studies were conducted either in the UK or USA. However, what emerges next, is that almost all USA based studies included in this review are quantitative, with aims often articulated as: assessing satisfaction (Nerney et al. 2001), identifying specific problems and solutions (Baraff et al. 1992), or describing and ranking priorities (Hunold et al. 2016), while, on the opposite, almost all UK studies are qualitative, with aims ranging between: describing experiences (Way et al. 2008), critique methods (Blackwell et al. 2017) and exploring experiences (Spilsbury et al. 1999). One might wonder if this is possibly related to the USA private healthcare system which following a business model, might be looking more at customer satisfaction and corporate service delivery.

Among the qualitative studies, only seven stated the specific methodology used: Han et al. (2017) made use of phenomenography, Blackwell et al. (2017) used experience-based co-design, Kihlgren et al. (2004), and Lyons and Paterson (2009) used grounded theory. Olofson et al. (2012), used Giorgi's descriptive phenomenology, Kelley et al. (2011), used ethnography, and Spilsbury et al. (1999) is described as forming part of a larger action research study.

The only mixed-methods study (Richardson et al. 2007) does not state the specific methodologies used.

Quantitative studies were either: cross-sectional studies (Liu et al. 2016; Hunold et al. 2016), prospective cohort studies (Nerney et al. 2001, Guttman et al. 2004) or not stated (Hedges et al.1992; Majerowitz et al.1997).

Eighteen studies used interviews as a method. Two of them used also non-participant observations (Spilsbury et al. 1999; Kihlgren et al. 2004), one used focus groups (Baraff et al. 1992) one used focus groups in addition to interviews. (Goodridge et al. 2018). Parke et al. (2013), made use of interviews, a photographic narrative journal and photographic focus groups, and Kelley et al. (2010) used semi-structured interviews, a survey, and observation.

Among the quantitative studies, Hedges et al. (1992), Nerney et al. (2001) and Liu et al. (2016) used surveys, while Hunold et al. (2016) made use of a single open-ended question.

The large percentage of studies making use of interviews as a method does not come as a surprise, given that interviews are widely recognised as the most suitable method to explore experiences from the point of view of who is living them (Guest et al. 2013). In the following sections, I will discuss each of the three Lifeworld elements which emerged from the literature. These were Temporality, Embodiment, and Intersubjectivity.

2.5.2 Temporality for older people in A&E

Temporality can be defined as time as we experience it. This is made of a subjective experience of time as opposed to the more objective or chronological time, and it refers to the ways in which we can experience life on a temporal level (Rich et al. 2013). The way we feel can affect our experience of time, and, conversely, demands, constraints, or opportunities placed by time can also affect how we feel and how we measure that subjective time (Rich et al. 2013).

Perceived length of waiting time is a prominent theme in many of the participants' accounts in this review: time represented a critical factor for them, and it was almost always noticed, whether it was experienced as short or long (Watson et al. 1999; Lyons and Paterson 2009; Considine et al. 2010). A short waiting time was listed as one of the top priorities for many older patients (Hedges et al. 1992; Lyons and Paterson 2009; Hunold et al. 2016). Perceived long waits were described as a “hardship” (Lyons and Paterson 2009, p.30), eliciting feelings of frustration for some (Considine et al. 2010), and increasing levels of anxiety for others (Baraff et al. 1992). This is not surprising as, like participants in Baraff et al. (1992) pointed out, patients in A&E often wait to be informed about the nature and seriousness of their condition, and when they feel that there are substantial delays in the provision of care, waiting, for them, can become significantly challenging. Perhaps, waiting is also challenging for those patients because being left waiting makes them feel diminished and threatens their sense of dignity and significance, as is noticed by Parke et al. (2013). Moreover, waiting in A&E might be challenging because it might make people feel that for some time nobody is giving them attention just when they most need it, which might make them feel unsafe.

This particular dimension of temporality as experienced by older people in A&E seems validated by Thompson et al. (1996) who, in their study on the effects of actual waiting time, perceived waiting time, information delivery, and perceived quality on patient satisfaction in the Accident and Emergency department, found that perception of waiting time was a much stronger correlate of satisfaction than actual waiting time.

But time can also feel too short for older patients in A&E. This might be related to the length of time of the medical visit and might relate to the opportunity for the older person to ask questions and feel heard. Goncalvez et al. (2015), for example, in their qualitative study on the perspective of older patients during risk classification (a way of performing triage) in an A&E hospital department in Brazil, found out that some of the patients complained of dissatisfaction with the short duration of the doctor’s visit, which, in their view, did not provide for a thorough consultation and impacted negatively on the care received afterwards. Irrespective of the actual time needed for providing physical care to those patients, these studies' participants, with their experience of Temporality, seemed to show that it is not only the time for the physical care of the patient which is needed, but the time for making the patient feel heard and seen.

2.5.3 Embodiment

Being human, we live within our bodies and experience the world through them (Habermas 1990). Embodiment relates to how we experience the world through our bodies, including our perceptions of our context and its possibilities or limits (Hemingway 2011). In a healthcare setting, this could be seen objectively as the presence or absence of an illness or condition, and as the enactment of medical procedures on a human body/person. However, subjectively, the presence and quality of those elements, including whether our basic physiological needs are met, the quality of our sensory perceptions, physical limitations and/or possibilities, pain, comfort or discomfort, can create a world of perceptions, sensations, feelings, and thoughts, and above all: meaning. In healthcare, and more specifically, in A&E, Embodiment can be experienced differently if the patient’s body is humanised, rather than objectified. When, for example, our attention is focused on our basic physiological needs, or discomfort, or pain, our whole perception of what it means being in the world changes. As a result of this, as Todres et al. (2009) point out, a humanising perspective will view the patient’s treatment as something that can make their life worthwhile and not just as the elimination of a symptom, with the body viewed as merely an object to fix. Moreover, it would become clear that our body is part of our intersubjective make-up and, if seen in a relational way, then consideration given to the use of physical proximity, touch, or other senses can have a lot to contribute to how each patient perceives their world.

2.5.3.1 Basic Physiological Needs

Having basic physiological needs attended to, such as: hunger and thirst, sleep, hygiene, and temperature, was reported as a significant element of older people’s experiences in A&E in a number of studies (Baraff et al. 1992; Nerney et al. 2001; Goodridge et al. 2018). Often older patients experienced being cold (Baraff et al. 1992; Kihlgren et al. 2004; Kelley et al. 2011). Some of them clearly stated that the A&E department was too cold when they visited it and that they were not offered blankets (Baraff et al. 1992), others (Khilgren et al. 2004), have been observed shivering with cold, particularly when arriving thinly dressed from nursing homes, and they were left like that while waiting for a doctor or during examinations. Later, in the same study, some of those patients confirmed that they had experienced cold (Khilgren et al. 2004). If we look at this through the lenses of Embodiment and embodied knowing, the experience of being cold and not being offered blankets, although not verbalised, can be telling us that either people are unaware of us and our experience or don’t care about us and therefore we could start feeling ignored, and start doubting our own significance. We might wonder if we should have come to A&E in the first place, and if we are being a burden to the staff. Some older patients might be hungry or thirsty and struggle to get those needs met in A&E (Nyden et al. 2003; Kelley et al. 2011; Goncalvez et al. 2015). Some patients also complained about water and food being brought, but being left out of their reach, or about staff giving them plastic cups which are too hot for them to hold (Spilsbury et al.1999). Others talked about interrupted sleep in A&E (Kelley et al. 2011) or of their perception of lack of cleanliness and hygiene (Goodridge et al. 2018).

A number of patients, while acknowledging the central importance of having basic physiological needs met in A&E, generally thought that these needs had been met, as stated by participants in Lyons and Paterson (2009) study. However, it is interesting to notice that all participants in that study had been interviewed while in their in-patient beds (as opposed to patients in most other studies in this section) and this could have impacted on them being reluctant to complain for fear that they could be over-heard by members of staff. Patients might avoid making negative comments about their care openly in order to maintain safe and constructive relationships with the staff caring for them (Calman 2006). Given that many participants were still receiving treatment, it is possible that their responses were influenced by the presence of other patients and staff during the interviews. Reluctance to criticise is an element to be considered when choosing suitable data collection methods in studies like these.

2.5.3.2 Sensorial or physical limitations

Some older patients acknowledged that they could not hear or see properly when in A&E, particularly those who had forgotten any aids that normally helped overcome such problems (Spilsbury et al. 1999; Goodridge et al. 2018). They often felt that staff would need to be more aware that, for example, the patient without their walking frame might feel less confident, while patients without hearing aids might experience increased feelings of isolation, and they thought that staff often did not adapt communication to compensate for age-related losses of hearing and vision. Again, the relational aspect of our embodied dimension emerges very clearly: not being able to walk for those patients means losing confidence, and not being able to hear means feeling isolated. The world they were experiencing was possibly increasingly scary and uncertain for these reasons, and if staff made something to help them move, or to ease communication, that meant they were doing something to make them perceive their world as a safer place to be. From participants’ accounts in Spilsbury et al. (1999), it clearly emerged that age-related sensory losses in A&E were not only a problem per se: in their own embodied context of having their sensory/physical problems ignored by staff, older people might very possibly have experienced, through their own bodies, embarrassment and anxiety together with their sensory limitations, almost like one thing, and trying to make meaning out of those sensations, they might very possibly have felt neglected, or unimportant: almost like their embodied knowing was telling them they were undeserving of care in that situation.

2.5.3.3 Comfort/Discomfort and Pain

In the literature, participants seemed universally unhappy about the comfort of the trolleys and the mattresses in A&E (Baraff et al. 1992; Spilsbury et al. 1999; Kihlgren et al. 2004). Trolleys were described as too narrow and mattress as too hard, thus making the surface too hard and painful to lie on for prolonged periods. Moreover, pillows seemed often unavailable, making older patients even more uncomfortable. Several patients reported having had difficulties in finding a comfortable position, thus developing back pain (Baraff et al. 1992; Watson et al. 1999). After all, it is easy to notice how hospitals' trolleys are designed more for staff's convenience and ease of use than for patients' comfort: patients have to slide down when trying to descend from a trolley, the mattresses are uncomfortable and there is no way of preventing downwards slipping on trolleys, with patients easily ending up with their feet over the end. Again, if looked at through a Lifeworld lens, these data seem to fit a scenario made of sterile environments and uncomfortable beds, where the focus is mainly on physical safety and ease of use, rather than on the creation of a comfortable, homely, and therefore psychologically safer environment for patients.

Pain emerged as a significant concern, in more than one paper (Hedges et al. 1992; Nerney et al. 2001; Goncalvez et al. 2015). Some older people complained that their need for pain management was not addressed in A&E (Goncalvez et al. 2015). These findings are of particular interest if read alongside other existing studies showing that despite the high prevalence of pain in older patients, they are routinely given less analgesia than younger patients in A&E (Hwang et al. 2010) and across other healthcare settings (Cavalieri 2005; Denny and Guido 2012). This is particularly true for patients with dementia or other cognitive impairment (Horgas and Miller 2008; Hadjistavroupolous et al. 2014; Wang et al. 2021) Moreover, older people are reported to have more stoic attitude toward pain (Crowe et al. 2017), and other concerns, which prevent them from openly asking for pain relief, such as fear of becoming addicted to analgesia, or fear of polypharmacy (Hall 2016). However, from Nerney et al. (2001), it is possible to appreciate that the patient's perception that A&E staff were doing everything they could to treat their pain represented a strong predictor of high satisfaction in their research, showing that concerns were not 'just' about pain, but also about feeling that someone was taking care of them and wanted to make them feel better.

Some older people also reported that the A&E department was too noisy (Baraff et al. 1992; Kelley et al. 2011), and that for this reason they had trouble hearing and understanding the nurses and physicians (Baraff et al. 1992). The world they found themselves in, what they could see and perceive "from the inside-out" (Ellis-Hill personal communication) was probably chaotic and unpredictable for the reason that with their own senses, they could not hear clearly and therefore understand and gain meaning about what was happening to them. This is exemplified in Parke et al. (2013) where older adults with dementia described having felt panicky due to the rushed, chaotic, and unfamiliar place.

2.5.4 Intersubjectivity

Intersubjectivity, from a Lifeworld's perspective, is how the subject is in the world with others (Duranti 2010). It is through Intersubjectivity that we make sense of our interpersonal world and others who share it. Intersubjectivity also helps us navigate our cultural contexts which impacts, among other things, on our self-perception and our sense of significance and dignity (Hemingway et al. 2015).

Intersubjectivity allows us to frame our thinking, our feelings, identity, and relationships in time and space. For example, it can be reflected in our consideration of who we trust or who we want to be with, and whether we feel safe where we are (Hemingway et al. 2015). Isolation is disconnection from others in the realm of Intersubjectivity, and that can feel threatening. This is because human beings are biologically wired for connection between one another, as human connection increases their sense of safety (Porges 2011). Human disconnection, on the other hand, can make them feel in real danger (Porges 2011).

Both the dimension of Temporality and Embodiment, discussed above, are intimately linked with Intersubjectivity, as waiting without anyone checking on them, feeling ignored when in discomfort or pain, is all part of the patients' Intersubjective dimension (and it is inextricably interrelated with empathy and compassion), which emerged in the literature as the most important theme. In the following sub-sections, I am going to discuss it in relation to the polarities of human connection and human disconnection.

2.5.4.1 Sense of Dignity/Personal Significance and Human Connection/Disconnection in A&E

A number of older people experienced their dignity and significance as diminished or not acknowledged in A&E (Way et al. 2008; Bridges and Nugus 2009; Considine et al. 2010). Some felt ignored and unimportant (Parke et al. 2013), questioning the very legitimacy of their presence in A&E and believed that they mattered less than other patients. This belief was often, but not always, related to long waiting times and significance related to waiting could, in some cases, be enhanced if patients felt well informed and were checked on frequently (Bridges and Nugus 2009). It is possible that older people already bring this belief with them from other contexts and settings: a survey by Brunel University, De Montfort University and older people's charity the Royal Voluntary Service, shows that most older people feel as they are a burden to society due to the way services are provided (Hoban et al. 2013). Other patients had a mixed view on the subject: some described feelings of equity, others thought that factors, such as personal characteristics, arriving by ambulance, socio-economic status or age influenced access to care and waiting time in A&E (Considine et al. 2010). Older peoples' need for a sense of personal significance in A&E could also be shown through their desire for affectionate relationships to the staff: being kindly and respectfully received by the healthcare personnel,when that happened, helped some older people in maintaining their dignity (Nyden et al. 2003).

Literature shows that there are small but significant things that can make a difference to older patients' sense of dignity and significance, most of which can easily be provided even in the most chaotic A&E environment, such as eye contact, smiling or supportive comments (Spilsbury et al. 1999). These are all ways to establish a warm human connection and, while definitely not expecting staff to know every detail of their prognosis or future treatment, patients valued being seen and acknowledged and, when the care they received showed that staff were seeing the person in the patient, acknowledging and validating their individual significance, their experience was enhanced (Spilsbury et al. 1999; Parke et al. 2013; Blackwell et al. 2017).

On the other hand, when older patients experienced a diminished sense of dignity in A&E, they were more reluctant to express their needs or ask for help (Way et al. 2008; Bridges and Nugus 2010) possibly for fear of appearing excessively demanding or ungrateful (Majerowitz et al. 1997), thus prompting further disconnection. It is quite common for older people to refrain from voicing complains or criticising the care they receive in A&E (Majerowitz et al. 1997; Khilgren 2004; Richardson et al. 2007). Moreover, it appears that a number of older patients arrived in A&E with an already low expectation of care, appearing to understand and justify many of the limits and constraints which staff were working under, in particular, believing that A&E professionals are often under-staffed and overworked (Splisbury 1999; Kelley et al. 2011; Stein-Perbury et al. 2015). In some cases, patients even expressed their gratitude despite there being evidence showing that they had received sub-optimal care (Richardson et al. 2007). In view of the consequences related to experiencing a diminished sense of significance outlined above, these findings might suggest that older patients tended to make concessions for staff because they did not always feel entitled to receive adequate care in A&E.

Another form of disconnection which might threaten older people’ sense of significance and dignity in A&E is the lack of involvement in decisions about their care. Sadly, despite a number of older patients believing that they should be active participants in decisions about their care (Majerowitz et al. 1997) and despite knowing that being involved in this process is directly correlated with higher satisfaction in A&E for some of them (Nerney et al. 2001), a number of them not only did not remember being offered alternatives about their admission and/or treatment, but they also had no expectation to be regarded as participants in discussion about themselves (Nyden et al. 2003; Richardson et al. 2007). One may question the accuracy of the recollections of events in older patients whose interviews were initially conducted soon after admission, and then completed a significant amount of time after their A&E stay, like in the case of Richardson et al. (2007) whose telephone interviews took place two weeks after the A&E stay, however, these patients' lack of expectations of being involved in decisions about their care confirms that they took on a passive role in this respect, assuming that they would be told what to do rather than being involved. With regard to involvement, the already mentioned survey performed by Brunel University, De Montfort University and the Royal Voluntary Service, disclosed that one in six people thought that the services offered reflected a stereotypical view of older people rather than their true needs and preferences and that there was a need to harness their expertise to make services better for older people by involving them more in decision-making (Hoban et al. 2013).

2.5.4.2 Sense of Safety and Human Connection/Disconnection in A&E

Despite often facing significant hardship, many older patients seemed to experience a feeling of trust towards healthcare professionals in A&E (Nyden et al. 2003; Richardson et al. 2007; Goncalvez et al. 2015). One would think this to automatically imply the experience of a sense of safety, but this was not always the case, as there were factors which could drive the experience either towards a sense of human connection or disconnection thus influencing the possibility of experiencing safety.

Feeling isolated emerged as a significant element of disconnection impinging on patients' sense of safety in A&E (Nyden et al. 2003; Kihlgren et al. 2004; Blackwell et al. 2017). It looks like older patients not only wanted to be where someone else could see them in case their health conditions took a turn for the worse (Nyden et al. 2003; Blackwell et al. 2017), but they also felt safer if they were somewhere they could see what was happening around them: in Spilsbury et al. (1999), for example, it was possible to observe that participants were often left alone looking at blank walls or trolley backs. In the interviews, they expressed a need to see what was happening. They commented that they needed to feel that they could get a nurse if necessary, and it helped them feel more in control if they could see what was going on around then.

This is a further indication that any form of human connection, even if only through sight, can give older patients an increased sense of control and therefore a feeling of safety. From one participant's account, for example, we appreciate that, from their point of view, the worst thing that could happen in A&E was staff closing their cubicle door, because in that way, there was no indication of when they would come back (Spilsbury et al. 1999). This might also exemplify the importance of two-way communication, as the healthcare professional may possibly think they are preserving the patients' privacy by closing the doors, while this should be verified and not assumed.

The presence of a family member or a friend alongside the older patient in A&E was valued as very important (Goncalvez et al. 2015; Palonen et al. 2016; Goodridge et al. 2018) and might also contribute to alleviate a sense of isolation and disconnection thus enhancing a sense of safety. Older people's relatives or caregivers were particularly valued for their role of company and support, but also for the assistance they could give to the older patient in understanding the treatment and advice offered to them by healthcare professionals (Way et al. 2008), and for their role of advocates (Baraff et al. 1992).

When looking at older people's priorities and advice, several of the studies reveal that older people thought that family and friends should be encouraged to stay with patients and, when possible, patients' advocates should check on the patients regularly and help see that their fears are allayed, and their needs met (Baraff et al. 1992; Goodridge et al. 2018).

Family members and carers, however, were not always encouraged or facilitated to support the older patient: Palonen et al. (2016), for example, in their qualitative study focused on family involvement in discharge education for older people in A&E, described a situation in which older people felt that their relatives were not directly involved. This made them feel ostracised, as their need for having their family member with them was not considered. Patients felt that families were excluded from the discharge process, and it required effort to even enter the A&E premises to meet them and the healthcare professionals taking care of them. The ostracism made older people feel angry and appalled, because for them - as for most older people in A&E - it was very important to have their family's presence and involvement. However, when considering findings from this study, it can be relevant to consider that the aim of the study was to look at both patients' and their carers' points of view, and that, in doing so, participants were interviewed either as a couple (patient-caregiver) or individually. This can clearly have affected older participants in their being more or less willing to share certain opinions whether they were in the presence of their carers or not.

Communication seems to have a significant impact on older patients' sense of safety in A&E (Spilsbury et al. 1999; Kihlgren et al. 2004; Liu et al. 2016). When older patients did not receive adequate and timely communication, they might assume the worst (Spilsbury et al. 1999; Lyons and Paterson 2009; Han et al. 2017). Spilsbury et al. (1999), for example, in their qualitative study looking at the experience of older patients and their carers in A&E, in England, described a situation in which participants felt that staff did not keep them informed and that information about treatment and condition was poor. As a consequence of this, they tried to make sense of what was happening to them by interpreting other 'signs', for example: being transferred onto a pressure-relieving mattress was interpreted as a long wait ahead; the insertion of a cannula was seen as an indication that they were to be admitted; and any movement of their trolley elicited the expectations of being close to seeing a doctor. However, those assumptions were not always correct, which further increased their anxiety. Observation of patient care by the researcher in the same study, revealed that staff did not use opportunities at hand, for example, while giving physical care, to share such information which may have helped to reduce uncertainty and alleviate patients' anxiety.

When older patients do not immediately assume the worst, they might still be left in a state of confusion by miscommunication or lack of communication (Kihlgren et al. 2004; Stein-Perbury et al. 2015). Confusion, being a form of disconnection from meaning, can jeopardize their sense of safety: Stein-Perbury et al. (2015), in their small-scale qualitative study on the expectations and experiences of older people and their carers in relation to A&E department arrival and care in Australia, showed that one of the most frequently reported aspects in relation to older participants' experiences within A&E in their study was the lack of communication about their condition and the processes that would take place, such as the assessments that would be carried out and treatment options that may be presented. While staff communicated individual episodes of care, the management plan remained unclear. As a result, older people were often left confused and agitated. It can be worse with bad communication and confusion: Khilgren et al. (2004) observed that while upon arrival, some patients were totally lucid, they became increasingly confused during the waiting period. Equally, patients who were already in a confused state at arrival, became noticeably more confused if information was given in an unclear manner, this becoming evident when they began to question everyone who passed by. Therefore, confused patients had problems in co-operating during examinations. They exhibited signs of fear, refused to undress, or expressed that they were in pain. For this reason, frequently, two or three nurses were needed in order to carry out an examination that could have been carried out by one nurse if the older patient had been calm. These findings are consistent with previous studies on the link between long and stressful A&E stays and the emergence of delirium symptoms in older patients, such as Bo et al. (2016) or Emond et al. (2017) mentioned in Chapter 1 .

When they were asked, many older patients clearly expressed that they wanted clear and effective communication (Nerney et al. 2001; McLeod and Ollson 2006; Lyons and Patterson 2009) and were able to articulate what they needed: in particular, they wanted A&E staff to explain the reasons for delays in care, what to expect, and when they might be admitted or discharged (Baraff et al. 1992.). In addition, researchers have suggested that written instructions should be given to every A&E patient on discharge, possibly using an A&E specific notebook in which they could record their questions, and which could incorporate discharge instructions (Goodridge 2018). They also listed other aspects of communication which could be improved, such as the quality of signage to promote wayfinding, and the enhancement of staff-patient communication, including the adoption of a more respectful vocabulary, and consideration given to sensory deficits that might be present (Baraff et al. 1992; Goodridge et al. 2018).

It is possibly just because when communication improves, their sense of connection and therefore their perception of safety is enhanced that when intentional interventions to improve communications are put in place in A&E, these are met very well by older patients. This was the case of the Emergency Department-based Nurse Discharge Plan Coordinator (NDPC) role, whose function was that of patient education and coordination of appointments, investigated by Guttman et al. (2004) in England, and it was also the case of a

Social Worker present in A&E whose aim was to provide both practical and psychological support, explored by McLeod and Olsson (2006), both in England and Sweden.

In addition to those mentioned above, a number of intentionally humanising interventions aimed at improving older patients' experience in A&E have been carried out over the past years, clearly demonstrating what a compassionate care intervention for older people in A&E can be. These initiatives have taken place in different countries and have been described in reports or descriptive articles or in actual research studies, like in Hullick et al. 2018 (in this last case the paper has not been included in the main peer-reviewed literature analysis because its focus was not on the older patient's lived experience).

In the following section, I will look at those which have a clear focus on meeting patients' psychological needs through human-to human interaction, and I will show how they are similar or different from the ICCI.

2.6 Experiences of services tailored to provide compassionate care interventions for older people in Accident and Emergency department

As already mentioned in Chapter 1 , over recent years the unique identity of older people presenting to A&E as a specific patient group, with their own complexities and peculiar needs, has risen to the attention of both researchers and national health services worldwide (Hayes 2000; Gasperini et al. 2016). For this reason, a movement of opinion in healthcare has developed whereby older people should have access to their own, uniquely dedicated hospital Accident and Emergency departments (Hwang 2007; Argento 2014; Rosenberg and Rosenberg 2016). This idea has become a reality in few hospitals, like St. Joseph regional medical centre, Encino hospital, and Mount Sinai hospital, in the United States (Rosenberg et al. 2013; Hospital Management 2015; Cohen 2019) which are acting as pioneers in the field. In UK, the first NHS hospital to open an OPED (Older People Emergency Department) has been Norfolk and Norwich University Hospital (The King's Fund 2019). However, as Shi et al. (2022) states, running an older-people-only Accident and Emergency department is not an endeavour which any hospital can afford, at least, not yet. For this reason, however, many hospitals’ A&Es have strived to become at least ‘Age-friendly’, providing modifications to the physical environment (Wilber et al. 2005), and/or to the organisation of the department in order to ensure better clinical outcome and increase patients’ satisfaction (Mullholland et al. 2019).

A few of them (Triggle 2012; Clarke 2013; Sanon et al. 2014; Bray 2015; Kostyshyn 2016), however, have also dedicated a greater attention to other aspects of the older patients’ lived experience, openly recognising how stressful, frightening, and disorientating an A&E stay could be for some of them, and striving to meet their emotional and psychological needs through human-to-human interaction and compassionate communication. In this section I will focus on those initiatives.

Volunteers in A&E can be used to meet older people’s cognitive, psychological and emotional needs. St Boniface Hospital, in Manitoba, for example, acknowledged that while the physical space of the Accident and Emergency department reassessment unit could be improved to meet the needs of their older population, there was also a lack of mental and social stimulation for some of their older longer-stay patients (Kostyshyn 2016).

It was evident that, combined, physical and psychological barriers might be putting older patients at a higher risk for delirium and falls (Apold 2018). After tackling the physical environment to make it more older person-friendly - for example changing lighting and curtains and installing handrails and signage - the focus moved to increase social and mental stimulation in their reassessment area where patients tend to have more prolonged stays: this meant having volunteers playing gentle music in the evenings, interacting with older people by providing art at the bedside, bringing in pet visitors, and offering library book and movie options for patients. Therapeutic activity kits (TAKs) were developed and implemented to assist with stimulation and distraction for patients with dementia and/or delirium. Staff also donated fabrics and materials for the volunteer services department to make therapeutic touch blankets that were gifted to patients with advanced dementia.

This intervention took a holistic approach to older people's wellbeing, also trying to meet their psychological and emotional needs, exactly as the CARE (Care and Respect for Elders) programme in Mount Sinai Hospital's Accident and Emergency department (USA) did, with their volunteer-led service (Sanon et al. 2014).

Before opening their very own Geriatric Emergency Department in 2012 (Cohen 2019), this was a geriatric-focused volunteer program developed to help prevent avoidable complications such as falls, delirium and functional decline in vulnerable elders presenting at the hospital's A&E. The CARE programme consisted of bedside volunteer interventions spanning from conversation to various short activities designed to engage and reorientate older, high-risk, unaccompanied individuals.

Both St. Boniface Hospital (Kostyshyn 2016) and Mount Sinai Hospital (Sanon 2014) have developed interventions which try to meet older people's cognitive, psychological and emotional needs and, in this respect, they are very much aligned to the ICCI, with the exception that they are volunteer based.

The Royal College of Nursing (RCN) SPACE principles of providing environments that are dementia friendly are five principles for the care of people with dementia in hospital, outlined in collaboration with people with dementia and carers:

1) Skilled staff who are informed and have enough time to care;
2) Partnership working with carers;
3) Assessment and early identification of dementia;
4) Care plans which are person-centred and individualised;
5) Environments that are dementia friendly.
   (RCN 2019)

Reflecting on these principles, the Queen Elizabeth Hospital King's Lynn NHS foundation Trust in Norfolk, as part of the wider Royal College of Nursing's development programme to improve dementia care in acute hospitals, allocated four of their A&E bays exclusively to patients with dementia and refurbished them accordingly (Bray et al. 2015). They also created a dementia-friendly observation area, representing a secure environment due to the presence of swipe-access doors at one end and open doors at the other. This meant that any patients who - more or less intentionally - would leave the area, would have to use the open doors and pass alongside a desk where there would always be a member of staff. Additionally, interventions as part of this initiative have targeted the social environment by focusing on staff training and awareness of issues related to dementia: the A&E nurse consultant had a strong dementia background and engaged in encouraging the whole team to think about the needs of individual patients, and how to support them. The hospital also hired dementia support workers. They were informed about patients with dementia shortly after their arrival at A&E and they made sure that information about patients - including non-medical needs - was captured in a *This is Me* document (Alzheimer’s Society 2022), which remained with them at any moment during their stay in hospital. Lastly, Accident and Emergency staff (including the security team) had to attend dementia training to help them understand the perspective of those patients.

This initiative, like the one in St. Boniface Hospital (Kostyshyn 2016), even if initially focused on the physical environment, also took serious consideration of aspects related to staff awareness of issues of dementia, their attitude, and intersubjective approaches to patients. It was run by paid staff - although not formally focusing on older people, but on people with dementia, we know that dementia mainly affects older people (World Health Organisation 2022). This is also the case of a scheme run by Age UK at Hillingdon Hospital, in Middlesex (Triggle 2012), whose emphasis is on taking care of patients’ emotional needs. This scheme has been designed to help support both Accident and Emergency department staff and older patients. It was run by a support-workers’ team (thus, paid roles) who assisted patients with non-clinical activities, such as going to the toilet, eating meals and finding out care-related information, as well as taking care of their emotional needs by attentive listening and reassuring patients.

As we have already seen in Sanon’s (2014) and Kostyshyn’s (2016) studies, in order to prevent functional decline (including the prevention of falls and delirium) it is necessary to adopt a holistic approach, which must include a focus on emotional and psychological needs. The Older Person Technical Assistants (OPTA) were introduced in a tertiary referral hospital’s A&E in Australia (Hullick et al. 2018). This was a workforce dedicated to improving the quality of care for older people in A&E and to reduce preventable adverse events, particularly delirium and is described below.

The OPTAs’ focus was on screening activities and supportive care for people over the age of 75 years who were not experiencing life-threatening situations. The prerequisites for selection as an OPTA included having had previous training or experience as a healthcare assistant or equivalent. At the beginning of their role in A&E, OPTA received a five-day induction training, during which they were oriented to the environment, trained and assessed as competent in several tasks, included maintaining patient privacy and dignity, and using a variety of screening tools and recording systems. At the hospital site, OPTAs were considered as part of a delirium prevention strategy whose tasks consisted in orienting the person to the A&E environment, comforting them if needed, conducting and recording a variety of screening, supporting hydration and nutrition, supervising and assisting moving, providing sensory and mobility aids and offering one-on-one support when agitated, also facilitating the presence of a family member or a carer with the patient as often as possible. OPTAs were also provided with a delirium prevention box that included daily newspapers, playing cards, games and puzzles, crosswords, a radio and a clock to use with patients. They also provided support to family members in the A&E.

Montessori Methods, normally used with children, can also be used to reduce distress and reassure older people with a cognitive impairment in A&E, at the same time helping to preserve their abilities (Clarke 2013). Diana Adams, a geriatric emergency management nurse, at North York general hospital in Canada led an intervention aimed just at this, looking also at improving older patients’ overall experience. Ms Adams and her collaborators would sit down with a patient in A&E for 30 minutes or so, set up materials and allow the patient to interact with the items following the Montessori philosophy (looking at individual’s needs, skills and abilities and then matching them with purposeful, stimulating activities).

In this section I have presented papers which show the existence of services which have at their focus an intentional compassionate engagement with older patients in A&E. Although the anecdotal evidence shows good reception of those services, to the author’s knowledge no formal study exploring the experience of older patients who have received them has emerged so far.

2.7 Gap in the knowledge and confirmed aim of the study

The experience of older people in A&E has been researched extensively both through qualitative and quantitative studies and, today, we know much more than what we knew only 26 years ago. We know that most of them experience fear and anxiety when in A&E (Baraff et al. 1992; Way et al. 2008; Han et al. 2017) and are prone to confusion and disorientation, even more so if they have a cognitive impairment (Reynish et al. 2017), and that when they present to the A&E alone, they may be particularly vulnerable as they may struggle more with sensory and/or cognitive deficits, finding it difficult to understand and/or retain the information they are given.

Waiting, as a general role, is an issue for older people (Spilsbury et al. 1999; Goodridge et al. 2018) possibly because the longer the waiting, the stronger the feeling of not being safe, diminished sense of dignity and confusion (Nyden et al. 2003; Considine et al. 2010; Kihlgren et al. 2004). Some older people do not even expect to be involved in decision-making about themselves (Nyden et al. 2003; Richardson et al. 2007). Many older people prefer not to ask questions or request help, even when they do need it, as they do not want to bother the staff (Way et al. 2008; Bridges and Nugus 2010).

However, there are aspects of the A&E which can enhance older people’s experience to a great extent, and which can even allow them to perceive an increased sense of safety and self-significance; a primary role is played by communication. Communication with staff in the studies presented in this review often emerged as fragmented and not effective, prompting uncertainty and confusion rather than reassurance (Spilsbury et al. 1999; Kihlgren et al. 2004; Stein-Perbury et al. 2015), but in those cases in which communication did work effectively, we can see that it fostered a sense of trust, dignity, and hope. It could soothe, reassure, reorientate and make the patient feel valued and cared for. This communication is described as involving an actual presence and willingness to relate to the person in the patient, to meet patients’ non-clinical needs, to carefully listen to them, and to provide relief and reassurance. It goes beyond technical jargon and often involved eye-contact, physical contact, kindness, sense of humour and an affectionate attitude. Most patients in the studies were sensitive to the healthcare professionals’ intention beyond their words or their gestures and felt they could appreciate when an intervention was made with authentic care and compassion (Kihlgren et al. 2004; Olofsson 2012). Moreover, studies like those of Guttman et al. (2004) and McLeod and Ollson (2006) which investigated the experience of older patients who received the intervention of an Emergency Department Nurse Discharge Coordinator, and an A&E Social Worker, respectively, also show that when an intentional intervention to enhance communication is put in place, older patients’ experiences improve.

A significant difference to older patients’ experience can also be made by the presence of relatives or carers alongside them, which they very much value for practical and psychological support, but also for their potential role as advocates for them (Baraff et al. 1992; Way et al. 2008). If family members or other carers are not available, patients value the presence of volunteers to do this for them (Baraff et al. 1992). Descriptive studies or service reports show the existence of a volunteer-based service, or schemes where support workers or other members of staff engage compassionately with older patients (both with or without dementia or other cognitive impairments) with the intention of reassuring them, offering psychological support and reorientation, minimising distress and cognitive decline in A&E (Clarke 2013; Sanon 2014; Kostyshyn 2016), but no formal clinical study has emerged so far with the aim of gathering rich, evocative accounts of older patients - who may have felt disorientated in the Accident and Emergency department of a hospital and who received an Intentional Compassionate Communication Intervention (ICCI) - which, in addition, is run by a paid professional rather than by volunteers, but with no clinical background or technical training to inform their intervention, solely relying on human-to-human compassionate interaction, about their personal experience of the A&E.

Exploring their personal experiences, getting to know how it was for them, listening to their accounts and to their words as they arise, without a pre-planned agenda, and then telling their stories, was my intention in this study, in order to fill the gap in the literature. Pursuing this aim has the potential to contribute to a deeper understanding of older, potentially disoriented, patients' lived experiences of being in A&E and receiving an A&E-based ICCI. This study could impact upon NHS consideration of new roles in A&E that are responsible for ICCI and how to make older patients' care more effective and sustainable and give this patient group a better experience and outcome. Moreover, including people living with dementia or experiencing other cognitive disorders in the study is not only a way to improve their care, but also a way of valuing their contribution to society and thus enhancing their dignity and their sense of significance. In a number of studies reviewed, older people with impaired cognition were automatically excluded from recruitment (Majerowitz et al. 1997; Way et al. 2008; Stein-Perbury et al. 2015) while Baraff et al. (1992), included only "articulate" (p.64) older people in their sample. But the voice of these patients is just as valuable and ought to be heard.

For the above reasons, after the review of the literature, the aim of my study was confirmed, together with the research question:

What is the experience of older, possibly disorientated patients who receive an Intentional Compassionate Communication Intervention (ICCI) while in Accident and Emergency department (A&E)?

Chapter 3 - Methodology - Study Phase A

3.1 Outline of the chapter

In this chapter, I am going to explain the ontology (assumptions on the nature of reality) underlying the choice of the epistemological paradigm (approach to knowledge) I used in this study, outlining the reasons why a qualitative approach was considered the most appropriate choice, as opposed to a quantitative one, to investigate older people's subjective experiences in A&E. I will then guide the reader along the process I went through when choosing the specific methodological approach, namely: Interpretative Phenomenological Analysis (IPA). In doing so, I will give an in-depth explanation of why phenomenology has been considered the ideal framework to move from when evaluated against other qualitative approaches, including a critical evaluation of what phenomenology is, an account of its most relevant philosophical concepts, and how those concepts have informed the specific Interpretative Phenomenological Analysis (IPA) methodology and its application to this study. I also give an outline of further theoretical influences on IPA, such as idiography, and the concept of the double hermeneutic. I conclude with a reflection on how my identity as a dramatherapist has informed my use of phenomenology in this study.

3.2 Nature of reality

> "Traveller, there is no path.
> The path is made by walking.
> Traveller, the path is your tracks
> And nothing more.
> Traveller, there is no path
> The path is made by walking.
> By walking you make a path
> And turning, you look back
> At a way you will never tread again
> Traveller, there is no road
> Only wakes in the sea".
>
> (Machado 2003, p.25)

The philosophical field concerned with the study of the nature of reality (all that is or exists) is ontology (Guarino et al. 2009). In conceptualising the nature of reality, positivist sciences start from a natural ‘naivety’: the tacit belief in the existence of a truth or of a reality which is independent from the mind. This realist assumption is so engrained in our beliefs that it is not only accepted by positivist sciences, but it actually informs how we live our daily life, and it is for this reason that Husserl called it ‘natural’ (Zahavi 2018).

On the other hand, an existentialist view of reality sees it as completely subjective (Tillich 1944). As Yalom writes:

> “The existential position cuts below this subject-object cleavage and regards the person not as a subject who can, under the proper circumstances, perceive external reality, but as a consciousness who participates in the construction of reality”
> (Yalom 1980, p.23).

This interpretivist paradigm views human beings as meaning-makers, acknowledging that the way we see the world gives shape to the world, and the world gives shape to the way we see the world. Just like Antonio Machado’s poem at the beginning of this section - which beautifully evokes an experience of reality as a constant endeavour of constructing forms out of the formless, implying that nothing exists outside of a subject making sense of it - the interpretivist’s ontological position looks at the world and its objects as not independent from the mind, and embraces the belief that there is not an objective reality out there and a separate subject who perceives it, but rather, we, as human beings, live immersed in a world of “multiple realities”, as Schutz (1945, p.573) named it, showing that knowledge about the world is shaped by intersubjective experiences and contemplate multiple domains, such as everyday life, dreams, arts, and science (Schutz, ibid).

In this research, I started from this position to look at the data. This does not mean that I am advocating the non-existence of a so-called external reality and I am not moving from the belief that the mind makes up features of reality, as a metaphysical Idealist approach would do (Guyer 2015). I am advocating instead a concept of reality as always relational, non-independent from the subject, and somehow co-created. Specifically, in looking at the subjective experience of older people receiving an ICCI when in A&E, my assumption was that both the participants and myself were “consciousnesses who participate in the construction of reality” as Yalom (1980, p.23) says, and that the participants’ feelings and perceptions - and even the very factual accounts they shared with me - did not coincide with ‘the truth’ but rather with ‘their truth’: only one between a number of “multiple realities” (Schutz 1945, p.573) I could explore. At the same time my analysis of their accounts has been my interpretation of their experience: a different researcher would unavoidably provide an alternative analysis, similar in many ways and also different due to their unique perspective.

3.3 Nature of knowledge

Epistemology is the study of how we get to know what we know, the reality/realities discussed in the previous section (Couper 2020). In research, quantitative methodologies belong to an epistemological paradigm which has its origin in the scientific method and in line with the positivistic belief in the existence of an objective reality ‘out there’ born out of the so-called Cartesian dualism which looks at mind/body, subject/object, person/world, and so on, as separate (Stanford University 2020). This approach relies on standardisation, predictability, numerical and statistical procedures for gaining knowledge. Approaching the patient’s experience through a quantitative framework, there could be a risk of treating feelings and emotions as if they are something permanent and concrete (Bergson 2001), thus trying to compare emotions and measure them. Moreover, as Todres states, I was aware that “we can count quantities, but we cannot count qualities. With qualities, the only things we can do is to describe or to interpret them” (Phenomenology in Research: a conversation with Prof Les Todres, Dr Vanessa Heaslip and Dr Jane Fry, Introduction to speakers and the philosophical background of phenomenology, 2016). In contrast, qualitative methodologies move from an epistemological paradigm rooted in the acknowledgement of subjective realities and rely on narrative and description for understanding (Berrios and Lucca 2006). Based on a long-standing tradition, quantitative studies dominate the research literature; however, qualitative studies are increasingly recognised as an important source of knowledge which cannot be gained in any other way (Renjith et al. 2021).

Like Bergson, using an interpretivist approach, I believe that using a quantitative approach to research subjective experiences can be carried out, but the risk is that, in search for objective measurements, the results would be affected by predetermined views of the researcher on what is or is not real, and thus be superficial. To study the experience of older people in this research with some standard instrument as though they inhabit the same objective world, as a quantitative approach would do, would mean introducing a misleading assumption into my study (Yalom 1980). This is because perceptions, feelings and emotions, as well as pain, do not exist objectively and concretely and therefore, cannot be measured. The best thing we can do, instead, is to understand how these aspects of life are experienced (Bergson 2001).

To explore the experience of older patients receiving an ICCI when in A&E, and to try and understand how those patients had lived that particular moment of their life, I needed a qualitative approach which, taking an inductive stance (allowing meaning to emerge rather than trying to test an hypothesis like a deductive approach would do) focuses on providing a rich and contextualized understanding of the participants' subjective experience through the intensive study of how it felt like to be them in that particular situation (Polit and Beck 2010). This is because I needed to understand the meanings that those people gave to their experience rather than try and measure something objectively. It is for this very reason that a qualitative approach represented the most useful way of understanding an experience from the point of view of those who had it (Cohen et al. 2000) in this study.

However, using this approach to explore participants' experience, I knew I should be careful to remain aware that I would always filter it through my own subjective lenses, and I needed to acknowledge that, ultimately, I did not have direct access to any 'truth' and I could not 'know' for sure. This is at the core of the existential doubt (Yalom 1980), and in clear contrast to quantitative research methodology.

3.4 Methodological choice

There are multiple criteria underlying the choice of the epistemological paradigm which guides a particular study. In this case the methodological approach was chosen taking into consideration both the paradigm which would better serve the scope of the research as well as my personal starting point as a researcher. This was influenced by my professional identity and the philosophy I felt was most coherent with my personal way of making sense of the world around me (I will talk more extensively about this in section 3.7 “Phenomenology and my position as a dramatherapist”).

In the landscape of qualitative research methodologies, I needed something which could allow me to run an in-depth exploration of how individuals, who received the ICCI while in A&E, experienced their A&E stay. My main aim being for their experiences to be recognized. Moreover, as a dramatherapist, whose background is both in the arts and in psychology, I wanted the beauty of their embodied lived experience to come out as well as the complexity of their psychological response to the A&E experience (meaning making, perceptions, feelings). By beauty, here I am referring to an aesthetic dimension, which concerns the qualities, patterns, feelings, and emotions which make meaning possible for us (Johnson Steinerberger 2019).

I explored several approaches. I considered ethnography, which is a research method originating in the field of anthropology, now widely used in various social science fields. Ethnography entails the researcher gaining access to the culture and practices of a group or community and it is a useful approach for learning – through personal deep and prolonged immersion - about the behaviour and interactions of people within a particular context or social group (Caulfield 2020). However, I soon realised that ethnography would have been useful if the aim of the study was the impact ICCI had on the culture of compassion in the emergency department, as it focuses on the cultural description of a setting or a community (Atkinson and Hammersley 2007). Eventually, because I am interested in individual lived experiences, I chose not to use this approach.

I then explored grounded theory. Grounded theory originally developed in order to offer a clear and systematic guide to qualitative investigation and analysis

(Glaser and Strauss 1967) and its aim is to generate a theoretical-level account of a particular social situation or issue. I thus realized that grounded theory would have been the best choice if my aim had been to formulate a more general theory from the experience of patients (Corbin and Strauss 1990). Grounded theory would have enabled a theory of explanation around patients' experiences in A&E, which could have been easily translated into practice, however, its approach was created to allow the researcher to study "basic social processes" (Willig 2001, p.69) while for me, the focus on the individual's experience was more important and grounded theory would not allow me to reach the detailed and nuanced analysis of individual cases I was looking for.

I also briefly considered narrative analysis, which is a methodology that includes the analysis of the characteristics of the narrative text (Hoshmand 2005; Felton & Stickley 2018). It is concerned with people's narratives about themselves or a set of events. Rather than looking for themes that emerge, it focuses on structures within a narrative and possibly the sequential unfolding of the participant's story. A positive aspect when considering narrative methodology was that it focuses on stories as they are told by participants, but the aspect which did not fit my aim was that this methodology not only asks 'what' the story means but also 'how' meaning is assembled through the narrative structure (Gubrium & Holstein 1997). The focus is the narrative structure rather than the lived experience.

I thus realised that phenomenology was the right approach for me because it is a method of exploring what it is like to be a particular individual having a particular experience, and it would allow me to do so using both *the head and the heart* (Galvin 2010). Using phenomenology therefore, I have been able to access what Galvin and Todres call an "empathic knowledge" of the participants' experiences (2011, p.523).

3.5 Phenomenology

Phenomenology - which, before being a research methodology, is a philosophy - using Kant's words (1999) - is the study of phenomena, as opposed to noumena. Noumena are the things themselves, the material, immutable things, while phenomena are our experience of the things (Cohen et al. 2000). The word *phenomenology* comes from two different Greek words: “phenomenon”, which means “to show or to appear” and “logos” which means “discourse, reason, or judgement” (Moran 2000, p.229). By looking at the etymology of the word it can be seen very clearly how phenomenology represents the infinite dialectic between what appears to our consciousness, what we can sense, and the meaning we make out of that.

Phenomenology deals with the exploration of the nature and structure of human conscious experience (Smith and Osborn 2003) rather than with the so-called objective reality, and it does so by reflection upon our lived experience in order to reach some understanding of its underlining order, coherence and structures (Smith and Osborn 2003). Todres, in a recorded talk for Bournemouth University students (Phenomenology in Research, a conversation with Prof Les Todres, Dr Vanessa Heaslip and Dr Jane Fry: phenomenology as a way of being and its influence on practice and research, 2016) gives a very poignant explanation of what constitutes a phenomenological attitude in research: all appearances of *something* to our consciousness are equally real to phenomenology, for example, if one was to explore the experience of a person hallucinating, they would regard that experience as something as real as any other experience, because phenomenology does not rely on consensus or on objective measures in order to define something as real. The heart of all phenomenology has to be found in its assumption that there is *something* that appears to our consciousness, but which is not independent from it, and in its commitment to discover what we can know about that *something* (Todres 2007). Selecting a phenomenological approach for this study represented a fairly logical choice: researchers using phenomenology are interested in individual subjective experience, recognising it is relational and embodied and, as such, it emerged as the best paradigm to start from in order to pursue the exploration of how participants experienced the A&E department from within and to make sense of their emotional, cognitive and embodied response to that particular experience. However, I needed to look closer at different approaches to phenomenology in order to be able to choose the one which would better serve the research question.

It can be stated that in the vast world of phenomenology there are two main approaches: descriptive and interpretative. There are basic differences between the two, which mainly lie in the juxtaposition between Husserl's faith in the very fact that there is something beyond interpretation that we need to discover and describe before interpreting it (Husserl 1962) and Heidegger's belief that we are interpreting from the very first moment we come into this world (Heidegger 1962) and there is not a possible alternative to that.

Todres (2007) points out that Husserl was interested in universal essences, almost wanting phenomenology to reach the features of a science. He articulates the difference between descriptive and interpretative phenomenology using a number of powerful images, such as descriptive phenomenology aiming at the *bare-bones* of existence, while interpretative phenomenology aims at the *flesh*, or conveying it as the difference between looking at the *structure* (descriptive) or at the *texture* (interpretative) of existence (Phenomenology in research, a conversation with Prof Les Todres, Dr Vanessa Heaslip and Dr Jane Fry: The distinction between descriptive and interpretative phenomenology, 2016). I had to carefully consider both in order to choose the one which would best suit the research question.

3.5.1 Descriptive phenomenology

The origin of descriptive phenomenology, also known as transcendental phenomenology, can be traced back to Edmund Husserl who initiated the phenomenological movement in 1900 (Moran 2000). He was interested in epistemology, the theory of knowledge and how we know, consciousness, and the structure of consciousness (Kurthen et al.1998). Husserl has made important contributions to almost all areas of philosophy and has anticipated central ideas of disciplines such as sociology, linguistics, and cognitive psychology (Kjsovick et al. 2020).

Husserl's focus was on "the experience as it is before we have thought about it" (Crotty 1996, p.95). He was interested in primitive forms, what can arise immediately to our consciousness, "before we have applied ways of understanding or explaining it" (Crotty 1996, p.95). Therefore, following his view, descriptions of experience come necessary before we reflect on it (Husserl 1962)

Before Husserl, the debate in Western philosophy was mainly between realist approaches, where academics were interested in the object of knowledge - *the known* - and idealist approaches, which were focused on the subject of knowledge instead - *the knower* - (Korab-Karpowicz 2017). Descarte, for example, father of modern philosophy, whose beliefs were for Guyer (2014) certainly infused with ontological idealistic elements, openly doubted the certitude of the world outside of the self (Descarte 1986) while Husserl, in turn, accused him of failing in understanding the nature of consciousness, which for him was always a consciousness of something other than itself (Husserl 1962). However, rather than offering an alternative philosophical view of reality as a way out of the realism/idealism debate, Husserl argued that philosophy should instead turn to pure description of the things “as they appear to us” without obscuring them with preconceptions or hypothetical speculations (Popa 2018, p.53).

For Husserl, phenomenology should aim at the rigorous study of things as they appear, to get to an essential understanding of human consciousness and experience (Valle et al. 1989). For this very reason, one of his central concepts was that of *“*phenomenological reduction*”* or *“*epoché*”* (Dowling 2007, p.132) which referred to the rigorous and consistent acknowledgment of one’s own assumptions or pre-conceptions on reality to make them overt and separate them from the phenomenon: to be able to see it in its pure essence. This phenomenological reduction should be applied to all assumptions, included the so-called “natural attitude” (De Warren 2006, p.86), which for him represents the belief humans commonly share about the existence of a reality which is separable from the subjective experience of it (Dowling 2007). He called *bracketing* the process of putting aside the taken for granted world (Ashworth 1999). Bracketing means to unblend our own assumptions about a phenomenon from our direct perception of that phenomenon (Moustakas 1994). Only by doing this we can, in Husserls’ view, get to the essential qualities of a particular experience which for him consisted in the essential characteristics which can transcend the particular circumstances of their appearance and might then illuminate a given experience for other people too (Smith et al. 2009).

3.5.1.1 Phenomenology and the Lifeworld

As already mentioned in Chapter 2 , in 1936 Husserl coined the term *Lifeworld* - in German: *Lebenswelt*. With this word, he aimed at encapsulating the concept of the world as directly experienced by a subject from his own, unique, existential position, as neatly distinguished from the objective world of the positivistic science. Husserl believed that, although positivism originates in the Lifeworld, the objectivism of science can conceal both its origin in the subjective perceptions of the Lifeworld and the Lifeworld itself (Harrington 2006). Lifeworld is *the World of Lived Experience* (van Manen 2002), thus the lived experience of patients who received the ICCI in this study, is to be looked at part of their Lifeworld.

3.5.2 Interpretative phenomenology

Throughout the 20th century, the approach of phenomenology became the most important and influential development of European thought, with a number of philosophers providing different turns away from Husserl in the years to follow. Among them was Martin Heidegger (Moustakas 1994), who developed interpretative phenomenology, also known as hermeneutic phenomenology (Laverty 2003; Langdridge 2007), and as existential phenomenology (Spinelli 2005).

Heidegger was Husserls' student. He turned away from his transcendence towards a much more embodied and *worldly* concept of existence (Smith et al. 2009; 2022). Husserl's notion that the essence of experience can be examined by setting aside one's own assumptions, or bracketing them, was dismissed as too simplistic by Heidegger (1962), who saw *pure experience* as something elusive (Smith et al. 2009).

Heidegger (1962) declares nothing can be encountered without reference to the person's background understanding, and every encounter entails an interpretation based on the person's background in its "historicality" (Koch 1996, p.180). In this way, Heidegger brought to phenomenology the awareness that bracketing is always only partially achievable (Finlay and Gough 2003): he saw phenomenology as an essentially analytical and interpretative activity, stressing that

> “an interpretation is never a pre-suppositionless apprehending of something presented to us”
>
> (Heidegger 1962, p.191).

Moreover, Heiddeger, in Being and Time (1962), introduced the concept of *Dasein* (literally: *there-being*) which for him is the nature of *Being*, as to say, something inherently inter-subjective: “Dasein is essentially being with” (Heidegger 1962, p.156). Dasein replaces the individual predicated by Cartesian dualism (mind/body, subject/object, person/world, and so on) with individuals as *being-in-the-world* with others and with things. It sheds light on our relatedness to and involvement in the world as mutually constitutive - *humans as being-in-the-world* who is also a *being-with* (Mitsein) in a *with-world* (Mitwelt) - (Eatough and Smith 2017). This is his way to conceptualize that our consciousness is not separate from the world, that there is not a world separated from the mind (Dowling 2007) but also that understanding is always a relational and reciprocal activity (Koch 1996) where “subject and object are correlated without dissolving one into the other” (Feenberg 2004, p.130) and where “activity and receptivity complement each other” (Feenberg 2004, p.130). It is not surprising that researchers from the caring movement such as Benner and Wrubel (1989) took on a Heideggerian approach in their study of caring in nursing. Moreover, Walsh (1999), for example, moved from Heidegger’s existential position in his study of nurse-patient encounter in psychiatric care, making a point that the concept of *being-with* allows the nurse to attune more deeply and fully to the human experience of the patient as it becomes part of their “shared humanity” (p.7). This *being-with* in nursing, entails a circular, iterative act of co-creation of meaning where interpretation is central. In the following section, I will better explain what it is meant by interpretation, through the concept of hermeneutic and the hermeneutic circle.

3.5.2.1 Hermeneutics and the hermeneutic circle

Hermeneutics is the theory of text interpretation, rooted in the renaissance interpretations of biblical and ancient texts (Cohen et al. 2000). Traditionally, hermeneutics had been associated with the interpretation of texts only, but Martin Heidegger developed it, by associating it with the interpretation of the existence (*the being*) of Dasein (1962). He realised that texts are meaningful products of human actions, and therefore that hermeneutics could be used successfully to explore and understand problems that arise from every human action and its products, not only texts; ultimately, to understand human existence itself.

For traditional hermeneutics, interpretation was a way to gain understanding. It was a means to understand something that we did not understand before interpretation (Hoy 1993). This means that at the beginning there is no understanding, which arises only after interpretation:

Interpretation → Understanding (Martinkova and Perry 2016)

Heidegger looked at hermeneutics differently: he changed the relationship between interpretation and understanding and gave those terms different meanings (Martinkova and Perry 2016). He pointed out that interpretation cannot arise from nothing to create understanding: he believed interpretation itself operates on the basis of some form of already-existing understanding which is then deepened and extended (Heidegger 1962). Heidegger sees the human being as always-already understanding itself or something. For him, interpretation is always related to some primary understanding being worked upon and worked out, so that his hermeneutic becomes:

Understanding → Interpretation (Martinkova and Perry 2016)

Just as Heidegger re-interpreted hermeneutics, he also re-interpreted the idea of the hermeneutic circle. Traditionally, hermeneutics focussed on texts, and the *hermeneutic circle* meant that parts of the text could not be interpreted without an understanding of the whole of the text, and the whole of the text could not be interpreted without an understanding of its parts (Hoy 1993). Heidegger applied the hermeneutic circle to an understanding of human existence. He was convinced that human beings understand themselves in some way, but often not adequately, or fully, rather they understand themselves on the basis of their understanding of other entities in the world. Through the commitment to attempt to understand the world and its entities, human beings can start to position themselves in relation to them, gradually coming to an understanding of aspects and characteristics of their own existence, thus achieving a new self-interpretation accompanied by a more adequate self-understanding. This new self-understanding may, in turn, inform new understandings and interpretations of things and entities in the world and, as a result, this changed understanding of the world once again influences self-understanding, and so on (Heidegger 1962):

Understanding → Interpretation → Understanding.

Gadamer was Heidegger's student and made an essential contribution to the development of hermeneutic philosophy. He was initially interested in Plato's dialectic philosophy which is a method of proceeding against the common notions to show what contradictions they hide, with the purpose of directing oneself towards what *is* instead of what *appears* (Mitchell 1988), which will then have a significant influence on his view of hermeneutic phenomenology (Barthold 2009). Today he is recognized as one of the most important voices for hermeneutic phenomenology (Cohen et al. 2000).

There are four principles at the core of Gadamer's phenomenological philosophy:

1) Hermeneutic philosophy is and must be a practical philosophy: according to Malpas (2003), this is a fundamental contribution from Gadamer, which took him beyond Heidegger. For him, all knowledge and understanding always stems from practical human concerns and one must be very careful not to lose the way in abstraction (Gadamer 1975). He also clarifies that with practical philosophy he means a philosophy which is rooted in human existence, which - for its nature - is never a solitary event but always a shared experience (Barthold 2009). He firmly believed that an excessively theoretical or scientific knowledge might run the risk of forgetting that knowledge comes from and must return to praxis (Gadamer 1975).

2) Truth is not reducible to scientific method: Gadamer fully developed his unique concept of truth in Truth and Method (1975). Here*,* following Heidegger’s wish to broaden the scope of hermeneutics beyond that of texts, Gadamer, embraces the view that human beings’ existence and understanding are intrinsically related. To get to know ourselves authentically, he says, we need to figure out what such an understanding entails in both its possibilities and limitations. Proceeding further than Heidegger, he asks: if this would happen, what would it mean? (Gadamer 1975). Moving against traditional conceptions of truth, Gadamer looks at truth as an event, a happening, one in which we can encounter something that is larger than and beyond ourselves (1975).
3) All knowledge is historically situated: Gadamer, looks at understanding as always historically situated (Gadamer 1975). However, he argues, historical situatedness does not automatically means restrictive limitations: limits are precisely what can allow us to be open to what is new (Barthold 2009). He uses the term “horizon” (Gadamer 1975 p.302) to suggest the limits that make perspective possible, and which makes knowledge always situated and perspectival. In the same way as the literal, visual horizon:

   > “provides the boundaries that allow us to see, so the epistemic horizon provides boundaries that make knowledge possible”
   > (Barthold 2016, p.13).

   This concept of horizon for Gadamer is a fertile one: without the limitation of a horizon there would be no seeing. One’s horizon is not an obstacle to overcome or eliminate, because the “view from nowhere” would see nothing (Gadamer 1975, p.302).
4) All understanding reflects the ubiquity of language: in Truth and Method, Gadamer stresses the importance of the linguistic nature of human existence. He does not consider language as mere propositions and shows us how meaning is made through linguistic expression that lies on a whole (Being) which is greater than its parts (the expressions of language, for example, propositions). This mechanism makes language functioning not as an object but as a horizon that embraces us and our understanding (Sugarman 2006). Language, however, cannot fully

contain *Truth*. Truth (Being) exceeds and cannot be fully grasped by language. This is the reason why for him, understanding never means having the final word (Gadamer 1975). At the same time, we do not run the risk to be trapped inside language because language is an open device, “a productive limit that makes possible the continual creation of new words and worlds” (Gadamer 1975, p.361). Language for him is:

> “A medium where I and the world meet, or, rather, manifest their original belonging together”
> (1975, p.474).

In the same text, Gadamer states: “Being that can be understood is language” (p.474). Barthold (2009) views this claim as meaning that neither everything is language nor all Being is reducible to language.

3.5.3 Conclusion

When choosing between descriptive and interpretative approaches to phenomenology, I found myself strongly resonating with the following conceptualization: a purely descriptive phenomenological approach would aim at *summarising* what appears to consciousness (the phenomena) while an interpretative approach, far from being interested in any form of synthesis, would aim at *evoking* the richness of what appears to us (Todres 2007). I considered that rather than transcending the particular in order to identify the invariant structures in the participant’s experience, as Husserl would want, I rather aimed at shedding light on the A&E experience as lived by a number of embodied socio-historical situated individuals (Eatough and Smith 2017) as Heidegger and Gadamer would want. Therefore, it became clear to me that I needed to look into the field of interpretative (also known as hermeneutic) phenomenology in order to pursue the research task.

3.6 Why IPA?

While working on the choice of the specific interpretative phenomenological approach to take, I considered van Manen’s hermeneutic phenomenology, which I felt was close to the ideal fit. Like Heidegger, van Manen does not fully embrace Husserl's view of bracketing and asks:

> "If we simply try to forget or ignore what we already 'know', we might find that the presupposition persistently creeps back into our reflections?"
>
> (van Manen 1990, p.470).

However, van Manen's proposed phenomenology is focused on:

> "letting a phenomenon [lived experience] show itself in the way that it gives itself while living through it"
>
> (van Manen 2017b, p.813).

He suggests that phenomenology should focus on a study of the pre-reflective meaning of an experience (Dowling 2007), before we can articulate it and make-meaning out of it. Considering that this approach is purposefully quite unstructured (Zahavi 2019), as a novel researcher, I felt I needed a more structured container to support my enquiry. This search and reflection eventually led me to Interpretative Phenomenological Analysis.

3.6.1 Interpretative Phenomenological Analysis (IPA)

Even if the main concepts underlining IPA comes from a long time ago, this methodology has a quite short history. Jonathan Smith started to talk about IPA in the mid 1990's while trying to conceptualise an accessible research approach to psychology which would be able to capture the experiential and the qualitative (Smith 1996). Much of the IPA early work was in psychology (Smith et al. 2009), however, we can see that, lately, this methodology has been applied to different fields like organisational studies (Tomkins and Eatough 2014), education (Denovan and Macaskill 2013; Thurston 2014), health (Seamark et al. 2004; Cassidy et al. 2011), sports science (Stacey et al. 2019) and the humanities (Hefferon and Ollis 2006).

IPA is a phenomenological approach concerned with the examination of how people make sense of their major life experiences (Smith et al. 2009; 2022). When talking about major life experiences, IPA refers to the difference between two states which can be seen as on a continuum: on one end of the continuum, we find ourselves unselfconsciously caught up in the everyday flow of the experience, while at the opposite end side of the continuum we find those moments in which we become strongly aware of what is happening and that what is happening is breaking the everyday, usual, flow of events, representing something significant. This is when we are having *an experience* as opposed to just *experience*. Dilthey (1976) explains what *an experience* is:

> “Whatever presents itself as a unit in the flow of time because it has a unitary meaning, is the smallest unit which can be called an experience. Any more comprehensive unit which is made up of parts of a life, linked by a common meaning, is also called an experience, even when the parts are separated by interrupting events”.
>
> (p.210).

Dilthey’s definitions of *an experience* provided above is certainly the one which best fit the participants’ contribution to this study: during the data collection process and later during the analysis, I looked at their experience in A&E as a whole, as “the smallest unit which we can call an experience” (ibid). This is important, as even if during the data collection I might have supported their recall of the experience by mentioning different moments of it (their arrival to A&E, the triage, the waiting time, the ICCI, their transition to the ward), what I wanted to elicit was an account: the telling of an event, a story which was not broken up into parts or a series of events. IPA shares the view that human beings are sense-making creatures, thus the accounts which participants provided mirrored their attempts to make sense of their own experience. It also acknowledges the role of the researcher’s own interpretation of the participant’s account in order to understand their experience: the researcher acts as an audience to the participant’s story, and in this respect, represents their co-creator (Smith et al. 2022).

IPA is based on the analyst’s own interpretation of the individual’s accounts. It is phenomenological because it is concerned with the participant’s own experience of the phenomenon, it is idiographic as it is concerned with the individual particular case, it is inductive, as its aim is not to test a hypothesis rather to reveal meaning, it is interpretative (hermeneutic) as it acknowledges that insight is dependent upon interpretation and the researcher is implicated in the analysis, and it is reflective, as it acknowledges that the researcher’s own assumptions, conceptions and interpretations will influence the understanding of the individual's experience (Smith et al. 2009; 2022).

3.6.2 Main influences

As the focus of the inquiry in IPA is the moment in which the regular flow of everyday existence is somehow broken and we have *an experience*, so the approach of the IPA researcher involves an active disengagement from the regular flow of everyday existence to bring their attention back to everything they take for granted in that flow, what in IPA is called "fore-structures*"* (Smith et al. 2009, p.25), in order to make the creation of understanding a transparent process.

In this study, following IPA directions, and informed by Husserl, I have been consistently committed to make the mechanism of meaning making as transparent as possible, through the ongoing use of self-reflection aimed at disentangling my own feelings and expectations from the participant's authentic expression; However, I recognise, like Heidegger did, that separating the participant's experience from my own is never totally attainable. Moreover, I never attempted to capture the 'essential' of a phenomenon, and I limited myself to exploring the experience of a particular phenomenon as lived by particular individuals.

IPA takes from both Heidegger and Gadamer a conception of experience as always perspectival, always temporal and always in-relation to something (Smith et al. 2009; 2022). IPA draws on those philosophers' awareness that, for the very nature of their own humanity, a researcher always brings their assumptions, prior experiences, or expectations to the encounter with the participant and, unavoidably, will look at anything new in the light of their own prior experience, or fore-structures (Smith et al 2009; 2022).

In IPA we see the dynamic relationship between parts and whole of the hermeneutic circle operating - at the analysis stage - between a single word and the sentence where we can find it, a single extract and the whole text from which we extrapolate it, a particular interview and the whole study, and so on. It is an iterative, non-linear but rather circular way of thinking (Smith et al. 2009;

2022). In this study, I engaged with the hermeneutic circle by moving back and forth between the parts and the whole rather than completing one task after the other, both during the data collection - by cyclically coming back to specific words the participants might use and that I might find particularly interesting - and during the data analysis. This, as Smith (2004) states, should bring me “closer and closer to the participant’s personal world” (p.46). Following the hermeneutic circle, it is not only that our prior knowledge affects the interpretation of the phenomena, but also that the phenomena, affecting our interpretation will, in turn, affect our knowledge, which will then again affect the interpretation (Moran and Mooney 2002). When I faced a new encounter with a participant, or I attempted to analyse a new transcript, there has always been something old (coming from my previous participants’ encounter and my previous analysis in the same study, but also from prior life experiences) which somehow engaged in a dialogue with that new encounter or transcript: this is the dialogue that in IPA takes place between what we bring to the phenomena and what the phenomena brings to us (Gadamer 1975). Sometimes we can know our fore structures in advance, sometimes they will emerge during the analysis (Smith et al. 2009; 2022). In both cases, this has required me to stay open at any given moment.

It is also worth noticing that while the participant tried to make sense of their experience, they also were entering the hermeneutic circle. When the participant named and shared their experience, they were somehow re-shaping it. New meaning emerged as they kept on talking about it and, at each step, this new meaning-making operation was influenced by what they had noticed/acknowledged/reflected on at the previous step, but also from what I had asked them and how I had posed the question and, in turn, what they said and how they said it affected what I asked next, and possibly, how. This is the inextricably relational nature of the existence of Dasein (Heidegger 1962).

IPA also takes from Gadamer a very humble approach to interpretation. It moves from his idea that interpretation does not objectify, does not attempt to determine something as an impartial observer: it rather tries to understand what is actually to be understood in a complex fabric of meaning, trying to almost make it speak, bringing out what is inside all those structures of meaning (Gadamer 1975). IPA is also very loyal to Gadamer’s commitment to practical enquiry, and fully embraces his belief that all knowledge and understanding always stems from practical human concerns and it is there that they need to return, without losing their way in abstraction (Gadamer 1975). Finally, Gadamer's insistence on the key role of language for human existence - a language which is always dialogic - is key in IPA where the focus is on letting *the language speak* (Gadamer 1975), as he would put it, and which, both for him and Heidegger, was one of the key aim of hermeneutics (Heidegger 1962 and Gadamer 1975). *Linguisticality* for Gadamer is an ability to learn to come to an understanding with others, because language for him only exists in conversation, which means that there is a linguistic togetherness which needs to be developed (Gadamer 1975). This relational and dialogic approach colours IPA at each single step of the process.

3.6.2.1 The Hermeneutic circle (or double hermeneutic)

Smith and Osborn (2003) use the term *double hermeneutic* to describe the two interpretations involved in a research process: the first involves the participant making sense of their own experience, and the second involves the researcher interpreting the participant (Smith et al. 2009; 2022). The circularity of the process (making the question, allowing meaning to emerge, and then keep on questioning) which is involved in the interpretation of a phenomenon is usually called the hermeneutic circle (Moran 2000; Smith et al. 2009; 2022), as already mentioned in previous sections.

In IPA, the concept of Double Hermeneutic captures that particular dynamic of the researcher trying to make sense of the participant trying to make sense of their own experience already mentioned when referring to the hermeneutic circle in section 3.5.2.1. Specifically, writing about IPA, Smith et al. (2009) make a comparison between interpretation and the work of detection: in their view, the researcher is “mining” the material for possible meanings which allow the phenomenon of interest to “shine forth” (p.35), then, these meanings are critically analysed and compared with each other and with the researcher's evolving positionality and pre-understandings. However, it is always important to remember that this shining forth of the phenomenon is positioned in the context of the Lifeworld of a particularly situated person. IPA's double hermeneutic is a reminder of this and is captured by the phrase:

> "The researcher is trying to make sense of the participant trying to make sense of what is happening to them"
> (Smith et al. 2009, p.3).

Here, the double hermeneutic is to be intended in the context of how interpretation and understanding involve a synthesis of both participants' sense-making and the researcher.

The double hermeneutic also emerges when the IPA researcher relates to a participant's account adopting a "both/and" approach (Eatough and Smith 2017, p.194): on the one hand, the researcher is to adopt an empathic stance and try and imagine what it is like to be the participant, whilst, on the other hand, they need to be critical of what appears to be and searching for meaning in ways which participants might be unwilling or unable to do themselves. (Eatough and Smith 2017). This suggests a dual interpretative engagement: a *hermeneutics of faith* or affirmation and a *hermeneutics of suspicion* (Ricoeur 1970). Looking at the process through the lenses of the double hermeneutics, in this study I was in some respect like the participants, as we were both trying to make sense of something. However, I did this in a structured and rigorous way through my engagement with the text of the transcripts, the operations of the hermeneutic circle, the dual hermeneutic attitude of faith and suspicion, and my commitment to reflexive practice and acknowledgement of my assumptions, making regular use of a reflective journal.

Having discussed the double hermeneutic, I am now going to discuss another pillar of Interpretative Phenomenological Analysis, which is the concept of idiography.

3.6.2.2 Idiography

Idiography represents the commitment to the particular case (Smith et al. 2009). Idiographic enquiry needs to be seen as opposed to *nomothetic* enquiry, whereas the first is concerned with the particular and detailed case and the second is interested in making claims about groups or populations and in establishing general laws of human behaviour (Smith et al. 2009; 2022).

IPA is idiographic in its commitment to reveal how a particular experience has been understood by a particular individual, and it is idiographic in its systematic and rigorous methods of analysis which aim to go in-depth and reveal richness of detail (Smith et al. 2009; 2022). Idiography does not purposefully avoid generalisations, rather, generalisations may possibly be individuated by moving from the particular, therefore they need to be developed very cautiously (Harre' 1979).

Idiography perfectly reflects the nature of the specific interest that brought me to formulate the research question: I wanted to explore in detail the depth of the experience of individual beings allowing each voice to emerge, and by doing so in the study, I never rushed to generalise their experiences. The idiographic nature of IPA can beautifully be represented by the following lines from Goethe:

> "The particular eternally underlies the general, the general, eternally has to comply with the particular"
> (Goethe cited by Hermans 1988, p.785).

3.6.3 Conclusion

IPA is a very accessible phenomenological methodology and offers a flexible and versatile frame to the understanding of people's experiences (Tuffour 2017), yet it also provides a clear structure, which represent a reliable container for exploration to a novice researcher like me. However, these are not the only reasons why I have chosen it. My main consideration was that between other phenomenological methodologies, not only its idiographic nature would allow me to run a detailed and in-depth exploration of each participant's experience, but also, being interpretative, it would allow me to interpret the voice of older, potentially disorientated participants for the wider academic community. Older people, particularly people with dementia belong to that group of *seldom heard* voices in our society (O'Connor et al. 2022) whose contribution is much needed if we want research to be an agent of social change. I felt that IPA hermeneutic nature – emphasising interpretation in the research for meaning – coupled with its accessibility, could make the difference to me being able to enable communication between those participants, the academic community and the NHS.

3.7 Phenomenology and my position as a dramatherapist

Phenomenology, as a philosophy, informs dramatherapeutic practices and theories as well as other forms of psychodynamic psychotherapies. Psychodynamic psychotherapies have their theoretical roots in psychoanalysis, which, as Weitz (1956) points out, present several points of contacts and convergences of approaches with phenomenology.

If we think about what Gadamer (1975) describes as the pre-verbal stream of experience which exceeds language, and which will never be fully contained by language (the phenomena), it feels quite natural to recall classic psychoanalytic concepts of pre-conscious or sub-conscious thought (Freud 1999), and the three dimensions of *Real, Imaginary* and *Symbolic*, and the trauma of entering the language which Lacanian psychoanalysis tells us about (Lacan 2006).

Gadamer taught us that the attempt at articulating experience (the phenomenon, which at the same time underlies, exceeds and makes language possible) with the awareness that this will never be fully possible, is the endeavour of phenomenology (Gadamer 1975) and it is also the endeavour of dramatherapy.

Moreover, today, neuroscientific studies on psychological trauma treatment are showing us what phenomenology and psychoanalysis have been telling us for decades: that language cannot fully contain our experience, that there will always be something more, something *unspeakable* (Van Der Kolk 2014) to our being in the world. This is the reason why arts can convey our lived experience in a deeper way than everyday language can do. Todres brings storytellers as an example of this: he asserts that storytellers can retain the connectivity of all those elements of our stream of experience as we live them, before we separate them for the sake of language (Phenomenology in research, a conversation with Prof Les Todres, Dr Vanessa Heaslip and Dr Jane Fry, Breadth and Depth: Concrete Examples from the Lifeworld 2016). It is not by chance that storytelling and story-making are between the main techniques used in dramatherapy.

Both Heidegger and Gadamer were persuaded that this was the case (Heidegger 2008 and Gadamer 1975): In Truth and Method (1975) Gadamer talks extensively about play and art (both obviously central tenets in dramatherapy), showing many resonances with Donald Winnicott's psychoanalytic theory of psychological development (1971), another strong theoretical influence in dramatherapy practice, stating that play represents a paradigmatic example of experiencing "truth" because of its "medial" nature (1975, p.103) – Winnicott would say "transitional" (1971, p.1). For Gadamer experiencing truth entails losing oneself in something greater and more extensive than oneself (Gadamer 1975) and this is exactly what players do when they are being caught up in play rather than striving to control or direct it.

This is also exactly what happens when clients fully engage in dramatherapeutic processes involving play, dramatic play and improvisation, relinquishing control and self-consciousness. Here is when psychological insight (Wallas 1926) usually happens, and healing can follow. In his writings, Gadamer also clarifies why and how this process of insight, in his words: "recognition" (Villhauer 2010, p.44), comes about. He calls "presentation" the second nature of play which explain how play becomes transformed into art (Villhauer 2010, p.44). For him, the self-presentation of human play lies in the player's being faithful to the make-believe goals of the game, however, the meaning of these goals does not depend on their achievement, rather, it depends on the very fact of spending oneself in the task of the game, in "playing oneself out" (Gadamer 1975, p.108). The self-presentation of the game is in itself the player's own self-presentation by playing – that is, presenting – something (Barthold 2009). For Gadamer (as it is for Winnicott and for dramatherapy), play is always a presentation of something and, in being this, it is always self-presentation (Villhauer 2010, p.44).

Gadamer provocatively states that an artistic representation is more true than the original it endeavoured to imitate (Gadamer 1975). This is because recognition (psychological insight, a dramatherapist would say) requires something more than seeing objectively where we can bracket our subjectivity while remaining at distance from the art. Recognition, he says, means "being played by, drawn into, the work of art in such a way that one's own being is altered" (Barthold 2016, p.121). As Gadamer points out, an encounter with art capable to reveal truth (and thus healing, a dramatherapist would say) only occurs when we feel as if the art was speaking directly to us:

> “it is not only the ‘This art thou!’ disclosed in a joyous and frightening shock; it also says to us; ‘Thou must alter thy life!’”
> (Gadamer 1977, p.104).

Referring directly to theatre, Gadamer adds:

> “In being played the play speaks to the spectator through its presentation; and it does so in such a way that, despite the distance between [the play and the spectator], the spectator still belongs to play”
> (1977, p.116).

The belongingness Gadamer speaks about is a core concept in dramatherapy: we experience ourselves through drama, belonging to it, and this is possible only “as we look ahead, envisioning ourselves anew” as he would say (Barthold 2016, p.121).

Once we acknowledge this, it is easy to understand why losing oneself into play and then reflecting back on that experience in dramatherapy can bring about deep psychological insight, healing and change.

Dramatherapy, as I said in Chapter 1 , is to be considered a phenomenological practice and shares with phenomenology its relational and embodied stances, together with its interest in the subjective experience of human beings.

There are several specific contributions/overlaps between phenomenology and dramatherapy, for example:

- A phenomenological approach requires a systematic suspension of our assumptions about the shared world. This is exactly what enables us dramatherapists to transpose ourselves even into the most different ways of perceiving the world, assuming – in our strenuous effort to understand the client – both differences and resemblances between one’s own way of experiencing the world and the other’s (Stanghellini 2013);
- “Phenomenology entails a view of human beings’ interaction that is based on concepts of empathy, attunement, embodied resonance and

intercorporeality rather than cognitivist notions such as theory of mind or mind-reading" (Fuchs et al. 2019, p. 2). This is exactly where dramatherapy basic notions of attunement, containment, active listening, mirroring, embodiment and *betweenness* (Pitruzzella 2018) come from;

- Dramatherapy relies on a phenomenological view of the unconscious as an embodied, relational dimension, residing in the realms of "intercorporeality and intersubjectivity" (Fuchs et al. 2019, p. 2), rather than on the idea of a more pre-programmed unconscious typical of classical psychoanalytic theories;
- Finally, there is a long-standing tradition of translating "phenomenological concepts of being-in-the-world into existential and daseinsanalytic approaches of psychotherapy" (Fuchs et al. 2019, p. 2) such as dramatherapy, which is also based on more recent existential-hermeneutic concepts, like, for example, human vulnerability and trauma as basic conditions of emotional distress, and on the dialogical nature of existence (Fuchs et al. 2014).

From my point of view, if phenomenology represents a humanising response to the failed attempts at measuring feelings and perceptions through quantitative methods, dramatherapy (like other forms of psychotherapy) represents a humanising way to respond to the failed attempts at treating mental health through a purely biomedical or cognitive-behavioural approach. Like phenomenology, dramatherapy is holistic, person-centred, non-directive and permission-giving.

As already stated in Chapter 2 , when I started my PhD and for part of my first year, the research aim, and the chosen methodology were different. However, it was the meeting of my 'dramatherapist self' with older patients in the hospital during months of informal observations and emotional support at the bedside that led me to change my research question and relative methodology. I can see now that my interest in the research subject has itself stemmed from a relational stance, as it was by being in relation to a number of older patients that the beauty (aesthetic dimension of my identity as an artist) and the density of emotional human experience (my therapist/clinician dimension) of what I was relating to made such a strong impression on me to push me to a phenomenological kind of enquiry, where the depth of lived experience of individual participants and the embodied nature of my encounter with them would have shined.

What I found as a cornerstone of my practice both as a dramatherapist and as a phenomenological researcher is the awareness that *communication* and *communion* share the same etymology (Dolci 1965): real communication happens between two people only when each one gives up to his power over the other and connect to a deeper level. This is where my dramatherapist self has been feeling free to exist fully, with no risk to pollute my role as a researcher, as in this aspect the two roles could live in perfect communion.

3.8 Summary of the chapter

In this chapter I reflected upon the ontology (existential/interpretative) underlying the choice of the epistemological paradigm (qualitative approach) used in this study, outlining the reasons why a qualitative approach was deemed as the paradigm of choice, as opposed to a quantitative one, to investigate older people’s lived experiences in A&E. Guiding the reader through the process I went through when choosing Interpretative Phenomenological Analysis as a specific methodology, I presented an in-depth explanation of why phenomenology has been considered the ideal framework to move from as opposed to other qualitative methodologies, and I presented a critical view of what phenomenology is, an account of its most relevant philosophical concepts, and a consideration of how those concepts both inform IPA and have informed its specific application to this study. I also provided an overview of further theoretical influences on IPA, such as idiography, and the concept of the double hermeneutic. I concluded with a reflective section on how my identity as a dramatherapist has informed my use of phenomenology in the present study.

Chapter 4 – Study Design and Methods – Study Phase A

4.1 Outline of the chapter

In this chapter I am going to give an overview of the research design and methods involved, including how I obtained access to the setting and to the participants, the process of recruitment (outlining inclusion and exclusion criteria and their rationale), how I ran the data collection at the site, how and why I used semi-structured interviews as a method, a description of the methods of transcription and analysis involved, a more in-depth report of how I ran the analysis, and a thorough reflection on the main ethical challenges involved in running the study with this participant group, from planning to dissemination, and how I faced them. I will also present a narrative and reflexive account of how the COVID-19 Pandemic affected and re-shaped the study design.

4.2 Overview of the research design and methods

In this qualitative study, data have been collected using in-depth one-to-one semi-structured interviews. In-depth interviews have been carried out with eight patients over a period of seven months between September 2019 and March 2020 and the transcripts have been analysed thematically. The whole process, from data collection to data analysis and writing up, followed IPA suggested guidelines (Smith et al. 2009; 2022).

4.2.1 Gaining access to the setting

The research site is part of a medium sized NHS General District Hospital in the South of England. In 2019, the hospital provided healthcare for approximately 200.00 patients annually from a diverse demographic. The A&E was attended by 58.000 patients annually, out of which 30 per cent was aged 65 years and over, well above the national average for the UK (NHS 2019).The A&E at the site was divided between an external waiting area communicating with reception, which in turn communicated with a triage room, two internal waiting areas, X-ray and examination rooms (one just for children), two nurses' stations, two doctors' offices, minor injuries units and major injury units, a large resuscitation area, two eye rooms, a relatives' room, a child play area, a kitchen, and 18 cubicles (see Figure 3, p.86).

Figure 3 – A&E floorplan

as it was when I ran the study -no longer accurate- (with permission from the Trust)

When I started the recruitment process in August 2019, in my role as part of my clinical doctorate’s requirements, I had spent more than one year collaborating with the dementia care team both providing emotional support to patients at their bedside and supporting staff and volunteers in relating to older patients in hospital. I had also conducted informal observations of the ICCI delivered in A&E to orientate myself to the setting. As a result of this, I had developed a network of gatekeepers and had gained access to the wards and to different professionals, particularly among the dementia care team’s members.

4.2.2 Recruitment of participants

The dementia care team in the hospital regularly referred potential participants for the study among those patients who had been referred to the team by A&E, after having screened them against the criteria of the eligibility checklist. Only after this, the team would ask the patients’ permission for me to approach them.

An appropriately qualified professional member of the dementia care team assessed participants’ mental capacity specifically around the decision to consent to participate in the research at all three key points of the study:

- At introduction;
- Immediately before Informed Consent was given;
- Immediately before the interview.

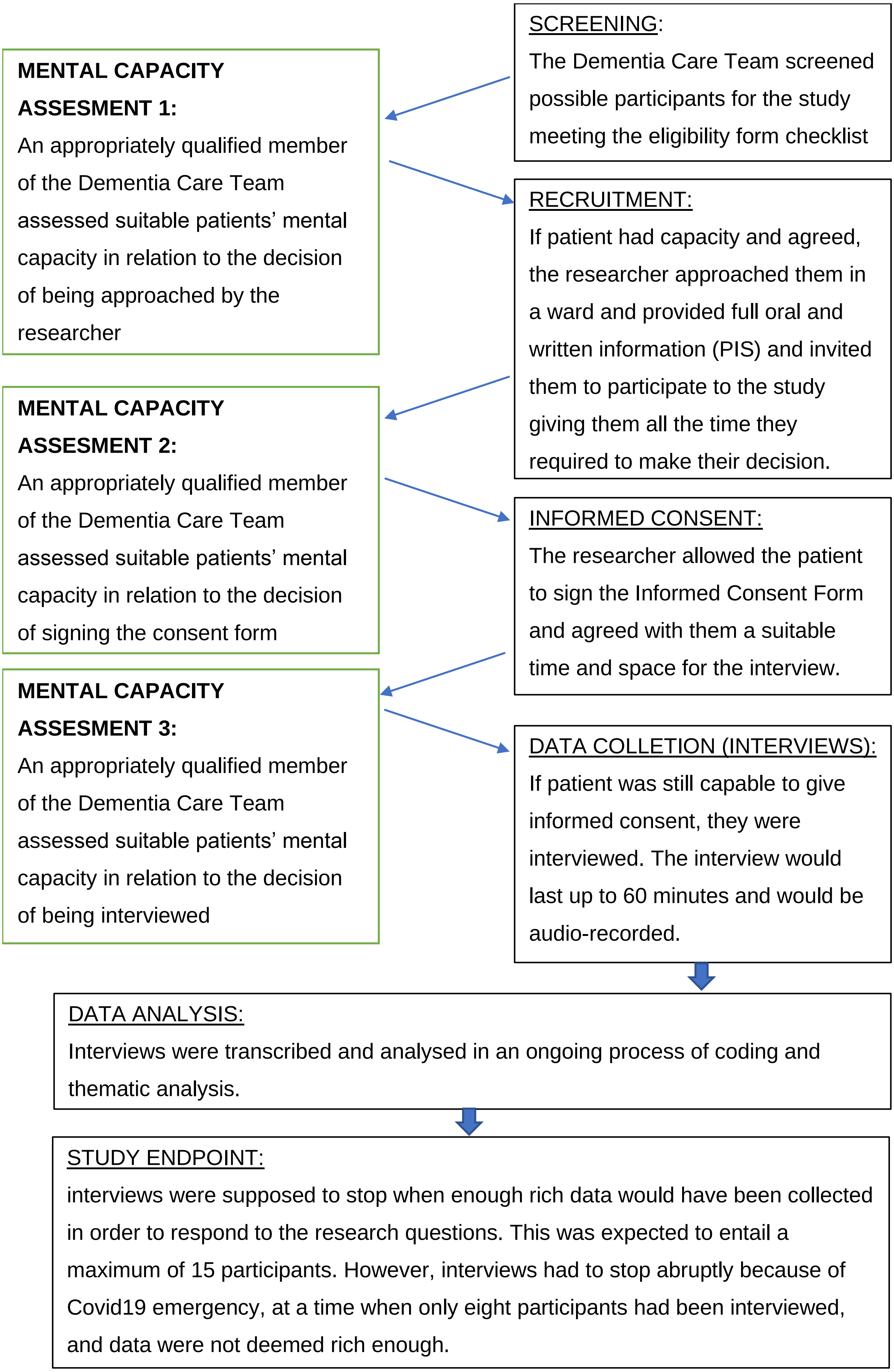
At the introduction, after patients’ permission for me to visit them had been gained by a member of the care team, I would approach them – this usually happened at their bedside, between a few hours and few days after they had been transferred from A&E – to give oral and written information (see Appendix 5 – PIS for patient participants – p. 341) and to ask for consent. This happened only when the care team had considered them physically and mentally fit. In accordance with the Mental Capacity Act 2005, the professional was used to verify if the patient was able to understand, retain, use and weight the information provided and to communicate their decision

Patients were always given as much time as they needed to make their decision on whether to participate, however, they were usually available and willing to sign the informed consent and to be interviewed straight after they had read the Patient Information Sheet. After this, and after their mental capacity was reassessed one last time, they were interviewed (see Figure 4 – Study Flow Chart – Phase A, p.89).

My aim was to recruit a minimum of eight and a maximum of 15 participants between those eligible patients who were admitted to the hospital via A&E and who received the ICCI. This number of participants in qualitative research is recognised to be sufficient to extract in-depth data for analysis (Morgan et al. 2002). Morse (1991) also state that sample size must be determined by the purpose of the study and since statistical representativeness was not the aim of my research, larger numbers were not required. Moreover, Smith et al. (2009; 2022) point out that being IPA primarily concerned with a detailed account of individual experiences, and most human phenomena being fairly complex, IPA studies tend to benefit from a concentrated focus on a small number of cases. Although in the new edition to their IPA guide, Smith et al. (2022) state that in case of a PhD study, 10 participants is considered optimal, when I ran the study back in 2019 the recommended sample number in IPA for a PhD researcher, new to the methodology, ranged around eight participants or less (Smith et al. 2009).

4.2.2.1 Inclusion and exclusion criteria

To pursue my aim, as IPA suggests, I needed a purposive sample of participants (Smith et al. 2009; 2022). This sample-specificity has consequences for the applicability of findings, as each account needs to be local, and the analysis needs to be cautious and built cumulatively (Smith 2009; 2022). I was looking at the particular, thus I did not need a population but rather a homogenous sample of people who could share their unique perspective on a given experience (the A&E stay, inclusive of the ICCI). This rationale, together with more strictly ethical factors (described in section 4.3, p.103), lead me to use the criteria showed in Table 8 (p.90):



SCREENING:
The Dementia Care Team screened possible participants for the study meeting the eligibility form checklist

MENTAL CAPACITY ASSESMENT 1:
An appropriately qualified member of the Dementia Care Team assessed suitable patients' mental capacity in relation to the decision of being approached by the researcher

RECRUITMENT:
If patient had capacity and agreed, the researcher approached them in a ward and provided full oral and written information (PIS) and invited them to participate to the study giving them all the time they required to make their decision.

MENTAL CAPACITY ASSESMENT 2:
An appropriately qualified member of the Dementia Care Team assessed suitable patients' mental capacity in relation to the decision of signing the consent form

INFORMED CONSENT:
The researcher allowed the patient to sign the Informed Consent Form and agreed with them a suitable time and space for the interview.

MENTAL CAPACITY ASSESMENT 3:
An appropriately qualified member of the Dementia Care Team assessed suitable patients' mental capacity in relation to the decision of being interviewed

DATA COLLETION (INTERVIEWS):
If patient was still capable to give informed consent, they were interviewed. The interview would last up to 60 minutes and would be audio-recorded.

DATA ANALYSIS:
Interviews were transcribed and analysed in an ongoing process of coding and thematic analysis.

STUDY ENDPOINT:
interviews were supposed to stop when enough rich data would have been collected in order to respond to the research questions. This was expected to entail a maximum of 15 participants. However, interviews had to stop abruptly because of Covid19 emergency, at a time when only eight participants had been interviewed, and data were not deemed rich enough.

Figure 4 – Study Flow Chart – Phase A

Table 8 – Study participants – Phase A – Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion
Patients aged 65 years and over	Any patient with a physical condition that is immediately life-threatening or unstable
Patients admitted for any reason to the hospital via A&E	Patients who are involved in other clinical trials which present a significant burden to them
Patients presenting alone or confused or with a diagnosis of dementia	
Patients referred to the dementia care team	
Patients who received the ICCI when in Accident and Emergency Department	
Patients who can give informed consent to participate in the study as identified by a registered healthcare professional	

The decision to limit the recruitment to patients aged 65 years and over has been taken after careful consideration – informed by the literature – of what it means to be an older person in England today: defining old age is an ever-elusive issue, much related to the socio-historical context rather than to biology only (see section 1.3 “An increasingly older population”, p.4).

Eventually, I decided to set the line at aged 65 years as even if the average beginning of biological *slowing down* is indicated by the NHS (2015) to start around 70 years, the current average pension age in England is around 65 years (Age UK 2019) and that could potentially be considered as a significant symbolical transition towards old age

I had no reason to restrict the recruitment to patients admitted for certain medical reasons rather than others. I was interested in potentially disorientated older patients and these individuals might be found in all kinds of referrals. However, it makes sense to believe that people who arrive to the A&E

for any reason, but also having a diagnosis of dementia, presenting confusion, or being alone, are more at risk of feeling disorientated. Shapiro et al. (2012) observes that cognitive decline, sensory loss and reduced physical ability – all of which are generally present in people with dementia (Alzheimer’s Society 2019) – may make people feel more passive and prone to feel disorientated in an emergency department. Also, arriving to the emergency department without the support of a carer may be stressful and prompt disorientation as older people may suffer from lack of company and lack of support in understanding information given by healthcare professionals and, also, from feeling that there is nobody there to advocate for them (Way et al. 2008).

The decision to include only participants who, after their time in A&E had been admitted to the hospital, rather than including also those who were discharged straight after, was taken in consideration with regards to the ethical need to obtain informed consent, which required that a mental capacity assessment was carried out by a member of the dementia care team, at different points in time, thus setting the requirement for the participant to be in hospital.

The decision to include only patients referred to the dementia care team was taken partly for convenience (this was the team where I was based in the hospital, and the most part or my gatekeepers were based there) but also because that would allow me to reach many potentially disorientated patients given that the dementia care team supports patients admitted into the hospital who have a cognitive impairment either as a result of an underlying dementia - diagnosed or otherwise – or who are experiencing transitory cognitive symptoms such as confusion as a result of a delirium. The rest of the criteria were set for ethical reasons (see section 4.3 “Ethical considerations”, p.103).

4.2.3 Data collection

4.2.3.1 Notes on IPA further developments

As already stated, IPA is a very flexible methodology, it does not aim to be prescriptive and encourages researchers to be creative and experiment new ways to practise it. However, just before running this study, I had been trained in Dublin City University by Prof. Paul Flowers who is one of the authors of the first edition – the most updated back then – of the IPA manual, which gives precise guidelines on how to structure an IPA study from the design to analysis and writing up stage.

In 2022, a new manual was published, and although the authors still encourage researchers to be flexible and creative, there has been some change to the terminology used and substantial change to the guidelines for running analysis. This study, although acknowledging the new terminology in use and the variation in the processes suggested, is based on the guidelines in use prior to Smith et al. (2022), as data analysis has taken place before this publication. Smith et al. (2022) acknowledge that it is acceptable for either the old or the new guidelines to be followed in different studies at the moment.

4.2.3.2 Data collection plan and the impact of COVID-19

Interviewing, transcribing and data analysis have all been parallel processes beginning with the data collection phase. The data collection was set to end when I had collected enough rich data to answer my research question. According to Smith et al. (2009; 2022), in IPA there is no such concept as saturation of data due to its idiographic and not easily generalisable nature. In IPA, data collection should end when the researcher had collected enough rich data to answer their research question (Smith et al. 2009;2022). As already stated in Chapter 1 , the data collection for this part of the study ended abruptly in March 2020 due to the COVID-19 Pandemic (see section 4.4 “COVID-19 emergency”, p.123). Given that the supervisory team and I did not deem the data collected thus far as being rich enough, I made major amendments to the study protocol, and I added a new study aim to be able to gather more data on the ICCI phenomenon in an alternative way. This second phase of the study will be explored in the second half of this thesis.

4.2.3.3 Why semi-structured interviews

Data for this study have been generated through in-person, one-to-one, semi-structured interviews.

Semi-structured interviews are probably the best way to collect data for an IPA study (Smith et al. 2009) as they can facilitate the emergence of detailed stories, thoughts and feelings from the participants (Smith et al. 2009;

2022). The main reason for using semi-structured interviews as a data collection method was to allow each individual to tell their experience in their own terms, and in a way which was meaningful to them (Reid et al. 2005). Even if semi-structured interviews can reduce the control the researcher has over the interview process itself and are harder to analyse than structured ones, I believe, with Smith and Osborn (2003), that this method prompts rapport and empathy, and opens up the possibility to go into new and unexpected areas. This might produce richer data. However, it's important that the researcher accepts, from the beginning, the almost inevitable sense of discomfort which derives from sitting with the unknown for a certain amount of time.

4.2.3.4 Preparation of the interview schedule

In this study, a predefined set of points to cover during interviews was generated starting from my research question, therefore a range of questions for the participants which, once answered, would provide me with an opportunity to answer the research question (Smith et al. 2009; 2022). I then arranged them in a sequence which could provide structure for the participant to revisit their experience, and hooks for memories (see Appendix 7 - Topic guide for interviews patient participants – p. 349), but this was only used as a guide, not to dictate the process of the interview. I often asked questions in a different order, or I totally dropped some of them, or added new questions which came out of what that specific participant was telling me at a specific moment.

4.2.3.5 Preparation of the researcher

Before starting the data collection, I practised the interview with my supervisors, who provided me with useful feedback (for example about the pace, the best way of handling silences and the most helpful wording of questions for the specific participant group).That was particularly useful for me in order to notice that, for example, I didn't always use plain English, so that I had to be careful to adjust my use of language, and that I had to be very cautious in nodding after a participant's response as that might give them a sense of me favouring some responses over others.

4.2.3.6 The interview

Before the interview, after mental capacity had been reassessed by a qualified healthcare professional who was part of the dementia care team, I greeted the patient and made sure that they felt comfortable and ready, that they were wearing their glasses if needed, as well as their hearing aids and their false teeth, should they have needed them. I reiterated my duty of confidentiality and gathered permission to audio-record.

Interviews were carried out mostly at the bedside of participants – following participants' needs – and with bed curtains closed, while they were on different wards (see Chapter 5). Participants have been interviewed between a few hours and few days after their admission to the hospital. The duration of interview ranged between 15 and 40 minutes although both the participants and I were prepared for the interview to last up to one hour. Each interview was audio-recorded.

The structure of each interview was flexible and centred on the participant, and I always tried to encourage description rather than explanation by asking 'how' questions rather than 'why' questions. As the focus in IPA is lived experience, the questions needed to relate to experience and also be as open as possible so that the participants could be followed in how they described their world. The main points which I tried to cover each time were:

- Their experience of entering the A&E department;
- Their experience of being in the A&E department;
- Their experience of moments of receiving ICCI;
- Their experience of leaving A&E (and being moved to a ward), the focus remained on A&E rather than the ward setting;
- Anything else the participant would like to share about their experience in A&E.

During the interviews, I always tried to create a relaxed and informal atmosphere, and I was always open to leave time for general chatting both at the beginning and in between questions before coming back to the main points. This was because I wanted participants to feel at ease and to trust me, as I knew this would affect to a great extent their availability to go in-depth and to be honest. Silences were always attended to and, when possible, not broken. I often came back to some keywords or key-concepts from the participant’s account which I found particularly relevant and asked them to tell me more about that. This was very useful in order to facilitate depth and details to emerge. I paid attention to my and the participant’s body language. I always tried to use an interested but non-confrontational body posture, sitting at 45% degrees and not in front of the participant whenever this was possible. I used eye-contact to establish connection, but at the same time being careful not to over-use it in order to avoid intimidating the participant, and I was always aware of maintaining an open physical attitude by, for example, keeping my arms and legs uncrossed. Smiling and nodding was used carefully in order to encourage the95eason95on95tt to open-up without appearing to privilege some of their answers over others so to avoid over-influencing the interview process. I believe this was, to a certain extent facilitated by my skills as a dramatherapist (for more details see section 4.3.8 “Notes on reflexivity”, p.120), however, there has been space for new learning to emerge from practicing the interviews: for example, I soon became aware that I needed to slow down the pace at times and, also with some of the participants, I needed to be ready to follow them into more general chatting and small-talk in between questions before they would be ready to go back to the topics of the interview.

Immediately after the interview, I gained permission from the participant to receive the following information from the care team: age, time and date of admission to A&E, and length of stay in A&E. At the end of the interview, I would normally check with them how they were feeling, thank them, and make sure that the nurses knew the interview was finished. Immediately after having left the place of the interview, I would write fieldnotes and I would also regularly write a reflective journal about the research process.

4.2.4 Transcription

I transcribed data by repeatedly listening to the recordings of the interviews. This was usually made one or few days after each interview had been carried out. I captured words as well as pauses and verbal utterances from both the participants and myself. Suspension marks plus numbers (i.e.: … 3) were used to indicate the seconds of silence which made up each pause. Punctuation was kept to a minimum in order not to inadvertently alter meanings as a result of the transcription process itself. Often, it was necessary to use a software to slow down the speed of the recording given that some of my participants had strong regional accents and/or did not articulate their speech very clearly. Moreover, using a second language myself added to the above-mentioned difficulties in understanding and transcribing. Whenever I was not able to understand or hear their words even after repeated listening at a slower pace, I checked the audio recordings with my supervisors, and only when this last step did not bring results, I wrote: ‘inaudible’. I used pseudonyms for names and places in order to protect confidentiality.

4.2.5 Overview of the analysis process

An IPA analysis is to be considered as a joint product of participant and analyst. It involves stepping out of our everyday fast and economic meaning-making attitude to slow down and light-up our attention in order to reach a depth of understanding (Smith et al. 2009; 2022). Personally, it required me, above all, to constantly maintain a very open and inquisitive attitude.

After transcription, I immersed myself in the data. I listened again to each interview while reading its transcript, any correction needed was made at this very moment and then I read and re-read the transcript. This allowed me to feel like I was hearing the voice of the participant in my head, which assisted in further immersing myself into the data, recalling body language and tone of voice. Smith et al. (2009; 2022) state that repeated reading allows active engagement with the data meaning that richer data may emerge. This phase was important as it gave me the possibility of mapping out the interview structure and its narrative to help to develop a mental model of the person and of the interview content. This was also the moment in which I checked back to all my reflective notes to recall my impressions, feelings, thoughts and contextual data of the day. The transcription was then copied onto the second column of a table made up of five columns and was line-numbered (Table 9, p.97).

Table 9 – Extract of data analysis table before completion – Phase A

MAOYDH 05			**Explorative Comments**		
Emerging Themes	**Original Transcript**		**Description/content**	**Language use**	**Interrogative/conceptual**
	…	…			
	108	**I:** And that attention she gave			
	109	you, how did it feel?			
	110	**M:** … (3) very good			
	111	**I:** tell me more			
	112	**M:** … ahem… (3) ahahahahah!			
	113	**I:** I know, we are talking about			
	114	feelings here! Ahahahaha!			
	115	**M:** no, well, that's like you giving			
	116	me the call on button			
	117	**I:** the call on button?			
	118	**M:** yes, the call on button is			
	119	when you can have someone			
	120	from the staff with you the			
	121	minute you want them. Well,			
	…	…			

The table above (which is the one I chose to use) is an adaptation from Smith et al. (2009) following the principles of linguistic, descriptive and conceptual notes still present in Smith et al. (2022). The first step in using the table was to highlight different parts of the text of the transcript which stood out as significant in relation to the research question. Then I started writing the first exploratory notes using different ink colours. Exploratory coding, to me, represented the interpretative work of striving to envision all the potential meanings the participants might have made of their experience rather than what I could quickly guess they might have meant. However, even if I was the first one to try and see different possible interpretations, supervision was key at this stage. It opened the possibility for me to receive cues on different ways of seeing the data, and having a large supervisory team was an asset to this.

In practical terms, there is no fixed way to conduct analysis in IPA. However, Smith et al. (2009) suggest – particularly to new researchers – to divide the analysis in stages ranging from a first, more descriptive approach, which is still very much grounded into the transcript's text, (Description/Content, blue ink) followed by a more interpretative one, where the researcher is looking for evidence of the ways language reflects meaning-making (Language use, red ink) and ending up with the most abstract level of interpretation (Interrogative/conceptual, green ink) where the researcher uses themselves and their own experiences as a benchmark against which to think about participants. Once I had worked at these three initial steps of explorative coding for a single transcript, I was then ready to start developing some (provisional) emergent themes – which equate to what Smith et al. (2022) would call today "Experiential Statements" (p.86) – by the interpolation of the three levels of analysis, and I noted them on the first column on the left (Emergent themes, black ink). An example of the finished process can be seen in Table 10, p.99.

Table 10 – Extract of data analysis table after completion – Phase A

MAOYDH 05			**Explorative Comments**		
Emerging Themes	**Original Transcript**		**Description/content**	**Language use**	**Interrogative/conceptual**
Feeling safe with the ICCI.	… 108 109 110 111 112 113 114 115 116 117 118 119 120 121 …	… **I:** And that attention she gave you, how did it feel? **M:** … (3) very good **I:** tell me more **M:** … ahem… (3) ahahahahah! **I:** I know, we are talking about feelings here! Ahahahaha! **M:** no, well, that's like you giving me the call on button **I:** the call on button? **M:** yes, the call on button is when you can have someone from the staff with you the minute you want them. Well, …	The attention of the ICCI professional felt very good He compares the experience to the feeling one has when has the "call-on" button: having someone from the staff with you in the moment you need them.	Laughs. Embarassed? He uses a powerful metaphor here: "the call-on button"	Did the presence of the ICCI professional give them a feeling of safety, as he felt she was there to attend to how he was feeling and he could rely on her? Like when you have the call-on button?

4.2.6 Analysis in detail

The first step of the analysis process involved analysing each single transcript (exploratory coding within participant) trying to describe and summarise its content.

This phase of coding was very face value and aimed at describing what the participants had said, with no – or minimal – interpretation attached to it. For each line of the transcript, I basically asked myself: ‘what is the participant talking about here?’ I tried to describe the key objects, events, and experiences of the participant’s Lifeworld (Smith et al. 2009; 2022) as they emerged in the interview. It was necessary to come back to this stage further on to check again for issues I may have missed initially. This phase of coding was essential to further familiarise myself with the transcript.

The second step of exploratory coding – always within participants – involved thinking carefully about language use.

Here a more interpretative action took place: I started to interrogate myself about all the possible meanings of single words in the sentences or single sentences in the text. I noticed and tried to open-up different possible meanings of pauses, utterances, repeated words, all in the context. I was focused on the ways content and meaning were presented in the transcript to try and shed light on the ways in which language and meaning were related.

The third phase of exploratory coding within participants involved a more advanced conceptual and interrogative coding.

This was the most strictly interpretative work of the whole process of coding and moved my analysis away from the superficial and closer to the depth of the participant’s meaning. In order to try and open-up different possibilities, I made a consistent use of question marks. It was more about asking questions rather than giving answers and it required me to make use of myself and my previous experiences to investigate the text in search for possible underlining conceptual meaning. It was possibly the most challenging step of the whole process of analysis as I had to try and distillate meanings, moving constantly back and forward between the whole and the parts of the text, acknowledging my pre-understanding and trying to remain as close as possible to the participant’s actual account and its context. This was a journey into a far more abstract and conceptual dimension of analysis and provided me with a range of provisional meanings for the transcripts.

At this point, I was ready to shift towards an analytic process of ‘coding the codes’, always within participants. My task here was to reduce the volume of data whilst still maintaining complexity by mapping the interconnections and patterns between the three exploratory codes. Moving back and forth between single parts and the whole text and between the original transcript and the exploratory codes, I had to be able to individuate a few themes (and name them) which could logically be used to wrap-up the tentative possibilities expressed in the exploratory notes. However, it represented far more than a summary or merely descriptive labels. Emergent themes at this stage represented the possibility to give a more unifying and solid status of meaning to my explorative codes and reflected both the participants’ interpretation of their experiences and my own. The result was an operation of capturing and reflecting understanding.

After the analysis within participants, I moved to the first stage of analysis between participants, searching for patterns and connections across emergent themes and creating super-ordinate themes. As Smith et al. (2009) state, the phase of looking for patterns and connections between emergent themes can be made both at the *within participants* analysis stage, or later, at the *between participants* analysis stage, after each transcript has been analysed and a table of emergent themes has been completed for each of them.

My choice was to wait until the between participants phase to look for clusters of emergent themes, as Smith et al. (2009) suggest this to be the more suitable way of proceeding when analysing more than six transcripts. The task here was to individuate clusters of emergent themes crossing the tables of each single transcript and discovering how these emergent themes related to each other in terms of in-context logic and meaning, and then to group them under a new, more comprehensive title, which would represent the super-ordinate theme. Today Smith et al. (2022), would call it “Group Experiential Theme” (p.100).

Example shown in Figure 5, p.102.

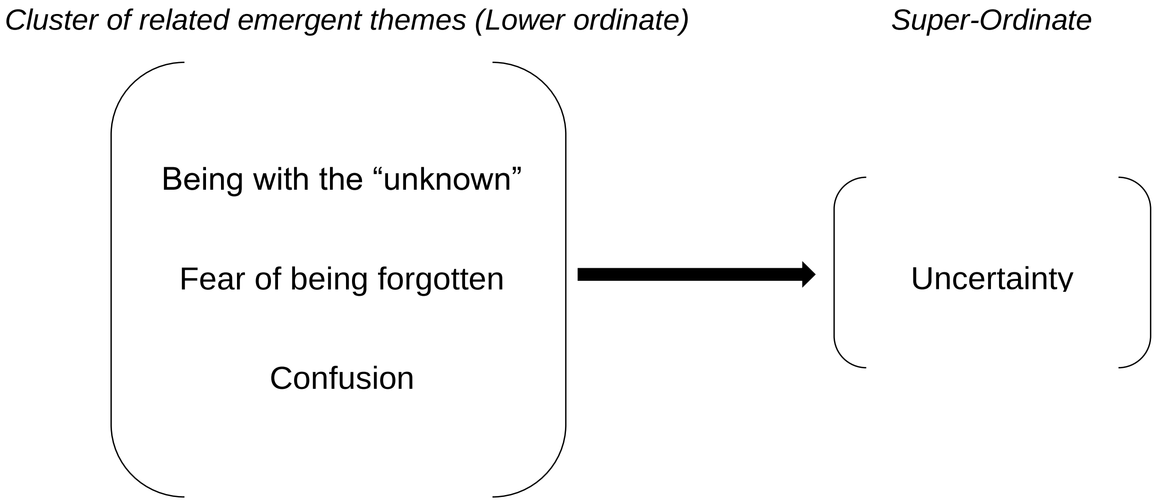


Figure 5 - Clusters of related emergent themes

The result of this work has been a table of themes for the whole group of participants showing how themes are grouped under super-ordinate themes and illustrating the theme for each participant (see Table 14 – Recurrences – Phase A, p.135).

The last stage of analysis involved me looking for recurrent themes between lower-ordinates across all participants.

As my sample size was not particularly small (I interviewed eight participants, and in IPA a small sample is considered one with up to six participants) I followed Smith's advice (2009) to try identifying recurrent themes. The key decision at this stage was how to define the status of 'recurrent' in my study. Although Smith et al. (2022) state that, as a rule of thumb, a recurrent theme is to be considered a theme which recurs for at least one half of the participants, in 2009 (which is what I could base myself upon at the time of running the analysis) they stated that there was not yet a fixed agreement in this methodology on when a theme is to be classified as recurrent (Smith et al. 2009). Wanting to practise a very sensitive analysis of the findings, I therefore decided that when an experience at the lower-ordinate level emerged for at least three participants or more, it would be considered a recurrent experience/theme. Moreover, I decided not to discard experiences recurring for less than three participants, in order to remain close to the idiographic nature of my enquiry.

4.3 Ethical considerations

Any research involving human participants presents ethical issues, even more so when carrying out research involving vulnerable participants while investigating possible sensitive issues. In such cases, it is important to carefully consider all the risks and benefits involved at any stage of the research process and to take appropriate measures to guarantee both the participants and the researcher's safety.

A number of national and international ethical codes guide research involving human subjects. At their core, there are principles such as beneficence, respect for autonomy of participants and justice for them. The protocol of this study has been reviewed and approved by the Research Ethics Committee (REC) Oxford C, Health Research Authority (HRA), Bournemouth University, and the NHS Trust Research and Development (R&D) department before the starting of recruitment and data collection (see Appendix 3 - REC approval for Study Phase A – p. 335 – and Appendix 4 - HRA approval for Study Phase A – p. 339) but ethical considerations do not stop when the official approvals are obtained; rather, they accompany the researcher at each and every stage of the study process.

4.3.1 Involving people with dementia in research

As Alzheimers Europe (2011) Heggestad et al. (2012) and Ries et al. (2020) state, including individuals with dementia in research raises some particular ethical dilemmas. These are challenges which may be encountered from the planning to the reporting phase. Writing an ethically robust proposal informed by solid principles may function as a guideline, but even if one can carefully and rigorously anticipates the ethical challenges which might arise, there will always remain a grey area, some elements of unpredictability, particularly around how the research participants will react to the researcher.

Garand et al. (2009) also states that in dementia research, risks might be intensified by the stigma associated with the illness, the impaired cognition of participants and the possible fluctuating nature of their mental capacity, and Hellstrom et al. (2007). Pesonen et al. (2011) add that an important part in the landscape of possible risks is played by the sensitive nature of discussing the illness experience if /when this is involved. For those very reasons, people with dementia were excluded from research for a long time (Beattie 2009; Whitfield and Wismer 2006) and are often still excluded from many areas of research (Gove et al. 2018). However, the principle of justice entails including marginalised voices in research, allowing their stories to be heard (Pesonen et al. 2011).

Not allowing research involving persons with dementia or other vulnerable groups because of the ethical and moral challenges involved would result in an unacceptable lack of new knowledge about the condition and how it is experienced by people. In addition to this, it needs to be acknowledged that in order to develop effective services and policies we need to get to an understanding of the perspective of the lived experience of people with dementia which would not be possible without involving them in research (Whitfield and Wismer 2006; Beattie 2009; Novek and Wilkinson 2019). Equally important is that excluding vulnerable people from research may even increase their vulnerability, reinforcing negative stereotypes and contributing to social exclusion (Cotrell & Schulz 1993; Hellstrom et al. 2007). On the other hand, more knowledge may reduce the stigma associated with the condition and lead to more openness around it (Heggestad et al. 2012).

Accordingly, the UK Government (2015) has made it clear that it aims at more than doubling research participation among people with dementia, and Alzheimer’s Disease International (2018) called for a doubling of world-wide research on dementia by 2025. In response, the body of qualitative research involving people with dementia has grown (Novek and Wilkinson 2019).

What this process shows very clearly is that instead of avoiding research with groups who are deemed to be vulnerable, one should focus more on the importance of robust ethical considerations and planning, and, as Heggestad et al. (2012) state, on moral sensitivity in research and how researchers may develop it. As Pesonen et al. (2011) point out, the question in dementia research today is no longer whether people with dementia should participate in research, but what the most ethical way of doing this is.

I have been asking myself this question since the planning phase of this study. First of all, I considered that a study like this, which entails in-depth interviews focused on sensitive issues, can have an impact on the well-being of both study participants and the researcher, regardless of their age or cognitive skills (Pesonen et al. 2011). However, considering that the study participants were all potentially vulnerable due to their age, their condition or in-patients, and, for some of them, their diagnosis of dementia, its impact could potentially be greater and specific considerations needed to be made at each and every stage. These considerations include issues of consent, communication, protecting from harm while offering opportunities for inclusion, the important role of the researcher's skills, knowledge and moral sensitivity, confidentiality, and data protection, reporting and disseminating data in a sensitive way. These are discussed in turn below.

4.3.2 Consent

The subject of consent is paramount when considering the involvement of this participant group. The concept of Informed Consent lies on the assumption that one can make a free and voluntary decision based on adequate information about the subject, including risks and benefits involved (Mental Capacity Act 2005).

Dementia does affect a person's decision-making capacity at some point; however, consent is always context-specific (one may demonstrate capacity to consent to participate in an interview, for example, yet at the same time show a lack of capacity to consent to be administered a specific drug). As Mayo and Wallaghen (2009) state, the challenge in including people with dementia or other cognitive impairments in research is to determine their capacity to give context-specific informed consent in a way that maintains their rights and their autonomy and preserve their dignity.

As the International Ethical Guidelines for Health-Related Research Involving Humans (Council for International Organizations of Medical Sciences – CIOMS – and WHO 2016) states, even adults who are not capable of giving informed consent must not be automatically excluded from health-related research, possibly seeking proxy consent, unless a good scientific reason justifies their exclusion. However, the issue of mental capacity is extremely delicate for this participant group as it often fluctuates and must be reassessed continuously.

Ries et al. (2020) point out that Research Ethics Committees and those caring for older people with cognitive impairments play a vital role in protecting the interests of those unable to give their own consent, or whose capacity to give consent can fluctuate' however, they must also refrain from taking decisions based on stereotypes and assumptions. In their study, they underlie the importance of improving the understanding of dementia among ethics committee members, stating that most ethics committees wrongly

> "consider any person with dementia, at any stage of the disease as 'vulnerable' and unable to make a decision about participation"
>
> (p.293).

Brydon-Miller (2008) also questioned this wide-spread perceived need for protection, suggesting that it might rather reflect deeply-held prejudices toward marginalised groups considered less competent to participate in research. While it is true that people with dementia may experience particular difficulties such as confusion and memory loss, there is a common tendency to overemphasize problems and underestimate skills and capacities that people living with dementia have (Gove et al. 2018). There is, on the contrary, clear evidence that many people with dementia can actively contribute to research and provide rich data on their experiences (Beuscher and Grando 2009; Murphy et al. 2015; Digby et al. 2016).

I would suggest that a lack of understanding of ethics committees about issues pertaining inclusive research, mental capacity and consent in this participant group may have contributed to a severe reduction in the involvement of people with dementia or other cognitive impairment in research, thus being unethical in itself.

The research section of the Mental Capacity Act –MCA- (2005) makes it "lawful to carry out intrusive research involving people without the capacity to consent for themselves" (p.30). 'Intrusive' research in this case, means research which, under common law, would require the consent of the participant (MCA 2005, p.30). Intrusive research needs not to be physically invasive and may include several forms of qualitative research but excludes “research that is classified as a clinical trial” (MCA 2005, p.30).

Ideally, I would have wanted to plan this research project to include people who lack capacity, particularly because excluding them can dramatically contribute to under-representation and stigmatization of this important part of population.

The Mental Capacity Act (2005) articulates the criteria for including adults lacking capacity in research in the following way:

> “1. Research must be connected with an impairing condition affecting the participant (P) or its treatment;
> 2. Research of equal effectiveness cannot be carried out if confined to participants with capacity;
> 3.(a) Research must have the potential to benefit P without imposing a disproportionate burden, or (b) provide knowledge of the causes or treatment of others with the same condition, and involve negligible risk to P, not interfere significantly with the freedom of action or privacy, or be unduly invasive or restrictive”
>
> (p.30).

In addition to this, the MCA also details a few important safeguarding steps to take. One of these is the requirement to “consult others” to ensure that any decision to include an adult lacking capacity is not against their own interests (p.32). Therefore, researchers must seek advice from a person – a “consultee” – (p.32) who knows the candidate participant and is concerned for their wellbeing. The researcher must inform the consultee that their role is to advise the researcher as to whether recruiting the person concerned is consistent with what the participant “would likely choose for themselves if they had the capacity to do so” (p.32).

Buchanan and Brock (1986) and Torke et al. (2008) point out that such substituted judgement approaches might be looked at with some scepticism as they might expose vulnerable people to forms of abuse; however, as Woods (2016) notices, it is likely that a person willing to act as a consultee will be genuinely inclined to act in the best interest of the person who is unable to consent. In addition, and this is independent of the consultee, the researcher must always monitor the status of the participant and promptly withdraw them from the study should they give any sign of distress or express a wish to be withdrawn.

I believe, together with Johansson and Broström (2014), Shepherd (2016) and Woods (2016), that the rigorous use of the consultee procedures combined with other safeguarding procedures might mean that important research for the benefit of people with impairing conditions – including people with dementia – can be lawfully and ethically conducted.

Therefore, it is also my belief that including adults lacking capacity in this study, when possible and when appropriate to obtain proxy-consent from a carer, would have not exposed them to disproportionate risks, thus adhering to the MCA core criteria. This would have been done with appropriate explanation of what the process of giving proxy consent actually is: providing advice on what the person lacking consent would have most probably wanted rather than giving an opinion based on what the consultee thinks is best for them, or what they themselves would prefer. The role and importance of this education process is made evident in Tomlinson et al. (1990), who ran an empirical study where three treatment decision scenarios were presented to 43 competent older persons and 115 persons related to them, and whose results shows that carers or relatives who were explicitly asked to make a substituted judgment (what they thought the person would want) came significantly closer to the older person’s preferences than those who were asked to make their best recommendation.

However, as reported in Table 8 – Study participants – Phase A – Inclusion and Exclusion Criteria (p.90), only people capable of consenting for themselves have been included in this study. This decision was taken in order to meet the requirement of gathering rich and detailed accounts from the participants, a task which – in the case of people with impaired cognition – may require highly sophisticated skills and considerable experience which I, as a new researcher, still needed to acquire. I consider this as one of the limitations of this study.

As already mentioned, participants’ capacity to consent has been assessed at each three key stages of the study:

1) before the researcher would meet them to give information and the Participant Information Sheet (PIS);
2) after the participant had read the PIS and spoken to the researcher/before signing the ICF;
3) after the ICF was signed/just before the beginning of the interview.

Participants have also been given as much time as they needed to make their decision; however, most of them chose to be interviewed immediately. In addition to this, I have always remained particularly sensitive to all possible signs of distress or fluctuating capacity – such as the participant becoming agitated, restless, or particularly quiet and withdrawn, or not capable to understand and retain information – ready to suspend the interview if needed. This process was put in place on the awareness that obtaining informed consent, in particular with this participant group, should be approached as a reflexive and ongoing process if the aim is to ensure that participation remained voluntary (Pesonen et al. 2011). Also, the way of obtaining consent can make a big difference. As Juritzen et al. (2011) point out:

> “a rule-bound obtainment involves a risk of making the process routinized and mechanical, and remote from the ethically reflective practice which is desirable”
> (p.644).

To evaluate the capacity to consent when including persons with dementia, neuropsychological tests, such as the Mini Mental State Examination (MMSE), are often used (Heggetsad et al. 2012). These are screening instruments normally used for cognitive impairment. However, Liamputtung (2007) argues that they cannot say anything about the patients’ abilities to express their feelings or experiences nor they can capture a complete picture of a person’s competence with respect to giving informed consent. Moreover, he insists, the very fact that individuals with dementia may alternate mental states of lucidity and confusion also entails that the results of such tests may be very inconsistent if taken at different points in time. Finally, as Khrone et al. (2011) point out, patients who are administered such tests may find them humiliating and experience them as a form of threat to their dignity.

Considering the above, in this study, instead of letting the participants go through cognitive screening, I opted for a nurse – or other clinical member of the team who cared for the patient – to undertake more general and holistic evaluation of the person's capacity to consent at the three key stages already mentioned. This required more comprehensive knowledge about the person, which the practitioner had developed through previous conversations with them. However, I had to stay open to re-evaluate that judgement if necessary. A few patients changed their mind regarding participation just before the interview, for various reasons – like physical pain or tiredness – but I never had any concern about their mental capacity to consent while I was interviewing the actual participants, after the three-stage holistic mental capacity assessment had been carried out.

4.3.3 Communication

Difficulty in remembering information, problems with self-expression, disorientation and confusion are all symptoms that can be encountered by a person with dementia (Alzheimer's Association 2020). Despite this, qualitative research so far has shown that many research participants with dementia can express their thoughts and experiences in a rich way (Pesonen et al. 2011). In this study, I was able to meet and interview several participants who were perfectly capable of communicating in a rich and articulate way; however, some of them had clear difficulties remembering, reflecting and expressing themselves because of the progression of their condition or their current poor health state. In some of those cases, I was helped by a few strategies to facilitate communication. These will be discussed below.

As recommended by The Scottish Dementia Working Group Research Sub-Group (2014) I always asked participants if they wanted someone to accompany them during the interview: family members, friends, or a familiar nurse can contribute to participants feeling more comfortable (Pesonen et al. 2011), and they may also provide communication assistance and emotional support (Digby et al. 2016; Pratt and Wilkinson 2003). Moreover, allowing participants to choose if they want more support can promote a sense of inclusion and safety. In this study, this happened twice. Once in the case of a participant who wanted their wife to be present during the interview, and a second time with a participant wanting a nurse with them. This allowed me to appreciate the pros and cons of this method and raised issues for consideration. During the interview where the participant's wife was present I noticed that she dominated the interview and, at times, as Digby et al. pointed out (2016), appeared to undermine the participant's responses. Moreover, the interview was particularly difficult both to facilitate and to analyse. In the second situation, when a nurse was silently present, I could appreciate that the presence of a familiar and caring member of staff appeared to put the patient at ease, possibly reassuring them and enriching the conversation without intruding or interfering. This is in line with Dickson-Swift et al. (2007) considerations around building trust and creating a comfortable atmosphere being between the main factors which can enhance conversation and encourage participants to share personal experiences.

Another way of building trust and create some sense of comfort is to try and develop some rapport with research participants before starting the actual interview (Corbin & Morse 2003; Nygard et al. 2006; Dickson-Swift et al. 2007). This can also assist in reducing power inequalities between participants and researchers, as Hellstrom et al. (2007) point out. In order to achieve this, I always tried to involve participants in some form of informal conversation, jokes and small talk before starting the interview process, also giving them some information about myself – from human being to human being, rather than from researcher to interviewee – and acted in a way that would allow the interview to flow organically from our chat, for example, by linking my questions to their own observations or to our more general chat, whenever possible.

Developing rapport, as Digby et al. (2016) and Nygard et al. (2006) suggest, also allowed me to identify any communication issues, and to adapt my approach to each participant. This could include regulating the timing and pace of interviews – which at times would require more silence and pauses -, repeating the questions, repeating the questions using different words, repeating back to the participant their own words, and adjusting the specific wording of questions (for example, introducing more concrete words and less metaphorical language).

Dickson-Swift et al. (2007) and Digby et al. (2016) point out that allowing participants to direct the conversation and discuss issues that matter to them rather than following a pre-determined agenda can minimize the power imbalance of the research relationship. The ethical need of privileging their narrative over my own agenda matched perfectly with the basic principles of the chosen methodology (IPA); however, this was always only partially achievable, as I always needed to balance my openness with what they wanted to tell me with the need to answer the research question. This was particularly evident when some of them appeared to lose track of the subject of the conversation, in which case, as Novek and Wikinson (2019) suggests, I had to gently remind them what the research was about. As Hubbard et al. (2003) says, finding a balance between being participant-led and supporting the flow of conversation in order to answer the research questions can be challenging, and it has been challenging in this study.

Enabling participants to choose the time, location and duration of interviews is recommended (Hubbard et al. 2003; McKillop & Wilkinson 2004; Scottish Dementia Working Group Research Sub-Group 2014). While I have always been able to respect participant’s preference in terms of time and duration of the interview, I was not able to allow them to choose the location. Running the interview in the participant’s homes or in another familiar place of their choice would have possibly improved their sense of comfort (Hellstrom et al. 2007; Beuscher & Grando 2009; Pesonen et al. 2011), but I had to balance this consideration with the need to interview participants as soon as possible after their experience in A&E in order to maximise their memory recall, and this meant that I interviewed all of them at their bedside or at least within the hospital ward they had just been admitted to. Moreover, I needed them to be in hospital where a member of the dementia care team could assess their mental capacity at each key stage.

4.3.4 Protecting from harm and offering opportunities

Kavanaugh and Ayres (1998) underlie how the ethical principle of beneficence requires the researcher to take into consideration all the possible harm that in-depth interviews could cause on study participants, and for them to have strategies in place to prevent or minimize the risks.

In this study, on top of their condition of potentially disorientated and vulnerable individuals, it was crucial to consider the delicate circumstance (just been admitted to hospital after having been through A&E) the study participants were going through. For this reason, it was decided to introduce two specific exclusion criteria which consisted in excluding all patients whose health conditions were not suitable for them to be interviewed, and all patients who were already involved in another clinical trial which might have represented a significant burden to them.

This process required the consistent assistance of the dementia care team, who was involved not only in the mental capacity assessments, but also in the screening of potential participants against the eligibility criteria checklist. Literature on the role of gatekeepers in dementia research suggests ambivalence towards their impact on the research process. On one hand, it seems like gatekeepers can unnecessarily restrict access to participants so to undermine their autonomy (Bartlett & Martin 2002). On the other hand, it has been argued that gatekeepers can provide invaluable help by sharing information about participants' needs and skills, and by supporting participants' decision-making or providing assistance to those of them who might experience distress (Bartlett & Martin 2002; Pratt 2002; Digby et al. 2016).

This debate on the role of gatekeepers clearly represents the tension between protection from harm whilst enhancing autonomy and finding a balance between the two can be challenging. In this study, I had the possibility to develop a relationship of mutual knowledge and trust with the dementia care team – to whom all the potential participants had been referred to – collaborating with them over more than a year before starting the recruitment process, and I could verify the high level of commitment that all professionals part of the team always put in enhancing participants' freedom of choice and inclusion, and the high standard of moral sensitivity and respect they always abide to.

In order to protect participants from any emotional harm during the interview, I always strived to be respectful and participant-led, by, for example, as Reason

& Bradbury (2008) suggest, always trying to engage them as a whole person and basing the exploration of their experience directly on their understanding of it, rather than filtering it through my own perspective, at least, as much as this was possible. I always also intentionally aimed to create an approving and optimistic atmosphere.

Another way of protecting participants from harm has been to constantly look for verbal and non-verbal signs of distress, as Digby et al. (2016); Heggestad et al. (2013) and Pesonen et al. (2011) suggest. Paying attention to body language is also essential to maintain ongoing consent (Digby et al. 2016). Strategies to deal with possible signs of distress have included checking on how the participant was feeling, asking if they needed anything, asking if they were comfortable or needed some help to change position in their bed, offering breaks, offering to stop the interview, and changing to a more neutral topic for a while before going back to the subject of the interview.

Distress can potentially arise for the researcher too when investigating into sensitive topics. I was personally prepared to deal with the emotional burden that the interviews could pose to me, and – as I used to do with my clients as a therapist – I always draw on what the Anthropologist, Buddhist teacher and Zen priest Roshi Joan Halifax (2008) calls the *Strong back-Soft Front* approach. As a therapist, this is an everyday exercise of developing emotional resilience by constantly working on myself and my own trauma in order to develop a spine, metaphorically speaking, which is flexible but sturdy, which is necessary if one wants to risk having a soft front. Soft front for me means openness, empathy, capacity for containing emotionally-charged material, and compassion. By exercising my inner emotional strengths – strong spine – I remained able to authentically meet the research participants and welcome all of their emotion without feeling overwhelmed or burned out. Keeping a reflexive research diary and sharing my experiences with my supervisors was part of the ongoing process of maintaining a soft front and a strong back. Moreover, I always had my line-manager (also my clinical supervisor) at the hospital to talk to, if in need of debrief, and the hospital trust's mental health support system for staff available in case I might need it.

Though careful consideration of possible harm is paramount, one does not have to forget that research interviews may also be beneficial to the study participants as they offer an opportunity to share their experiences and can provide with a sense of purpose and altruism (Pesonen et al. 2011). As Beuscher and Grando (2009) observed, most study participants with dementia consider participation to be important and helpful. On the one hand, they feel that participation offers them a possibility to share their personal experiences and reflect on them and, on the other hand, they hope that their participation and the results of the research would benefit others in the same situation (Beuscher and Grando 2009). Being highly aware of this, I always reiterated to the participants how the contribution they were giving to the study was precious, and how it could potentially be of considerable help to other people in the future. This was often encountered with a smile and a sparkle in their eyes.

Another important factor emerging from the literature around the ethic of running research interviews in healthcare is that of the possible misperception of the researcher's identity. Hewitt (2007) and Richard and Schwartz (2002), point out that, from the perspective of participants, the boundaries between researcher and practitioner may be confused, in particular when the researcher is also a health practitioner, or when the research is conducted in person. It makes sense to think that this can be even more so when participants' cognition is somehow impaired. In the context of this study, I did not come across such confusion, probably because my clinical role in the hospital had never been known to the participants, not having any clinical relationship with them. Moreover, I did not wear any uniform and I was always introduced to them as a PhD student or researcher. This possibly prevented them from getting confused, so that I never faced any ambivalent attitude. However, from an ethical point of view, what was certainly more delicate was how I needed to balance my own perception of myself when relating to them, as I was always looking at them both as a researcher and as a therapist, and I have always had to carefully choose how to behave and how to relate to them.

4.3.5 The role of the researcher’s knowledge, skills and moral sensitivity

Considering the complexities of the whole research process, McKeown et al. (2010) ask the question: *who should conduct research with people with dementia?* According to them, the complex ethical challenges and sensitivity of dementia research calls for specialist knowledge and skills from part of the researcher. A number of other writers have highlighted the importance of those experiences and skills (Hubbard et al. 2003; Beuscher and Grando 2009; Digby et al. 2016).

According to Hubbard et al. (2003), in addition to knowledge of qualitative methods and research ethics, researchers have the responsibility to understand the potential effects of dementia on memory, decision-making capacity and emotions in order to be able to detect possible issues as they arise, therefore adapting the research process accordingly. The Scottish Dementia Working Group Research Sub-Group (2014) calls for researchers to learn about the various types of dementia and to recognize the heterogeneity of symptoms. Beuscher and Grando (2009), Digby et al. (2016) and Hubbard et al. (2003) also point out that researchers should be aware of the range of communication issues which may possibly arise when interviewing people with dementia and should be prepared to adjust to participants’ communication skills.

In addition to the above mentioned, specific researcher skills identified in the literature include: active listening skills (Nygard et al. 2006), critical thinking skills and reflexivity (Dewing 2007; McKeown et al. 2010; Pesonen et al. 2011), sensitivity (Digby et al. 2016), moral sensitivity (Heggestad et al. 2013), empathy (Hellstrom et al. 2007; Scottish Dementia Working Group Research Sub-Group 2014; Digby et al. 2016), respect (Scottish Dementia Working Group Research Sub-Group 2014; Digby et al. 2016) and authenticity (McKillop and Wilkinson 2004).

In the specific case of this study, my knowledge of qualitative methods arises from a number of academic learning experiences, study and trainings started in 2014 during the dramatherapy MA programme I attended in Roehampton University and followed during the whole PhD programme in Bournemouth University from 2017 to 2021, which included ethical-related trainings such as

Research Ethics, Research Ethics with human subjects, Informed Consent, Informed Consent with people lacking capacity, Principal Investigator training, and Good Clinical Practice (GCP).

My knowledge of the participant group – including different types of dementia and their symptoms and how those may affect people's memory, communication skills, decision-making capacity and emotions – has built-up not only through my personal study during the PhD programme and through my participation to conferences and dementia study days, but above all through my experience of emotional support to patients with dementia at the bedside, as part of the clinical element of the programme, and by the invaluable mentoring role of the whole dementia care team and, in particular, of my clinical supervisor and manager at the hospital, Consultant Nurse for older people and lead of the dementia care team.

Active listening, critical thinking, reflexivity, sensitivity, empathy, and respect, these are all skills essential to a practising dramatherapist, which I believe I already possessed in a certain measure even before qualifying as such, being all these skills required to an artist too – my early background is in performing arts – but which have been definitely further cultivated, developed and refined during my dramatherapy training and after, in clinical practice. I also believe these are skills I am purposefully cultivating as a human being in my journey of self-awareness.

Lutzen et al. (2006) define moral sensitivity as:

> "attention to the moral values involved in a conflict-laden situation, acknowledging what principles are involved in the situation, as well as awareness of one's own role in the situation"
>
> (p.187).

The concept of moral sensitivity is holistic in itself as it takes into consideration both emotions and cognition (Jaeger 2001). This means that to grasp the moral significance in a situation one has to be touched both emotionally and cognitively (Heggestad et al. 2012).

I strongly believe this is something a researcher can reach only if seriously committed to work psychologically on themselves, gaining a knowledge of primitive psychological defence mechanisms. Fear and anxiety trigger automatic and often unconscious coping mechanisms in humans (Winnicott 1971). Some of these coping mechanisms can involve splitting or dissociation, which might happen just between our cognition and our emotions in order to protect our psychological integrity by preventing psychotic disintegration of the self (Laing 1960). A researcher with a lack of awareness of these issues might run the risk of feeling overwhelmed by strong feelings, thus lacking the mental lucidity needed to make ethically sound decisions, while another might have their capability for empathy impaired, experiencing themselves as emotionally detached, thus basing their ethical considerations on cognition only.

It is my belief that a sound psychological training and both my job and life-related experience made me a good candidate as a morally sensitive researcher, capable, as Pesonen et al. suggest (2011), of operating situation-specific ethical decisions informed by ethical engagement and personal responsiveness in my relationship with study participants.

4.3.6 Confidentiality and data protection

In this study, GCP (Health Research Authority 2017) guidelines have been respected at all times. With regard to confidentiality and data protection, GCP recommends that Data Protection Act (1998) and General Data Protection Regulation -GDPR- (2018) principles are carefully put in practice. According to this, all participants' identifiable information which includes name, date of birth and wards, have been stored on an NHS password-protected server and all identifiable paper data have been stored in a locked cabinet in the office I shared with the other care team's members at the hospital. The hospital would keep this data up to 12 months after the end of the study, after which they would be destroyed. No personal identifiable information has ever been transferred. Pseudonymised data have been stored on a secure, password-protected Bournemouth University server and only accessed by me and the supervisory team. Audio from the recorded interviews have been transcribed and pseudonymised as soon as possible and the original recordings stored until the end of the study (should I need to listen to them again for the purpose of the study).

4.3.7 Reporting and disseminating data in a sensitive way

When thinking about reporting and disseminating study findings in a sensitive way, one of the most important points to consider is “the possible impact on research participants, their families and associates, organisations, and populations from which the sample is drawn” (UK Research and Innovation - UKRI- 2019), and all this needs to be thought through very carefully.

Full anonymisation in a qualitative study like this is never possible. However, through careful pseudonymisation of both participants and the study site, and by withholding any detail which could bring third persons to identify the participant, it is possible to avoid most harm, which is what I did in the reporting phase of this study.

However, participants might always recognise themselves; a close relative or a healthcare professional who cared for them may also be able to This is the reason why when reporting, preserving participants’ dignity at all times is a priority.

The use of language can very much assist in this. As Novek and Wilkinson (2019) point out, the way we describe older people and people with dementia who are participants in research, and the language we use to do that, stands as a very important consideration for researchers.

Age UK (2019) state that the way older people are represented in any form of communication can also have a wider impact on the public’s attitudes, including the possibility of prompting ageism if not addressed correctly. Ageism is age discrimination. It is “the stereotyping, prejudice, and discrimination against people on the basis of their age” (WHO 2017). Several studies show that ageism is widespread in most Western societies and can be both overt and covert in form (North and Fiske 2012; Australian Human Rights Commission 2013). Ageism can potentially have severely harmful effects on the health of older adults (WHO 2017), shaping the way older people see themselves and how they believe they are perceived in society (Duffy 2017).

In this study, I chose to refer to participants as *older people* rather than elderly because, as Avers et al. (2011) point out, using the term *elderly* for a person who is usually relatively independent and strong as well as for a person who is frail and dependent can be very misleading.

Furthermore, older people dislike the term elderly applied to themselves. A European survey asking older citizens their preferred term (Walker and Gemeinschaften 1993) indicated a preference for *older* or *senior* and strongly rejected terms *aged*, *old*, and most strongly *elderly*.

Terms like *demented* or *dementia victim*, also reduce the person to his or her disease and reinforce the stigma associated with dementia (Novek and Wilkinson 2019).

Several organizations have highly recommended to end the use of stigmatizing language and have offered more appropriate and respectful terminology as well as suggesting terms to avoid (Dementia Engagement and Empowerment Project -DEEP- 2014; Scottish Dementia Working Group Research Sub – Group 2014). DEEP (2014) guidelines recommend using the terms person/people with dementia or person/people living with dementia, and this is what I adhered to through the whole thesis.

Giving the participants the possibility to be informed of the study findings at the end of the study is also a way to promote their dignity and involvement, and this is what I did by including my contact details in the PIS in order for them to contact me should they wish to know the findings.

In the dissemination phase, I will try and involve representatives of the participant group – older people as well as people living with dementia – by presenting at conferences aimed at them and their carers, for example, and by asking for their feedback, promoting their inclusion into the project and its possible developments.

4.3.8 Notes on reflexivity

I already mentioned the importance of reflexivity and the influence that my own assumptions and past experiences (in IPA, fore-structures) have on the research process. In IPA, reflexivity is paramount to the transparency of the study (Smith 2009; 2022) and, therefore, to the ethical robustness of the research process. In order to ensure reflexivity, I took the following actions:

- I always kept notes of my own emotional state and thoughts before and after each interview;
- I shared the process from conception of the research study to dissemination of findings with the supervisory team：this helped my reflexivity by offering different points of view on the same process, and by allowing me to put in discussion my own assumptions;
- I kept a reflective journal of the whole process of the research journey.

A few days before starting the interview process, I noticed I was feeling nervous and slightly anxious. I interrogated myself about those feelings and I discovered that they came from a fear of not being able to communicate at a deep level with the participants and to gather rich accounts. This, in turn, came from assumptions developed out of some of my previous experiences with older people at the hospital: I had noticed that many of them seemed quite resistant when invited to talk about their feelings and subjective experiences, often resolving to talk about facts and events in a seemingly objective fashion. Reflecting on this, I noticed that I believed that this was affected by cultural factors: I was aware I was going to interview people belonging to a generation who are not used to talk openly about feelings.

However, there were other factors concerning me: although I have a good level of knowledge of the English language, it is not my mother tongue, and I was concerned that I would not be able to find useful synonyms, using the wrong term, or a term that was not comprehensible to the participant. I was also aware that many of the participants would possibly have strong regional accent. Would I be able to understand their words? Moreover, would they be able to understand my words, having an Italian accent myself? Lastly, I was aware I was starting interviews in a Post Brexit referendum Britain. This was a very significant social factor to take into consideration. I came to England five years earlier and over the first year – even if aware of the significant cultural gap existing and of the language barrier- I never perceived myself as a foreigner, but as a fellow European. When Britain voted for Brexit, however, my perception changed dramatically: I was suddenly aware that to many, I was a foreigner, and to some, I was not welcome. Considering that media at the time tended to suggest that most people who voted for Brexit were not young people, I wondered if I would meet any form of diffidence or even xenophobia during the interviews. These were my assumptions and my fears where I started the interview process.

When facing the actual interviews, my fear of struggling to understand participants' speech was confirmed, at least with some of them. I resolved to remain very calm and to ask the participant to repeat their words whenever I did not understand. However, on some occasions, I felt that asking them to repeat too many times would have broken the flow of their disclosures, possibly negatively affecting the quality of the interview and making them feel uncomfortable. On those occasions, I opted to wait to listen to the recording again and again – possibly at a slower pace – rather than interrupting them. In general, this worked.

Getting some of them to go in-depth in their accounts was not easy. I sensed psychological resistance, such as avoidance or denial. Sticking to facts and events rather than talking about feelings and subjective experiences was a common issue; however, I noticed that using a sense of humour or changing the subject for a while, then going back to the interview questions, helped the participants to open-up. Obtaining rich and in-depth accounts of subjective experiences from this participant group has been possible, but it has been challenging. However, by practising IPA, I came to recognise my own personal bias in suspecting participants might not be particularly emotionally articulate. Participants did not have to be emotionally articulate; I was the one who had to be able to attune to their own personal way of expressing their experience, and try to make sense of that. That is the interpretative aspect of IPA in practice.

Being understood by them did not seem problematic. Of course, they had to ask me to repeat some words from time to time, as I did with them, but on average, I had a sense that they could understand me quite well. Xenophobia, or my fear of it, was not an issue, generally. Only on one occasion, I noticed myself becoming more tense during an interview, when a participant repeatedly stated that they could not understand what I was saying. After a few interviews, I started noticing that participants got very tired of the whole procedure of giving written informed consent. In order to obtain formal ethical approval, the PIS must be very detailed, and reading it all left some of them quite tired. At times, they had been helped by a nurse who read it out loud for them, but this was not always possible. Moreover, some of them struggled to tick the boxes on the ICF due to hand tremors. I increased the dimensions of the boxes in the document for future participants to have plenty of space to provide what was required of the form. This might seem an insignificant issue, but I believe it is not. I believe that not being able to tick inside the boxes may have made some of them experience a feeling of frustration and inadequacy. This did not seem to be the case once the boxes were enlarged.

4.4 COVID-19 emergency

In March 2020 I had to suspend data collection due to the outbreak of the COVID-19 pandemic in England. Following UK government's guidelines, I was required by the hospital Trust to not attend the hospital in order to comply with the role of minimising patients' contacts with external visitors: at that time, all non-essential research in hospital was halted.

Data collection needed to stop, as the focus of staff and patients during that emergency was on minimising risks and preventing clinical deterioration so that conducting interviews with patients was going to be neither essential nor appropriate.

In addition to this, the flow of patients through the emergency department was going to be entirely different to normal and would possibly create a very different pathway. Lastly, the dementia care team during the pandemic were re-deployed to different clinical areas and they were not going to be able to assist in screening patients and assisting with MCA (mental capacity assessment) for the research. Moreover, the ICCI was suspended.

At that time, I had interviewed eight participants. The idea – which today feels quite naïve – was that I would be able to re-start interviewing patients in the near future, when the pandemic emergency would be over, and restrictions would be lifted: although eight participants could, in theory, be an acceptable number in IPA, both my supervisors and I agreed that, in my case, the data collected so far were not yet rich enough.

The COVID-19 Pandemic was an unprecedented event which I, like many others, met with fear and disbelief.

A few days after I was recommended to pause data collection, the UK entered its first lockdown period which, in the moment of maximum restrictions, entailed all shops selling non-essential goods and other premises, including libraries, playgrounds, gyms and places of worship closing, and the halt of all social events, including weddings, baptisms and other ceremonies.

Most offices required people to work from home, people were forbidden to gather and meet other individuals outside of their household when indoors, and no more than one individual outside of their household when outdoors. Everyone could leave their house only up to once per day and only for essential needs (UK Government 2020).

That first lockdown lasted two months. After that period, the UK Government started to release restrictions – very gradually – so that in August 2020, most services were running again, and people were free to meet both outdoors and indoors while still respecting social distancing and face-covering roles (UK Government 2020). This was prompted by a dramatic drop in the number of daily new positive cases and involved the NHS seeing a gradual return to a more expected service with a lower presence of COVID-19 cases in Intensive Care Unit (UK Government 2020). During September 2020, unfortunately, there was a new peak in the infection rate which, however, mostly involved the north of the Country and, moreover, even if it entailed a rise in number of hospitalizations and Intensive Care Unit (ICU) attendances, was still relatively under control (UK Government 2020).

For this reason, at the end of September 2020, I had finally received formal approval from both BU (Bournemouth University) and the NHS Trust to resume data collection at the site – pending appropriate risk assessment and preventative safety measures in place. Unfortunately, by the time I had submitted the related IRAS (Integrated Research Application System) amendment to the protocol – to include the changes related to preventative measures – and I had received REC approval, the UK – as a result of a sudden and totally unexpected peak of COVID-19 cases – entered its second lockdown phase. Just after the Prime Minister had announced the second national lockdown to start from Thursday, 5th of November, I had received notification from the hospital site that their recent permission for me to resume data collection was withdrawn.

Given that the possibility to interview older people in person was beyond dispute again, at that point in time, my plan, after discussion with the supervisory team, was to prepare a further amendment to the protocol to try and interview older people by phone. However, after more careful consideration, I reached the conclusion – endorsed by the supervisory team – that this method of data collection was not suitable for the aim of my study and would not suit the specific methodology. This was because communication with older – and often confused – patients was not particularly straightforward even during in-person interviews, where it was assisted by a range of non-verbal information and messages. I was, therefore, persuaded that by phone I would have not been able to gather the rich and evocative accounts I was looking for, thus failing to fulfil my aim.

That was a very challenging stage for me as a researcher. I felt that I might not be able to continue conducting my study, and, considering that this was adding to the already stressful and concerning situation of a pandemic, which entailed a large degree of isolation and uncertainty, I had to draw upon all my resilience to keep on believing that I would eventually find a way through.

Supervision was key at this stage. In consultation with my supervisors, we identified a possible alternative way to keep on collecting data relevant to the ICCI phenomenon. This would entail me possibly running in-depth remote interviews with the ICCI practitioner about their experience of providing the ICCI to older people in A&E, therefore adding a new objective to the study, which was to explore the experience of the practitioner delivering the intervention.

Knowing the ICCI practitioner – having shadowed her work for a period of time during my first year of PhD – I knew her communication skills, and I was confident that interviewing her – either by phone or videocall – had the potential to generate rich data, resulting in an in-depth account of her experience.

As a result of these considerations, a decision was made that I would prepare and submit a substantial amendment to IRAS, to broaden the scope of the study. The data gathered through the interviews with the ICCI practitioner would provide enough richness to complete my doctoral study. However, to keep possibilities for data collection as open as possible, I left in the protocol the possibility for me to interview older people at the bedside – with appropriate safety measures in place – in case at any point in time, while the data collection phase was still open, both Government and NHS restrictions were lifted to the point of allowing me to carry on that task. This never happened.

When, in February 2021 I had received all ethical approvals needed, I was informed that the ICCI practitioner was unwell to the point of not being able to be interviewed at least for the foreseeable future.

Again, with the help of the supervisory team, I identified another alternative route to data collection, which would entail me collecting data about the experience of witnessing the delivery of the ICCI to older people in A&E, seeking volunteers from the hospital staff who had witnessed the intervention and who would be willing to be interviewed.

This would entail a further substantial amendment to IRAS which I engaged with. When that amendment was ready, in April 2021, just before submitting it, I was contacted by the ICCI professional, who was recovering and felt ready and willing to be interviewed remotely. I, therefore, did not submit that last amendment, and I rushed instead to set-up my first interview with her, which took place at the end of April 2021.

In the following chapter (Chapter 5) therefore, I present only the findings from the first phase of the study (the experience of older people who received an ICCI in A&E). The second phase (the experience of the professional delivering the ICCI for older people in A&E), will be fully described over the successive chapters, starting from a specific additional literature review on the experience of staff delivering care to older people in A&E in Chapter 6 , an overview of the methods in Chapter 7 and report of findings from the interviews with the ICCI professional in Chapter 8 .

4.5 Summary of the chapter

In this chapter, I offered a detailed presentation of the research design and methods used, providing a full study flow chart, and consistently linking the methods used to the methodology of choice and their rationale. I provided practical examples of how I ran the analysis of the data, and I presented an account of my reflexive process through the whole study, included a robust reflection on the ethical issues involved in running the study from planning to dissemination, providing a description of how I dealt with them. I also included a narrative section to outline how the COVID-19 Pandemic affected and re-shaped the study.

Chapter 5 – Findings – Study Phase A – experiences of older people

5.1 Outline of the chapter

The findings of phase A of the study will now be presented using IPA framework as a guide. Four key themes, called super-ordinates will be presented with three sub themes – called lower-ordinates – in each super-ordinate. Before that, I will present what I knew about the participants before and after running the interviews, reporting demographic data about them (impressions from my encounter with them in form of vignettes can be found in Appendix 8 - Encounters with patient participants vignettes – p. 351).

5.2 Analysis of data

5.2.1 Participants and fore-structures

When studying a phenomenon, the experience we have inherited from both our original family and the broader culture will inevitably influence our understanding and interpretation of it (Heidegger 1999), and, paradoxically, this influenced understanding, which may prevent us from finding answers due to our own perspective, is also necessary to enable us to formulate the questions in the first place.

These precious experiences, historical influences, assumptions, and desires form -as already mentioned- what in IPA is known as fore-structures (Smith et al. 2009; 2022). Fore-structures are constantly present and, if ignored, can represent an obstacle to interpretation (Smith et al. 2009; 2022), a barrier to understanding from another's perspective. For this very reason, it has been important to me to notice and reflect on my fore-structures, at all stages of the study. In Chapter 1 and Chapter 3 , I have presented my personal and professional background, and how those might inform my approach to the study. In Chapter 4 , I also presented an account of my reflexive process – which includes the fore-structures I could become aware of step-by-step, along the whole process of data collection and data analysis. In this section, I will focus on any information I possessed about the participants before interviewing them so that my prior knowledge can be made clear. In Appendix 8 - Encounters with patient participants vignettes – p. 351 – it will also be possible to see how my fore-structures were in continuous transformation, when, at the bottom of each participant's vignette, I describe the experience of the encounter with them from my perspective, drawing on my fieldnotes.

After screening from the Dementia Team, eligible patients who had agreed to be approached were met by me and a member of the team to be provided with more information about the study and to start the informed consent process (after assessment of mental capacity). Prior to this encounter, I had received from the team a completed eligibility criteria form, which provided me with the following information about each patient: their name, their age, their gender, and the ward they were in. Before the interview, because of the inclusion criteria that participants needed to meet, I also knew that each of them might either have dementia or might have presented to A&E in a confused state, and/or might have presented to A&E on their own. However, I did not know which one of these options applied to each single participant. I also did not know anything about the reason which had brought each of them to A&E, about any chronic condition they might have and about their overall health conditions.

From Table 11 (p.131) it can be seen that data have been generated from the encounter with eight participants, five of whom were males and three females. The youngest was a 65-year-old man, and the oldest were two 91-year-old men, bringing the average age to 84 years. Four of them were in the Early Assessment Unit of the hospital (EAU), which is a unit where adults patients are referred – either from the Emergency department or by a General Practitioner – to receive early assessment and treatment, two of them were in the Orthopaedics ward, one in the Respiratory ward, and one in the Acute Cardiovascular Care Unit (ACCU), which is a specialized ward designed to treat people with serious or acute heart problems.

Table 11 – Data known before interviews – Phase A

Participants pseudonyms	Ward	Age	Gender
Walter	Early Assessment Unit (EAU)	91	Male
Anne	Early Assessment Unit (EAU)	84	Female
Dave	Early Assessment Unit (EAU)	82	Male
Robert	Early Assessment Unit (EAU)	83	Male
Michael	Acute Cardiovascular Care Unit (ACCU)	91	Male
Pauline	Orthopaedics	84	Female
James	Respiratory	65	Male
Barbara	Orthopaedics	90	Female

5.2.2 Diversity of the participants

After the encounter with each participant for interviews, I was left not only with a series of impressions and feelings to process (outlined at the bottom of each vignette in Appendix 8 - Encounters with patient participants vignettes – p. 351) but also with a few additional pieces of information about them. All of this would necessarily affect my fore-structures and thus the analysis of the data collected. These elements are also important in order to honour the idiographic nature of my enquiry, as they contribute to showing the diversity and uniqueness of each participant and of their experience.

After the interviews, I found myself with the following additional demographic data collected from healthcare staff by protocol: participants' time of admission to A&E and their length of stay in A&E and I could therefore calculate the amount of time passed between presentation to A&E and the interview. From participants’ accounts – this was not planned – it also emerged whether they had arrived at A&E on their own, and, from some of them, I also learned if they had come to A&E without a relative or a carer, and if they had arrived by ambulance. Additionally, from a couple of them, I learned the physical symptoms which had brought them to A&E.

Obviously, after the interview, I also knew where the interview had taken place, at what time, and how long it had lasted (between 15 and 40 minutes, see 4.2.3.6, p. 94), all of which might have an influence on the interview process.

As it could be seen from Table 12 (p.133) all participants had been admitted to A&E between 10.33 am and 3 pm (daytime), the length of stay in A&E was very similar (between 3 hours and 20 minutes and 4 hours), the time between their admission to A&E and the interview ranged between 1 and 8 days, and all interviews took place between 2 pm and 4 pm, for everyone in the same ward they had been admitted to.

Table 12 – Diversity of the participants

Demographic data known after the interview	Walter	Anne	Dave	Robert	Michael	Pauline	James	Barbara
Gender	Male	Female	Male	Male	Male	Female	Male	Female
Age	91	84	82	83	91	84	65	90
Arrived by ambulance	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Not Known
Time of Admission to A&E	3 pm	1.54 pm	3.18 pm	10.33 am	11.15 am	11.25 am	2.30 pm	10.55 am
Reason for emergency visit	Not known	Not known	Not known	Not known	Symptoms of cardiac attack	Not known	Shortness of breath	Not known
Presented at A&E alone	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Length of Stay in A&E	3 hours and 47 minutes	4 hours	4 hours	4 hours	3 hours and 20 minutes	3 hours and 44 minutes	4 hours	3 hours and 40 minutes
Time between the A&E stay and the interview	1 day	1 day	1 day	5 days	4 days	6 days	8 days	3 days
Place of the interview	Early Assessment Unit (EAU)	Early Assessment Unit (EAU)	Early Assessment Unit (EAU)	Early Assessment Unit (EAU)	Acute Cardiovascular Care Unit (ACCU)	Orthopaedics	Respiratory	Orthopaedics
Time of the interview	3 pm	2.15 pm	2 pm	3.30 pm	2.30 pm	2.45 pm	4 pm	2.15 pm

5.3 Super-ordinate themes

Following IPA methods running all initial stages of analysis, from exploratory coding to emergent themes within participants (see Chapter 4), I found myself with 12 themes emerging across the eight participants I interviewed. These themes represent my interpretation of the participants' lived experiences. I could clearly appreciate that some of those experiences related thematically to each other and could easily be grouped into clusters, to which I gave a title. These titles represent the four super-ordinate themes which conceptually embrace the 12 sub-themes (lower-ordinates) in groups of three.

Below, I present a table (Table 13 below) which shows all the experiences which were identified and the relations between super-ordinate and lower-ordinate themes.

Lower-ordinate experiences recurring for three participants or more are underscored and signalled with a '*R*'.

Following this, in Table 14 (p. 135), it is possible to appreciate how each single experience recurs for individual participants.

Table 13 – Super-ordinate and lower-ordinate themes – Phase A

Super Ordinate Themes	**Lower Ordinate Themes**	
1 - Helplessness	1A Passive Role	*R*
	1B Resignation	
	1C They Are Too Busy for Me	
2 - Uncertainty	2A Being with The Unknown	*R*
	2B Fear of Being Forgotten	
	2C Confusion	
3 - Unpleasant Sensations	3A Unpleasant Waiting	*R*
	3B Disappointed Expectations	
	3C Negative Reminiscences	
4 - Sense of Safety	4A Feeling Looked After	*R*
	4B Relief and Reassurance	*R*
	4C Feeling Involved	*R*

Table 14 – Recurrences – Phase A

	Experience	**Walter**	**Anne**	**Dave**	**Robert**	**Michael**	**Pauline**	**James**	**Barbara**
SOT 1 Helplessness	Lot 1A Passive Role	X	X			X	X	X	
	Lot 1B Resignation	X	X						
	Lot 1C They are Too Busy for Me		X			X			
SOT 2 Uncertainty	Lot 2A Being with the Unknown	X	X		X				
	Lot 2B Fear of Being Forgotten		X					X	
	Lot 2C Confusion		X		X				
SOT 3 Unpleasant	Lot 3A Unpleasant Waiting	X	X					X	
	Lot 3B Disappointed Expectations	X	X						
	Lot 3C Negative Reminiscences		X					X	
SOT 4 Sense of Safety	Lot 4A Feeling Looked After	X	X	X	X	X	X	X	X
	Lot 4B Relief and Reassurance	X	X		X	X		X	
	Lot 4C Feeling Involved	X					X	X	

The experience of older and potentially disorientated people who received an ICCI while in the Accident and Emergency department, rarely emerged as openly linked or directly related to the ICCI. My interview questions were purposefully very open as I wanted to capture each patient’s journey across the department as a whole: after all, I knew the ICCI would be somehow part of it, given that all patients interviewed had received the intervention. However, a large number of patients did not openly refer to it and some, when asked directly, did not appear to remember the ICCI practitioner or were not sure. It was essentially not easy to tease out a direct account of the specific encounter they all had with the ICCI practitioner. Nonetheless, as it will emerge when combining this set of findings to the one in phase B of the study (Experience of the ICCI practitioner) it is plausible to believe that these patients' experience in A&E was influenced by the ICCI, and that this intervention at times shone through their accounts, even when they were not directly – or consciously – referring to it.

5.3.1 Helplessness

This theme appears as a very relevant factor influencing older people's psychological distress in A&E.

Helplessness was experienced as disempowerment, as lack of control and agency over what happened to them and, despite some of the participants' feeling that they have at some point experienced an increased sense of agency and control, Helplessness had still been experienced by most of them in A&E.

Helplessness is informed by: Passive Role, Resignation, and They are Too Busy for Me.

5.3.1.1 Passive Role

Most participants seem to have inhabited a passive role, at least at some stage, during their A&E experience. Passivity was never acknowledged directly, but it is suggested in the transcript by the use of grammar, as the subject in the phrase is almost never the patient. Expressions such as: *"they come and take you up"* (Walter, line 157), or*: "they popped me in"* (Pauline, line 24), or: *"they came and did different things to me" (*Anne, lines 128-129), are very common, suggesting a sort of – at least – temporarily passive existential position for these participants, who possibly felt they had something 'done to them' rather than being active protagonists of their experience.

Michael, whom I interviewed at the bedside in the presence of his son who was visiting him, displayed a lively sense of humour and a willingness to share, and seemed to have quite an ironic outlook towards the passive role he found himself in, saying:

> *"while they take your temperature and wire you up all that bloody palaver, make sure you are breathing and all that… (3) and they ask you all the questions A, B, C…"*
> (Michael, lines 31-37).

Walter appeared more resigned to passivity:

> *"They come and take you up, give you x-rays and all that, bring you back there, then they keep you on the side, where they all start, you know, lie there, and ahem, raise your arm…"*
> (lines 157-162).

From his facial expression, tone of voice, words, and utterances he used, I sensed he had felt quite powerless and passive in A&E. This passive role, suggested by the use of grammar and by the words used both to describe what has been done to them by healthcare professionals in A&E, and to describe the geography of the hospital building, in the participants' interviews, seems to indicate that patients were often not totally aware of where they were and of what each procedure entailed. For example: Walter said he was sent *"in there"* (line 100) where some procedures had been done to him, without being precise about where it was, and Anne said she was moved *"up"* (line 254*)* leaving me to wonder whether she knew what department it was.

A "*bloody palaver"* was what Michael was *"wired-up"* with (ECG equipment), using his words (lines 33-34), while Anne said she had *"different things"* done to her (line 139), like Pauline, who said she received*:" tests and things"* (lines 25-26).

In contrast with the above, we find James' active stand, when he asks staff directly for what he needs and, ultimately, his needs are met:

> *"I said: 'sorry, I cannot stay in here'. They said: 'why not?' I said: 'I've got early stages dementia, I want to be in a bit [of space] with other patients', anyway, an hour later they moved me to a bit with some more patients in it"*
> (James, lines 128-135).

Despite James' active stance, data suggests that most participants might have experienced a passive position at least at some point during their A&E experience. This is not openly and directly acknowledged by them, but it is suggested by the use they make of language and grammar.

5.3.1.2 Resignation

Resignation emerges out of my encounters with Walter and Anne.

For those participants, Resignation seemed to be experienced in relation to being on their own in A&E or in relation to waiting time.

Walter – a thin man, with a gaze which immediately evoked a sense of vulnerability – was lucky enough to have his daughter alongside him whilst waiting in A&E; however, when asked about the experience of waiting, he reacted this way:

> *"W: oohhh…(3) you have to wait in there and that's all.*
> ***I**: you have to wait. What does it feel like to wait when you are unwell in an emergency department?*
> *W: well, what can you do, you got to wait and that's it. Wait till they come. And sometimes it takes a long time"*
> (Walter, lines 125-133).

Waiting sometimes takes a lot of time, but this is how things are, it even doesn't matter how you feel, as there is no choice: you must wait *"and that's all"* (Walter, line 126*).* This is what Walter appears to say in my interpretation, and everything in the words he used, in his tone of voice and utterances *("ooohhh…you have to wait",* line 125) indicates resignation to how things are and suggests to me that he would not even dream about complaining or advocating for shorter waiting times.

Anne also expressed resignation towards waiting times: *"you just got to have to wait…"* (lines 189-190). Her use of language here suggests to me that she had no expectation or hope for waiting to be shorter or for her being able to do something about it.

Anne, with her pale skin and weak voice, evoked in me the same sense of vulnerability which Walter did, but she also came across to me as very lucid and articulate. I also felt we established some form of personal connection to each other, from the beginning, and I felt that her resignation expanded to another domain, which is represented by being alone in A&E. When I asked her how it felt like to be alone in that situation, she answered:

> *"It didn't worry me too much, because the thing is: my daughter was at work and the other one is in X and the other one is in Y, so I mean I just can't call them up and say: 'come down'. I mean my eldest daughter did come and see me last night but, the trouble is they have got such a busy life"*
> (Anne, lines 322-331).

How much it did not worry her to be alone in an emergency situation is not very clear, but what seems clear is that she felt she could not just call any of her three daughters and expect anyone to be with her.

In both these participants' accounts, some form of resignation to how things were for them in A&E emerges, either in relation to waiting times or in relation to being alone in that experience.

5.3.1.3 They are Too Busy for Me

A sense of staff being too busy was identified from Michael and Anne. Even if technically this is not to be considered a recurrent theme in this study, I felt that the patients who mentioned it, did so very decisively and with some form of emotional involvement attached to it. This comes out for me from the emphasis put in their tone of voice and repetition of words or phrases. Michael, for examples, stated:

> *"I would say they are overworked. They are overworked. They need double… (2) they need, they need double the staff […] well, they are asked to do too many things at a time… (2) you know what I mean? That sort of things"*
> (Michael, lines 140-144 and 148-152).

It is interesting to notice that in Michael's case, this comment happens at the very end of the interview, when, after he had shared with me mainly positive comments about the staff and about how he had felt treated by them, I asked him if there was anything else he wanted to add before closing the interview. Considering this contextual element, I wonder if the gratitude he was possibly feeling towards the staff having treated him at a very critical moment (he had gone to A&E because of a heart attack and was feeling miserable and scared) had prevented him from sharing directly any experience of dissatisfaction towards the service and, if stating that "*they are overworked*" (Michael, lines 150-151) and that *"they need double the staff*" (Michael, lines 143-144), might be a way for him to express that dissatisfaction in a concealed way and/or find a justification for any episode of sub-optimal care.

Anne expressed her feeling of staff being very busy repeatedly, at different points of the interview: *"they were very busy"* (line 39) and:

> *"yes, because, ahem, you know, ahem, I know they are all so busy and there is always someone worse than you"*
> (lines 67-70)

and:

> *"there's always other people who are worse than you but, they seem to be very busy doing an awful lot of stuff there… (3) everyone's got different jobs… (2)"*
> (lines 267-272)

and:

> *"cause doctors and nurses are always so busy"*
> (lines 220-21).

These statements mainly come out after her having said that *"they were all very good*" (lines 105-106*)* and that she had *"no complaints"* (lines 106-107). Again, like Michael, considering that many older people are hesitant to share criticisms towards services upon which they depend (Age UK 2015) I wonder if this might not be a concealed way to express her criticism.

Anne, however, when she stated that the staff was very busy, she also said that *"there is always someone worse than you*" (lines 69-70), adding a further element to her narrative: in my interpretation, this might suggest that it is not only that the staff was generally too busy*,* but also that she felt she was not 'unwell enough', like other people were and, possibly, she felt she might have been a burden for the clinical staff. This would be coherent with other statements she made when she commented about the usefulness of the ICCI. For example, she said:

> *“doctors and nurses are always so busy and someone like that, you know, it does … (3) help, you know, don’t feel you are wasting their time or anything”*
>
> (lines 220-224)

and it would also be coherent with existing literature which suggests that older people often do not feel totally entitled to receive care and fear they might be a burden to the system (Hoban et al. 2013; the Parliamentary and Health Service Commissioner for England 2011).

For Anne, however, it was not only the clinical staff in A&E who were too busy for her, but her daughters too. When she was asked what it felt like to be on her own in A&E, she commented that she could not even consider calling her daughters to ask them to reach her as*: “the trouble is they have got such a busy life and that”* (lines 330-331). Again, this seems coherent with research showing older people feel to be a burden to their families when unwell and for this reason might tend to avoid asking for their help when needed (Cahill et al. 2009).

A perception of staff being too busy emerges strongly from these two participants. Moreover, for one of them, it is not only the staff that are too busy for her, but her relatives too, adding to the experience of helplessness which this theme contributes to inform.

5.3.2 Uncertainty

Some form of uncertainty was experienced at least by half of the participants to this study. Uncertainty, in their A&E experience can be perceived at different times, both at arrival – before triage – or subsequently, either whilst waiting for a doctor to visit them or after the visit, when they are waiting for results, and they do not know if they are to be admitted or discharged. The experience of Uncertainty takes different forms for them, which I attempt to articulate here through: Sitting with the Unknown, Fear of Being Forgotten, and Confusion.

5.3.2.1 Being with the Unknown

The very dimension of an emergency situation faces us with something ‘unknown’. An emergency is obviously something sudden and unexpected -

otherwise it would have been planned -. This is articulated differently by Robert, Walter and Anne.

Robert, whom I interviewed while he was sitting in a wheelchair, in the company of a nurse who clearly represented a familiar presence to him, let me understand that his A&E experience, psychologically, started before he physically arrived at A&E. In that time of transition just before arrival, he was probably trying to envision a possible scenario, to grasp what might happen to him, but he did not manage to. At one point, he stated: *“I didn’t know what to expect before I arrived*” (lines 42-44) and then, while talking to me during the interview, he seemed to make sense of that feeling and concluded: *“I think I was a bit scared of the unknown”* (lines 53-54).

The sense of having to ‘be with’ the unknown for some time, as an inherent aspect of the A&E experience also emerged from Walter, who, even if he did not acknowledge it openly, described his waiting without knowing, in the A&E cubicle *“for the man to say to you where you have to go”* (lines 96-97), therefore for someone to unveil the next step, to reveal what was still unknown.

Anne added details of her thought processes during her being with the unknown in the corridor, after examinations, which somehow evokes a sense of fear and anxiety: *“and well you know, just wondering what’s gonna happen, how long is gonna be and all the rest of it”* (lines 262-264). In my interpretation, her account, in particular, suggests fears which might go well beyond the A&E and even the hospital stay in itself: when she mentioned *“all the rest of it”* (line 264), one might think that, as an older lady living on her own, with three very busy daughters who live far from her, she might possibly have been wondering if her life would become very different after that experience, whether her daughters would need to take care of her and, if they could not, who would do so. She might possibly have been wondering if that was just the beginning of a different, and more complicated, stage of her life.

“Being with the Unknown” is an aspect of the uncertainty older people face when in A&E. For this study’s participants, the unknown is represented by their struggle to imagine what the setting will be like – just before arrival – or by the unpredictable outcome of their diagnosis and therefore the following step in their hospital’s journey.

For some of them – very possibly – what becomes unknown might also be what will happen to the life they have led up to that point.

5.3.2.2 Fear of Being Forgotten

Fear of Being Forgotten might lie at the core of Anne's experience, when she described waiting for someone to help her transition from the A&E to the ward, after discharge:

> *"it does seem a long time when you're just sat there doesn't it? (12:21- 12:23 inaudible) and you keep wondering, you know, when they are coming for you"*
>
> (lines 304-309).

It certainly was the case for James, who articulated this very clearly:

> *"Well, I couldn't see anything, you know what I mean? All I could see was a clock, you know, they put curtains around you, and you think: you lie there, and you think: I am sure they have forgotten me. You know what I mean? But they haven't, but that's what it feels like, you know?"*
>
> (James, lines 101-110).

James – who came across to me as a blunt and self-aware individual, also very willing to chat and share his experience – seemed to connect his fear – which was actually a certainty, from what he said – of having been forgotten, to the very dimension of seclusion in the A&E cubicle: he could not see anything apart from a clock on the wall and the curtains around him. There was nobody with him. He seemed to have lost all reference points. It is comprehensible that he felt he had been forgotten: having been deprived of most visual references and having temporarily lost connection to other humans, in a moment of vulnerability – possibly exacerbated in his case by early stages of dementia – this is how he made sense of what was happening to him: *'I am sure they have forgotten me'* (lines 106-107).

Fear of Being Forgotten by the staff certainly adds to the experience of Uncertainty. In this study, this is clearly experienced by James, and might have been experienced by Anne.

5.3.2.3 Confusion

Confusion is experienced both by Anne and by Robert when it comes to ‘who is who’ in A&E.

Anne, for example, stated: *“someone came and talked to me, but I can’t remember”* (lines 91-93). Listening further to her and to Robert, it emerged that this might have been due to the large number of professionals these patients were faced with during their emergency stay. Robert, for example, admitted: *“I don’t know names… (2) you know, there are so many of you!”* (lines 127-129), and he is echoed by Anne, who said:

> *“you see so many different people… (2) you sort of forget who they are, they are coming and going”*
> (lines 190-193).

Anne experienced some confusion also in relation to time:

> *“and then I had to wait to come up to the ward and then I can’t remember what time it was when I came up to the ward, it must have been around five I think”*
> (lines 93-97)

and, eventually, she disclosed to me that a sense of confusion was also triggered when interacting with non-British staff. She reiterated this, which gave me a sense of it being a significant issue for her: *“but I do find it a bit difficult with the foreign accents”* (lines 376-377) she says, and then: *“I keep asking what they say because I don’t want to get confused, ahaha!”* (lines 383-385), and then she added: *“it is difficult to understand”* (lines 400-401).

There was not a single moment in which Anne’s disclosure about her issue with foreign accents came across to me as related to a form of xenophobia. She was very friendly and open with me, and very generous in her disclosure over the whole interview – and she could appreciate my Italian accent -. This impression I got from her informed my belief that she was genuinely scared of not being able to understand clearly what she was told, when interacting with someone with a foreign accent in the A&E setting.

Confusion is a further shape taken by the experience of Uncertainty for older people in this study. It happens that they cannot remember names – or get confused between members of staff – possibly because they are faced with many of them in A&E. It happens that they become uncertain about what time it is, and it can also happen that they feel confused about what they are told by staff, when that is communicated by a professional with a foreign accent.

5.3.3 Unpleasant Sensations

Unpleasant Sensations; it's the title under which I grouped a range of sensations which emerge – more or less directly – from a number of participants' accounts.

These can be represented by actual sensorial experiences – like feeling cold, or uncomfortable in a chair during a long wait – to more emotional ones, like the sense of disappointment after the setting-up of unrealistic expectations, or like boredom.

Unpleasant Sensations are experienced through Unpleasant Waiting, Disappointed Expectations, and Negative Reminiscences.

5.3.3.1 Unpleasant Waiting

The experience of waiting was referred to as negative when it was perceived as long and boring by the participant, like in the case of James, who initially said: *"It felt long"* (line 95) and then added: *"you know, I mean, cause you know, hospitals are boring!"* (lines 97-98). In the case of Anne, it is not immediately clear why waiting in the corridor was *"the worst thing"* (line 255) for her:

> *"A**:** I went to the ahem… (3) x-ray and, and, after that, ahem, I think I might have been back into the cubicle and then they put me out into the corridor and I was sat there some time before they moved me up… (2) stairs, and that was pretty the worst thing, just sitting in a chair, waiting… (2)*
> *I: in the corridor*
> *A**:** yeah, mmh"*
>
> (Anne, lines 248-258).

When I tried to deepen the subject, she referred to unmet basic physiological needs:

> *“I: and how did it feel like?*
> *A: I was a bit cold; I wasn’t terribly warm””*
> (Anne, lines 259-261)

and then she added: “*I was tired, you know and… (2) I just wasn’t terribly comfortable in the chair*” (Anne, lines 309-312).

There is another section of the interview where Anne refers to impending physiological needs which were not adequately met because of the long wait:

> *“I said to the nurse: ‘I need to go to the loo’ and he sort go and get a nurse and he was gone ages and ages, that it’s the worst thing, I think, I mean that’s the only complain, really, and I thought: ‘I am not gonna last’”*
> (Anne, lines 45-51).

However, in other sections of the interview, as it has been shown in section 5.3.2.1 “Being with the Unknown” (p. 141), the discomfort of the waiting time for Anne seems more connected to the uncertainty prompted by waiting without knowing what will happen, i.e.:

> *“it does seem a long time when you’re just sat there doesn’t it? (12:21-12:23 inaudible) and you keep wondering, you know, when they are coming for you”*
> (lines 304-309).

Walter did not address directly the waiting time as unpleasant, but in my interpretation, the expression he used suggests that, at least, it felt long: “*I spent, ooh, three-four hours [waiting]”* (lines 40-41) and:

> *“well, what can you do, you got to wait and that’s it. Wait till they come. And sometimes it takes a long time”*
> (lines 130-133).

As we have seen in section 5.3.1.2 “Resignation”, p.138, Walter seemed to be resigned to a long wait.

5.3.3.2 Disappointed Expectations

While interviewing both Walter and Anne, I perceived the same frustration when they mentioned someone from the staff having set up unrealistic expectations regarding the waiting time. What seems crucial here is not so much the long waiting, but the creation of unrealistic expectations which eventually have been disappointed. Anne seemed to allow me to see glimpses of her disappointment when she said:

> *"And there is always someone worse than you, but they sort of said: 'oh, hang on a minute' and then (3:00 to 3:02 inaudible) and it's a long time [to wait] when, when I was dying to go to the toilet, you know. And that's the worst thing, otherwise they were very, very good. No complaint at all"* (Anne, lines 69-77).

Even if, probably, the reason for Anne to include this experience among the "worst things" that happened to her in A&E is the very fact that she needed the toilet – as we have seen in section 5.3.3.1 "Unpleasant Waiting" (p.145) – the betrayal of her expectation seems to have had a role in her making sense of that experience as negative. It looks to me like the unreliability of the member of staff who casually said: 'hang on a minute' has hurt her, at some level.

I interpret in the same way Walter's expression when, stepping into the role of a member of staff he said: *"and: 'I'll come back in a minute…'* (lines 141-142)" and then, with some irony, he added: *"the longest minute it has ever been!"* (line 143).

I might push my interpretation further, wondering whether they have actually felt 'cheated' by staff, but I don't have enough elements to come to this conclusion. It is very possible that they did not think the staff lied on purpose, but only that they had inadvertently set up unrealistic expectations.

5.3.3.3 Negative Reminiscences

Both James and Anne had reminiscences of previous negative hospital experiences during their recent A&E stay.

When James was put behind closed curtains, he seem~~s~~ to have thought: 'not again!' as he revisited a memory from few years before:

> *"It's like when they sent me to X, they put me on a side, I said: 'sorry, I cannot stay in here'. They said: 'why not?' I said: 'I've got early stages dementia, I want to be in a bit [of space] with other patients', anyway, an hour later they moved me to a bit with some more patients in it"*
>
> (James, lines 126-135).

James seemed to have learned from that experience, as this time he also decided to ask for what he needed without waiting for the staff to understand it, therefore asked the nurse to open the curtains, and his request was satisfied.

Anne remembered: *"I have been here before 'cause I fell over a couple of years ago, you know, that was not very nice"* (lines 276-279), but she had already mentioned this in a previous section of the interview:

> *"because a couple of years ago I had a fall (2:36 to 2:38 inaudible) and I was dying to have a wee, and they said: 'we can't take you' (2:44 to 2:47 inaudible) and that was very embarrassing"*
>
> (Anne, lines 59-64).

It seems like Anne's expectation of A&E care, based on a previous experience of neglect, was already partly negative. She might have approached A&E with the fear that what had happened to her two years ago would repeat itself, possibly causing a great degree of physical discomfort *("I was dying to have a wee"* line 61), together with a feeling of rejection *("they said: we can't take you"* line 62) and embarrassment *("and that was very embarrassing"* lines 63-64), and her fear eventually has been confirmed.

These reminiscences seem to add a peculiar temporal feature to the participants' experiences in A&E. Anne, stated: *"it's…ahem, quite an experience!"* (lines 274-275), seemingly echoing what Dilthey (1976) calls *an experience* as opposed to just *experience*, as to say something that breaks our everyday, unselfconscious flow of experiencing life and events, in the exact moment in which we become aware of what is happening, therefore also affecting our perception of time. For both Anne and Walter, time stopped being linear, as they became aware of what was happening to them in the present through a flashback in time. If looked at from this perspective, there seems to emerge some features of a re-traumatisation process, where re-traumatisation is intended as the re-experiencing of a previously traumatic event, either consciously or unconsciously (Schippert et al. 2021). This interpretation appears validated by Anne when she stated: *“but it is a bit traumatic”* (line 233).

Negative reminiscences from previous A&E experiences are triggered both in Walter and Anne during their recent A&E stay. It is possible that these two participants already had a heightened sensitivity to certain uncomfortable aspects of the A&E stay at arrival, just because of those very previous experiences, and this has affected the way they made sense of the events during their more recent admission.

It is also possible that these re-occurrences of possibly traumatic events have triggered some form of re-traumatisation in them, certainly altering their perceived temporal dimension for a while.

5.3.4 Sense of Safety

A Sense of Safety represents the one experience that all patients reporting positive or partly positive experiences in A&E seem to share.

The experience of a Sense of Safety took many forms for each of the participants and/or at different stages of each participant’s journey. I articulated them into: Feeling Looked After, Experiencing Relief and Reassurance, and Feeling Involved.

5.3.4.1 Feeling Looked After

For almost all participants, the A&E staff was *good* or *nice* or *caring*, even when this appeared in striking contrast with the rest of their account, as in the case of Anne, who kept repeating that the staff “*were really good”* (lines 77; 108; 115; 187;315) and that she had “*no complaint*” (lines 77; 107; 283) after the account of a number of negative experiences she actually had with the staff.

For Walter *“they were nice”* (line 197), while Dave, who, during the interview visibly struggled with recalling facts and articulating his thoughts, still could remember that he felt treated *“very well”* (line 22) and felt the staff showed him respect.

Barbara, whom I consistently perceived as extremely dismissive of her experience and very resistant, still said: *“Everybody was very nice”* (line 12).

Pauline stated: *“they made sure I was all right and that I had something to eat, because I haven’t eaten”* (Pauline, lines 100-102) revealing that, on top of her clinical needs, her basic needs had also been taken into consideration by the staff.

Pauline came across to me as a very articulate woman, though slightly resistant in sharing the emotional aspects of her experience. Despite this, I could see that she seemed to have experienced a sense of safety by being enabled to see what was going on around her in A&E, probably because of the very fact that she noticed the staff were intentionally making sure that she was “*somewhere safe*” (Pauline, line 19), and that she was somewhere she could see “*what was going on*” (Pauline, line 36). Here, the sense of safety seems to arise as a result of her acknowledging the staff’s intentional caring act of making sure she could see what was going on, so that she would not be “*nervous*” (Pauline, line 37). It looks like Pauline has felt looked after by being seen in her need to perceive a degree of control of her situation; after all, being able to see what happens can be particularly important for someone who – for the very fact that they are unwell – is very reliant on others.

I could summarise the above by stating that Pauline ‘felt seen in her need to see and to be seen’.

But it is in the accounts of Michael and James that the feeling of safety brought about by the caring attitude of the staff is described more passionately.

Michael started with some general: *“They were very good actually, they were very good”* (Michael, lines 40-41), but after a few of my attempts at digging deeper into his experience, unexpectedly, he almost challenged me: *“do you want to know the personal side of things?*” (Michael lines 80-82) he asked me, almost provocatively, and then went on:

> *“they showed me how to use a bottle easily, I can easily use a bottle and I am all right as I couldn’t do it standing up, things like that. And they don’t make nothing of it”*
>
> (lines 82-87).

In sharing such an intimate detail of his experience, which up to that point he had seemed to have carefully avoided, I felt he really wanted to give the staff credit.

James, on his side, when I asked him what he would say to a friend of his age having to go to the same A&E, declared with enthusiasm:

> *"if you haven't been here before… (2) you don't have to worry about it, you know, you'll get looked after like I did, like they did it with me, I'd say that you might think you have been in there for hours, you know, but once you are in the A&E, especially if you come in by ambulance, they don't forget you. They put you in a bay and you think: 'oh, that's it', but they don't, they keep coming in, you know, checking on you often"*
>
> (James, lines 201-215)

making it clear that, despite the fears and the uncertainty, even the fear of having been forgotten, he had eventually felt safe and looked after, thanks to the caring staff who checked on him regularly.

In summary: there was not a single participant who did not state that they have felt looked after by a caring staff at least at some point during their A&E stay - definitely the most recurrent experience of all – most of them did not go into many details regarding how and why they had felt looked after, but the ones who did, presented a fierce and vivid account of what feeling looked after in A&E had felt to them, and of how it had made them feel safer.

5.3.4.2 Relief and Reassurance

The one word Walter used to communicate to me of his experience of arrival at A&E was: *"relieved!"* (Walter, line 22). He used the same word to describe his experience of being discharged and transferred to a hospital ward after A&E.

Robert also seems to have experienced some form of relief at arrival; this emerges from the contrast between his clearly articulated fear of the *"unknown"* (Robert, line 54) before arrival, and the unexpected welcoming atmosphere he found in A&E:

> *"… (2) it was just a welcoming atmosphere because I didn't know what to expect before I arrived…they came with a cup of tea and they made me feel welcome… (2) it was really good"*
> (Robert, lines 41-46).

Then, he used a word: *home*, which seems even more powerful, in this context: *"I would say that I slowly became to feel at home here"* (Robert, lines 61-63). The use of the word *home* sheds light on the use of the word *unknown* a few lines above: *home* could be seen as the opposite of *unknown*; it represents something familiar and safe. It seems logical to conclude that he feared something (unknown) and found the opposite (home).

Anne seemed to have experienced relief by the simple act of sharing her experience and worries with the ICCI practitioner, at the same time possibly feeling relieved in knowing that she was not doing so with a doctor or a nurse - thus *"wasting their time"* (Anne, line 224)-

> *"She was quite easy to talk to, and that… (2) ahem, I mean, luckily, I haven't got dementia but, ahahah, you know, she was just, ahem… (3) that's her job I suppose, just to go around and reassure older people, you know, that, yes I think is very useful to have someone like that, cause doctors and nurses are always so busy and someone like that, you know, it does… (3) help, you know, don't feel you are wasting their time or anything"*
> (Anne, lines 211-224).

The ICCI seems to have provided Anne also with some relief from the fear of unknown prompted by her A&E visit, possibly making her feel safer, as it emerges from the following lines, where, while trying to minimise her fears, at the same time she admits that the emergency department attendance had made her wonder where things would be going 'to end':

> *"I think just talking to her and that, you know, because, well, I am not scared about coming into hospital, but it is a bit traumatic and that, you know, I felt so rotten yesterday, I feel a bit better today in myself but yesterday I felt so dreadful, you think: 'where is that all going to end?' you know, and I think she was just… (2) you know, you just chat about things and yes, I think it's very nice to have someone like that"*
> (Anne, lines 230-243).

Michael also seemed to have been provided with a sense of safety by the ICCI, through the awareness of a reassuring presence which is there exactly when you want them:

> *"M: well, that's like you are giving me the call on button*
> *I: the call on button?*
> *M: yes, the call on button is when you can have someone from the staff with you the minute you want them. Well, with her it was like that, having someone when you want them"*
> (Michael, lines 115-123).

Relief and Reassurance – feeling suddenly safer – happened for James when, after having felt isolated and unsafe behind the closed curtains of the A&E cubicle, he asked the nurse to open them, and he finally could see people *"walking past*" (line 125) around him. He could see what was happening and that felt good, which prompted a sense of relief:

> *"So, I said to the nurse: 'nurse, is it possible to just open it?' she said: 'certainly' all right then, I was relaxed then"*
> (lines 118-122).

For most participants, a greater sense of safety – after having felt unsafe or powerless – ensued in A&E, through the experience of reassurance – or relief. This, for some, happened at arrival, when they were greeted and welcomed, feeling suddenly at home, or at discharge, when, presumably, being admitted to a specific ward after having received the results of the first tests and examinations had left them with less unknown. For others, the ICCI intervention was openly acknowledged as reassuring, either because it enabled them to share their worries and fears without feeling to be a burden on the busy clinical staff, or because it provided the certainty of having someone alongside, exactly when needed, without having to wait too long.

Moreover, for some, like James, relief – and relaxation – ensued when he was enabled to see other people around him through the very act of someone opening the curtains of the cubicle where he had felt secluded.

5.3.4.3 Feeling Involved

For Walter, Pauline and James, being involved in their own care through communication seemed to be a way through which a sense of increased safety in A&E came about.

When I asked Walter how his experience with the staff in A&E had been, he said it was good without going into many details. However, the first thing that he said when asked to deepen his answer was that the staff had talked to him:

> *"I: how would you describe your experience with the staff when you were at the emergency department?*
> *W: oh..(2) good. There were nice chaps there.*
> *I: can you tell me more about this?*
> *W: they were nice and talked to me…"*
> (Walter, lines 190-198).

In a previous section of the interview, Walter had already mentioned *nice chaps* – possibly paramedics – who talked to him informing him about what would happen next (on the ambulance), and that seemed to have made him feel safer. For this reason, it seems to me that for him, *chaps* being *nice* are 'chaps who talk to him' in A&E, so that his answer: *"they were nice and talked to me…"* (line 197) appears to me to also possibly mean: 'they were nice because they talked to me'*.* To be talked to is to be involved, it does not matter what the subject of the conversation. Patients label as very negative the experience of hearing staff talking to each other without addressing/involving the patient, almost like they were not actually there in the same room (Cornwell and Goodridge 2008). It is easy to understand while 'just' being talked to, no matter about what, can give a patient the feeling of being acknowledged and involved. The sense of increased safety is a fairly logical consequence, as in such a situation the more a person feels connected to other people in the room, the safer they experience to be (Cacioppo and Patrick 2008).

For other participants, the experience of being involved through communication was more clearly defined as being involved in details about the care they were receiving: Pauline, for example, stated that the staff making her involved with what *"was going on"* (line 36) felt good, and added: *"they told me what they were doing all the time"* (Pauline, lines 61-63). Here we cannot know how the actual knowledge of details about her treatment was important to Pauline, but it makes sense to think that, again, like for Walter, what was central to her positive experience was the very act of being acknowledged and involved through communication: telling somebody what you are doing "*all the time*" is important to the maintenance of a shared narrative, thus a shared reality: a togetherness, that, automatically, makes us human beings feel safer at a very primitive level (Porges 2011).

James adds to this picture the very experience of being listened to:

> ***"****Yeah, yeah… (2) you know, I mean, you can talk to them, like I am talking to you… (2) and they listen. And then they'd tell me what I want to know, and then before they got all sat, like you said: 'is there anything else you want to ask me?' You know, that's it, yeah, it's just… good, good, I like it"*
>
> (James, lines 275-284).

Being listened to, being encouraged to ask questions, is an effective way of making someone feel empowered. For an older person in a health emergency situation, it can foster some sense of control and agency in a situation where the very control over one's body seems lost and where all one can do is to rely on other people's help. James is describing a sense of involvement through communication which goes one step forward: not only has he felt acknowledged and connected: he has also felt valued and empowered because he was listened to. This must have positively affected his sense of safety.

In conclusion: feeling involved through communication in A&E can take many shapes and can happen at many levels. For those three participants, it certainly happened through the feeling of being acknowledged in one's very presence, through receiving a direct and open communication about treatment, and through the experience of being listened and being encouraged to ask questions about the treatment.

All the above must have added to their sense of connection and control, and thus safety, as per the very way our human brains are wired (Porges 2011).

5.4 Summary of the chapter

In this chapter I have presented what I knew about each of the participants before and after running the interviews, showing demographic data about them in tables and signposting the reader to my impressions from my encounter with them in form of vignettes (in Appendix 8 - Encounters with patient participants vignettes – p. 351). I reported the findings from the analysis of my interviews with them, divided into super-ordinate and lower-ordinate themes, informed by an IPA framework.

STUDY PHASE B

Experience of ICCI practitioner

Chapter 6 – Literature Review – Study Phase B

6.1 Outline of the chapter

In this chapter, I will give an account of the processes and reasons which brought me to define the focus of this second literature search. I will then describe how I structured and ran the additional literature review, presenting the process of screening the articles (outlining inclusion and exclusion criteria), and I will give an account of how the articles were appraised, analysed, and of how data were extracted and organised for synthesis and writing.

I will then move to discuss the findings which emerged, structuring them by main themes, and showing how they link to each other eventually leading to identify a gap in the literature. Finally, I will explain how this study can fill that gap.

The approach to this literature review and to the structure of this chapter mirrors the process already undertaken in Chapter 2 of the study for the literature review related to phase A (Experience of older patients).

6.2 Defining the focus of the review

As mentioned in Chapter 1 and Chapter 4 (section 4.4, p.123), in 2020, because of the COVID-19 pandemic and related UK Government and NHS policies and guidelines, I was denied access to hospital wards to interview older patients. I then focused on finding an alternative way to keep on collecting data about the phenomenon of older people in A&E and the ICCI. Eventually, I decided to widen the scope of the research to include my exploration of the lived experience of the practitioner who delivers the ICCI to older people at the hospital site, through remote interviews. This is how phase B of this study evolved. The process prompted a further literature review to explore what was already known about the experience of staff and/or volunteers delivering care to older people in A&E.

The review question was:

What is known about the experience of staff and/or volunteers delivering care to older people in an Accident and Emergency department as it is told from their own point of view?

I found a significant body of literature on the topic area, but no study was found on the lived experience of a member of staff or volunteer delivering an intervention similar to the ICCI for older people in A&E.

6.3 Search strategy

In this additional literature review a narrative approach was also adopted.

This review focused on research studies (only primary research) exploring the experience of any member of staff – or volunteers – delivering care to older people in A&E, from the staff point of view. Again, I focused on primary research studies because my literature review question required me to remain as close as possible to first-hand information from subject participants.

Studies which explored the experience of A&E from multiple points of view (for example, from both the point of view of staff and older people) were included, which meant I also included some of the studies already part of the first literature review about the experience of older people (Chapter 2).

In order to answer my review question, exactly as I did for the first literature review, I needed to formulate it as a PEO (Population, Exposure, Outcome) question, to find literature concerned with the outcome (experience) of the exposure to something (delivering care to older people in A&E) of a specific population (staff and/or volunteers).

In order to create a research string with suitable key terms, I searched for synonyms with the help of a thesaurus, and I looked at MESH terms and alternative terms as I identified them from existing papers during the search. My key terms, including the appropriate Boolean operators and modifiers, can be seen in Table 15, p.161.

Table 15 – Literature search Key Terms – Phase B

Framework	Key terms
P	staff OR nurs* OR "healthcare professional*" OR professional* OR volunteer”
E	(“emergency department” OR “ED” OR “accident and emergency” OR “A and E” OR “A&E” OR “emergency room” OR “a&e” OR “ER” OR “emergency service”) AND (“older patient*” OR “older user*” OR “older people” OR elderly OR geriatric OR “senior citizen*” OR “senior patient*” OR retired OR aged OR senior)
O	experienc* OR feeling* OR attitud* OR perception* OR opinion* OR view* OR challenge

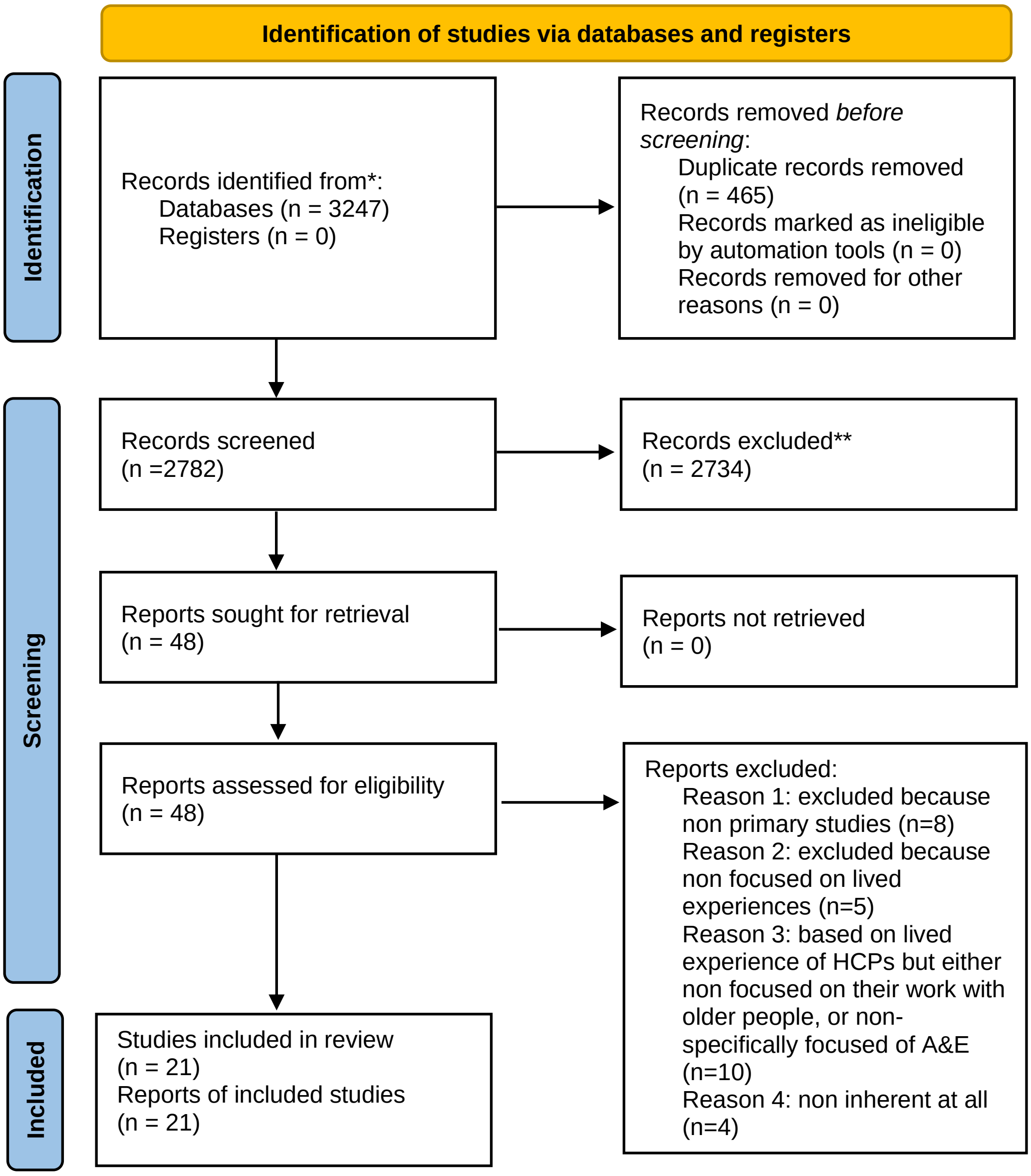
The search was carried out from January to April 2021 using the following databases: Scopus, Medline Complete, Science Direct, CINHAL complete; SocINDEX and PsycINFO (the reasons behind the choices of those specific databases has been articulated in Chapter 2).

I chose to limit the search to any paper published until April 2021 because that is when the data collection for this second phase of the study started. Both qualitative and quantitative studies have been included, for reasons already outlined in Chapter 2 . The search has been limited to peer reviewed articles written in English, because although I can understand Italian language – it being my mother tongue – relevant Italian scientific studies are normally published in English.

Further literature searches for each of the themes that emerged from the findings of this part of the study has been repeated in July and August 2022 to ensure that any new data which might have emerged, would be included in the discussion.

6.4 Literature review diagram

PRISMA 2020 flow diagram for new systematic reviews which included searches of databases and registers only



From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n7

Figure 6 - The experience of staff/volunteers caring for older people in Accident and Emergency department

This search identified 3247 articles through a very sensitive database search.

After removal of duplicates, 2782 articles were left and screened via title and abstract of which, 2734 were excluded because of non relevance.

At this point I was left with 48 articles whose full-text I read and assessed for eligibility: 27 of those articles were excluded. Eight of them because they were not primary studies, five of them because they were not focused on lived experience, 10 of them because even if they were primary studies and focused on staff lived experience, they were either looking at the experience of staff with the general population rather than with older people, or at the experience of staff with older people but not specifically in A&E, or both. Four of them were excluded because they were not relevant at all.

Of the remaining articles,16 studies were included in the qualitative synthesis, one study included in the quantitative synthesis, and four were mixed-method studies.

All studies entailed the point of view of registered healthcare practitioners. No study was found about the experience of volunteers.

6.4.1 Critical review

All the studies included in this review (only peer-reviewed primary research studies) were appraised using the Critical Appraisal Skills Programme (CASP) checklists for evaluating the quality of either qualitative or quantitative research (CASP 2006), or, in case of the quantitative study which was cross-sectional – using an AXIS checklist (Downes et al. 2016). Findings from these appraisals were not used to determine the inclusion or exclusion of papers, because – as already stated in Chapter 2 – there are no accepted methods to guide these decisions (Thomas and Harden 2008). However, engaging with the appraisal checklists helped me to acknowledge the strengths and weaknesses of each single study and to be able to consider them and the strength of the evidence when discussing the literature findings.

There was a range of different levels of quality within the articles, which is possible to appreciate in the following appraisal table (Table 16, p.165).

6.4.2 Literature review tables

After the appraisal, all papers were analysed using literature review tables, exactly as it was done in Chapter 2 for the literature review belonging to phase A of the study. These tables are provided in Appendix 9 - Literature review table phase B – p. 357.

6.4.3 Synthesis matrix chart

The literature review findings were synthesized and organised with the help of a synthesis matrix chart as done for phase A. This is available in Table 17, p.166.

6.4.4 Links to Lifeworld

As already carried out for the literature review in phase A, I looked at these literature findings through the lenses of Husserl's Lifeworld (Chapter 2).

Each of the nine categories I was able to identify in the literature could be linked back to one or more of the Lifeworld dimensions (see Table 18, p.167). Specifically, I identified four of the Lifeworld's dimensions: Temporality, Spatiality, Mood and Intersubjectivity.

Exactly as it happened in Chapter 2 , Intersubjectivity emerged as the key – and most complex – aspect, oscillating between the two polarities of human connection and disconnection.

These themes/dimensions have been used as headings to structure the review that follows over the next sections.

Table 16 – Appraisal table – Phase B

Authors	Was there a clear statement of the aims of the research?	Is a qualitative -or quantitative-methodology appropriate?	Was the research design appropriate to address the aims of the research?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?
Seffo et al. 20	YES	YES	??	??	YES	YES
Wolf et al. 19	YES	YES	YES	??	YES	YES
Lennox et al. 19	YES	YES	YES	YES	YES	YES
Parks et al. 19	YES	YES	??	YES	YES	YES
Gorawara-Bhat et al. 17	YES	YES	YES	YES	YES	YES
Hunter et al. 17	YES	YES	YES	YES	YES	YES
Wright et al. 18	YES	YES	YES	YES	YES	YES
Fry et al. 17	YES	YES	??	YES	YES	YES
Palonen et al. 16	YES	YES	YES	YES	YES	YES
Bulut et al. 15	YES	YES	YES	??	??	YES
Fry et al. 15b	YES	YES	YES	YES	YES	YES
Fry et al. 15a	YES	YES	YES	YES	YES	YES
Gallagher et al. 15	YES	YES	YES	YES	YES	YES
Taylor et al.15	YES	YES	YES	YES	YES	YES
Fry et al. 14	YES	YES	??	YES	YES	YES
Gallagher et al. 14	YES	YES	YES	YES	YES	YES
Parke et al. 13	YES	YES	YES	YES	YES	YES
Kelley et al. 11	YES	YES	YES	YES	YES	YES
Robinson and Mercer 07	YES	YES	YES	YES	YES	YES
Kihlgren et al. 05	YES	YES	YES	YES	YES	YES
Meyer et al. 99	YES	YES	YES	YES	YES	YES

?? = cannot tell’

Table 17 – Synthesis Matrix Chart – Phase B

Categories	**Meyer et al. 99**	**Kihlgren et al. 05**	**Robinson and Mercer 07**	**Kelley et al. 11**	**Parke et al. 13**	**Gallagher et al. 14**	**Fry et al. 14**	**Taylor et al.15**	**Gallagher et al. 15**	**Fry et al. 15a**	**Fry et al. 15b**	**Bulut et al. 15**	**Palonen et al.16**	**Fry et al. 17**	**Wright et al. 18**	**Hunter et al. 17**	**Gorawara-Bhat et al.17**	**Parks et al. 19**	**Wolf et al. 19**	**Lennox et al 19**	**Seffo et al. 20**
1 - Workload/Pressure/Time	x		x	x	x	x	x	x	x			x			x	x		x	x	x	x
2 - Equipment, Staffing Levels, and Specialist Skills to Care for Older People in A&E	x	x	x	x				x				x			x	x	x	x	x	x	x
3 - Environment				x	x							x	x		x	x		x	x	x	x
4 - Biomedical Care vs Holistic Care in A&E	x	x		x	x	x		x				x									x
5 - Relationship to Patients' Family Members		x	x	x		x	x	x		x			x	x		x				x	x
6 - Communication		x	x	x	x					x	x		x	x	x	x	x		x	x	x
7 - Assessing and Addressing Patients' Pain/Appropriate Triage			x							x	x			x			x				x
8 - Continuity of Care Across Settings/Systemic Issues	x	x	x	x				x	x					x	x	x	x		x		x
9 - Feelings and Satisfaction at Work			x	x		x	x	x	x	x		x				x		x	x		x

Table 18 – Synthesis Matrix Chart with Lifeworld themes – Phase B

Lifeworld dimensions	**Categories**	**Meyer et al.99**	**Kihlgren et al. 05**	**Robinson and Mercer. 07**	**Kelley et al.11**	**Parke et al.13**	**Gallagher et al. 14**	**Fry et al .14**	**Taylor et al .15**	**Gallagher et al .15**	**Fry et al. 15a**	**Fry et al. 15b**	**Bulut et al. 15**	**Palonen et al. 16**	**Fry et al. 17**	**Wright et al. 18**	**Hunter et al .17**	**Gorawara- Bhat et al. 17**	**Parks et al. 19**	**Wolf et al. 19**	**Lennox et al. 19**	**Seffo et al. 20**
Temporality, Intersubjectivity, Mood	1 - **Workload/Pressure/Time**	x		x	x	x	x	x	x	x			x			x	x		x	x	x	x
Temporality, Spatiality, Intersubjectivity	2 - **Equipment, Staffing Levels, and Specialist Skills to Care for Older People in A&E**	x	x	x	x				x				x			x	x	x	x	x	x	x
Spatiality	3 - **Environment**				x	x							x	x		x	x		x	x	x	x
Temporality, Spatiality, Intersubjectivity, Mood	4 - **Biomedical Care vs Holistic Care in A&E**	x	x		x	x	x		x				x									x
Temporality, Intersubjectivity, Mood	5 - **Relationship to Patients' Family Members**		x	x	x		x	x	x		x			x	x		x				x	x
Temporality, Spatiality, Intersubjectivity, Mood	6 - **Communication**		x	x	x	x					x	x		x	x	x	x	x		x	x	x
Temporality, Intersubjectivity, Mood	7 - **Assessing and Addressing Patients' Pain/Appropriate Triage**			x							x	x			x			x				x
Temporality, Intersubjectivity	8 - **Continuity of Care Across Settings/ Systemic Issues**	x	x	x	x				x	x					x	x	x	x		x		x
Temporality, Intersubjectivity, Mood	9 - **Feelings and Satisfaction at Work**			x	x		x	x	x	x	x		x				x		x	x		x

6.5 Themes identified – The experience of staff and/or volunteers caring for older people in Accident and Emergency departments

Four of Husserl’s Lifeworld dimensions were identified as relevant ways of presenting the literature in this section of literature: Temporality, Spatiality, Mood and Intersubjectivity. Having first described the nature of the literature reviewed, each aspect will then be discussed in more depth.

6.5.1 Overview of sources

The analysis revealed the presence of papers covering a timeframe of approximately 20 years of research (between 1999 and 2020) in different Countries: seven in Australia, five in Canada, two in USA, two in England, two in Sweden, one in Finland, one in Turkey and one in Canada, USA and Hong Kong. It is evident that, over a comparable timeframe, research in England produced many more studies focused on older patients’ experience in A&E (six) than studies on the experience of staff working with older people in A&E (two). This might possibly have happened as a result of a recent focus on patient-centred care and patient satisfaction in the NHS in UK (2012).

Most of the papers (14), covered the experiences of nurses; some covered the experiences of A&E nurses and managers (Meyer et al. 1999), nurses and physicians (Bulut et al. 2015; Wright et al. 2018) nurses, doctors, occupational therapists, social workers and physiotherapists (Hunter et al. 2017; Lennox et al. 2019) or included a larger variety of staff, like A&E managers, nurses, physicians, support workers, diagnostic imaging technicians, palliative care staff, rehabilitation staff, laboratory staff, community service staff, clerical staff, housekeeping staff, dieticians, pharmacists, security staff, and paramedics (Kelley et al. 2011); One covered only the experience of physicians (Parks et al. 2019). No study about the experience of volunteers caring for older people in A&E was found.

Between them: Parks et al. (2019) used Theoretical Domains framework (TDF), Wright et al. (2018) made use of Experience-Based Co-Design (EBCD), Hunter et al. (2017) and Parke et al. (2013) stated that they moved from a Social-Ecologic perspective, Fry et al. (2015a and 2017) stated that they have used a Constructivist paradigm, and both Taylor et al. (2015) and Kelley et al. (2011) used Focused Ethnography.

Between the mixed-methods studies, Meyer et al. (1999) stated they have used Action Research, while Wolf et al. (2019), Gallagher et al. (2015) and Bulut et al. (2015) did not state which methodology was used.

The quantitative study from Robinson and Mercer (2007), used a cross-sectional approach.

Twelve studies used interviews as a method. Between them, two used both interviews and focus groups (Parke et al. 2013 and Lennox et al. 2019), one interviews and non-participant observations (Taylor et al. 2015), one used field notes, observation, focus groups and data from the hospital’s records on top of interviews (Meyer et al. 1999), one used a questionnaire and interviews (Wolf et al. 2019) and one used observation, a questionnaire, and administrative data on top of interviews (Kelley et al. 2011). Of the remaining studies, six used focus groups only (Gallagher et al. 2014; Fry et al. 2014, 2015a, 2015b and 2017; Seffo et al. 2020), while Gallagher et al. (2015) and Bulut et al. (2015) used respectively patients’ medical records and a questionnaire on top of focus groups. Finally, Robinson and Mercer (2007) used a survey and patients’ medical records.

From this overview of the sources, it is evident that studies about the experience of staff caring for older people in A&E made use in almost equal measure of one-to-one interviews and focus groups, while literature about the experience of older people in A&E reviewed in Chapter 2 showed a higher prevalence of one-to-one interviews as a method in the studies. One might wonder if this can be due to the fact that, healthcare workers’ experience in A&E is not only individual, but also collective: it is a clinical team’s experience, therefore authors possibly felt that group interviews might well reflect the ‘team’ dimension of their experience by eliciting staff interactions. This was openly acknowledged by Fry et al. (2014) in their study on nurses’ experiences and expectations of family and carers of older patients in the emergency department but might well apply to other studies too. Overall, it makes sense to assume that focus groups might be easier to arrange and to run with staff members than with older patients. The discrepancy of methods is also possibly due to the fact that older – and potentially disorientated – people might feel more at ease and more focused in one-to-one interviews rather than in a group setting (hearing for some of them may also be more difficult when in a group).

In the following sections I am going to present my analysis of the themes which emerged from the literature, through the lens of Husserl's Lifeworld elements.

6.5.2 Temporality for staff caring for older people in A&E

In the studies reviewed, A&E staff – as opposed to most older patients – experienced time as almost always too short. This lack of time was often associated with a sense of pressure (Taylor et al. 2015; Hunter et al. 2017; Seffo et al. 2020).

This pressure was felt by staff as pressure to perform different and often competing tasks in a short amount of time, having to juggle between conflicting priorities in a setting where there is a significant degree of unpredictability (Parke et al. 2013; Kihlgren et al. 2005; Taylor et al. 2015).

Some members of staff (Wright et al. 2018) saw these time constraints in A&E mainly as policy-driven, referring to the *four-hour target*: a quality improvement measure implemented by NHS in England, which states that the time from arrival to admission, transfer, or discharge should not exceed four hours in total (Department of Health 2000). The target aimed at improving the flow of patients through the A&E, making sure that seriously ill patients would not be waiting on trolleys in corridors. However, as Wright et al. (2018) notice, this measure increased the pressure on A&E staff to process patients through the department. Some feel the time-pressure also stems out of the very reality of staff shortages in A&E (Robinson and Mercer 2007; Kelley et al. 2011; Seffo et al. 2020).

Staff were also aware that older people in A&E would require more time because of their often-complex presentation and associated needs – and that therefore, they represent the patient group which are affected the most from that lack of time and that pressure to perform (Kelley et al. 2011; Bulut et al. 2015; Gallagher et al. 2015), particularly older patients with dementia (Hunter et al. 2017; Seffo et al. 2020). Wolf et al. (2019), for example, noticed that the extended care time needed for older patients often translates in them waiting longer to be seen.

Nurse participants in Taylor et al.'s (2015) study, for example, described their experience of older patients in A&E as if the older adult was "out of synch" (p.187) with the A&E. They portrayed an image of the older patients' slower movements in "an environment of rapid action and intervention" (Taylor et al. 2015), underlying how everything about the speed of these patients differs from other patients from their point of view: their speech, their thought processes, and their movements. Moreover, everything about older patients felt in real contrast with the nurses' need to rapidly accomplish their clinical tasks and move to the next patient. These nurses described their struggle to slow their pace to match the older patients' speed, and in the effort to move these patients through the system, they were aware they often focused on the most evident problems without looking for less apparent, yet possibly more significant issues. They are echoed by nurses interviewed by Parke et al. (2013), who spoke about older patients being generally under-triaged because of time-constraints. For these nurses, being under-triaged meant that the older person stayed in the A&E, and "the longer the stay, the greater is the risk for harm from acquiring a new problem" (Parke et al. 2013, p. 1212). Some of these problems might arise from neglected basic care needs such as nutrition, toileting, mobility and hydration and could have potentially serious repercussions, in particular for older adults with dementia.

In a number of studies in this review, A&E staff did not hide that they are perfectly aware of neglecting older patients' basic needs but feel that they do not have any other choice (Meyer et al. 1999; Parke et al. 2013; Hunter et al. 2017). Some admitted that many times they had to opt for the quicker option regarding the care of older people, even if that was not the best one. For instance, while the use of a commode or toilet is recommended for older patients in A&E to encourage mobility and autonomy, and to preserve dignity, they rarely do so, as it would require too much time and too many resources – even two or three nurses are needed to help a patient move and they opt for giving the patient a bedpan instead (Meyer et al. 1999). At times, they feel that they have to keep the catheters in older patients because they do not have time to clean up their incontinence. Often the catheters are put in without an actual clinical need, with some members of staff pretending they don't know it, as it is easier and quicker to care for a patient who has a catheter (Parke et al. 2013).

A&E staff's Lifeworld, with regard to Temporality, is a fast-paced world (Kelley et al. 2011; Kihlgren et al. 2005; Seffo et al. 2020) where lack of time and ever increasing demands, are all obstacles to meet the needs of the older patients they are supposed to care for (Wright et al. 2018) and translate into a less-than -optimal care for this patient group (Kihlgren et al. 2005; Hunter et al. 2017). This becomes even worse when the older person is cognitively impaired: staff feel that this pressure-filled hectic 'world' they are in aggravates confusion in older people with dementia (Hunter et al. 2017; Seffo et al. 2020), prompting them to use restraints because there is little time to attend to mobilization needs in these patients and a concern for safety (Parke et al. 2013).

Some nurses find that the hectic pace of the A&E also decreases family involvement in discharge education, and, again, they do not see any way of changing that, experiencing a sense of powerlessness (Palonen et al. 2016).

6.5.3 Spatiality for staff caring for older people in A&E

Spatiality in Husserl's Lifeworld is the lived space. It stands for what the space we occupy or move through come to represent to us, and how that space informs how we feel and how we create meaning (Husserl 1970).

Lived space is closely interrelated with lived time. Husserl (1970) stated that:

> "the world is a spatiotemporal world; spatiotemporality (as living, not as logicomathematical) belongs to its own ontic meaning as lifeworld"
>
> (p.168).

According to the above definition, lived space is not a mathematically measurable space but rather an existential theme (Norlik et al. 2013). Merleau-Ponty pointed out that not only the space in which we find ourselves affects the way we feel, but also that, to a certain extent, we become the space we are in and the space becomes us (Norlik et al. 2013). According to Todres (2007), lived space is our encounter with a world of places, things and situations that have meaning.

Looking at staff experience through the lenses of Spatiality, it is possible to see that, in most cases, staff also experience a *lack of fit* between the older patient and the A&E.

This lack of fit was articulated by some as the awareness of lacking adequate furniture and equipment for this patient group (Bulut et al. 2015; Lennox et al. 2019; Wolf et al. 2019) and by others as an overall inappropriateness, where a sensorial overload (excess of movement, excess of light, noisy environment, alarms going off, etc.) would overwhelm the older person, thus preventing staff from providing adequate care and from meeting their needs (Parke et al. 2013; Hunter et al. 2017; Seffo et al. 2020). Wolf et al. (2019) stressed that inadequate resources in A&E would affect both older patients' safety and dignity. In relation to older people with dementia, it emerges that because of the environment, patients often end up feeling more anxious and more agitated in A&E (Parke et al. 2013; Seffo et al. 2020). As a result of this lack of fit with the environment, some members of staff struggle with keeping the older person with dementia in a location where they can see them or locating them in a quiet area (Hunter et al. 2017). The struggle of staff, in this case, is about how to create a balance between protecting patients with dementia from the frantic and chaotic environment while avoiding the psychological harm of isolation. In many cases, staff were aware of A&E as a setting lacking those normal cues which serve to reorientate people with dementia, like windows, colour-contrast I or wayfinding cues, possibly reinforcing patients' sense of confusion and distress (Kelley et al. 2011; Parke et al. 2013; Wolf et al. 2019). Finally, there was acknowledgment that Accident and Emergency services are not the right setting for older people, identifying the physical environment as primary factor affecting treatment and care, pointing at the need for specific Geriatric Accident and Emergency services (Bulut et al. 2015).

The Lifeworld experienced by A&E staff caring for older patients – in relation to the physical environment- is a world which does not fit. Their lived space in this case, not only represents an obstacle for them to provide adequate care and to keep older patients safe, but at times, it can also become harmful to the most vulnerable.

6.5.4 Intersubjectivity for staff caring for older people in A&E

As already outlined in Chapter 2 , Intersubjectivity in Husserl's Lifeworld is how the subject is in the world with others (1970). The struggle of staff dealing with the A&E space and rhythms outlined so far, are at the same time intersubjective struggles, i.e.: 'how do I relate to this older person in this place and with the time I have available? How can I deliver person-centred, appropriate care, in the context of a care relationship, to this confused patient, and how can I keep them safe in this place, and with the time I have?'

The intersubjective dimension emerged in the literature findings through a number of themes which, together, represent the most significant and relevant aspect of staff experience of caring for older people in A&E. In the following sub-sections, I am going to discuss it in relation to the polarities of human connection and human disconnection, as I did for the literature findings on the experience of older people in A&E (Chapter 2).

6.5.4.1 Biomedical Care vs Holistic Care

The conflict between biomedical care and holistic care seems an unsolvable one for most studies' participants. Many of the staff involved in these studies recognised that older people in A&E need much more than biomedical care alone (Kihlgren et al. 2005; Gallagher et al. 2014; Taylor et al. 2015), meaning with that that they also need personalised care, with attention to specific, individual needs, which might range from basic care needs (toileting, nutrition, hydration, and mobility) to social-emotional needs, such as privacy, comfort, reassurance, reorientation and targeted communication (Meyer et al. 1999; Kelley et al. 2011; Taylor et al. 2015). At the same time, they acknowledged that this level of *good nursing care* (Kihlgren et al. 2005; Bulut et al. 2015) is very rarely achievable in the A&E setting, where the main focus is on acute biomedical care centred around ABC (airway, breathing, circulation) priorities, typical of acute care settings (Taylor et al. 2015).

These two apparently polarised dimensions of care are also two intersubjective modalities: they represent two ways of relating to the patient which might shift the interaction either in a direction of human connection or disconnection. On the one hand, we have a focus on technicalities and tasks (tests, injections, or other urgent medical procedures) implying that, at least temporarily, the healthcare professional relates to the patient and their body almost exclusively as an object of standardised tests or treatment (disconnection), while on the other hand, the focus is on the uniqueness of one person's needs at that specific moment in time, their bodily sensations, their feelings, their perceptions and understanding of their situation. This locates the healthcare professional in a different relationship with the older patient, who now becomes a subject of care (connection).

Even though many participants in the studies included in this review reported a considerable level of distress in not being able to meet the older patients' non-medical needs (Fry et al. 2014; Gallagher et al. 2015; Hunter et al. 2017) it was quite common for them not to challenge the status quo, also always locating the cause of this disconnection from a more personal relationship to older patients outside of their sphere of control, and pointing at organisational factors as the only cause (Meyer et al. 1999; Taylor et al. 2015). It is fairly common for newly-qualified healthcare professionals who are being socialised into practice to accept and acquire role-modelled non-written roles and behaviours which might at times be different from or even at odds with ideals of person-centred and compassionate care delivery that they have been taught and which they endeavoured to practise during their degree programmes (Hunter and Cook 2018). After all, conformity is a social behaviour stemming from a need to fit and belong to a social group (Cialdini and Goldstein 2004).

Challenging the status quo, therefore, might threaten a sense of belonging and feel unsafe to many. Participants in Taylor et al. (2015), for example, whilst trying to manage the "lack of fit" (p.187) between the type of care needed by older patients and the A&E environment, still showed a strong alignment with the A&E culture. While acknowledging that "under care*"* occurred, (p.188) every single participant seemed to accept this as a necessary outcome of competing priorities in the A&E. Interestingly, a study from Meyer et al. (1999) which included different datasets (interviews with older patients and family carers, observations, hospital records and focus groups with nurses and managers) interpreting the different data, came to the conclusion that without using more time, nurses could actually do a number of things to provide more personal and human care to older patients, i.e.: talking to the patient while they are performing a clinical task, enquiring on the broader effect of the patient's condition on their life, or checking if they are hungry or maybe cold. Similar little extra attentions were mentioned by some nurses as effective strategies to improve older people's care, also pointing at the need for reassuring patients, by making eye-contact, holding their hands, and reiterating that they had not been forgotten (Kihlgren et al. 2005).

However, A&E nurses might also be reluctant to engage in holistic care as opposed to urgent medical care because, for example, they might not feel that it is "their job" (Meyer et al. 1999, p.335) and they might perceive it as falling out of both their scope of practice, and clinical interests (Kihlgren et al. 2005; Taylor et al. 2015). Some emergency nurses think that they have not been trained for geriatric care, but only for urgent medical care, and feel that geriatric care also clashes with their expectations of becoming an emergency nurse (Kihlgren et al. 2005). Others showed a considerable level of criticism towards colleagues who lack interest in geriatric emergency nursing care by stating that they had got to emergency nursing only to do "the sexy stuff" like resuscitations and traumas (Meyer et al. 1999, p.335) and they think that some colleagues hide behind technical tasks in order to avoid a more personal meeting with the older person (Kihlgren et al. 2005).

The perceived polarisation between urgent medical care and holistic care in A&E can also translate in a form of clinical bias – also ageist assumption – whereas, for example, older people – particularly if they have dementia – might be by default labelled as non-urgent by nurses assessing acuity at triage, which could potentially compound the danger of an unrecognized but urgent atypical medical problem (Parke et al. 2013).This phenomenon being known as *diagnostic overshadowing* (Shefer et al. 2014).

The apparently unsolvable dichotomy between biomedical care and holistic care in A&E when caring for older people is an important theme for A&E staff, also clearly indicating the presence of two different intersubjective dimensions of human connection and disconnection.

6.5.4.2 Communication

Several studies reveal that communication is an issue for staff when caring for older people in A&E (Robinson and Mercer 2007; Fry et al. 2015a; Wright et al. 2018). The problem, from the staff point of view, arises particularly with cognitively-impaired patients (Kelley et al. 2011; Fry et al. 2015b; Seffo et al. 2020) or patients with hearing difficulties (Kihlgren et al. 2005), and it is aggravated by chaos, confusion, noises, and the hectic pace of the A&E (Hunter et al. 2017). Staff appear aware that there might possibly be serious consequences because of this impaired communication, which could involve the older patient being under-triaged because they are unable to explain their symptoms – possibly leading the clinicians to ignore, for example, urinary tract infections or sepsis (Parke et al. 2013) – or suboptimal pain management (Fry et al. 2017; Seffo et al. 2020). Participants in Wolf et al. (2019) add that older people's vague complaints might be misinterpreted as stemming out from loneliness or anxiety and depression rather than from an actual illness, this contributing to older people' being often under-triaged. Staff delivering palliative care for older people in A&E also pointed out that the A&E environment hinders difficult conversations, inhibiting initiation and exploration of deeper issues (Wright et al. 2018). It looks like, on an intersubjective level, this impaired communication represents a form of disconnection between the healthcare professionals and the older patients' medical and non-medical needs. Studies' participants in the literature indicated a number of ways for them to try and repair this disconnection: tailoring the communication approach when caring for older patients, by increasing voice volume or slowing rate of speech (Lennox et al. 2019), using touch and eye-contact to assist in communication with older people with dementia (Seffo et al. 2020), using plain language and taking more time to ensure that older people understand what is happening and their care plan, and continuously reiterating information in order to make older people's participation in their care easier, also using a sense of humour (Kihlgren et al. 2005; Kelley et al. 2011). Some professionals acknowledged the tremendous role that family members can play in assessing older people's pain: they feel they could often gain a broader and deeper understanding of the patients' pain when family or carers are present as they can help in managing the communication processes (Fry et al. 2015a). In particular, they feel that by involving family members in the discharge education process enables them to ensure they maintain and deliver more accurate information (Seffo et al. 2020; Palonen et al. 2016).

The experience of human connection/disconnection, mediated by communication appears central to older people’s pain assessment and its management in A&E. Nurses caring for patients with dementia presenting with a hip fracture, for example, feel that difficulties in communication with patients, because of the cognitive impairment but also because of the lack of time, the high dose of stress, and the lack of information accompanying the patient, greatly affect the assessment of pain and treatment of this patient group (Seffo et al. 2020). Nurses seem to appreciate that older people with a cognitive impairment who experience pain often received suboptimal pain management (Fry et al. 2017) – their claim is a fact, reinforced by much literature on pain management in A&E, (Stanilcowicz et al. 2005; Hwang and Plat-Mills 2013; Carter et al. 2016), and they feel that this shortcoming often arises from communication barriers between them and the older person with cognitive impairment. They identified in the lack of a systematic approach and/or a pain assessment tool, factors which can make the situation worse, causing the marginalisation of the cognitively impaired older person and delayed analgesia. For this very reason, they recognised the need for a standardised pain assessment tool suitable for use specifically with people with cognitive impairment in order to repair this form of unacceptable disconnection. Their argument was that not only would a standardised tool facilitate the detection of pain and its intensity, it would also make it easier for the nurse to communicate the results to a physician, so that they could start appropriate pain management strategies (Fry et al. 2017). Other nurses echoed this, suggesting that looking at behaviour and non-verbal communication and integrating them with verbal communication and contextual information about a particular patient (whether they had a bone fracture, for example) to search for some form of alignment and coherence between them can be particularly helpful in pain assessment, as well as making the assessment script more patient-centred, for example, by modifying the numerical script if and when needed to meet the communication needs of a particular patient – i.e., rather than using a scale from one to 10, using the words: small, medium or large (Gorawara-Bhat et al. 2017). The belief that pain is often being under-treated is extended to all older people in A&E, irrespective of their cog–itive state. Nurse participants in Gorawara-Bhat et al. (2017) know that often older people try to be stoic or simply have no idea that they could have more effective pain treatments or are afraid of mixing the analgesia with other medications they are taking. However, what make these nurses' experiences different from those emerging in Fry et al. (2017), is that pain in older people from their point of view could also at times be over-medicated: nurses stated that physicians might prescribe strong narcotics too easily, and they expressed concern both with respect to possible dependency issues, and with respect to possible side effects on frail older patients. This significative difference might be explained with the different practices in use in United States in relation to analgesia and the prescription of narcotics (U.S Food and Drug administration 2021).

The experiences articulated by staff delivering care to older people in A&E suggest that effective or less effective communication can make the difference to both patients and healthcare professionals' experiences. This, however, not only applies to communication between patients/family members and healthcare professionals, but also to communication between nurses and doctors in A&E, or between the A&E and other community services related to the patient. Communication, in these cases, can either weave connections between different professionals and different settings and contribute to enhance continuity of care for older people presenting to an A&E, or it can break – or even prevent – those connections, contributing to fragmentation in the system and sub-optimal care. In Robinson and Mercer (2007) for example, A&E staff rated *continuity of care* as low (2.28) on a 5-point Likert scale where 1 equated to *not very satisfied*, 3 to *somewhat satisfied*, and 5 to *very satisfied*, reflecting less satisfaction with that aspect of care for older people. Participants in Meyer et al. (1999), Kihlgren et al. (2005), and Wright et al. (2018), all agreed that communication problems affecting continuity of care often start off when the patient arrives to A&E with not enough documentation and background information provided by the community nurse or doctor who referred them. Participants in Kihlgren et al. (2005) in particular, explained that when a patient arrives at A&E with too little background information, it is more difficult for the doctor to make a decision, therefore meaning that the patient will wait longer, and that the emergency nurses might become nervous and frustrated which could influence the quality of care they deliver. Unfamiliarity and lack of communication between the A&E and other services is also revealed in Kelley et al. (2011) whose participants reported being unfamiliar with community and other specialized geriatric services. This lack of familiarity with services, their scope, their availability and contact information affects the time required to plan and refer, suggesting that a more effective sharing of information would make the difference. If we add to this picture the loss of connection with such services during weekends, when many community services are not available (Hunter et al. 2017). It becomes very clear how extremely challenging for A&E staff must be to refer and move older people out of A&E. Emergency nurses also mentioned the need for improved communication with medical staff in A&E, as in their experience, communication difficulties with them, greatly limit their capacity to initiate analgesia (Fry et al. 2017). Nurses also feel that better cooperation is needed between systems in the hospital (Seffo et al. 2020).

Communication seems at the core of staff experience when caring for older people in A&E. In a number of studies, healthcare professionals agreed that difficulties in information sharing severely impact on many aspects of older patients care: from under-triage, to inadequate assessment and treatment of pain, to possible inappropriate palliative care, to compromised continuity of care between settings, included increased length of stay in A&E, and sub-optimal care provision due to nurses' frustration about lack of access to essential information and community services.

6.5.4.3 Older people's family members in A&E

Being in relationship with older patients' family members emerges from the literature as one of the most significant intersubjective experience staff faces in A&E. Participants in most studies agreed that the presence of family members in A&E can make the difference to the older patient's experience, but also to their own (Kelley et al. 2011; Gallagher et al. 2014; Seffo et al. 2020). Family members can provide staff with valuable information to establish medical urgency and optimise their decision-making process (Gallagher et al. 2014; Fry et al. 2015a) as well as being crucial to help determine pain intensity and changes in the older person’s pain levels (Fry et al. 2017). It looks like a family member can function as a bridge connecting the older person to the A&E staff, drawing on their deep knowledge of the patient and of their ways of communication. For example, staff believe that for older people with a cognitive impairment, the presence of a family member or a familiar carer can reduce the degree of confusion and agitation often associated with pain, but also that their presence can assist in modifying agitated behaviour which could obstacle treatment. Moreover, family members often appear to the staff to be in the perfect position to advocate for older patients’ adequate pain management. All of the above, from the staff point of view, translates in an overall reduction of the negative impact of the emergency department environment on the older person (Fry et al. 2015). It looks like family members are seen by staff as a safety net for older people in A&E (Gallagher et al. 2014; Hunter et al. 2017). Despite this, however, some members of staff displayed an ambivalent attitude towards family members, showing a much more nuanced picture of the complex intersubjective dynamics at play between the healthcare professional, the older patient, and their relative/s in A&E. At times, nurses attribute presentation at A&E to the family’s inability to manage the older patient at home rather than to a true emergency (Taylor et al. 2015), and other times, relatives (or carers) could be perceived by staff as a barrier to appropriate care (Fry et al. 2014 and 2015a) fostering disconnection between the patients and the staff rather than connection. This could happen when the family member interferes with the patient’s right to communicate with the nurses, by interrupting the flow of communication (Fry et al. 2014) or when they challenge nursing decisions about pain medication, prompting tension in the interaction. This could get to the point of the family member refusing analgesia on behalf of the older person, which is seen by nurses as an infringement of the patient’s rights (Fry et al. 2015a).

Nurses can feel judgemental towards older patients’ family. Some expect family members to keep delivering basic care to older people in A&E as they would do at home (Fry et al. 2014), and when this does not happen, and the totality of patient’s care is left to the nurse, they experience a sense of frustration. Family members could also be experienced as a “nuisance” and a “challenge” when involved in discharge education (Palonen et al. 2016, p.3340).

Despite these ambivalences, however, older patients' family members and their opinions and experiences are important to healthcare professionals in A&E: some nurses would experience considerable distress when family or carers are disappointed with the lack of individualized care provided and when they do not show an understanding of the nurses' difficult position in A&E (Gallagher et al. 2014), and others believe that the emergency department encounter not only involves the care of the older person, but also fostering a relationship of trust with the family (Kihlgren et al. 2005; Fry et al. 2015a). This would entail a duty of care both to the older person and their family members – which, particularly in the case of older people with dementia, might be seen as a "unit of care" (Hunter et al. 2017, p.7) – with the awareness that, even if challenging, involving the family in, for example, discharge education is *"*a part of good nursing*"* (Palonen et al. 2016, p.3339).

6.5.4.4 Training and specialist skills

In order to step into a fruitful intersubjective relationship with their older patients – necessary to form an effective clinical alliance and interventions – A&E clinicians need geriatric-specific skills (Kelley et al. 2011; Gorawara-Bhat et al. 2017; Lennox et al. 2019).

Most participant in the studies agreed on the very fact that it is essential for them to have those skills to be able to relate to and to treat older patients (Meyer et al.1999; Bulut et al. 2015; Lennox et al. 2019). The mix of skills necessary is varied and complex, as varied and complex is often older people's presentation to A&E: knowledge and skills in assessing and treating geriatric pain were acknowledged as very important (Robinson and Mercer 2007; Gorawara-Bhat et al. 2017), skills related to common health problems associated with ageing, such as, for example, how to treat pressure ulcers, or managing in-dwelling urinary catheters, also emerged as important (Robinson and Mercer 2007; Kelley et al. 2011).

Other intersubjective skills were widely acknowledged as essential for staff to feel able to deliver good care to older people in A&E, such as: addressing emotional responsibilities with terminally ill older patients, in particular, being able to talk to them and to their families in a sensitive way (Wright et al. 2018); knowing how to ask the right questions to older patients with dementia in order to understand their background, putting the pieces together and seeing the bigger picture when deciding the appropriate clinical response (Kelley et al. 2011; Hunter et al. 2017) and knowing how to respond to symptoms such as confusion, agitation and aggression in those same patients (Kelley et al. 2011).

Despite agreeing on the importance of the above skills and knowledge, a number of A&E professionals felt unprepared, and voiced discontent with regard to the lack of training received on those specific areas (Bulut et al. 2015; Hunter et al. 2017; Parks et al. 2019). Few of them believe that self-efficacy – and confidence – in treating older people are gained not so much through training but rather through the process of developing positive interpersonal relationships with older patients which, in turn, also shapes their pain management practices (Fry et al. 2015b). Once again it is possible to see how A&E staff are aware that in order to treat older people in A&E, they need a mix of biomedical and holistic care, where the personal, human-to-human relationship is not something different, separated or disconnected from biomedical knowledge and practices. Disconnecting the two types of care seems to lead to a superficial approach where the complexity of the clinical encounter with the older patient might be disregarded (Kelley et al. 2011). The intersubjective world inhabited by hospital staff caring for older people in A&E seems often threatened by some form of disconnection: this can happen in the realm of expectations (Biomedical Care vs Holistic Care), Communication (particularly with people with dementia or other cognitive impairments, or when relating to family members) and in response to specific geriatric – clinical or non-clinical – needs, when staff feel they lack the most appropriate skills.

6.5.5 Mood of staff caring for older people in A&E

Mood colours our lived experiences and it is both impacted upon and impacts upon our temporal, spatial, and intersubjective dimensions (Hemingway 2011). Mood reveals our own experience to us, and it is a powerful messenger of the meaning of a situation (Todres et al. 2007) as well as affecting how we perceive life in all the other dimensions: joy for example, will open-up a completely different world to us, filled with completely different possibilities in time, space, and relationships, than grief would do.

A&E staff caring for older people in A&E often experience worries (Seffo et al. 2020) frustration (Gallagher et al. 2014; Fry et al. 2014; Gallagher et al. 2015) if not distress (Taylor et al. 2015), moral distress (Hunter et al. 2017) moral angst (Kelley et al. 2011) and despair (Gallagher et al. 2014). They might also feel sad, angry and hopeless (Bulut et al. 2015).

These moods seem to emerge as a consequence of the struggles in other Lifeworld dimensions of their experiences with older people (Temporality, Spatiality and Intersubjectivity). For example, nurses can feel worried because they struggle in communication with older patients with dementia presenting to A&E with a fracture and, as a result of this, pain-assessment and treatment can trigger even more worries as they might not be sure whether they are giving appropriate pain relief to those patients (Seffo et al. 2020). Other nurses might experience frustration because of a clash of expectations: feeling that the tailored care older people would need in A&E could not be provided due to lack of time and competing acute care priorities. This frustration would spiral up and despair would ensue if nurses felt that the family of the older patient was also disappointed with the lack of care (Gallagher et al. 2014). For the same reasons, emergency nurses can experience lower job satisfaction in relation to care of older patients (Gallagher et al. 2015; Parks et al. 2019) and frustration, again, when dealing with older patients’ families, as they might feel that excessive time spent responding to family/carers’ concerns further limited the time available for patient care (Fry et al. 2014).

Both emergency nurses and doctors in Bulut et al.’s (2015) study, run in Turkey, expressed sadness towards the evident neglect they could notice in older patients, which eventually could develop into anger towards their families. These data are interesting if looked at in the context of Turkish culture, where older people are highly valued (Bulut et al. 2015). Previous studies have showed that both Turkish physicians and nurses display a more positive attitude towards older patients when compared to similar professionals in other cultures (Gözüm and Tan 2003; Öğenler et al. 2012).

When caring for older patients, nurses and physicians can get to the point of experiencing moral distress, moral angst or hopelessness if feeling troubled about the care they cannot provide and about not being able to control everything and being aware of those specific care needs which they are unable to meet (Kelley et al. 2011; Bulut et al. 2015; Hunter et al. 2017). Consequently, recognizing both unmet patients’ needs and their own distress about this, staff find themselves in the position of having to find ways to manage both the situation and their response (Taylor et al. 2015;Bulut et al. 2015). Eventually, treating older patients causes them stress. Some healthcare professionals, as a result of stress, might develop a negative attitude towards older people (Meyer et al. 1999; Bulut et al. 2015), and this could, in turn, negatively affect relationships between patients and staff (Bulut et al. 2015).

Despite the fact that the aims of the studies included in the review were not directly focused on identifying challenging feelings or negative experiences, the world experienced by A&E staff when caring for older people in this body of research – with the exception of nurses in Seffo et al. (2020) who described their experience with older patient as stressful and difficult, but also as positive and “full of empathy” (p.227), stressing that caring for them “spice-up” (p.227) their routine – appears largely coloured by negative moods, frustration, distress, sadness, anger, hopelessness and moral angst, all of which, in turn, will almost certainly affect the way they relate to older patients and their families, but also the broader relation to their job and the whole healthcare system.

6.6 Gap in the knowledge and confirmed second aim of the study

This literature review revealed that much is known about the experience of hospital staff delivering care to older people in A&E. However, this is particularly true for countries like Australia, or Canada, while only two studies were found in England.

In addition, no study emerged about the experience of volunteers or about the experience of staff (either clinical or non-clinical) delivering an intervention like the ICCI to older people in A&E. For this reason, the second aim of the study was confirmed.

Exploring the ICCI practitioner personal experience, getting to know what it means for her to deliver this intervention, listening to her account and to her words as they arise, and then telling her story, is my intention in this part of the study, in order to fill the gap in the literature. Pursuing this aim has the potential to contribute to a deeper understanding of the ICCI phenomenon as a whole, and to the experience of staff caring for older people in A&E in England. This specific aim of the study also could impact upon NHS consideration of new roles in A&E that are responsible for ICCI and how to make not only older patients' care more effective and sustainable and give this patient group a better experience and outcome, but also how to improve staff experience, possibly impacting on NHS staff retention's rates.

For the above reasons, after the review of the literature, the second aim of the study was confirmed, together with the research question:

What is the lived experience of a member of staff of a district hospital who delivers an Intentional Compassionate Communication Intervention (ICCI) to older people in Accident and Emergency department?

Chapter 7 – Study Methodology, Design and Methods – Study Phase B

7.1 Outline of the chapter

In this chapter I am going to give an overview of the research design and methods involved in this specific phase of the study, including how I prepared, ran and reflected upon my online interviews with the ICCI practitioner, and how I analysed the data gathered from them. This will lead to a thorough reflection on the main ethical challenges involved in running online interviews, and how I addressed them.

7.2 Overview of the research methodology, design and methods

In this second phase of the study, the same qualitative (Phenomenological) approach has been taken, using IPA as detailed in Chapter 3 and Chapter 4 (study phase A). Four in-depth, semi-structured, online interviews were carried out with the ICCI practitioner over a period of two months – between April 2021 and June 2021 – and the data created from the transcripts have been analysed using IPA suggested procedures, always referring to Smith et al. (2009).

7.2.1 The participant and their recruitment

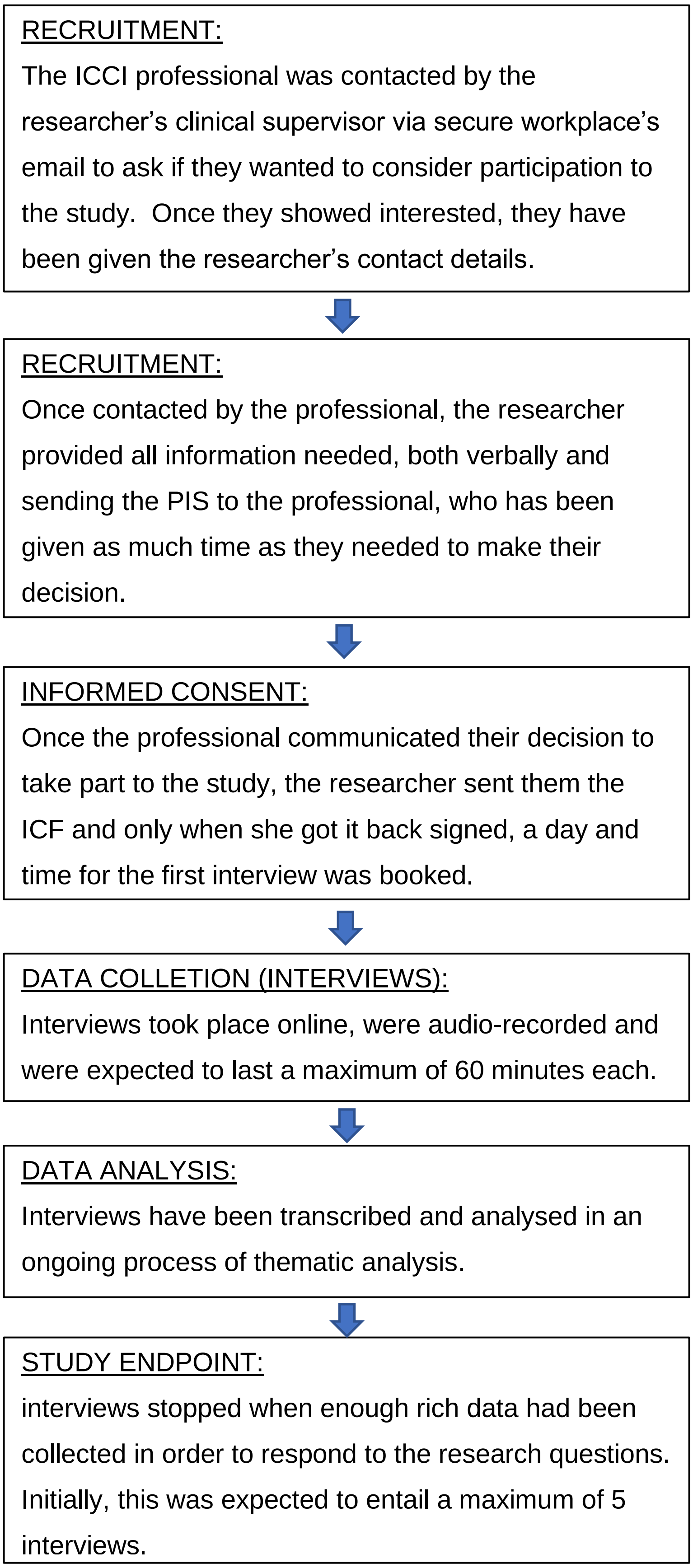
Sarah (this is the pseudonym I will use from now on for the ICCI practitioner) is a British woman in her 60s who has been running the Intentional Compassionate Communication Intervention in A&E at the hospital site since 2016.

She usually worked there five days per week, from Monday to Friday for around five hours each day, approximately from lunch time until 5 pm, although there might be exceptions when she might work in the morning (her intervention was stopped for more than one year during the COVID-19 Pandemic). She has not received any specific training for this position, and does not have any clinical background, whereas her personal lived experience of being a carer for her own mother (who had mild dementia) and her experience as a volunteer at the hospital site have made her feel able to take on this role. She is part of the dementia team of the hospital, and her intervention is mainly aimed at older and disorientated people and their families; however, when possible, she also supports younger patients. In our interviews, however, when Sarah referred to ‘patients’ she was always referring to older patients, unless otherwise specified.

Sarah had been initially approached by email – to her secure NHS trust email address – by my PhD clinical supervisor to ask if she wanted to consider participating. Once agreed, it was suggested for her to make contact with me directly. After an initial contact, however, I did not hear from her for a while, and I was then informed that she was unwell to the point of being unable to participate for the near future. Eventually, in April 2021, I was contacted again from Sarah directly, stating that she was recovering and therefore felt able to be interviewed.

At that point, I sent her the complete information about the study and her participation, included a copy of a specific PIS (Appendix 12 - PIS for ICCI practitioner – p. 393) and I allowed her to ask any question via telephone or email and gave her as much time as she needed to make her decision. She confirmed her willingness to participate, therefore she was sent a copy of a specific informed consent form (Appendix 13 - ICF for ICCI practitioner – p. 397) and only after she had signed it – in accordance with HRA and MHRA (Medicines and Healthcare Products Regulatory Agency) joint statement on seeking consent by electronic methods (2018) a typed electronic signature is sufficient for this study – and sent it back to me, an appointment for the first interview was booked.

I was expecting to run between three and five interviews with Sarah, as that felt – both to my supervisors and myself – like a realistic number of interviews to gather a rich and evocative account of her experience with older people in A&E.



RECRUITMENT:
The ICCI professional was contacted by the researcher's clinical supervisor via secure workplace's email to ask if they wanted to consider participation to the study. Once they showed interested, they have been given the researcher's contact details.

RECRUITMENT:
Once contacted by the professional, the researcher provided all information needed, both verbally and sending the PIS to the professional, who has been given as much time as they needed to make their decision.

INFORMED CONSENT:
Once the professional communicated their decision to take part to the study, the researcher sent them the ICF and only when she got it back signed, a day and time for the first interview was booked.

DATA COLLETION (INTERVIEWS):
Interviews took place online, were audio-recorded and were expected to last a maximum of 60 minutes each.

DATA ANALYSIS:
Interviews have been transcribed and analysed in an ongoing process of thematic analysis.

STUDY ENDPOINT:
interviews stopped when enough rich data had been collected in order to respond to the research questions. Initially, this was expected to entail a maximum of 5 interviews.

Figure 7 – Study Flow Chart for study phase B – Interviews to the ICCI practitioner

7.2.1.1 Inclusion and exclusion criteria

There was only one member of staff who had delivered the ICCI over the previous three years. Therefore, I only had one inclusion and one exclusion criteria for this phase of data collection.

Inclusion Criteria:

- The member of staff who has delivered the ICCI at the site over the past three years.

Exclusion Criteria:

- If the member of staff was unable or unwilling to participate for any reason.

7.2.2 Data collection

Interviewing, transcribing and data analysis were all ongoing and parallel processes beginning with the first online interview. The data collection was set to end when I would become aware that, in the time frame available to me, I had collected enough rich data to answer my research question. However, I was confident that I would not need more than five interviews with the ICCI practitioner to get to that stage. Eventually, I ended up running four interviews with her. The first three were run at a fairly regular interval of time (on average, every two weeks). After that, I needed a bit more time to deepen the analysis of the data collected in order to understand if the research would benefit from more data. Eventually, my decision was that I wanted to ask some more questions, therefore, I agreed with Sarah to have our last interview. This happened five weeks after the previous one.

7.2.2.1 Semi-structured online interviews

Data for this phase of the study were generated through online, one-to-one, semi-structured interviews (using a GDPR compliant platform, Zoom). The reason for the interviews to be online rather than face to face was that at the time, UK government and organisational guidelines still suggested to limit face-to-face contacts as much as possible, for obvious COVID-19 related safety reasons (UK Government 2021). The interviews were carried out in the afternoon hours. The ICCI practitioner was interviewed while she was at home. At that time, she was not working as – for the above mentioned COVID-19 related reasons – the service could not resume yet. The time of interview ranged between 27 and 57 minutes. Each interview was audio-recorded.

For the rationale to use semi-structured interviews as a data collection method also in this phase of the study, refer to section 4.2.3.3 “Why semi-structured interviews” (p.92, Study phase A).

7.2.2.2 Preparation of the interview schedule

For this phase of the study, the structure of each interview with the ICCI practitioner had been planned to be flexible and centred on the participant, with me encouraging descriptions rather than explanations, as IPA requires. I was prepared for the first interview to be unstructured, starting with a *core* question (Smith et al 2009; 2022), and I knew that how the interview would unfold would depend on how the participant would answer. As it is expected in IPA, how the participant answers the first question, informs what further questions will be asked during the first interview (Smith et al. 2009; 2022). The whole content and analysis of the first interview then informed the structure of the following interviews, which were semi-structured, with a list of possible questions to function as a guide, but which were dropped, changed, or asked in a different order depending on the answers of the participant. This is exactly how I approached my whole interviews schedule with Sarah.

7.2.2.3 The interviews

Before starting this online interview process, I made sure that I could always connect via a Bournemouth University laptop which had all the required firewalls in place and that my internet connection was protected, and I asked Sarah to ensure her connection was similarly protected. For each interview, I made sure that the online meeting was password protected – sending her a personal code before starting the meeting – and I always ‘locked’ the meeting as soon as it started, to maximise security. I made sure that nobody else was physically in the room with me, and I always wore headphones, asking Sarah to do the same in order to protect her own confidentiality. I greeted her and I checked with her that she felt ready to participate, also asking permission to audio-record the interview.

As expected, the structure of each interview was flexible and centred on the participant, and new questions developed as a consequence of the subjects brought about by her. I opened our first interview with the following core question:

> *Please, can you tell me what delivering the ICCI means to you?*

Over the following interviews, together with new subjects which came out organically from our conversation, I made sure to cover the following main points:

- Her experience of the elements involved in the delivery of ICCI for older people in the A&E department;
- Her experience of starting to deliver the ICCI to older people in the A&E department years ago;
- A typical day at work delivering the ICCI for older people in the A&E department;
- How she feels after a typical day at work delivering the ICCI for older people in the A&E department;
- Examples and description of specific moments of Intentional Compassionate Communication Intervention she will never forget.

(See Appendix 14 - Topic guide for interviews ICCI practitioner – p. 399).

7.2.2.4 During the Interview

During the interviews, I always tried to create a relaxed and informal atmosphere, and I was always open to leave time for general chatting both at the beginning and in-between questions before coming back to the main points. This was because I wanted Sarah to feel at ease and to trust me. Silences were always attended to, and when possible, not broken. I often recapped key topics from the previous interview to check my understanding with her, and often came back to some keywords or key concepts from her account which I found particularly relevant and asked her to tell me more about them.

This was very useful in order to facilitate depth and details to emerge. Attention to body language was definitely more challenging than it would be during in-person interviews, given the nature of the online communication, but still partly possible. On my side, I applied good practices such as making sure the lighting was appropriate, allowing the participant to clearly see me and my facial expression. I wore contact lenses rather than glasses whenever I could, to avoid disturbing light reflections, and I always took care of maintaining an open posture, exactly as I did with older participants face to face, for example, keeping my arms and legs uncrossed. Smiling and nodding was used carefully in order to encourage the participant to open-up without appearing to privilege some of her answers over others so to not over-influence the interview process.

At the end of each interview, I checked with the participant how she was feeling, thanked her, and closed the online meeting. Immediately afterwards, I wrote reflective notes about the research process. In between each interview, I usually ran a first level of analysis, which I would send to my supervisors. We would then discuss together the most relevant topics that emerged and agreed on which ones would need to be deepened over the following interview.

7.2.3 Transcription

I transcribed data by repeatedly listening to the records of the interviews. This was usually made one or two days after each interview with the ICCI practitioner had been carried out. I aimed at capturing words as well as pauses and verbal utterances from both the participant and myself. Suspension marks plus numbers (i.e: …3) were used to indicate the seconds of silence which made up each pause. Punctuation was kept to a minimum in order not to inadvertently alter meanings as a result of the transcription process itself. With a couple of exceptions (few not audible seconds) I almost never needed to use the software to slow down the speed of the recording as it had happened with some older participants, because Sarah’s speech was usually very clear to me. I used pseudonyms for names and places in order to protect confidentiality.

7.2.4 Analysis

When analysing Sarah’s interviews, I followed the same IPA process I used for the analysis of older people’s interviews over the first phase of this study (see sections 4.2.5 “Overview of the analysis process” – p.96 – and 4.2.6 “Analysis in detail” – p.100)**.** The only difference was that once I had extracted emergent themes – or “Experiential Statements” as they are now called in IPA (Smith et al. 2022, p.88) – for each of the interviews with her, the search for patterns and connections across emergent themes to create clusters which would inform a super-ordinate theme was made across the four interviews to the practitioner (within the same participant) rather than between a number of participants as I did for phase A. This process brought me to a number of super-ordinate themes which today Smith et al. (2022) would call *Personal Experiential Themes* rather than *Group Experiential themes*.

7.3 Ethical considerations

Any research involving human participants presents ethical issues, and this obviously applies to interviewing members of NHS staff too. Considering all the risks and benefits involved at any stage of the research process and taking appropriate measures to guarantee both the participants and the researcher’s safety, is paramount to an ethical research practice.

The updated protocol of this study – to include this second objective/phase – has been reviewed and approved by the REC Oxford C, HRA, Bournemouth University, and the NHS Trust R&D before the start of data collection (see Appendix 10 - REC approval to Study Phase B – p. 387 – and Appendix 11 - HRA approval to Study Phase B – p. 391).

As already mentioned in Chapter 4 (study phase A), ethical considerations do not stop when the official approvals are obtained, but they accompany the researcher at each and every stage of the study process.

When I updated the protocol to broaden the scope of the study to the experience of the member of staff delivering the ICCI to older people in Accident and Emergency department, I was aware that there is always the potential for feelings of coercion in the workplace when asking a member of staff to take part in a study like this. With this in mind, I made it very clear – both verbally and in the PIS – to Sarah, that there was no obligation for her to participate and, that if she refused, or withdrew later on, that would not have any impact on her, on her job, or on her relationships with her manager and colleagues.

As already mentioned, I was aware that questions might touch on sensitive issues for her and, therefore, I always remained sensitive to any sign of distress during the interview and I was ready to suspend or stop the interview if indicated, also offering emotional support online, and, if further support would be needed, I was ready to signpost the participant to the appropriate psychological support services. Luckily, this was not necessary.

7.3.1 Online communication

Online communication presents peculiar ethical aspects to reflect upon. As a dramatherapist, I had to become aware of those in the context of my therapeutic relationship with clients during COVID-19 pandemic, as remote sessions had become the main therapeutic modality used at that time. For this study, I could use my knowledge as a therapist, but I also needed to become aware of the implications involved in the specific researcher-participant relationship.

7.3.1.1 Digital accessibility and literacy

I was aware that online communication might entail a range of technical and practical difficulties (Gregory 2018). Online interviews, by default, require participants to navigate the platform of choice, and researchers need to be very mindful in this respect, of possible issues of accessibility and/or technological literacy of the participants without taking the participant’s knowledge and skills in this area for granted. It is therefore responsibility of the researcher to assess the participant’s familiarity with technology (Sedgwick and Spiers 2009), ensure the platform is accessible to them and, if needed, incorporate further support (Forrestal et al. 2015; Moore et al. 2015). Mindful of this, I had investigated with Sarah via email (ahead of the interviews) whether she knew how to use the platform Zoom and was familiar with videocalls, and whether she had access to a stable and secure internet connection. Only after she confirmed this, I finalised the decision to use Zoom.

7.3.1.2 Unpredictable disturbances/advantages

Ahead of our first interview, I had provided Sarah with my telephone number and asked permission to get hers and agreed with her that I would call her in case of technical difficulties, in order to agree on what steps to take. This was important because, as Gray et al. (2020) point out, interrupting the flow of the conversation can very possibly influence the rapport between the researcher and the participant, which is particularly significant given the importance of ensuring the participant is comfortable to share information. For this reason, Anthony and Nagel (2010) suggest providing the participant with guidance on setting up and troubleshooting. In their view, it is wise to share a contingency plan should technical difficulties arise and offer to conduct the interview at another time or via another medium should the problem persist.

Interviewing online, the researcher has no control over the physical environment in which the interview takes place for the participant (Gregory 2018), and while I could make sure to be in a quiet room, with no distractions and interruptions, and where the participant's privacy and confidentiality would be guaranteed, I could only advise Sarah to make sure that the environment she was in during the interviews would offer similar characteristics. However, as McCoyd and Kerson (2006) point out, I was also aware that online interviews could offer an advantage to the participant in this respect: for some, the home environment may offer more privacy (McCoyd and Kerson 2006) or they might be more comfortable in familiar settings and therefore be more prepared, or even better able to talk about their experiences (Orchard and Fullwood, 2010; Hanna 2012).

The significant increase in use of videoconferencing technology during the COVID-19 pandemic has showed the tiring potentials of communicating via online platforms (Wiederhold 2019). Communication, online, is disrupted by the slight delay in the interaction, as well as by the lack of nonverbal body cues humans constantly and – usually inadvertently – rely on to communicate effectively (Anthony and Nagel 2013). This, coupled with my awareness of Sarah being at a recovery stage, heightened my sensitivity to any signs of fatigue, so that I would often check with her if she was feeling ok to continue, or whether she wanted to take a break or schedule another time for the interview.

7.3.1.3 Online disinhibition effect

As a therapist working online during COVID-19 Pandemic, I also had to educate myself to other aspects of remote communication. One such aspects – which might impact on the research interviews with the ICCI practitioner as well – is the one known as *online disinhibition effect* (Suler 2004), which would bring some people to share more during online conversations than they would do during in-person ones. Particularly accentuated during text- communications (even more if asynchronous), this effect can take place during video communications too (Anthony and Nagel 2013). Considering the nature of our interaction, I felt that on the one hand, this very aspect of remote interviewing would serve us well, allowing Sarah to open up and share a possibly richer account, however, on the other hand, it could provide us with some concerns: what if, for example, just after the interview, the ICCI would regret having over-shared about a colleague or a manager? It is also worth considering that if complete anonymisation is not always possible for research participants, this was particularly true for Sarah, she being the only person covering that role at the site.

To try and minimise the risk for her to feel over-exposed, whenever she talked about another member of staff, I reminded her that she could share only up to the point she felt comfortable to, and that I would make sure that identifiable details would be taken off the transcript as much as possible.

7.3.1.4 Data protection

Safety of data and transparency about the use and storage of them is critical in all research. In this phase of the study, I made use of the same measures with regard to data storage and data protection which I took for the previous phase (outlined in section 4.3.6 “Confidentiality and data protection” – p.118) and Sarah had been fully informed about them ahead of giving consent, through the PIS. However, privacy can be at a greater risk online due to the requirement of a third-party platform (Zoom, in our case) to conduct interviews (Lobe et al. 2020). Given that online platforms can potentially record conversations, save data, and track locations and identities (Sullivan 2012), it is crucial for the researcher to investigate the platforms and take all the steps necessary to ensure both the platform and connection are as safe as possible and to communicate this to the participants (Williams et al. 2012; Moore et al. 2015; Lobe et al. 2020). In our case, the platform of choice was deemed to be one of the most secure (Archibald et al. 2019).

7.3.2 Note on reflexivity

In Chapter 4 (study phase A), I already mentioned the importance of reflexivity and the influence that my own assumptions and past experiences (in IPA, fore-structures) have on the research process: in IPA, reflexivity is paramount to the transparency of the study (Smith 2009; 2022) and thus to its ethical quality. In order to ensure reflexivity, during this second phase of the study I kept on taking the following actions:

- I always kept notes of my own emotional state and thoughts before and after each interview;
- I shared the process from conception to writing-up with the supervisory team.

This helped my reflexivity by offering different points of view on the same process, and by allowing me to put in discussion my own assumptions.

Before starting the interview process, I took some time to check-in with myself. I noticed I was feeling excited and incredulous, as such a long time had passed since my last research interview, and – together with the rest of the world – I had been through a lot. I was aware that the chance to interview the ICCI practitioner for the study was coming as fairly unexpected at that time as – given her health conditions - I had already resorted to a different plan, updated the protocol one more time, and I was just going to submit it when she contacted me. I had, therefore, tried to be very quick, setting up the first interview's appointment at the earliest possible date, and I was still dwelling in that sense of surprise and incredulity when I approached it, with a pinch of fear that something else would happen which would prevent me from interviewing her. This very process highlighted for me the need for flexibility and personal resilience in research, qualities I believe I possessed only in part when I started the PhD journey and which have been undoubtely prompted to develop further by the very circumstances I found myself in, running a clinical research study during the COVID-19 pandemic.

There was also a much more personal feeling of relief. Sarah was recovering and that made me feel very glad: she was a person I had known for a period of time at the hospital trust, I had shadowed her work and had had informal conversations with her on a number of occasions. She was, all in all, a member of ‘my’ team at the hospital, and I had been worried about her.

When facing the actual interviews, I mostly felt both emotionally inspired and intellectually stimulated by our conversations. Even if a long time had passed since we had last spoken to each other (more than one year), it felt like that had happened just the day before. Overall, communication felt smooth and organic, and I perceived Sarah’s openness and willingness to share the deepest aspects of her experience. On my side, from time to time, I felt slightly concerned when asking about painful memories, particularly on occasions in which she seemed tired, mostly because I was aware she was recovering from an illness, and I could sense some vulnerability in that. Despite this, there have been plenty of occasions in which it felt right to ask about difficult or painful memories, particularly as she would mention some on her own initiative. On top of this, I was aware that knowing each other and having already had informal conversations on the subject matter, might influence the interview process. I then decided to be very mindful of not taking anything relevant for granted and to ask each question as it was the first time we touched the subject. However, I believe that as we were already known to each other and had already had meaningful conversations in the past, it was possible to reach depth and richness of data quite early in the process.

Our conversations have felt deep, dense, honest, and often very emotional to me. Reflective writing after interviews helped me process my own emotions, sharing the transcripts with my supervisors and discussing them together helped too. Each conversation has prompted my curiosity to deepen aspects I could not imagine I would end up exploring with her, and that added to a sense of thrill and excitement, between interviews. There was a real sense of sitting with the unknown waiting to discover what we would co-create during our conversations, and where that would lead us. On top of that, in my mind I often could link her experience, as it emerged during interviews, to that of the older patients I had interviewed the previous year, already seeing glimpses of the learning which would be generated by bringing together the two sets of findings.

7.4 Demonstrating rigour

When carrying out research it is important to demonstrate high quality and rigour in our findings.

I will now briefly discuss how quality and rigour can be differently appraised in qualitative and quantitative research, further highlighting the steps I took at each stage of the research process to ensure high quality and rigour. Eventually I will describe what the specific qualitative indicators are in an IPA study, and how I ensured all of them were met.

While in quantitative research the concept of rigour is used to indicate objectivity (Marquart 2017) rigour, in qualitative terms, is a way to build trust or confidence in the findings of a research study (Thomas and Magilvy 2011).

While human biases and perspectives act as a confounding factor in quantitative research, they are essential in qualitative research (Leung 2015), particularly when using phenomenology, where the researcher and the participants co-create the findings (Frechette et al. 2020).

There are a variety of criteria used to evaluate rigour in qualitative research, as it would be impossible to apply a single one to the diversity of methodological assumptions (Smith et al. 2022); however, all these evaluative criteria look for cohesion and coherence between the aims of the study and methodology chosen, and for robust justification of the research processes.

Validity, reliability and generalisability are commonly accepted terms for appraising quantitative research quality, but they are not easily translatable in qualitative research. Hauser (2013), points out that a qualitative researcher should not focus on indicators of reliability and validity normally used in quantitative research, but that does not entail that rigorous standards are not appropriate for evaluation of findings.

The traditional criteria for validity find their roots in a positivist tradition (Golafshani 2003). Validity is rooted in empirical conceptions such as evidence, universal laws, truth, objectivity, deduction, reason, mathematical data and fact. Validity in research is usually concerned with the accuracy and truthfulness of scientific findings (van Manen 1990): a valid study should be able to demonstrate what actually exists and is accurate, and a valid instrument should actually measure what it is supposed to measure (Merriam and Leahy 2005). It is easily understandable that to assume validity has the same meaning in qualitative research, would be – at least – controversial. However, as Cypress (2017) points out, in qualitative research, validity ought to be understood more as the authenticity, trustworthiness, verisimilitude, adequacy, plausibility and credibility of the findings.

For what concerns reliability, also a concept rooted in positivist science, it traditionally assumes that repeated measures of a phenomenon (with the same results) using objective methods, can establish the objective truth of the findings (Black and Champion 1976). This represents the idea of repeatability (Morse 2012), replicability (Winter 2000), and stability of results or observation (Simco and Warin 1997). However, the problem with qualitative approaches is that human behaviours and interactions are never static or the same: they exist in a flow. Furthermore, in qualitative research – particularly in phenomenology – the researcher is at the same time the research instrument and therefore one cannot expect from qualitative research the replicability that quantitative research can offer.

Similarly, Holloway and Galvin (2016) acknowledged that generalisability refers to the application of study findings to other settings and populations and, while this makes sense in quantitative research, most qualitative studies look at specific cases, and therefore generalisability of their findings is not possible (Leung 2015).

However, there are other concepts and terms which can more accurately illuminate what constitute quality and rigour in qualitative research:

- Credibility is what can best replace the concept of validity;
- Dependability is what can best replace the concept of reliability;
- Transferability is what can best replace the concept of generalisability.

7.4.1 Credibility

A qualitative study is considered credible when it presents an interpretation of an experience in such a way that inspires confidence in the coherence between a methodological approach and an epistemological paradigm in the research design, in the consistency of data collection and data analysis processes (Lincoln and Guba 1985) and in the plausibility of the findings. Examples of strategies used to establish credibility include: reflexivity, peer examination, using the participants' words in the final report, and more (Thomas and Magilvy 2011). In this study, I ensured and demonstrated credibility by justifying my methodological choice and the whole research design at each step (Chapter 3 , Chapter 4 and Chapter 7). By doing so, I demonstrated coherence between my research question, the chosen methodology and my epistemological standpoint. This was particularly clarified in Chapter 1 , where I talked about my own background and in Chapter 3 where I outlined in detail why IPA as a methodology perfectly fits both the study aims and my own positionality as a dramatherapist. By detailing each step of the data collection and data analysis, included notes on reflexivity (Chapter 4 and Chapter 7), I ensured credibility through offering full transparency. Credibility was further enhanced by my prolonged engagement in the clinical setting where I ran the study: consistently engaging in informal observations and shadowing of the ICCI practitioner intervention in A&E, engaging in conversations with older patients and their families and with the whole dementia team's members – and working with them- for one year before starting data collection, has definitely contributed to the rigour of the study during planning phase, informing, for example, the relevance of my interviews' questions, the coherence and robustness of rationale of participants' inclusion and exclusion criteria, and my approach as an interviewer. During the cycle of four in-depth interviews with the ICCI practitioner, as described in Chapter 7 , I always left enough time for me to transcribe the interview, start analysing it and sharing the process with my supervisors which greatly informed the relevance of the questions which I would ask at the following interview with her. During data analysis, the credibility of the findings has been greatly enhanced by consistently peer-reviewing the analysis with the supervisory team, who challenged and stimulated a rigorous process of enquiry. Finally, using an abundance of word-for-word quotes from participants both in phase A and B of the study findings chapters (Chapter 5 Chapter 5 and Chapter 8), clearly showed how those link and relate to the interpretation, ensuring the trustworthiness of the study results.

7.4.2 Dependability

Dependability occurs when a second researcher could potentially follow the decision trail used by the first researcher. Guba (1981) states that it is by documenting transparent decision-making and processes that dependability can be ensured and demonstrated.

In this study I ensured dependability not only by clearly outlining the aims of the study (Chapter 2 and Chapter 6), describing the study procedures step-by-step and in detail, and outlining the rationale behind each choice made, but also by providing a range of contextual information: this included my personal background and the background to the research itself (Chapter 1), my positionality as a dramatherapist (Chapter 3) and my thought processes, through keeping reflective notes which ensured I was aware of my own feelings and thoughts at each step (discussed in Chapter 4 and Chapter 7). I also described what I knew about the participants before interviewing them (Chapter 5 and Chapter 8), and in Appendix 8 - Encounters with patient participants vignettes – p. 351 – I offer detailed vignettes (which include description and personal impressions) of my encounters with the older patient participants which stem directly from my fieldnotes. Dependability of the findings was also ensured by consistent peer-sharing of data analysis with the supervisory team.

7.4.3 Transferability

Transferability is to be intended as the ability to transfer research findings from one group to another. One way of establishing transferability is to provide a detailed description of the participants and the setting by describing the demographics and geographic boundaries of the study and by offering a rich and detailed range of experiences on which one can rely to decide whether the research is applicable to other settings (Thomas and Magilvy 2011). In this study, this was again achieved by providing detailed description and transparency of processes and rationale across the whole thesis. On top of this, in Chapter 4 I offered a detailed presentation of the specific setting of the study, offering specific data on the A&E: from statistics on attendance to the actual physical environment, included the original floorplan. In Chapter 5 I offered a range of demographic data on the older patient participants. By doing so, I believe the reader is enabled to gain sufficient detail to assess whether the findings are transferable to other settings (Korstjens and Moser 2018).

7.4.4 IPA specific criteria

In addition to the criteria above, Smith et al. (2022), indicate specific ways in which a researcher can enhance the quality and ensure the rigour of an IPA study, such as:

- Detailing the complexity of the analysis

In a high-quality IPA research study there will be a super-ordinate theme (or group experiential theme) showing how different participants manifest the same super-ordinate theme in unique ways (Smith et al. 2009; 2022).

In this study, I made sure that the complexity of the analysis would emerge by including contribution from every single participant, informing a specific super-ordinate theme, and by quoting them word-for word and, by discussing each of them, I allowed their uniqueness to emerge. This is visible in both phases of the study (Chapter 5 and Chapter 8).

- Addressing depth rather than breadth

This is important because it ensures fidelity to the idiographic nature of the methodology rather than expanding nomothetically (Smith et al. 2009; 2022).

I ensured depth since the design of the research questions, by choosing a semi-structured approach, would allow me to target each question in order to deepen as much as possible the most relevant aspects emerging from the conversation. For the same reason the number of questions was limited, and the most relevant answers were followed either by silence (to allow for reflection and for deeper content to emerge) or by a strategic ‘tell me more about that’ to allow the participant to dig deeper (see Chapter 4 and Chapter 7).

- Saying more about less

Having few super-ordinate themes (or Group Experiential Themes), can allow the researcher to spend more time show-casing subthemes and demonstrating the quality of the data and of their interpretation (Smith et al. 2022).

I wanted to ensure that I was able to say more about less: since the analysis phase I strived to incorporate clusters of emergent themes under the lowest possible number of super-ordinate themes, and in the writing up I made sure my analysis was as deep as possible for each lower-ordinate theme (Chapter 5 and Chapter 8). In Chapter 9 , I focused on the discussion of those findings which would meaningfully inform the answer to my research question, rather than expanding on each factor, and I articulated each aspect of the findings in-depth. Supervision was key for this to happen as it helped me focus and deepen both my analysis and discussion.

- Illustrate analytic depth and avoid description

A high-quality IPA study will be multi-layered, and its narrative will move back and forth between group-level claims, individual-level claims and micro-analysis of the extracts used to articulate the argument made in the analysis (Smith et al. 2022).

I ensured analytic depth by focusing on both the specific (individual-level-claim) and the more general (group-level claims) for the older patient participants, making sure that both the uniqueness and commonalities of their experiences would emerge and by moving between the two (Chapter 5 and Chapter 9) thus showing a reflexive and critical approach rather than a descriptive one. When analysing the ICCI practitioner interviews, I looked at how claims she made in one interview would come back again in further interviews (Chapter 8). I could also push myself further in analytic depth, as having collected and analysed two sets of data (phase A and phase B) I was eventually able to bring them together (Chapter 8 and Chapter 9) and to articulate a complex and in-depth discussion of findings which dynamically moves back and forth not only between older patients individually and as a group or between the four interviews with the ICCI practitioner individually and as a whole, but also between the two sets of data and between the complex relationships of all of the above with existent literature.

7.5 Summary of the chapter

In this chapter I have offered an overview of the research design and methods involved in this specific phase of the study, guiding the reader through the stages of preparing, running, reflecting upon, transcribing and analysing the data. A thorough reflection on the main ethical challenges involved in running online interviews has been offered, together with a description of how those have been addressed. I also offered a reflection on my feelings and thoughts in interviewing the ICCI practitioner, and I concluded with a discussion on how this thesis shows the quality and rigour of the study.

Chapter 8 – Findings – Study Phase B

8.1 Outline of the chapter

In this chapter I am going to discuss the contextual elements which might inform my fore-structures when I interviewed the ICCI practitioner. I will then present the findings from the analysis of my online interviews with her, divided into super-ordinate and lower-ordinate themes, following IPA advice.

8.2 Analysis of data from the ICCI Practitioner.

8.2.1 Participant and fore-structures

As I did before, while presenting the findings from the patients' participants, I will now outline the contextual elements which might inform my fore-structures when I interviewed Sarah.

I met Sarah for the first time at the hospital site in 2017 when I was starting my PhD and when the exact focus of my research was still unclear.

I shadowed her during the ICCI intervention in A&E once a week for a number of months in order to learn about the intervention, and I had various informal conversations with her, where I learned both about her views on issues concerning older people and their families, and about her approach to her job. I also kept on meeting her occasionally at the hospital, until March 2020 when both her intervention and my data collection were stopped because of the COVID-19 Pandemic.

It is correct to say that she was one of my gatekeepers at the site and provided the rest of the team with the opportunity to screen potential participants by sending us lists of patients she saw in A&E, on a regular basis.

All of the above means that when I interviewed her, we already had developed a mutual knowledge in the workplace, having already had a number of meaningful conversations, and I feel this saved a lot of time that would have been needed to build some rapport, also making-up for the additional distance created by remote communication. However, as I mentioned in the previous chapter, it is also possible that this prior knowledge had somehow desensitised us in relation to taken for granted aspects of her work, and I had to try and guard against this, by intentionally formulating my questions in a way that would not imply any previous understanding of the subject, also remaining open to deepen the conversation even when I could think or feel that I already knew the answer.

My understanding of Sarah has always been that of someone who is deeply passionate about their job, and very much devoted to humanising her workplace. Before moving to the findings from Sarah's interviews, I present a table outlining the date and time of each interview – Table 19 below – each interview with Sarah lasted between 27 and 57 minutes.

Table 19 – Dates of interviews – Phase B

	Date	**Time**
1st interview	20/04/2021	12.10 pm
2nd interview	28/04/2021	4.03 pm
3rd interview	07/05/2021	3.20 pm
4th interview	16/06/2021	12.35 pm

8.3 Super-ordinate themes

The initial stages of analysis of the four interviews I ran with the ICCI Practitioner, led me to 11 emerging themes/experiences. These themes represent my interpretation of Sarah's lived experience. The experiences which seemed to relate to each other thematically, have been grouped into clusters, exactly as I did with the *across cases* analysis of patients' data in phase A. I then gave a title to each cluster. These titles represent the three super-ordinate themes which conceptually embrace the 11 sub-themes (lower-ordinates) in groups of three to four.

Following IPA principles (Smith et al. 2009) I did not feel the need to isolate recurrent themes in this case, given that this data set is limited to one individual.

Below, I present a table (Table 20) which shows all the experiences emerged and the relations between super-ordinate and lower-ordinate themes.

Table 20 – Super-ordinate and lower-ordinate themes – Phase B

Super Ordinate Themes	Lower Ordinate Themes
1 - Navigating the "Unknown"	1A Discovering as You Go 1B Trusting One's "Felt Sense" 1C Looking, Listening, and Thinking Deeper 1D Embodied Compassion
2 - Bringing Together / Connect	2A Connecting Patients and Relatives to a Sense of Safety 2B Connecting Patients and Staff 2C Re-connecting Patients and Relatives 2D Connecting the A&E to other Agencies/Departments
3 - A Values-Based Practice	3A The Value of Taking/Making It Personal 3B Advocating for Patients Needs and Rights 3C Challenging the System and Putting the Person before the Roles

8.3.1 Navigating the Unknown

This first super-ordinate theme represents the first of the core experiences which emerged from the interviews with the ICCI practitioner, in my interpretation.

Navigating the Unknown stands here for Sarah's experience of putting to one side her initial tentative agenda allowing for real, everyday interactions with other humans to shape the intervention. This, at times, might entail an act of faith in her instinct without the need – or the time – to verify rationally, and, at other times, might mean trusting that things are not always as obvious as they appear and there is the need to look/think deeper. Discovering and making-it-up as one goes, attuning to patients, families and staff's needs in order to co-create what is really needed -trusting the wisdom of one's own senses- at the time when is needed, rather than presuming to know it, taking in the uncertainty as an implicit, almost welcomed part of the job, allowing the unpredictability of events to surprise her: all of this emerges from the ICCI practitioner's account, prompting me to conceptualise it under the following titles: Discovering as You Go, Trusting One's 'Felt Sense', Looking, Listening, and Thinking Deeper and Embodied Compassion.

8.3.1.1 Discovering as You Go

Since my very first interview with her, Sarah made it clear that her role in the hospital's A&E has always been a source of new discoveries and surprises.

It is not that she did not start with a plan: it seems more that she quickly learned to put aside any plan. Initially, she was terrified: *"I would tell you I was terrified"* (1st interview, line 197) and she felt the staff were suspicious:

> *"The staff were very suspicious. Because, you know: 'why do we, why do we need this lay person just walking around being in the way', which is how it kind of felt initially"*
> (1st interview, lines 201-206)

but soon, she felt welcomed and part of the team. She thinks this is due, in particular, to the support she received from the A&E matron at the time.

She mentioned to me that the initially agreed strategy was for her to meet older disorientated patients in A&E and present them with a range of simple activities which might have helped their cognitive status and might have soothed their anxieties (this might have involved the use of small objects, sensory material, etc.), however, it was soon revealed that this was not needed so much. This is how she commented on her initial approach to the role*:*

> *"…and I knew it [the intervention] was needed, I wasn't aware in what way it was needed. Ehm… (2), initially I think we thought it was activity, but I found out that it wasn't really…"*
> (1st interview Lines 19-23).

When I asked her to tell me more about that, during our second interview, she gave me a specific example:

> *"So, I was doing this, showing this chap these things, and he suddenly picked up the mouth organ and started to play it. Not very well, but he started to play it and enjoy himself so, it did that on and off, so we started discussing music and got into a conversation, so the rest of the activity was… (2) ahem, stopped if you like. It got off on to other things, and it got some interest in what he wanted to talk about"*
>
> (2nd interview, lines 200-217).

She then added that similar situations started to happen regularly to the point that one day she realised that she did not need to bring the trolley full of objects for activities with her: she could simply go and take it when and if needed. The qualitative adjective she used to describe how this transition was for her is: *"natural"* (2nd interview, line 149). It looks like she knows very well that when one starts something new, one always needs to accept a degree of unknown and uncertainty:

> *"…yeah, I think it just became apparent that it wasn't going to be 100% activity based. And it's like anything, if it's new, you don't know really how it's going to work until you start it"*
>
> (2nd interview, lines 169-175).

A further source of surprise for the ICCI practitioner during her first days in A&E, was the important role that her relationship with patients' families could take. She soon started to realise that one of the things that was really needed was for her to be alongside families and carers as well as patients, and this was totally unexpected:

> *"the other thing that I think I didn't expect was the relationship with some of the relatives…"*
>
> (1st interview, lines 48-51),

as well as rewarding:

> *"ahem, so I think that, that's been an added… (3) bonus whatever you want to call it"*
>
> (1st interview, lines 80-83).

Her job took also other directions that she did not expect, like her taking over the role of communication's facilitator between older patients' nursing homes and the A&E (which will be described in section 8.3.2.4 – p.234). Mentioning that, she stated that her role had developed into *“a bigger thing”* (1st interview, line 282) than she would have ever expected.

Her relationship with patients at the end of their life and their families in A&E appears to me as paramount of the overall unknown and indefinable dimension of her role. When describing her drive to remain alongside an unconscious patient in his last moments, on one occasion, she stated that she did not know if that had made any difference to the patient, but still, she wanted to be there:

> *“I just… (4) I don’t know, you know people always say: ‘Oh, they [the dying] can hear you until they’ve gone’, well I don’t know how we know that because nobody’s ever came back [from death] saying ‘oh, I could hear every word you were saying!’”*
>
> (2nd interview, lines 1552-1560).

Always describing her relationships with patients at the end of life and their families, she stated that it can be very variable:

> *“Ahem… (3) very variable. Firstly, if I’m not with a specific patient I’m always wandering around all the bays, in A&E and resus, to see if there might be anybody that has nobody… (3) or if someone just might need to chat, or a relative…”*
>
> (2nd interview, lines 1582-1591).

Finally, she does not feel she has a typical working day:

> *“I haven’t got a typical day, I just go, you can’t go in, I think, with that attitude, you have to go completely with the flow of what’s happening”*
>
> (1st interview, lines 552-556).

She seemed quite resolute on this point: one cannot have *“that attitude”* (1st interview, line 554), there is a need to go *“with the flow of what’s happening”* (1st interview, lines 554-556). It looks like this openness to discovering and responding ‘as you go’ feels like a core value to her: something essential for the job.

At the beginning of her job, after the initial fear and sense of displacement, the ICCI practitioner seems to have approached the unknown of the new role she was taking over with openness, and a willingness to attune to each patient’s particular needs, remaining available to put aside any pre-existing plan. This seems to have been rewarding, as it allowed her to feel that what she was doing could develop into a *bigger thing*, to use her words. Eventually, she came to feel this to be a core value of her job.

8.3.1.2 Trusting One's 'Felt Sense'

For Gendlin (1984) *Felt sense* is the raw and direct experiencing of our body's feeling of a situation, before it can be clarified with words. Since our first interview I noticed Sarah often referring to a feeling sense inside her that she trusts, and which immediately reminded me of Gendlin's idea of *felt sense*. In fact, she often stated that she could have a sense of a situation in A&E and respond to it instinctively, without knowing why, and most of the time, upon reflection, she could see that was the right thing to do. When talking about how she judges whether a patient might want their hand to be taken, she said: *"but no, you just know [it]"* (1st interview, line 468), when referring to her knowing, since the beginning, that it is good for her not to wear a uniform in her role, she said: *"I just felt it, really"* (2nd interview, line 323), moreover, when telling about the use of a sense of humour and the importance of understanding when it is appropriate and when is not, she stated*:*

> *"…ahem… (2) and… (2) you can't explain how you know, but you know if somebody is… (3) prepared to have a bit of fun about what they've come in with or whatever"*
>
> (3rd interview, lines 295-299).

Finally, when describing her first experience with a patient at the end of life – who was unconscious at the moment – she declared:

> *"I just felt it was, ahem… (3) important that somebody was there holding his hands, it might not have been, but I felt it was, on that occasion"*
>
> (2nd interview, lines 1561-1567).

It looks like relying on her *felt sense* is the most effective way Sarah has found to navigate the unknown of the emergency department, where one needs to respond very quickly:

> *"you've got to quickly source them out to see: did they want to talk? Did they just want to sit? You know what I mean, you've*

> *got to very quickly, weigh out what they want from you or what might help them”*
>
> (1st interview, lines 313-319).

She also described it as a vibe:

> *“Ahem… (3) well, you know, if you meet somebody, well I do anyway, you get a vibe very quickly, don’t you? Or I do, ahaha!”*
>
> (2nd interview, lines 1179-1184).

When I tried to dig a bit deeper in this subject, and I asked her which elements inform her getting a ‘sense’ of a person or a situation, she said:

> *“S: yeah it’s all, it all is a very quick, together thing, yeah. That you would… (2) there must be a better word than ‘judge’ somebody, but, get an impression of somebody.*
> *I: yeah.*
> *S: Because you sort of might slightly change how you would speak to them. And I don’t mean that unkindly, it’s just that you would, ahem… (2) yes, I mean you know it’s listening, looking and feeling I think, [these] are the three… (2) three things that you would look at somebody for. You’ve got to, you’ve got to get some people very, very quickly. You know, within sort of, I don’t know, 15/20 seconds only: that’s all you’ve got. To not make a serious mistake”*
>
> (3rd interview, lines 365-372).

Prompted by my questions, she eventually seemed to realise that she has always followed her ‘gut sense’ in her role, but that she has refined it, and she has learned to trust it over the years:

> *“I used it from the beginning but it’s developed because I’ve got more confidence in it now, if that makes sense, before I was a bit hesitant to having a laugh with somebody that was in A&E or… (2) had a bad injury, but, although I felt sometimes that they wanted to, and I think the more I’ve done it, the more confident I’ve got to go with my gut.*
> *And I think that’s the bottom line, is having confidence in it”*
>
> (3rd interview, lines 376-387).

To summarise: Sarah’s description of her ‘gut feeling’ reminds me of Gendlin’s definition of *felt sense*. Sarah uses it as her instrument for navigating the unknown represented by each different patient and different situations she meets in A&E. She knows she has always used it; however, she also is aware that she developed it and learned to trust it more and more along the years.

8.3.1.3 Looking, Listening, and Thinking Deeper

Sarah seems deeply aware of a strong need for her to listen to her patients beyond words:

> *"And it is also to… (2) ahem… (2) work out what they might mean they might not be saying what they mean, but they might be saying it in a different way. Does that make sense? Yeah, and you know, I often think if, if somebody… (3) you'll often get a patient who keeps saying 'I can see my mum' or 'is my mum there?' and I feel, and it seems to be right, that, that it seems to be them wanting to be safe, feel safe like, that's what your mum does when you're little , you know, makes you feel safe, or should do… (2) ahem… (1)so sometimes you have to quickly decipher what they're saying, to really get what they're saying… (3) but yes, you do have to really listen. Yeah"*
>
> (2nd Interview, lines 532-562).

Here Sarah seems to be referring to patients with symptoms of delirium, or dementia, and points at her very predisposition to look for the meaning beyond the symptom: when they say they see things which are not real, they are not just hallucinating, and when they believe things which are not possible, they are not just delusional: they are expressing a need for which they have no words, and this need is the universal human need for safety, which we usually experience for the first time with our own mothers (if we are lucky enough). Thus Sarah says: one needs to learn to decipher, but first, one needs to learn to listen.

There is a further section where she seems to reiterate this concept:

> *"If somebody is aggressive, we immediately put that down to the fact they've got dementia and then they're aggressive, but it could be that they've got dementia and they're in a lot of pain"*
>
> (4th interview, lines 285-290).

However, in another interview, she mentioned her 'gut', stating that she believes it is really key to her job:

> *"I think I use my gut more. Yeah, my feeling. Yeah, I think. Yeah, I mean I use them all, but I think if I had to pick one, it would be that. But the others are just as important, really"*
>
> (3rd Interview, lines 722-727).

Sarah acknowledged that she needs to be connected to her gut most of the time to do her job in A&E:

> *"… (3) ahem, I mean, I use it most of the time, to be honest, because you've got to, you've got to get some people very, very quickly"*
>
> (3rd interview, lines 365-368).

She seems to challenge the superficial, straightforward equation which links aggressive behaviours to dementia, almost as if they were just part of the syndrome, pointing to the need to look at the meaning beyond the behaviour, rather than putting a label on it. She seems deeply aware that patients do not always have the words to express their needs, or, as she explains in another section, they might be afraid of telling the whole truth:

> *"They're scared. And they're scared of two things, as I said, they're scared of being out of their environment and they're scared that they're not going to go home again. These are the two bottom lines, I think. And, ahem… (2) and that's the reason why they will tell porky pies whether something hurts or not… (3) ahem, because they're thinking that if they say that something does hurt, then they will keep them in [hospital]. Ahahahaha! So, the fear of not going home for that… (3) ahem… (2) section of patients, I think, is, is really high"*
>
> (3rd interview, lines 490-505).

On other occasions, it might just be that they have learned not to "*moan*" (1st interview, line 726). This is a cultural factor, very much linked to their old age, and Sarah has learned how to listen for that and notice that, as she pointed out during our first interview:

> *"I was walking past the corridor, this was when I wasn't allowed in to patients, but I was walking down the corridor and I heard this nurse saying to this old boy: 'are you in any pain?' and he said 'not really' so she just ticked the box that he was in no pain, and I just stopped, and I said: 'just listen to his answer: he didn't say no, he said, not really'. It is that generation that don't*

> *moan, don't complain and the fact is that really, in the end, you should be digging a bit deeper"*
>
> (1st Interview, lines 714-728).

Then, in our fourth interview, she explains how she manages to get around that:

> *"S: Okay, so you know, I'd say to him, depending on his level of communication, I might smile at him and say – Come on, then what does 'not really,' really mean? -, I'd say, 'have you got a headache?' and if he'd say not, I would go through the body: 'and what about your hip, or your elbow or your wrist?' and sometimes they'll suddenly go 'oh right I've got pain in my wrist!', quite openly, but you've got to just make the question a lot more specific.*
> *I: it seems like you are doing a body mapping with them, you know? Like a form of mindfulness, I suppose it makes sense given that if you have a cognitive impairment and possibly anxious, you struggle to connect to your body and understand what's going on?*
> *S: yes, I mean, sometimes you can do it that way, and so, that's right, sometimes people don't understand what pain means so if you change the phrase, and you say 'does anything hurts?' sometimes that will get a different answer"*
>
> (4th interview, lines 306-328).

Sarah seems to know how to look deeper into patients' presentations and behaviour and how to listen deeper to their words. She expresses awareness that there might be a variety of reasons, particularly among the most vulnerable of them, for not being able to voice their real needs, and it is up to the professionals who care for them to learn to look, listen and think deeper in order to allow those needs to emerge and to be met. This seems to be central to the Intentional Compassionate Communication's approach, where Sarah knows she is also at the receiving end of communication, and she needs to learn to decipher empathetically – and compassionately – the patients' – voluntary or involuntary – communication messages. Putting a label or ticking a box will never be enough for navigating the unknown often represented by those patients.

8.3.1.4 Embodied Compassion

Gradually, along the course of all our interviews, I noticed compassion as an embodied dimension emerging more and more from Sarah's account. Embodying compassion seems an important aspect of the Intentional Compassionate Communication Intervention, as she needs her whole body and all her senses to assist her in both receiving and sending compassion through communication exchanges with older patients in A&E.

When, during our first interview, I asked her what delivering the ICCI means to her, this is how she answered:

> *"it's holding their hand, it's being compassionate, it's being their friend it's trying to understand them"*
> (1st interview, lines 29-33).

I immediately noticed that the first image she had given to me in relation to her job was related to touch (*holding their hand*), and when, later on, I asked her what *being their friend* meant to her, she spoke about touch and senses again:

> *"Mmhh… (2) well, it's a strange thing, I mean… (4) again, it's one of those things that there's not necessarily a verbal… (3) explanation for, I mean there was one lady who… (3) came in, who was quite distressed and agitated and I just held her hand and was chatting away and now, after five minutes, the doctor came in and she wouldn't have anything done unless I was there… (2) like, the relationship seemed to happen that quickly"*
> (2nd interview, lines 246-263).

Sarah seems to struggle to convey her answer through a verbal explanation, therefore, she resorts to describe an embodied experience with a patient, when the bond – the relationship – *"seemed to happen"* (2nd interview, lines 262-263). I find the use of language and grammar very interesting here: there is not someone 'doing' something, i.e. 'building a relationship', but rather something 'happening' between two human beings out of an embodied encounter in a moment of distress.

When asked what compassion means to her, and how she would describe it, she talks about body and senses again, this time going into more detail:

> *"It's… uuh, it's hard, it's a hard thing to describe this, I think. If I'm being honest you either have it [compassion], or you don't. And I've noticed with other staff that some just have it, and*

> *others don't, but it's, it's trying to… (4) get some form of bond with the patient, whether it's through touch, or talk, or music…"*
> (1st interview, lines 135-144).

First, it is again not easy to describe what compassion means to her through words (I wonder whether using another expressive medium would have helped her). Second, she believes that one either has compassion or does not have it: it looks like she is saying that compassion cannot be taught or instilled.

Lastly, compassion is in the determination to get some bond with the patient, and it is described as an action: *"it is trying to…"* (1st interview line 141) and this action for her can take different forms, all of which are embodied: *"touch, or talk, or music…"* (1st interview, lines 143-144).

Touch takes a central place in her account, i.e.

> *"So it's just finding what gets to them, and what means something to them and, as I say, sometimes it's just touch, it's that simple. But you can feel in the way you grip their hands"*
> (1st interview, lines 164-170)

or:

> *"I leave my hand there, which I learned after a bit, and then they will come back to it, nearly always they will come back to it, and that just… (1), I mean whether you're a kid or an elderly person just hold in a hand means a lot sometimes"*
> (1st interview, lines 173-180).

Later on in our conversations, I decided to come back to her description of compassion in her job as strictly connected to the body and senses, inviting her to tell me more about each of the three dimensions mentioned (touch, talk, and music). When describing touch more in-depth, I see her linking it to a primary sense of safety she wishes to provide to her patients:

> *"I mean, the touch is very important. I would almost say vital. Even if you just put in your hand on their head moving the hair back, it's a maybe… (3) it's something that their mums did, which makes them feel safe, you know… (4) I'm really struggling to verbalize it"*
> (2nd interview, lines 1185-1196).

She learned how to use it and she does not give up easily when patients seem not to want it. This is how she describes her reaching out to patients offering to hold their hands:

> *"and as I say, sometimes that if I go for it, they will pull it away, but I have noticed if I leave my hand there, they will go back for it. Which is interesting, so it's going to be the initial touches shock them a bit and… (3) then they realize that's what they need"*
>
> (1st interview, lines 468-476).

Touch, however, is not only a gentle and comforting activity, or something a patient – or Sarah – would necessarily want. This is how she remembers a similar experience with a patient:

> *"so that, you know, to have his blood test I'm really having to hold him tight and, frankly, against his will, one can argue with that, you know what I mean? But, if I think it's for their own good… (3)"*
>
> (1st interview, lines 658-663).

Here Sarah is talking about physical restraint and is showing her point of view. Touch can be gentle but can also be strong, it can feel soothing and relaxing or containing and restrictive, but for her, both kinds of physical contact/touch have a space if they are moved by compassion. It looks like there are circumstances in which practising physical restraint is acceptable for her, but all depends on the intention: *"If I think it's for their own good"* (1st interview, line 663).

Sarah did not expand on the role of talking however, she gave me some examples of episodes when she has used music in her intervention.

The first episode is described as one of the most beautifully significant experiences she ever had in her role. She was trying to create a bond with an older lady, who, using her words, was *"locked-out with dementia"* (1st interview, lines 761-762).

The rest of the staff who had tried to interact with her had given up, because it seemed impossible to get any reaction from her. Sarah then decided to put some music on:

> *"So, I got my iPad again, and I put some classical music on, and I got a little smile. Now that's not a big issue for a lot of people […] but for me that was one of the most beautiful things because it had got through to her"*
>
> (1st interview, lines 389-397).

She goes on talking about her use of music by describing another episode, with a different patient, who initially seemed scared of having a CT scan:

> *"So, I've got a little microphone I can put on their pillow and I can keep hold of the iPad. So, we went all the way down the corridor to the CT scanner playing Abba, I left the microphone in the CT scanner so it was playing Abba while he was having a CT scan, but I mean it [music] can… (2) go through something we never thought we'd get through"*
>
> (1st interview, lines 407-418).

From both accounts, it emerges her belief that music is something which can go "*through*" people, which can make up for impaired cognition or sensorial limitations, something which can connect with a sense of pleasure, or that can reassure.

Certainly, it seems a way to create that *bond* she mentions, which seems to be an essential part of the ICCI.

Sarah does not engage her bodily dimension only through touch, talk and the use of music: other elements seem to have an important role in the embodied dimension of the ICCI, like the use of her own body and movements to reassure older people. She recalls an intervention with another patient who was afraid of going into the CT scanner:

> *"and so, I took him back to the scanner, and I laid on the scanner to show him what to do a few times, just to show them it's not scary… (3) ahem… (2), and he got off and he just laid on it"*
>
> (1st interview, lines 609-614).

In this description, she gained the patient's trust by actually showing that there was nothing to fear about the scan. This was only possible by physically putting herself into the patient's shoes.

Embodied Compassion seems to emerge as a central aspect of the ICCI, and it is certainly one of the ways Sarah has learned to navigate the unknown in A&E. This unknown of her experience of delivering the ICCI is also related to her not knowing how each patient can get to ‘know’, as to say, how each of them can get to an understanding of something in A&E. Everyone will have different levels of cognitive ability, communication skills, and sensorial functioning and she needs to find a way to get ‘through’ to them, to reach a place where communication is actually possible.

Compassion, in her description, is an action – it is *“trying to…”* (1st interview, line 32) and as an action, it is necessarily embodied and passes through the senses.

8.3.2 Bringing Together/Connect

Weaving connections, or bringing together, emerges as one of the core experiences of the ICCI practitioner in my interpretation of Sarah’s account.

Feeling connected is a necessary condition to experience a sense of safety (Cacioppo et al. 2002), while older people who may feel disorientated in A&E in this study, seem to be facing a sense of disconnection, which might happen both as a result of having lost connection to a sense of shared reality and shared meaning (because of a transitory confused state or because of dementia), and as a result of having lost connection to the very relationships which are significant to them. This is the case for those older patients who arrive to A&E on their own (which, again, can be a transitory loss, in case their relatives will join them at a second time, or a permanent loss, in case they just don’t have anyone in their life anymore). Sarah appears to me as very aware of this reality, and very much engaged in trying to weave the missing connections.

This ‘connector’ role, in her experience, might entail her trying to reconnect patients and their families to an internal sense of safety, re-orientate and reassure, reinforcing their connection to the staff by advising A&E nurses and doctors on effective ways to communicate with older patients, or by reconnecting A&E staff to the end result of their job (mentioning when patients are doing good after A&E), but it can also entail facilitating relationships between patients and their own families, which is not an easy task in time of pressure. Finally, and unexpectedly for Sarah, her role has also developed into facilitating connections and communication between the A&E and other agencies, such as the ambulance staff, or the patients' nursing home staff, or into facilitating the sharing of information between the A&E and the hospital departments where patients are going to be admitted.

Bringing Together/Connect includes the experiences of Connecting Patients and Relatives to a Sense of Safety, Connecting Patients and Staff, Re-connecting Patients and Relatives and Connecting the A&E to other Agencies/Departments.

8.3.2.1 Connecting Patients and Relatives to a Sense of Safety

Listening to Sarah's words, it looks like there are several different ways in which she feels she can make patients feel safer. One of these is offering them a cup of tea and some biscuits. This, usually, can happen either at arrival or shortly after. We talked about what this means for her:

> *"But it is a… (3) very British thing of, of making friends isn't it, that's what you do, you have somebody around, for, you know, if you meet somebody new that you like, you say 'you must come around for a cup of tea' that's, that's what we do. With biscuits. Ahahaha!"*
>
> (3rd interview, lines 419-426).

She seems here to use a culturally-shared social ritual to communicate to the patients that she wants to be their friend, that they are welcome, which very possibly can make them feel immediately more safe. Furthermore, after the tea, she usually keeps *"popping in and having a chat"* (3rd interview, lines 244-245) with them.

There are other ways she feels she can contribute to the patient's sense of safety straight from the beginning, one of these is that she, unlike nurses and other members of staff, does not wear a uniform:

> *"I think, from a patient's point of view it [not wearing a uniform] just seems to be less threatening, it's less official it's… (3) it's more like the normal human beings they see on a on a regular basis, or their family"*

(2nd interview, lines 308-316).

A further way to reassure patients at arrival is described by her in the following lines:

> *"Ahem… (4) it's just general chatting to them really, but it's, again it's reassuring them that… (3) you won't be, I mean I usually say something like, you know 'we're really busy hospital, trust me you won't be coming in here unless you really need to' and that sort of stuff and normally, you know, 'if you behave yourself will kick you out at 5', again that's a bit of humour. Yeah. Problem that, really… (5) It's just general, it's just general talking and being a friend and making them feel safe. It's quite simple really, ahahaha! It's simple to me, put it that way"*
>
> (3rd interview, lines 538-554).

This example suggests that she can use her sense of humour as a way to create a more relaxed atmosphere. She can use it also to reorientate patients' sense of time:

> *"I mean we've now got dementia clocks in all the bays in majors, which is a clock with the dates and the time. So that can be helpful, and I'll tease them sometimes when they say: 'oh you've been [away] forever' and I'd say: 'look its quarter to 5, and I was here at half past 4!' ahaha!!"*
>
> (3rd interview, lines 269-277).

She expands on humour, giving me another example:

> *"And you know you have these classics: 'well, it's all right X, because you've got another one', you know what I mean, or: 'actually, the replacement ones are quite nice' and all that sort of thing and it just relaxes them a bit, I think, I mean half of it is absolute rubbish… (3) ahem, I'm just trying to think… (3) I'm trying to think what I joke about, ahahahah !!!!! Yeah, I mean we have a laugh about… (2) ahem… (2) I'm not very politically sensitive, as you know, you know we'll have a laugh about the doctors, because the doctor will have been in and they can't understand a word he said. And I'll go: 'don't worry about it because I only got every other word!' so that develops a bit of the relaxation, and that sort of'stuff"*
>
> (3rd interview, lines 300-323).

It seems realistic that having a laugh can release some tension and create an immediate bond between her and the patients thus contributing to a sense of safety. Moreover, that immediate bond can make the patient sense that someone is recognising their Lifeworld, making them feel seen and valued.

Being able to see what happens around them can also be key for older patients to relax and feel safer.

In the following extract, it is possible to appreciate Sarah's understanding of how being able to see people around them rather than being enclosed in relative isolation, could help a patient feel better:

> *"Ahem… (2) [it was] very hard to get through to her, she… (1) in the end I ended up putting her chair at the end of the base so that she could see everybody walking on… (1) she obviously didn't like being enclosed in a bay. So, I got a chair and I sat her at the end so she could see what was going on"*
>
> (3rd interview, lines 51-59).

When Sarah meets a patient who is in a confused state – possibly having psychotic symptoms – she feels the better way to make them feel safer is not to try and convince them that what they see or believe is not real, as that would make them feel even more agitated instead*:*

> *"if they think that there's 58 rabbits coming out of the ceiling, there's 58 rabbits coming out of the ceiling, and go with it, you know, don't start arguing with them because that's actually what they are seeing"*
>
> (4th interview, lines 383-387).

Sometimes, she reminds them that they are safe, but for her it is also important not to lie. This is how Sarah articulates it, while telling me about a very agitated lady who she welcomed straight from the ambulance:

> *"S: She… (1) from what I was told by the ambulance and they commented that she'd calmed very quickly the minute I just sort of started speaking to her explaining where she was in that she… (2) I always tell them that they're safe. Because I think that's important.*
>
> *I: So, for example, what, what did you tell her when she first arrived?*

> *S: I mean, basically, I had a name, so I said: ‘hello X, yeah my name is Sarah, and I’m here to look after you, you’re safe and you’re in hospital, and we’re going to do all we can to make you better’, I’ll say something like that… (2) ahem, and I will often say… (2) again try not to tell them fibs. But often their first question is: ‘I want to go home, I want to go home’, so, I usually say something like: ‘I promise we will get you home as soon as we can’, which isn’t telling them fibs”*
>
> (3rd interviews, lines 72-100).

There are rare occasions, however, when Sarah feels that telling them *fibs* is the right and best thing to do. She recalls an encounter with a lady with dementia when she came up with a very successful plan to allow the patient to take a much-needed nap:

> *“S: And I heard her saying: ‘I only sleep upstairs’. Now, in all my dealings with patients with a dementia, I always try and tell the truth. But there is an odd occasion where I might fabricate a bit of a fib if I think it’s for their benefit. So I said to the nurse: ‘just let me try something’, and the nurse said; ‘No,no,no,no, it will never work’, so I put the lady in a wheelchair, and went into the main department. I took her over the ambulance ramp which whizzes them down again. So, we’ve been in the lift, we’re upstairs now, go back to exactly the same bed, and she got in [bed], covered her up and she said: ‘night night’.*
> *I: ah!*
> *S: because she felt she was upstairs. So, although I tell some fibs it was… (2) I felt it was fair enough to do it on that occasion”*
>
> (2nd interview, lines 482-514).

Every person she meets can have completely different needs. Attuning to them appears to be fundamental to understanding what could help them feel safer. In my interpretation, Sarah knows that there are occasions in which a patient can receive a sense of containment – and then safety – from a more challenging approach.

This emerges in the following account, where Sarah is telling me about a time when she challenged a confused patient who had been labelled by staff as potentially violent:

> *"So I went down to him and said: 'good afternoon, sir, how are you?' and he said: 'don't you fxxxing call me, sir!', and I, for whatever reason, said: 'actually, no, I won't, because I've got you have been a pain in the ass all morning', and he suddenly changed, and he went: 'have I'?' and I said: 'yes, you have', and he said: 'well then best get to hospital then', and I said: 'well, that's where you are!' anyway, in the end, we had this bizarre conversation, and he ended up as happy as Larry, and there's no violence, I mean, he was just scared and I just wanted to challenge him a bit"* (1st interview, lines 336-354).

It looks almost like Sarah was meeting the patient exactly 'where' he was, recognising and matching his energy. Finally, Sarah let me know how important it is to her to be there for the patient's family. She knows by experience how stressful it can be for them:

> *"So, it's not, it's not always the patient. It's often the relative. And if you can calm the relative, the patient calms at the same time. Because, having been a relative in hospital, you are stressed to the end of the earth and sometimes I'll just take them [the relative] away for a cup of coffee"*
> (1st interview, lines 107-114).

She seems very sensitive to the relatives' lived experience at a time when they might be having to take difficult decisions, like, for example, finding a nursing home for their loved ones, and she appears to have a deep understanding of the sense of guilt this might entail. She can help relatives to calm down and re-connect to a sense of safety by normalising their feelings:

> *"And I think people that feel that guilt, feel they are the, the only person in the world that feels it, and everybody else's managing perfectly well. So, again it's telling them that it's, it's normal"*
> (2nd interview, lines 757-766).

Sarah knows how important it is to connect older patients and their families to create a sense of safety. She uses every possible occasion to do that, as she feels it is an essential part of her duties.

8.3.2.2 Connecting Patients and Staff

One of the main ways Sarah experiences her role as a ‘bridge’ between patients and the clinical staff in A&E, is by teaching effective communication skills to the staff.

She seems to be persuaded that a number of members of staff lack these skills – particularly in the context of communication with patients with dementia – even if, for her, this was particularly true when she started her role, whereas by now, the situation has improved significantly. Here is how she articulates it:

> *“And [my aim] it’s teaching them that with a patient with cognitive impairment it’s not that simple, you have to do it in a different way, so you have to try and observe them more and speak to them more, and ask them slightly different questions”*
>
> (4th interview, lines 233-238).

She feels it is common for staff to use medical jargon which further confuses and disorientate the older patients, fostering disconnection:

> *“S: The stupid phraseology they use like: ‘I’m just going to put a line in you now’, is that a line of coke, or a plumb line?!? Ahahahaha!!!!*
> *I: ahahahaha!!!*
> *S: you know wat I mean, it’s natural language to us but it’s not to them”*
>
> (1st interview, lines 214-222).

Moreover, she feels it is very easy for the staff to get lost in their routine’s activities, forgetting the importance of explaining what they will do to the patient. She also feels the need to remind them of the importance of telling the truth:

> *“Well, [let’s] say that they are taking blood, and I don’t know, let’s say, 20/30 times a day and it becomes a commonplace thing for them and it’s very easy to forget that for the patient it’s the first time. If you’re going to tie something around the top of their arm before you take the blood, tell them what you’re doing… (3) and I always say tell them the truth: it will be painful for a while… (3) and this sharp scratch business when you’re taking blood is rubbish: it will hurt you for a second. So, I just make sure, I think, that they explain a bit better… (2): which makes it slower”*
>
> (2nd interview, lines 1441-1465).

She becomes particularly passionate when talking about the importance of not lying to patients.

From the previous extract, however, another important element for the analysis emerges, which is her feeling that the staff needs to slow down. She seems to be aware that the staff are under great pressure and that they feel they lack time; however, she trusts that, paradoxically, slowing down at the beginning would save them much time later:

> *"S: I think they think they don't have the time. But what I am trying to explain to them as they start is that, actually, it will save you a lot of time. You know, an extra five minutes at assessment could save you the CT scan down the road, you know, so it's, I think it's just because you know what we're all like with systems, this is what you do: a patient comes in, you do X, Y, Z and because A&E is under pressure.*
> *I: mm hmm.*
> *S: that's how they tend to work, there's nothing wrong with that, it's just that we, we need to adjust them for patients that don't fit that slot"*
> (4th interview, lines 241-256).

It seems clear that she sees it as a systemic issue, and she is available to try and make-up for that, trying to fill the gaps of the system:

> *"the doctors realized that by me having 10 minutes with that patient I could get a better history or a more reliable history"*
> (1st interview, lines 257-261).

This appears to me as a further way to weave a connection – between patients' stories and the doctors – so that they can see more about the individual person they are treating.

Sarah also facilitates staff interactions with patients when she feels staff are finding a patient somehow *difficult*:

> *"I think for some of them, they were just relieved that somebody was going to help them 'deal with', is not the right phrase, but 'be with' patients that could be a bit difficult"*
> (1st interview, lines 233-238).

Sarah mentions episodes with older patients who have been rude to foreign professionals*:*

> *"I have told a couple of patients off, to make them understand they were wrong, ahem… (3) they were quite rude, or said they didn't want to be treated by black men"*
>
> (2nd interview, lines 1357-1364).

Despite telling them off, Sarah can empathise and can understand where their reaction might come from:

> *"it's foggy enough if you've got dementia and you're slightly deaf… (3) yeah, so having someone that doesn't speak perfect English…"*
>
> (2nd interview, lines 1347-1352).

She explains that she is always available to support staff in helping an agitated patient to emotionally self-regulate, so that they can take blood or do a test or a scan. She gives me a specific example for this:

> *"And I just arrived, I think, and saw this patient being brought back into A&E, who they have taken for a CT scan twice and he wouldn't do it. Ahem… (3) and the doctor then said: 'I am really sorry but I cannot help him unless he has his scan'. And of course, they're very reluctant to sedate anybody unless they really have to, and he was kicking off at them and he was lashing out at them. And I just sat with him for 10 minutes and just got to know him a little bit and said 'come on let's have another go' and I explained to him what was going to happen, how much they understand, sometimes I don't know, but I always feel it's important I treat everybody as though they are you or me. And if they understand a bit of what I say then that's good, and so I took him back to the scanner, and I laid on the scanner to show him what to do a few times, just to show them it's not scary… (3) ahem… (2), and he got off and he just laid on it and the radiographer said: 'this isn't the same bloke that we had half an hour ago'. So… that, that would have been probably, shall we say, if I wasn't there doing that job that would have been very difficult"*
>
> (1st interview, lines 585-621).

Another path to connection is for her to enable doctors to know if a patient is doing ok after discharge from A&E to one of the hospital's ward:

> *"All I have to do is going to find the doctor that treated them or the nurse that was treating them to tell them it's amazing because they're up and they're talking and… (2) you know, so that's, that's good, that's nice"*
>
> (2nd interview, lines 1664-1671).

She seems very sensitive to this need of doctors and nurses to know, particularly for the less experienced among them:

> *"Yeah, I think... (2) certainly, with the junior doctors, the less experienced, it's nice for them [to know a patient is doing ok], because sometimes, you know, with, with elderly people they've got lots of different things wrong and there could be lots of different diagnoses and lots of different treatments, so I think it's nice for them and their confidence to know that what they did was right. So I think that helps them... (3) ahem... (2) and some of them just care, you know… (3) nice to have a results"*
>
> (4th interview, lines 128-138).

Sarah's attention to this specific aspect of clinical staff's experience is connected to the fact that she experienced herself what it means to have someone bringing precious information when you are worrying about a patient, and you don't know what happened to them. This seems evident in the following extract:

> *"S: And so it started, if you like, the other way around: I got in [A&E] the next day and the doctor came straight up to me and said: 'Oh, he died an hour later, and I was the one that signed his death certificate and he was very peaceful', so initially that had happened, they were doing it for me.*
> *I: hmm.*
> *S: and then I realized actually that once that patient leaves the emergency department, the doctors don't know. Sometimes it's nice for them to know that, whatever they treated them with, has helped them"*
>
> (4th interview, lines 49-61).

From all our conversations, it became quite clear to me that Sarah's experience of her role is to support older patients and their families as well as teaching and role-modelling for staff, in virtue of her own lived experience of being a daughter and carer of a person with dementia. In my interpretation, she feels this as a way to bring staff closer to the experience of older patients, in particular of patients with a cognitive impairment, so to build a better connection which ultimately would serve the patients' benefit. This is how Sarah comments on what she could observe when she first started the ICCI role years ago, and how she made sense of that:

> *"When I first started, and I get that this is going to sound awful, but it's not meant to be. When a patient arrived, with a cognitive impairment... (3) there was sort of a bit of an eye narrow and an 'oh heck'. And I think you've got to get a little bit deeper in that it wasn't because that person had a cognitive impairment: they [staff] knew it would take time, and I think that was their concern rather than 'we've got somebody that can't do this, do that, coming in', just, you know what I mean. It wasn't the fact that they didn't like dealing with it, like you know, whatever - although some are nervous and that's an issue that's got better because they'll just come and get me – but it's, I think it's because of the pressures in A&E, it's the 'oh heck this is going to take time, we might need an extra member of staff and we haven't got one'"*
>
> (4th interview, lines 359-377).

She appears very understanding of the systemic factors affecting staff behaviour, and when I ask her whether she feels something has changed in that system since she is working in A&E, this is how she responds:

> *"I think…I'm liking what I'm seeing now. Which is, we're not having patients arrive with a dementia and staff rolling their eyes because they think they'll be difficult or whatever. They know what to do, they know to come and get me, and that must be a big change from… (2) I'm not saying they were horrible to them, but they didn't really have any … (2) practical experience of how to deal with people with a dementia, especially those that were aggressive or agitated – I prefer to call it – and the ones that were passive"*
>
> (1st interview, lines 795-811).

It is evident here that Sarah experiences her role as one that, bringing practical experience, has enabled staff to feel more confident in relating to distressed older patients, both because they learned how to do it and because they know that when they don't know how to do it, she can always step in.

Ultimately, the core connection she has weaved between older patients and staff in A&E seems to be the basic human-to-human connection, which she felt was lacking. During our last interview, this is what she says about the staff:

> *"They now talk about them like they were talking about you and me, as a person. And not so much as a... (4) as somebody that's just being a nuisance to them"*
>
> (4th interview, lines 418-421).

8.3.2.3 Re-connecting Patients and Relatives

A further way of connecting and acting as a bridge, is for the ICCI practitioner to support the older patient's relatives in their relationship to the patient. She can be quite directive and step in, when necessary, to re-orientate relatives' behaviour in time of stress, for the patient's benefit. In my interpretation, this is a way of 're-connecting' as she acts as a third, less involved – but still empathic – part, at a time when the patient and the relative might have lost connection due to stress, fear or guilt, to ease their relationship. This comes out very clearly, for example, from the following extract, where she describes how she stepped-in to help three daughters in their relationship with their mother in A&E:

> *"They were all arguing about trying to justify what they did for their mother. And I thought oh my God this isn't doing anybody any good, so I went in and sort of said: 'excuse me, do you think you could leave us because I need a private word with your mother', so they all go and get a coffee or something. So, I said to the lady: 'are you all right?' and she said: 'I don't know what to do with them', and she said: 'it upsets me that they're going on like this', which you could see it was, so anyway… (2) the girls came back after a bit and I just was, was honest with them, outside from the mother, and said: 'look: I'm sure you're all doing what you can for your mother and you're all in different situations and some of you right now can do more than others, but please don't do it in front of your mother, because it's upsetting her'"*
>
> (2nd interview, lines 615-646).

It looks like on that occasion she felt her intervention was successful, as she comments:

> *"And I think they were quite taken aback, ahaha, from somebody telling them off really, ahah, but, I think they appreciated it in the end, one of them before she went said thank you for that, ehm… (1), we obviously didn't realize what we were doing"*
>
> (2nd interview, lines 646-656).

Another way to work on that bond between a patient and their relatives seems to be for Sarah to provide reassurance to the relative when it becomes evident that their loved one might need a nursing home. She knows very well how relatives of an older patient in A&E may feel, because she has been one of them, and her lived experience gives her that *"thing to relate to the relatives"* (1st interview, lines 57-58). By being able to relate and to connect to the families, however, she is at the same time helping them to connect or re-connect to the patient. This is evident when she says:

> *"And it was having that conversation, which I think I said before, is that… (3) you explain them that, as I said, I thought I'd never put my mum in a [nursing] home, I always said that I would never put her in a home, and I did. Ahem… (3) And I said, what I realized, was that it allowed me to become her daughter again and not her carer"*
>
> (2nd interview, 742-755).

By sharing her own lived experience with the relatives, she hopes to ease their guilt, and to encourage them to re-connect to their loved ones as someone they love rather than just as someone they have to take care of.

8.3.2.4 Connecting the A&E to other Agencies/Departments

After having disclosed with me her initial surprise at finding herself involved with relatives, not only with patients, in the ICCI role, Sarah shares with me that, actually, her role has taken a broader dimension over the years, to the point that now she also liaises with the ambulance staff, with the patients' nursing homes, and with the hospital departments where the patients are discharged after A&E:

> *"I suppose it's developed into a bigger thing, more diverse, you know I just expected it to be with patients, it now includes relatives, it now includes the nursing homes, and even some of the ambulance staff would phone me to say they've got*

> *somebody coming in. So it's a far bigger… (3) relationship, with a bigger group of people 'han I probably ever imagined"*
>
> (1st interview, lines 280-294).

Listening to her account, it seems to me that – again – the role she experiences while handling these multiple relationships is the one of a 'connector', for example, talking about the relationship with nursing homes she says:

> *"And I started to visit a lot of the nursing residential homes, so a lot of their frustration was [related to] information… (2), and so, they've got my number so they'll often phone me now if they have a patient coming in to say he was coming in, etc, etc, which is really great and then I'll tell them what's happened and, whatever…"*
>
> (1st interview, lines 274-280).

Her words suggest that Sarah is mentioning a feeling of frustration from part of the patient's nursing home staff in not knowing what has or will happen to the patient. It also looks like she feels she can and wants to repair the disconnection which causes the frustration by building a sort of bridge of communication between the two systems. This, realistically, not only helps the nursing home, but the A&E too, and, ultimately, can make the difference for a patient's experience. For example, Sarah acknowledges that if the nursing home – or the ambulance team – phones her to inform her that a patient is arriving, this may influence the way she is involved during the very first moments of a new patient's arrival at A&E:

> *"It could be that…ahem… (3) I know that they are coming as the nursing home might have phoned me or the ambulance might have phoned me, and if I can, I'll be there, waiting at the door"*
>
> (3rd interview lines 18-24).

The ICCI practitioner not only builds connections between different agencies and systems upon a patients' arrival but also at patients' discharge. When a patient is discharged to a hospital ward, whenever possible, she goes with them and liaises with the ward's staff:

> *"ahemm… (2) it depends, if you are sent up to a ward. Pre-Covid, obviously, then I would go with them, and I will give them*

> *any little tips that I thought might be helpful ahem… (2) and I would usually, then the next day follow them up"*
>
> (3rd interview, lines 111-118).

She might even be involved when they are discharged back to their nursing homes. For example, she might go in a taxi with them, and, on such occasions, she might need to weave understanding and connections between the patient and other people involved:

> *"S: So, I once got to know a lady I took back to a nursing home in X… (1) ahem, and she wouldn't get out.*
> *I: From the taxi.*
> *S: Yeah. I have no idea why; it took ages just to get her in. And once she was in and we got to the [nursing] home, she wouldn't get out. And the nursing home came out and her favourite caretaker, now she would not get out of the car, but there was absolutely no rhyme or reason why. But the taxi driver was getting cross because he's meter was running… (3) ahem… (2) it took about 20 minutes.*
> *I: How did you convince her?*
> *S: Just kept talking to her and in the end, I sent everybody away, including the taxi driver, because sometimes we have too many people and, ahem, people with a cognitive impairment they just need a one-to-one, but she wasn't happy, but she got out. Eventually, ahahahaha!!! I think she got bored, ahah"*
>
> (3rd interview, lines 184 -206).

In my interpretation, taking on the role of mediator/facilitator of communication between the A&E and other agencies and departments, the ICCI practitioners contributes to building connections among them. From her account, a need seems to emerge for these connections to be there for the patient's benefit, and ultimately, she is determined to meet it.

8.3.3 A Values-Based Practice

There appears to be a sense of mission emerging from various elements of Sarah's account. This mission seems to be based on some pillars which I interpret as core values which she is not willing to compromise on.

Firstly, being personal in her job is not something she wants to give-up for the sake of professionalism, despite the criticism this often attracts towards her.

Sarah believes that not feeling personally involved would negatively impact on the care she would be able to provide to the patients.

Second, older people's dignity and their rights as adult individuals – no matter their cognitive state – are never to be put into question.

Lastly, the person always needs to come before the roles of the system. Roles need to serve the individual, not the other way around, otherwise they are simply *"stupid"* (3rd interview line 153) in Sarah's opinion.

A Values-Based Practice is informed by: The Value of Taking/Making It Personal, Advocating for Patients Needs and Rights, and Challenging the System and Putting the Person before the Roles.

8.3.3.1 The Value of Taking/Making It Personal

Sarah's relationship with the hospital's trust where she works has started as a very personal one. During our interviews, she shared with me that she would have never known about the vacancy if she hadn't been involved with the hospital taking care of her mother (who had been treated several times by the hospital's staff). However, although she is not taking care of her own mother in A&E, but rather that of other people's mothers, fathers, or older relatives and loved ones, she still gets involved very personally, and she feels that this helps her to do her job *"properly"* (3rd interview, line 961):

> *"S: I mean sometimes people tell me off, sometimes, because there's always the odd patient that upsets you, or you get really involved with, and you can't help not, so, when people say you shouldn't get, you shouldn't get so involved, and I say, if I didn't, I couldn't do the job.*
> *I: yeah.*
> *S: I've got to feel it to do it, if you don't feel it and you don't…*
> *(3) you know what I mean?"*
> (2nd interview, lines 828-846).

There is another section where Sarah stresses the two aspects of being so involved with patients: on the one hand, it can get very painful; but on the other hand, there is something much more important for her, which is having the chance to make the difference to someone. This is very well encapsulated by the following section of her account relating to her first experience with a patient at the end of their life in A&E:

> *"S: Um… (2) and [if] you don't feel it, yes, you can do it, but… (3) let's put it into words again: I think you have to remind yourself, which I do often, that you could be the last person to be with this person. And you have to make it as good as you can. And therefore, again you get more involved, as I said before, you get more involved with some patients than you would with others, for whatever reason, or maybe… (3), but, he affected me because I just felt how sad it was that you've got no family no relatives, you know, there wasn't Covid back then, there's nobody with them there was nobody to phone to be with them. And I just found out that, that was for you to feel it.*
> *I: yeah.*
> *S: I can't describe it really. And I agree with them, you know, sometimes you think: 'oh blimey' you know, you got too involved or whatever, but… (3) another thing I always go back to the fact now you wouldn't have done the job properly if you haven't felt it"*
>
> (3rd interview, lines 934-962).

I believe it is possible to find a sense of inevitability emerging from Sarah's words in this extract: *"you <u>have to</u> make it as good as you can"* (lines 939-940), "*that <u>was for you to</u> feel it"* (lines 952-953). There is a sense here of something greater (greater than the price one might have to pay when deeply emotionally involved in A&E), which Sarah needs and wants to put first. This 'something' greater exceeds the words she has to describe it: *"I can't describe it, really"* (line 955).

A sense of gratitude also emerges from her account, which she expresses choosing a word, such as "*honoured"* (1st interview line 34), which again conveys a sense of humble contemplation towards the greater value involved in the human encounters she is enabled to have in her role:

> *"and I feel very honoured to do it, ahem… (1), because I've met some fantastic people, some really lovely people"*
>
> (1st interview, lines 33-36).

Sarah knows that getting so involved with patients can hurt, but it looks like she also knows that what she and the patient gain out of this warm and personal relationship compensates for the pain. Compassion seems key for this to happen, as opening the doors for connection through feeling another human being's pain, she can eventually come to experience joy too. This is how she responds when I ask her of a time when she felt compassion for a patient:

> *"Gosh I feel it a lot! I think probably that lady, the one I gave you an example last time that was locked away [with dementia] and I played the music and she gave me a little smile… (1) ahem… (2) and that was a real heart wrenching for me. There was a real heartbreaker for me, because it just… (2) I think I was cross nobody tried it before, because obviously she could hear it. I was sad that she… (2) ended up like that. It was a bit of a helpless feeling and a joyous feeling really, because I've got a reaction out of it"*
>
> (2nd interview, lines 932-954).

The words she uses*: "heart wrenching"* (lines 940-941) and "*heartbreaker"* (line 942) convey the image of something opening inside her in a traumatic way (wrenching, breaking), but what enters through that broken heart is also joy. Sarah describes the flowing inside her and the co-existence of apparently opposing feelings: *"a helpless feeling and a joyous feeling",* (lines 950-952); this might sound paradoxical, and it might well be so: psychoanalyst Carl Gustav Jung called the paradox one of our most valued spiritual possessions and a great witness to the truth. He wrote: *"*Only the paradox comes anywhere near to comprehending the fullness of life*"* (Jung 1980, p.15).

Sometimes, making it personal might appear simple as calling someone by their name:

> *"I mean, some of it is simple, it's making sure that I call them by the right name because you'd be quite surprised how many will come in, who are called [for example] Margaret Smith, but actually, all their life have been known as Betty.*
> *If you ask Margaret something, she's not going to respond, did she? And that is quite common"*
>
> (2nd interview, lines 1078-1092).

Sarah discovered this by chance and, from that moment on, she always checks with the patient how they want to be called.

She also discovered that by sharing with the patient’s families her own personal experience of caring for her mother, she could connect to them easily and help them more:

> *“My mum had a mild dementia she still knew who I was and all that sort of things, so I was very lucky but, ahem… (1) it does give me… (3) a thing to relate to relatives, especially when the… (1) relative, if you like, they’re coming to the end of their tether of care and it’s… (1) preparing them, which I had to do, to put their parents into care, or their loved one or whatever, which I always said, I would never do. But actually, I found a fabulous place and… (1), I was being able to become her daughter again, rather than a carer, which is… (1), so it gives me a bond with relatives who are struggling with that, ahem… (2) issue”*
>
> (1st interview, lines 53-72).

Sarah can “making/taking it personal” in a variety of ways, and, to her, this seems to be one of the core values of her job, deeply intertwined with the possibility of reaching patients and families at a human level and creating a bond with them, a connection, which is the real working force of her intervention.

8.3.3.2 Advocating for Patients Needs and Rights

I noticed Sarah’s experience of herself as an advocate for patients’ rights in A&E emerging gradually and consistently across our conversations. She talks passionately about her position in defence of those rights, particularly when referring to patients with dementia. For her, there is no excuse *“not to give proper compassionate care”* (1st interview, lines 829-830). This is how she talks about the need to improve the patient flow in A&E:

> *“So that needs to… (2) continue to improve… (1) to get people through quicker, I know we’ve got Covid, and I know we’ve got all this sort of stuff, but you can’t have excuses for care. I don’t care, who you are, where you are, where you work, how much under pressure you are, you cannot have an excuse not to give proper compassionate care”*

(1st interview, lines 820-830).

She appears very sensitive and committed to preserve patients' dignity, no matter their condition or their cognitive state:

> *"I find the ones who sort of lash out physically at you, it's… (2), it's not difficult but… (3) they probably make me the saddest because I think you know if they… (2) were how they used to be, they would be mortified at their behaviour, you know what I mean"*
>
> (1st interview, lines 627-635).

For her, it is important to treat them as adult human beings, no matter what:

> *"How much they understand, sometimes I don't know, but I always feel it's important I treat everybody as though they are you or me. And if they understand a bit of what I say, then that's good"*
>
> (1st interview, lines 602-608).

And she might intervene with doctors and nurses when she feels they are not doing so with people with dementia:

> *"Uhm… (3) We don't know how to deal with it, we don't treat them as grownups, a lot of them will… (3) I Listen to doctors now and listen to nurses talk to them, and they talk to them… (3) one of the things I say to the junior doctors: please remember that not every patient with dementia is deaf, there is no reason to shout… (1), and… (2) because it is, and I stopped myself on occasion, it's a natural reaction if somebody doesn't click you first time to think that they've not heard you, but it's not necessarily… (3) it's not necessarily that"*
>
> (2nd interview, lines 962-985).

She might even have to be confrontational with some patients who lose control of their behaviour, as she wants them in the first place to keep on considering themselves adult human beings:

> *"She used to be a midwife, and she was kicking off big time about a head wound and I suddenly said: 'hang on a minute, you used to be a matron, would you tolerate this behaviour from your patients?' and she suddenly quietened down"*
>
> (1st interview, lines 494-502).

Pain relief is another patients' right Sarah feels she needs to advocate for. During the interviews she mentions a few occasions in which she intervened to make sure patients were free from pain. This is one example:

> *"There was a chap who… (3) and he was in pain, so I lost my rag a bit and got him some pain relief"*
> (3rd interview, lines 225-228).

Another patient's right she got very passionate about is the right to have their end-of-life decisions respected, even if their cognitive state has changed or fluctuates. From her words, I understood there are two reasons for that: one is to respect a patient's dignity as an adult, self-determined human beings, the other is to protect them from pain and discomfort.

She told me about an occasion in which she got angry at a relative she thought was overriding the patient's will by standing against the DNR (Do Not Resuscitate) form his mother had signed:

> *"But the son got heavily involved… (2) and… (2) I wish he'd come in, because I would have killed him… (2) ahem… (3) she was just suffering unnecessarily for me, just, you know, sometimes, however hard it is whether it's your own relatives because I have done it with my mother, you just got to let them go. And you've got to let them go with as much dignity and as pain free as possible. And often these people are kept alive, not for them, but for the relative"*
> (3rd Interview, lines 777-791).

Patients' right to be free from pain and their need for a comfortable place to be, for Sarah, must be respected exactly in the same way for patients at the end of life and/or unconscious, as it emerges from the following extract:

> *"And the fact he was dying and didn't know what was going on, to me was no reason to leave him, or delay getting him up to a comfy bed, do you know what I mean?"*
> (3rd interview, lines 922-927).

Sarah's experience of herself as an advocate for patients' rights and needs, clearly emerges from the findings. She can get very passionate and even angry when those rights and needs are not respected and taken into consideration.

8.3.3.3 Challenging the System and Putting the Person before the Roles

Sarah finds herself in a very structured system (the A&E department) and she generally needs to abide within the roles of the system. However, she does not make a mystery of the very fact that she believes some of those roles are just *"stupid"* (3rd interview, line 153), and in those cases she does not mind challenging them openly: *"I don't mind breaking the rules when they are stupid."* (3rd interview, lines 151-153).

This is how she challenges the role for the staff to have a specific training in order to help a patient using a walking frame (she refers to a specific situation in which a patient who was otherwise ready to be discharged was told to wait, as she needed a walking frame, and there was nobody available at that moment who had received the relevant training):

> *"ahahahah!!! I'm always, I tried to be sensible, but something like that was just playing silly. You know my mother had a walking frame I could manage to adjust that for her quite happily"*
>
> (3rd interview, lines 155-160).

In my interpretation, Sarah becomes defiant when she perceives that a particular role does not benefit the patient, and she feels perfectly fine in breaking it. It is evident here that she moves from a values-based practice whose ethical perspective is deeply humanising; rather than seconding a form of objectivation of the patient – where paradoxically, it is the human being who is working for the role – she tries and put the human being at the centre: it is the role that needs to work for the patient, and if it does not, then, it can be broken.

It is evident that she finds those roles silly, and she even has an ironic outlook on situations when the staff try to enforce them. This for me comes out quite clearly from the way she expresses herself, for example, when she makes a pause after having reported what the staff said, and then bursts into laughter: *" 'no, because you're not trained in doing walking frames'… (1) ahahaha!!!"* (3rd interview, lines 143-145).

The same meaning'emerges from the following extract, where she talks about the need for official translators in A&E:

> *"Normally we have… (3) a nurse from some parts of the country, or some parts of the world, sorry, that we can get to*

> *translate, even though technically, they are not allowed to do that, we have an official translator, I mean, you know, get a life. We're trying to help a patient in an emergency situation, just, speak to her!"*
>
> (3rd interview, lines 609-618).

Sarah does not mind even challenging the hierarchy in A&E if this is a way to put the patient first. For example, she tells me that, at times, she 'told off' doctors for having restrained patients not in the 'proper way':

> *"S: 'restrain is the wrong word… (2), well it's not really. It's not an NHS word anymore, but I would help do it if I felt it was for their benefit. On the other hand, I have kicked off doctors who have not done it well as I think they should… (2), and that's where I… (2) I've got to be very careful because I'm a lay person…*
> *I: yeah…*
> *S**:** …in a very clinical environment, so I've got to be a bit careful, I get past care, you know, if it's to help the patient, that's fine I'll plow in"*
>
> (1st interview, lines 677-692).

From what she said in the above extract, it seems clear that she feels she needs to be careful in challenging the authority of doctors and other clinical staff; however, this awareness does not seem to prevent her from taking action when she feels is needed:

> *"I was trying to get him some pain relief, but, because I was new, I wasn't quite as insistent and confident as I might have been, or as I would be now. I mean I wouldn't take no for an answer now. I would stand there until they'd prescribed it"*
>
> (2nd interview, lines 1497-1507).

The A&E system and its roles are not unchangeable structures which are there not to be challenged. For Sarah, roles must make sense and be flexible, and above all they need to serve the patient and not the other way around. In my interpretation, she is available to take risks by challenging roles and hierarchies, as she feels it is the right thing to do. In the next section, I will look at the findings from both phase A and phase B of the study combined, and, where helpful, I will refer to relevant literature.

8.4 Learning from the two sets of findings (patients and ICCI practitioner) combined

8.4.1 The Unknown

Human beings have a need to be in control. At any level, we strive to know, understand, make sense, and know in advance what will happen in the future (Porges 2011). At a general level, not knowing makes us feel unsafe as it takes over that sense of agency and control that knowing seems to give us (Van Der Kolk 2014). If, in some circumstances, we might even enjoy letting go of control and allowing life to take us by surprise, this is never the case when we feel vulnerable and disorientated. A moment of crisis is a moment in which we want to know as much as possible to be able to react and fight back the perceived threat (Walker 2013). As a result, being with the unknown when in such a vulnerable position can be particularly uncomfortable and anxiety provoking.

The Unknown (and the fear it prompts) is a concept that permeates the findings. In the following sections I will discuss how.

8.4.1.1 Parallel processes

It seems almost as if the journey through The Unknown represents a parallel process in this study: both Sarah and the patient participants, at different times and in different ways, go through The Unknown. For patients, The Unknown is represented by the emergency situation in itself: in most cases, they don’t know what is happening and what will happen to them. When they are in A&E, they are faced with several unknown: how long will it take? What ‘things’ will be done to them? Will they be discharged or admitted? And, if admitted, to which ward? Even if not expressed directly, it makes sense to believe that some of them might be scared of having something very serious, therefore, they might wonder if they are going to die, or if their life and their level of autonomy will change for good.

Some patients feel confused about time or about the identity of professionals who interact with them. Others are scared as they do not understand what a nurse with a foreign accent tries to say (see section 5.3.2.3 – p.144).

In the middle of this sense of uncertainty and displacement, older patients, potentially prone to disorientation either because of a cognitive impairment or because they arrived alone to A&E, appear very disempowered. A few of them inhabited a passive role, and their reaction to a perceived long waiting time is one of helplessness and resignation (see sections 5.3.1.1 – p.136 – and 5.3.1.2 – p.138). The resigned attitude towards long waiting times for some of them appears to me as an example of the overall sense of powerlessness older patients experience when confronted with the unknown dimensions of their A&E admission.

Sarah also is confronted with The Unknown and with the fear it prompts. When she started her role, four years ago, she was terrified. She only had a vague idea of what was expected from her and of the ways she could meet those expectations. When not feeling immediately welcome, she started wondering whether she was being a nuisance to the staff, perceiving them as very suspicious of her as a ‘lay’ person intruding on their clinical environment (see section 8.3.1.1 – p.210).

Interestingly, this also resembles the experience of some of the older participants in A&E, when they state that the staff were always very busy and overworked, and that they didn’t want to waste their time (see section 5.3.1.3 – p.139). Very soon, Sarah resolved to put any plan or agenda to a side and to learn by trial and error because she felt she needed to find her own authentic path. She decided to embrace The Unknown and to navigate it day by day, allowing for ‘real’ encounters with older people and their families to shape the intervention (see section 8.3.1.1 – p.210). This required her to be present, open and responsive in the moment to what presented itself to her attention, being attuned to the individual patient in their specific circumstance, without any inner agenda. It has entailed an act of faith in her own felt sense (see section 8.3.1.2 – p.213), and, at the same time, an attitude to look behind the immediate appearance of things (see section 8.3.1.3 – p.215).

Sarah’s existential position in front of The Unknown in A&E, however, is very different to that of older patients: she has much more power and agency – for obvious reasons – and she feels much safer: this is possibly why she can embrace it.

Even though Sarah’s unknown and that of older patients have different magnitudes and different implications, it looks like Sarah needs to be able to go through her unknown in A&E first, in order to be able to accompany and guide patients through theirs.

First, she needs to find ways to know the patients. She will listen carefully to any cue, she will observe, and she will take in any visual input, she will read the patient’s file in search of information – what is known of their story, and of their everyday life? – she will ask the important questions: i.e., how do they want to be called (see sections 8.3.1.3 – p.215 – and 8.3.3.1 – p.237).

When possible, she will gather information from say, the nursing home and the ambulance staff, to reduce the amount of unknown she must face (see section 8.3.2.4 – p.234). But she is not going to delude herself: she knows and accepts that there will always be a degree of unknown to be with. When facing that residual unknown, she chose to use her gut. She chose to rely on that vibe one feels when meeting another human being as it emerges from “Trusting One’s ‘Felt Sense’” (see section 8.3.1.2 – p.213).

Sometimes, one can assume to know, while one does not really know. When this happens to a healthcare professional assessing and treating older patients’ pain in A&E, it can be detrimental to the patient. Sarah believes that, in general, older people belong to a generation who do not complain and try and stay ‘tough’ (see section 8.3.1.3 – p.215), therefore, when assessing pain, one needs to dig deeper and not to rely on the first answer that is given. In her view, older patients can also be reluctant to share about physical pain because they are scared that they will not be discharged home if they say they are in pain. In any case, Sarah wants to intervene, either prompting staff to ask more questions and/or different questions or asking the questions herself (see section 8.3.1.3 – p.215).

8.4.1.2 Navigating the Unknown with patients

As already mentioned, while Sarah goes through this process with her own unknown she helps older people to reduce the amount of unknown they must face and, when not possible, she helps them navigate it.

She can almost literally ‘unveil’ the unknown by acting on her intuitive understanding of someone who might feel in discomfort because they cannot see what happens around them, like when she moved a patient’s chair at the end of the bed, where she could see what was going on around her (see section 8.3.2.1 – p.223).

This resonates very much with the experience of some participants, who pointed out that it was important for them to be in a place where they could see what was happening, like Pauline (see section 5.3.4.1 – p.149) and James (see section 5.3.1.1 – p.136).

Sarah can wait for patients at the door when they arrive at A&E, and make sure they know they are safe. She can create a homely atmosphere, by offering tea and biscuits (see section 8.3.2.1 – p.223) – where the sense of home is to be understood as a sense of something known and therefore safe in opposition to the unknown represented by the A&E visit – and this seems reflected by some of the participants’ comments, like Robert, for example, who states that he has felt welcome when receiving that attention (see section 5.3.4.3 – p.154).

Patients in A&E are often presented with a number of different members of staff in a short amount of time (see section 5.3.2.3 – p.144). It makes sense to believe that by visiting them regularly along their whole A&E journey, Sarah might come to represent an element of consistency in an unpredictable journey, something known in the unknown: a referring point.

Some patients mention long and/or boring and uncomfortable waiting (see section 5.3.3.1 – p.145). While Sarah is aware that patients’ sense of time may be challenged by waiting without knowing how long they will have to wait, at the same time she states that older patients often think they have been waiting longer than they actually have, and when she re-orientates patients’ sense of time by reminding them what the time is and how long they have actually waited (see section 8.3.2.1 – p.223), she helps illuminate a side of that unknown that seems to make everything worse than it could be.

Patients, more practically, to find their way out of the unknown in A&E, need to be told what is happening and what will happen to them, which is not always the case, as it emerges from some of the participants' accounts (see section 5.3.2.1 – p.141).

Sarah is aware of this issue and put a considerable effort in advocating for patients' rights so that they have explanations for what is happening, which, in her opinion, involves the staff having to slow down (see section 8.3.2.2 – p.227). At times, patients fear they are not able to understand what they are told. This is the case of a patient who points out her struggle in understanding staff with a foreign accent (see section 5.3.2.3 – p.144). Sarah is aware of this issue and even if she must 'tell-off' some patients who had been rude (see section 8.3.2.2 – p.227) adopting discriminatory behaviours towards foreign staff, at the same time she keeps a non-judgemental attitude towards them taking into zconsideration the overall context they find themselves in.

As she points out, however, a foreign accent is not the only way to increase patients' confusion and fear of the unknown: she is committed to educate staff to express themselves in 'lay' terms, rather than using medical jargon to ensure everyone can understand (see section 8.3.2.2 – p.227).

The Unknown becomes deeper and even more difficult to take in – possibly prompting a degree of distrust – when older patients are given unrealistic expectations: this is acknowledged by two patients in the study, Walter and Anne (for both see section 5.3.3.2 – p.147) and reiterated multiple times by Sarah, who often stresses the importance of honesty and to tell patients that they might have a long wait or that they might feel pain (see section 8.3.2.2 – p.227). This is also another area she is very keen to support, through giving the staff advice and recommendations.

8.4.2 Disconnection

A sense of disconnection in human beings prompts a feeling of being unsafe (Cacioppo et al. 2002). This is particularly true when we experience a sense of disconnection from other people, but it is also the case when we feel disconnected from meaning and from our own identity and personal history (Van Der Kolk 2014). The reason for this lies in our very biology, in the way our brains have evolved to survive (Lieberman 2013).

The two polarities of connection/disconnection seem to pervade the findings and to colour the experience of every participant. In the following section I will discuss how.

8.4.2.1 Ways of disconnection

A number of patients have reported feelings of distress when they have felt disconnected from other people. Discomfort arising as a result of being in isolation and not being able to see other people around, like in the case of James (see section 5.3.2.2 – p.143), not only can be related to the very dimension of not knowing what happens – thus feeling less in control – but also to feeling disconnected from others, therefore unsafe. Anne, who could not understand what she was told by a nurse with a foreign accent (see section 5.3.2.3 – p.144), perhaps, not only felt concerned about the practical consequences of that non-understanding, but also cut-out from human connection and shared meaning-making which may have made her feel instinctively unsafe.

When some patients speak of staff being too busy or overworked (see section 5.3.1.3 – p.139), they might also be pointing at the staff unavailability, at a feeling of not being seen or heard, which is also disconnection. Broken, or disturbed connection in an emergency situation can mean feeling unsafe, or maybe just not totally safe. This may also be what James talks about when he reports about his fear of being forgotten (see section 5.3.2.2 – p.143).

8.4.2.2 Ways of connection

In reverse, this is equally true for the section of findings reporting experience of safety for the older patients. After having described his discomfort in being isolated from other patients, James recalled how relaxed he felt when, eventually, the nurse opened the curtains around his bed (see section 5.3.4.2 – p.151).

Michael seems to have been provided with a sense of safety by the attuned presence of the ICCI professional. The words he uses to describe his experience suggest a feeling of being protected by the caring presence of another, by having someone always connected and ready to intervene exactly when we need them (see section 5.3.4.2 – p.151).

In the same way, having the medical procedures explained step-by-step can also feel safe not only because one gains information and knowledge, thus a sense of increased control, but also because, by being talked to, by being given information, one's own presence is acknowledged and an immediate sense of connection ensues, like it was for Pauline (see section 5.3.4.3 – p.154).

When looking at the findings from the interviews with the ICCI professional, it comes out quite clearly that building those connections with the aim of increasing a sense of safety is one of Sarah's core experiences, and that she intentionally strives to build connections. This is evident from her overall account over the four interviews we had. She constantly describes herself in the act of making direct connection with older patients by welcoming them, by using a culturally-shared social ritual – like having a cup of tea – with them, checking on them often, telling a joke, reassuring them, holding hands, but also weaving other connections for them, acting as a metaphorical bridge which connects patients and staff through educating staff on issues of communication with older patients, or by reporting to the staff what she has learnt about the patients, or even by actually helping staff to carry out their tasks. She also sees herself fostering positive connections or re-connections between patients and their family members when needed.

8.4.3 Communication

After having discussed the relevance of the dimension of unknown and of the sense of disconnection to the patients' experience of safety as it emerges by bringing together the two sets of findings, it is inevitable to notice that what seems to make the difference to these patients' experiences in A&E is always related to communication.

By *communication*, I shall refer here to one specific definition of the term, which is the one described by Watzlawick et al. (1967), who point out that all human behaviour is interactional, so that all human behaviour – being it intentional or not – represents a form of communication. They stretch this concept stating that:

> “Behaviour has no opposite. In other words, there is no such thing as non-behaviour, or, to put it even more simply, one cannot not-behave […] it follows that no matter how one may try, one cannot not communicate. Activity or inactivity, words or silence, all have message value: they influence others and these others, in turn, cannot not respond to these communications and are thus themselves communicating”
> (p.29).

Communication happens at every interaction, as a result of any behaviour, being it intentional or unintentional, involving verbal or just physical interaction through any sense. This is because human beings are meaning-making creatures, who attribute significance at any single interaction, and most of the times this happens unconsciously (Watzlawick et al.1967).

It is important to see here every form of human behaviour as interactional, thus, as a form of communication, as in this way, we can appreciate the central role that being ‘intentional’ holds for the ICCI professional in her role. It is also essential to consider communication happening at any moment through any possible sensorial channel, because what emerges from the findings is that Sarah experiences herself as constantly involved in a form of communication using a variety of means and channels.

The main aim of her intentional communication seems to be to reduce the sense of fear and anxiety brought about by the unknown of their A&E stay for older patients, and to increase their sense of safety by providing them with the greatest possible sense of connection to herself and to other human beings.

She does so out of compassion. I shall refer here to the definition of compassion I gave in Chapter 1 :

> *“A feeling of resonance and participation to the suffering of another (emotional component) which immediately translates into an embodied experience (physical/emotional and cognitive component) of wanting to relieve that suffering (intentional component) through action (motivational component) and is accompanied by the belief that it is the right thing to do (value component)”*
> (see section 1.4 – p.8).

Sarah’s experience appears to overlap with the above definition of compassion, as through her feeling of resonance and participation to the suffering of the older patients, she strives to attune to each patient’s needs. Often, she perceives that the central need of a patient is to feel safe, or safer, and she intuitively knows that to feel safer they need connection, and they need support in dealing with the unknown, in a variety of ways, depending on the individual context or situation. Compassion in her case is an embodied experience and an embodied taking of action, definitely accompanied by a set of core values.

8.5 Summary of the chapter

In this chapter, after having discussed the contextual elements which might have informed my fore-structures when I interviewed the ICCI practitioner, I have presented the findings from the analysis of the data gathered from online interviews with her, dividing them into super-ordinate and lower-ordinate themes, as per IPA specific techniques. Eventually, I brought together the findings from phase A (interviews with older people) and phase B (interviews with ICCI practitioner) of the study, which led to the emergence of three key themes: The Unknown, Disconnection and Communication. In the following chapter I am going to discuss the findings from both parts of the study against relevant literature.

Chapter 9 – Discussion and Conclusions

9.1 Discussion

This thesis set out to answer the following two questions:

Phase A:

What is the lived experience of older, possibly disorientated patients who receive an Intentional Compassionate Communication Intervention (ICCI) while in Accident and Emergency department (A&E)?

Phase B:

What is the lived experience of a member of staff of a district hospital who delivers an Intentional Compassionate Communication Intervention (ICCI) to older people in Accident and Emergency department?

Findings from this phenomenological study suggest that the older patients interviewed – like most older patients in the literature – had a difficult time in A&E, facing a sense of unsafety which stemmed out of a feeling of disconnection and uncertainty (The Unknown). However, as opposed to many older patients in the literature, participants in this study also reported the experience of a sense of safety at least at one point when in A&E (when they felt involved in decisions about their care, or when they felt welcomed, or looked after, or reassured). This study also suggests that the ICCI practitioner experiences her role as one of a ‘connector’, who aims to facilitate not only the patients’ journey through The Unknown, but also the patients’ relatives and the staff’s interaction with the older patient and with the larger system. Bringing together the findings from the two phases of the study, Sarah, the ICCI practitioner, appears to be able to make the difference to these patients’ experiences. On the surface, she might come across ‘simply’ as a kind and caring individual, whose scope of practice is to reassure and reorientate older people, but the findings reveal that there is much more going on at a deeper level. What seems to make the ICCI practitioner’s experience essentially different from that of clinical staff explored in the literature, is the different form of knowledge she can draw upon, because of her specific position within the team (although she is in a paid role, Sarah is not charged with any clinical expectations from her organisation and from the patient's family and can therefore fully draw on her intuitive and empathetic understanding, in order to meet each patient's unique set of holistic needs). Additionally, she practises by virtue of being an expert by experience, having been a carer for her own mother with dementia. From this unique position Sarah seems to feel enabled to build metaphorical bridges, connecting, or re-connecting people who at times might experience disconnection due to the high levels of pressure, stress, and the often-chaotic A&E environment. The alternative form of knowledge she can draw upon is at the core of her intervention, which is compassionate – in the sense that it moves from an embodied drive to relieve patients' suffering – and is intentional – the primary intention being to connect on a human-to-human level as opposed to accomplish a strictly clinical task. In the following sections, I will discuss these findings in detail to see where they support, challenge or develop the previous literature. I will be framing the discussion within an understanding of Embodied Relational Understanding (Todres 2008) which I will describe in more detail below, and I will show how Sarah's embodied and relational knowledge leads to more humanising care being delivered to older patients in A&E using the Humanisation of Healthcare Framework (Todres et al. 2009) as a benchmark.

9.1.1 Embodied Relational Understanding

Todres (2008) has described a form of knowledge which is particularly relevant to being human in clinical practice. He called this knowledge: *Embodied Relational Understanding*. Embodied Relational Understanding (ERU) refers to a way of knowing that is holistic and contextual: it pays attention to "the rich and moving flow of individuals' lives in relation to others […] to very specific situations […] and to the inner worlds of what it is like for patients to 'go through something' " (Galvin and Todres, 2011 p. 523).

The <u>embodied</u> element of this complex way of knowing – and relating – can be linked back to what Gendlin (1984) called bodily *felt sense*, an inner feeling perceived in the body before it can be reflectively articulated in our thinking and our language. For example, one may get an anxious feeling in one's stomach before understanding what the anxiety is about: "this pre-reflective knowing is holistic in that it gives immediate and direct information to the self about one's perceived situation, one's relationship to the world and others" (Galvin and Todres 2011, p.525). Such a felt sense may not turn out to be accurate once reflected upon, but, nonetheless, it brings important information about one's subjective experience in the moment. This bodily felt sense is "full of meaning, but its meaning requires reflection before it can be expressed" (Galvin and Todres 2011, p. 525).

The relational quality of this kind of understanding implies that it is never duplicable: it is alive and flowing. This means that the known always meets with the unknown, and the term *relational* indicates a specific challenge: the creation of any knowledge about human beings is always in relation to a concrete circumstance and a specific person, which can never be fully covered by previous knowledge. Every time, at any clinical encounter, there is a need to look afresh at what that unknown unique situation needs. Holding on too tightly to previous knowledge, needing too much certainty, reduces the variety of possibilities that can be created in that moment, "Embodied Relational Understanding brings all these considerations together and indicates an empathic understanding of another's world, drawing on resources of both knowing and openness, and applying these resources relationally in very specific and concrete circumstances" (Galvin and Todres 2011, p.524).

9.1.1.1 The ICCI practitioner's embodied relational stance

This study's findings suggest that Sarah's presence in A&E when delivering the ICCI incarnates the idea of Embodied Relational Understanding (ERU). Sarah's presence and Sarah's knowing emerge from the analysis as fully embodied. This is immediately suggested by the use she makes of intuition. Although she appears almost always aware of the communicative implications of her interactions with older people, their families, and staff, and despite that part of that awareness is very much explicit (she could articulate it clearly to herself and to me using words), another part of it feels much more implicit and closer to the concept of *tacit knowledge* (Polanyi 1967). Tacit knowledge is formed by all those things that we know how to do but perhaps do not know how to explain: it is an embodied knowledge, difficult to communicate by language. It is contrasted with explicit or *propositional knowledge* (Pavese 2021), and it is reflected in Gendlin's concept of *entry into the implicit* (2004). Gendlin's *entry into the implicit* refers to when words, thoughts and representations are formulated and come from an experiential practice, based on attending to the lived body's sense (Galvin and Todres 2013) or *felt sense* (Gendlin 1984).

Not only did Sarah often refer to her felt sense, calling it a 'gut feeling' during our interviews, but I could also perceive Sarah's tacit knowledge every time she struggled to find words but still could somehow convey the depth of her intentions to me. Sarah often answered something along the line of 'you just feel it' or 'it's a vibe' to my questions starting with 'how do you know…?' These are examples of this embodied presence, as well as her experience of compassion as an embodied practice involving touch – through holding hands, or other affectionate physical contact – talk, and music: compassion in her intervention is experienced and conveyed through the senses. Sarah describes embodied knowing (or her gut sense) as a *"very quick together thing"* (3rd interview, line 365, section 8.3.1.2 – p.213), where at least three dimensions are involved at the same time: *"listening, looking and feeling"* (3rd interview, line 378, section 8.3.1.2 – p.213), which reflects the complex and holistic way of knowing through embodied understanding. Elsewhere, Sarah also refers to *"digging a bit deeper"* (1st interview, line 728, section 8.3.1.3 – p.215), trying to gather information through the patients' records, asking questions, and using her cognition to assess the situation, showing that she does not only act on her intuitions but rather that intuition itself can tell her when she needs to dig deeper and reality-check. This suggests that, for her, being connected to her own bodily felt sense while delivering the ICCI does not mean denying rationality or cognition; it is the opposite: it means integrating them in the wholeness of her *being-in-the-world*, intentionally, using the important information that her body brings about her subjective experience as a valid form of knowledge.

Eventually, it looks like it is through remaining fully embodied that Sarah is able to tolerate the unknown of the emergency situation, helping patients go through their own unknown in A&E and, possibly, facilitating family members and staff in relating to them.

As well as being embodied, Sarah's presence and the knowledge she draws upon is also relational – although it is important to remember that these are not two distinct categories: being embodied means to be relational and being relational requires embodiment – her understanding of the patient is, as Galvin and Todres would say: never duplicable, alive and flowing (Galvin and Todres 2011). A statement she made during our first interview is particularly poignant in relation to the above*: "you can't go in, I think, with that attitude, you have to go completely with the flow of what's happening"* (lines 554-556, section 8.3.1 – p.209).

'Flowing' is a distinctive quality of relational forms of understanding and, in the ICCI context, means intentionally deciding to let go of the need for knowing and control and allowing oneself to 'sit' with the unknown of what is presented to us – the *otherness* or *alterity* of the *other* in Derrida's terms (Derrida 1992) – to "trust the process" (Ellis-Hill et al. 2021, p.1040), and be with the flow of what is happening, exactly as Sarah articulates. Sarah's way of relating is never duplicable as it is not affected by a pre-defined agenda or protocol – on the contrary, she can at times become defiant and challenge roles and protocols – and intentionally remains open to be able to listen and to learn from each single patient's encounter. By doing so, she can respond in a particular and sensitive way to what is needed at that specific moment in time, so that the person's need can be feel fully met (Buber 1970). This way of relating is also full of aliveness: by sitting with the unknown long enough, Sarah allows what needs to be communicated to emerge rather than narrowing down her understanding to pre-constitute categories. Not knowing (Todres et al. 2014), as Ellis-Hill et al. (2021) notices, can allow for "kaleidoscopic movement between shared realities" (p.1040) leaving a number of possibilities open for a relational "figure" (p.1040) to emerge. The embodied relational awareness with which Sarah engages, resonates with the definition of compassion I gave in Chapter 1 – section 1.4, p.8 -, as it is an embodied experience, stemming out of a feeling of resonance and participation to someone else's experience. It also appears to resonate with elements of Sayers and de Vries' (2008) concept analysis of *being sensitive* in nursing, which for them entails being intuitive and perceptive, self-aware and aware of others, by listening, observing and being open, in order to respond to patients' needs. By remaining perceptive and responsive, Sarah engages in a dynamic co-creation of meaningful moments – particularly with distressed or confused patients. The moments they create together seem to mirror the description Keady et al. (2022) make of what it means to be “in the moment” (p.681) with patients with dementia:

> “Moments could be constructed as relational happenings where a number of dynamic and inter-related factors, such as biography, practice, time, settings and other people, combine to create and sustain the experience of being in the moment. In such circumstances, ‘other people’ are not simply to be positioned as facilitators or providers of moments for people living with dementia but, instead, as part of the complex processes through which moments are created”
>
> (p.695).

And again:

> “Being in the moment is a relational, embodied and multi-sensory human experience. It is both situational and autobiographical and can exist in a fleeting moment or for longer periods of time. All moments are considered to have personal significance, meaning and worth”
>
> (p.687).

Keady et al.’s (2022) description above of *moments,* in turn, resonates with Derrida’s idea of *event* which implies: “surprise, exposure, the unanticipatable” (2007, p.441) and where the very fact of communicating between two human beings counts as much more than the actual content of communication (Derrida 2007). Derrida was a post-modern philosopher who developed the concept of *deconstruction*, a way of criticising literary and philosophical texts but also political institutions. His idea of the *event* in relation to the encounter with the *Other* (Derrida 2007) implies a total surrender to welcoming the *Other* as they are without any possibility to predict and control neither who the *Other* is nor the outcome of the encounter which, for me, strongly resonates with that openness to the unpredictability of human-to-human encounters in the moment demonstrated by Sarah. Derrida’s philosophy stemmed out of close study of both Husserlian and Heideggerian phenomenology (Peters and Biesta 2009), and was also very much influenced by Levinas’ work. In talking about the *otherness*, the *event* and ethics, Derrida (2007), refers back to Levinas, who, in the 1950s, developed a philosophical thought centred around the ethics of the *Other.*

Levinas believed that sensibilities help human beings transcend their selfish egocentrism to arrive at an ethical self (Kennan 1999) who can fully meet and accept the Other. In turn, the ethical self is formed only by meeting the Other. It is the physical, in-the-moment stumbling upon the face of the other that gives starts to our sense of responsibility towards them, if we allow ourselves to be vulnerable enough:

> "the face opens the primordial discourse whose first word is obligation, which no interiority permits avoiding"
> (Levinas 1991, p.201).

He believed that when one goes through vicarious suffering for the Other, one comes closer to compassion, sympathy and mercy (Levinas 1978): his philosophy is a call to responsibility on the self's sensibilities towards vulnerability (Keenan 1999). I'n Sarah's values-based practice, in her role as advocate for older people's dignity, in striving to consider the *otherness* of the other, I very much sense Levinas' idea of an ethical openness to one's own vulnerability in order to meet the other and go together through their suffering. This kind of encounter in turns reminds me of Grotowski's idea of a *true encounter* (1973; 2002 explored in section 1.2 – p.1), which implies an empathic and compassionate stance, and an embodied acceptance of exposure and discomfort which Sarah intentionally takes and accepts when delivering the ICCI.

Having first described the ways Sarah engages with Embodied Relational Understanding during the delivery of the ICCI, I will now outline how this can lead to different possibilities beyond those usually accessed by clinical staff.

9.1.1.2 A different kind of understanding opens up different possibilities

Findings from this study, in line with most literature, provide evidence that the A&E department is a place of transition: a *liminal space* (Irwing and Wright 2017) where a decision on 'where to go next' should be made. Such a place where timely intervention is crucial, with its hectic pace, appears to amplify all the elements of fragmentation and disconnection which often affect healthcare systems (Stange 2009): information gets lost, expectations go unmet, human bodies might be temporarily objectified to quickly find out and fix what is causing distress. The unknown intrinsic to the liminal quality of the A&E experience, coupled with the need to keep to a quick pace to maintain adequate patients flow seems particularly difficult for clinical staff who want to care but who are practicing in a healthcare system which, as Ellis-Hill et al. (2021) argue, is dominated by the intellect:

> “In understanding and practice, linear thinking has been used to explore how objectified people, places and systems relate to each other. We explore cause (processes) and effect (outcomes), leading to specific approaches to problem-solving and clinical approaches which rely on rational responses. We make the (misleading) assumption that humans are rational, ignoring meanings from our embodied experiences (Galvin and Todres 2013). We severely narrow down the range of possible knowings which can be drawn upon to guide our caring action and we ignore our personal lifetime of human understanding” (p.1041).

It is not surprising that healthcare staff, moving through this technical and mechanistic culture can end up in vicious circles of linear thinking: what Crawford and Brown (2011) have called “fast healthcare” (p.1) and Yougson and Blennerhassett have named the “industrialisation of healthcare” (2016, p.355). This has left no space for “not knowing” (Todres et al. 2014, p.9) and has possibly contributed to silencing nurses’ and other healthcare professionals’ intuitive, embodied and relational voice in their never-ending search for granitic certainties and pre-constituted outcomes.

This ‘status quo’ seems to be rarely challenged by staff in the literature, who, although aware that the care they deliver to older people is often sub-optimal, appear resigned to how things are, in the sense that many of them, while pointing at systemic and organisational issues out of their control as the root cause, do not feel able to do something to change that system (Meyer et al. 1999; Taylor et al. 2015).

This study, together with most literature on the experience of both older people and staff in A&E, reveals the limits and problems of such unchallenged system/setting: not only do older people feel distressed and disconnected, but staff caring for them in A&E feel worried (Seffo et al. 2020), frustrated (Gallagher et al. 2014; Fry et al. 2014; Gallagher et al. 2015) and distressed too (Taylor et al. 2015). In the worst cases, they experience compassion fatigue and moral distress (Kelley et al. 2011; Hunter et al. 2017). Such an overall experience of disconnection also holds the potential to impinge on the effectiveness and timeliness of the very care delivered.

What both older patients and staff seem to need, in the middle of this fragmented and at times potentially helpless journey, is something or someone who could bring a sense of deep connection through a different form of knowledge. There appears to be a need for connection to meaning, identity, connection to a sense of time and space, connection to a sense of safety through stronger bonds within the system and within systems, and it looks as though the ICCI practitioner through her embodied presence and relational awareness can help to foster those connections and help both patients and staff in navigating uncertainties. One paradigmatic example of this is related to time.

As already mentioned, lack of time to deliver holistic care is a widespread feeling for A&E staff, emerging from most literature sources on their experience (Hunter et al. 2017; Seffo et al. 2020; Shagerdi et al. 2022). However, some authors have critiqued nurses' arguments of time limitation, arguing that implementing patient-centred care by having quality conversation with patients does not always require additional time (Meyer at al. 1999; McCabe 2004; Crawford and Brown 2011). Sarah herself notices that lack of time can, on some occasions, perhaps be more a perception rather than a fact, as she is convinced that spending more time providing comfort and listening to the patients from their arrival would allow clinical staff to gather more reliable information and might even save the time of additional investigations.

The overall picture emerging from the findings when matched against the literature on lived experience of A&E is one which includes two different dimensions of time: on one side we have chronological time (measurable time) and on the other side we have subjective time which reminds us of Hursserl's Temporality in the Lifeworld (Husserl 1970, see Chapter 2). Ancient Greeks had two different words to define these two concepts: Chronos and Kairos (Hartog 2021). Chronos time is how we measure our days and our lives quantitatively, with our clocks, and Kairos time is the qualitative time of life, which can be experienced subjectively, and which can feel too long or too short or just right depending on ‘how’ we live it and ‘with whom’ we are. For Walter and Anne, participants in this study, as well as for many older people in A&E in the literature, time felt too long (Lyons and Paterson 2009; Parke et al. 2013; Regen et al. 2022).

Clinical staff in A&E’s attention seems to revolve around Chronos (for example following strictly predetermined timing for tasks) which, because of its quantitative feature is constantly perceived as something which can be lost or wasted at any moment. On the other hand, Sarah’s experience appears mainly centred around Kairos. It is of interest to notice how her way of experiencing time spent in A&E is characterised by a flowing quality and does seem to involve a particular ability to ‘catch’ the opportunities at hand to make the difference – being in the moment and creating moments, as Keady et al. (2022) would say. In the flow of Kairos, Sarah seems to feel enabled to sense when it could be the right moment to persuade a scared patient to receive a test or a treatment, and even to help staff to intervene ‘just’ at the right moment.

Looking at care delivery in a less mechanistic way, the slowing down which Sarah proposes could paradoxically represent a creative solution to save time. This seems to evoke what Galvin and Todres, inspired by Gendlin, argue:

> “The essence of creativity requires the kind of space that only comes with a slowing down, an inbreath, that for a moment releases a relentless hold”
> (Galvin and Todres 2013, p.146).

Eventually the findings suggest that on top of all the obstacles in delivering holistic and humanising care experienced and shared by staff in the literature (staffing level/lack of time, lack of training and specialist skills, etc.), there is also a whole dimension of understanding, a whole set of knowledge (embodied and relational) which is not often accessed because of a narrowed focus on tasks and measurable outcomes, which does not let enough time – and head and heart space – for human-to-human meaningful connection and communication and deprives both older people and staff of a sense of safety, paradoxically also potentially undermining the timeliness and cost-effectiveness of the very clinical/technical interventions needed (Kourkouta and Papathanasiou 2014; Afriyie 2020).

It is evident that practicing Sarah's kind of relational understanding entails stepping into some degree of vulnerability – as mentioned in the previous section – where vulnerability is intended as a form of interpersonal openness with the implicit acceptance of the inability to fully control the outcome (Purdy 2004). Sarah clearly stated multiple times that she cannot plan a day but needs to go with the flow of what is happening, while looking, listening and thinking 'deeper'. When, for example, she talks about how she learned to reach out for older people's hands, accepting to tolerate the initial shock and rejection of some, still keeping her hand there for them to reach back in case they wanted, she is talking about the courage of vulnerability – which again reminds us of Grotowsky's concept of disarming (Grotowski 2002; 1973 see section 1.2, p.1). Most staff in A&E, on the other hand, express the need for certainty and standard knowledge, therefore they need a level of control they feel they do not have (Gallagher et al. 2015; Chary et al. 2021). However, vulnerability, while requiring a certain degree of confidence, at the same time can support in building that confidence, opening up a number of possibilities to humanise patients' care. I will discuss these possibilities with respect to the literature – included the Humanisation of Healthcare Framework – in the following sections.

9.1.2 Humanisation of Healthcare Framework

Human Beings have benefitted from technological advances and increased specialisation in healthcare, which have improved both their health and wellbeing (Todres et al. 2009). However, as already acknowledged, the human dimensions of care can be obscured by a sometimes necessary technological and specialised focus.

Moving from Lifeworld principles (see Chapter 2), the Humanisation of Healthcare Framework has been described in recent years. Through a philosophical phenomenological analysis of the question "what makes people feel more human in situations in which they receive care?" (Galvin and Todres 2013, p.9), Todres et al. (2009) have identified eight dimensions which represent a value base for considering both the potential to humanise and dehumanise caring systems and interactions (see Table 21 below):

Table 21 – Humanisation of Healthcare Framework
(From Todres et al. 2009)

Forms of Humanisation		Forms of Dehumanisation
Insiderness	vs	Objectification
Agency	vs	Passivity
Uniqueness	vs	Homogenisation
Togetherness	vs	Isolation
Sense-making	vs	Loss of Meaning
Personal Journey	vs	Loss of Personal Journey
Sense of Place	vs	Dislocation
Embodiment	vs	Reductionist Body

Each of the dimensions of humanisation/dehumanisation represent a spectrum of possibilities, they are on a continuum with no actual dualism, they are inter-related – meaning that a change in one dimension will unavoidably create change in others – and all point to the same phenomenon: feeling more, or less, human. These polarised concepts can help us orientate and take the right direction towards humanising both clinical practice and research.

I will now discuss the dimensions against those experiences of dehumanisation older people described in their accounts of being in A&E, and those ways of humanisation made possible by the ICCI practitioner's embodied relational presence.

9.1.2.1 The ICCI practitioner as a humanising catalyst – Looking deeper and reaching out as antidotes to Objectification and Isolation

Older people in A&E can experience dehumanisation in different ways and to different extents. One way is Objectification, as opposed to Insiderness. Every time this study's participants were left in a cubicle staring at a blank wall, like James, or when they felt ignored to the point of feeling like a burden to the staff, like Anne, they experienced objectification, and these data add to previous literature which has highlighted how older patients have been objectified. Examples from previous studies include being left shivering with cold without being offered a blanket (Baraff et al. 1992; Kihlgren et al. 2004) or being given a drink which was too hot for them to hold (Spilsbury et al. 1999), no drinks at all (Regen et al. 2022), or lacking physical and auditory privacy (Thadei Mwakilasa et al. 2021). All these experiences may have conveyed to them a sense that their Insiderness, how it felt for them to be in that situation, was not important to the staff. This, as Galvin and Todres (2013) state, would result in the experience of Objectification, which can happen in healthcare every time our individual lived experience is bypassed. As they point out:

> “What makes us human is that we have a sense of living our life from the inside. To be human is to live in a personal world which carries a unique sense for each individual”
> (Galvin and Todres 2013, p.12).

In some of the circumstances mentioned above, on top of Objectification, patients also experienced disconnection and Isolation as opposed to a humanising sense of Togetherness. The sense of isolation can stem out of the experience of being left alone while wondering how long they still needed to wait, like Anne, and could get to the point of making them fear that they were forgotten behind the curtains of the cubicle while waiting for someone to let them know what was happening, like James. These data add to previous research highlighting patients in the literature who felt ignored and unimportant (Parke et al. 2013; Goode et al. 2021). Questioning the very legitimacy of their presence in A&E, they might also have experienced a painful sense of isolation because of feeling cut-off from any meaningful connection to other human beings. Pauline and James in this study clearly stated that they felt safer when they could see what was happening around them, rather than being enclosed behind a cubicle’s curtain and this is also reflected in the literature (Spilsbury et al. 1999; Palonen 2016; Regen et al. 2022). Those experiences of Isolation might imply feeling alienated from a sense of belonging, like strangers between other human beings. As Galvin and Todres point out: “To be human is to be in a community. Our uniqueness exists in relation to others” (2013, p.14).

This is something Sarah is aware of: during our interviews she described having taken direct action to move a distressed patient to a chair where they could see what was going on as she felt that would make them feel less isolated.

When Sarah read the unresponsive older woman with dementia's records to find out more about her, she was actively valuing her Insiderness, how life might feel for her from the "inside out" (Ellis-Hill 2021, personal communication). On discovering that she had been a piano teacher and by playing gentle classical music, Sarah humanised her experience, and the woman, as a response, gave her a smile which Sarah will never forget. In that occasion, the ICCI practitioner moved from a desire to value the Insiderness of the individual rather than 'objectifying' her. She did not just see somebody living with the label of dementia; what she wanted to do was to reach that "person in there" (Galvin and Todres 2013, p.19) that unique human being with their unique background, identity, and memories, and, apparently, she was successful.

9.1.2.2 Using music as an antidote to Loss of Personal Journey and Loss of Meaning

The way Sarah approached the patient with dementia mentioned in the previous section also tackled another dimension of dehumanisation vs humanisation: she valued the patient's Personal Journey, rather than allowing it to get lost. As Galvin and Todres argue:

> "To be human is to be on a journey, we live forward from the past; how we are in any moment needs to be understood in the context of a 'before' and 'a next'"
>
> (2013, p.16).

As human beings we need to be able to locate ourselves on a timeline in relation to our own life-journey, to feel human is to feel we are moving from something familiar (our past) to something new (our future) and that that movement makes sense. When healthcare practices do not pay enough attention to our own history and to the future possibilities that can be available to us, we can experience a sense of Loss of Personal Journey, which also entails a diminished sense of self (Todres et al. 2009). Sarah honoured that woman's personal journey, investigating into her past and through that meaningful piece of music created a connection which possibly allowed the patient to experience a moment of humanising presence even in the depth of dementia. This happened through that non-verbal, implicit and embodied communication that, as Kroier et al. (2021) point out, characterises musical interactions, and that can be so effective with people with dementia. Music has been shown to activate specific neural pathways in areas of the brain linked to emotions and emotional behaviours such as the hypothalamus and prefrontal cortex (Boso et al. 2006), and there are indications that memory for familiar music is usually spared in people with dementia, and that the presence of music may elicit memory recall (Cuddy and Duffin 2005). Being reconnected, even temporarily, to a meaningful reminiscence, can contribute to a sense of identity, meaning and safety which for human beings is invaluable.

9.1.2.3 Role modelling the use of language as an antidote to Loss of Meaning

As sense-making creatures, we are constantly looking for a significant narrative to connect to and, when such meaning is taken away from us, we can experience a feeling of meaninglessness:

> "To be human is to care for the meaning of things, events and experiences. To be human is to be a meaning-maker, bringing things together, finding significance, and making wholes out of parts"
>
> (Galvin and Todres 2013, p.15).

A significant factor that can bring the experience of older patients away from meaning is the use staff makes of medical jargon. In virtue of her own lived experience of being a carer, Sarah feels committed to both teach staff how to communicate in a way which is understandable for older people and to intervene when they cannot. She champions the use of simple, plain language which, in her view, would greatly facilitate interactions. These data support the work of Kelley et al. (2011) and Kihlgren et al. (2005) who also acknowledged the importance of using plain, simple language.

By contributing to teach and role model for staff how to use plain language, slowing down and keep the patient consistently informed, Sarah's intervention shows the potential to help move the experience of patients from the polarity of Loss of Meaning of the framework towards Sense-making.

9.1.2.4 Using sense of humour and facilitating interactions as an antidote to Isolation and Passivity

The use of sense of humour is a further way in which Sarah brings the experience of patients away from Isolation and towards Togetherness. Being unwell in A&E may take away a sense of belonging to their social world and significant others from older people, particularly if they are confused and/or unaccompanied, making them more prone to experience a sense of isolation. Having someone friendly who shares a joke with them might mitigate that sense of isolation, moving the ‘barometer’ towards a sense of comradery and Togetherness. The literature endorses Sarah’s engagement with jokes in this respect, pointing at the potentialities for humour in healthcare settings to facilitate therapeutic relationships by creating special bonds between patients and nurses (Greenberg 2003; Dean and Gregory 2004), and contributing to patients’ comfort (Dean and Major 2008) and to a sense of safety and connection (Branney and Branney 2020).

Illness can take away a sense of control and agency over our life and being in A&E adds another layer to that loss of control: we are in a ‘foreign’ environment with its own rules and culture, which is alien to us. This must be particularly true for older people living with a cognitive impairment. Galvin and Todres state:

> “To be human is to experience oneself as making choices and being generally held accountable for one’s actions”
> (2013, p.12).

A sense of Agency represents both the freedom and the responsibility we – as humans – can have to be and to act. In healthcare, as patients, we can find ourselves in a state of Passivity when an excessive emphasis is put on attitudes and practices that make us powerless in relation to our condition or treatment. Agency is closely related to a sense of dignity (Galvin and Todres 2013). When Agency is taken away from us, we experience our sense of self and dignity as diminished.

The use of sense of humour mentioned above shall be also looked at through the lens of Agency vs Passivity: the aesthetic distance created by humour can possibly represent a supportive mechanism promoting a sense of safety and comfort for patients, and a way of helping patients to regain a sense of control.

This is because humour can offer people the chance to share personal painful events within a frame that reduces distress (Plester 2009) through distancing them from overwhelming feelings, which can feel empowering, therefore moving their experience - at least temporarily – towards Agency.

A number of older patients in the literature want to feel actively involved in the care they receive in A&E (Nerney et al. 2001; Phelps et al. 2022), and sadly, many state that they did not feel they were (Parke et al. 2013; Goodridge et al. 2018; Schouten et al. 2022). Some participants in this study seemed to have occupied a passive position, like Walter, Pauline, Michael and Anne, while others – or even the same patients but at different moments in time – said they have felt involved, like Pauline, Walter and James. Feeling involved included being listened to, being asked questions, and having procedures explained in a way that they could understand. Being involved made them feel safer because other people were seeking to understand their situation better and that led to an experience of human connection and possibly gave them a sense of agency and control (through knowledge). This, in turn, might help in preserving their sense of dignity. Kane and de Vries (2017) refer to Nordenfelt's *four notions of dignity* (2005), when looking at the care received by people in nursing homes, and conclude that the preservation of dignity implies that dignity is a quality inherent to all of us, and independent from external factors – the so-called "dignity of Menschenwurde" (Nordenfelt and Edgar 2005 p.18) but also that the promotion of dignity implies the notion of "dignity of identity" (p.19) or "relational dignity" (p.19) which is that sense of dignity attached to the individual's identity as a human being which can be altered or influenced by other and external events (Kane and de Vries 2017).

Sarah appears inherently aware of both of these dimensions of dignity while she relates to older people from a sense of shared humanity acknowledging dignity of Menschenwurde as well as constantly engaging in promoting relational dignity by facilitating conversation and respectful interactions between staff and patients.

9.1.2.5 A tea break as an antidote to a sense of Dislocation

> "To be human is to come from a particular place; such a habitat is not just a physical environment measured in quantitative terms but a place where the feeling of at-homeness becomes meaningful"
>
> (Galvin and Todres 2013, p.17).

Having a Sense of Place is also related to our sense of belonging and safety and can provide us with that much needed comfort, familiarity and ease. When we experience Dislocation, we feel we are a stranger in the place we are in, thrown in an unfamiliar environment where we don't know the culture and to which we struggle to relate (Todres et al. 2009).

As already acknowledged, older people in A&E are often faced with a sense of "strangeness*"* (Galvin and Todres 2013, p.17), suddenly dislocated from the perceived security of their familiar environment to a stranger and often noisy and/or crowded place, which can foster confusion. It was like this for Robert and Anne in this study, supporting previous data from many patients in the literature (Kelley et al. 2011; Goode et al. 2021; Regen et al. 2022). Looking at this through the lens of the framework it is easy to see how many older patients find themselves 'thrown' in an "unknown culture where norm and routines are aliens to them" (Galvin and Todres 2013, p.17). In this study, however, with the offer of a tea break – which is characteristic of her intervention – Sarah is intentionally bringing a sense of homeness in that alien place. She is introducing a significant social ritual – as Wang (2011) points out, in the UK drinking tea holds a particularly strong cultural significance – which has the potential to suddenly 'hook' back older people into a sense of familiarity, a sense of at homeness and belonging; therefore increasing their sense of safety. Robert openly acknowledged the welcoming atmosphere represented by being greeted at arrival and being offered a cup of tea, linking it to a homely feeling, which suggests that the offering of the tea had the power to give him a meaningful Sense of Place as opposed to a scary sense of Dislocation.

9.1.2.6 Affective touch as an antidote to Isolation and a reductionist view of the body

Sarah defined touch as ‘vital’ and gave a number of examples of how she uses it, including holding hands or moving a patient’s hair back with tenderness, like a mother would do. This is part of the embodied dimension of her compassionate intervention. The kind of touch she described has been described previously as *affective touch* (Levy-Storms 2008) or *comfort touch* (Connor and Howell 2009) and involves an emotional intention of demonstrating affection and a degree of emotional intimacy. This has been defined as part of the therapeutic presence in nursing, helping nurses in maintaining an *“*emotionally supportive environment*”* (Delgado et al. 2017, p. 83). Affective touch has been shown to have the ability to facilitate interaction between a caregiver and an older person – particularly if in the presence of a cognitive impairment – to support older people’s emotional regulation when under stress and to foster positive interpersonal relationships (Connor and Howell 2009; Mononen 2018). Sarah’s use of comfort touch seems to hold the potential to enable patients to move from a place of Isolation to an increased sense of Togetherness and belonging, as well as revealing her approach to the patients’ bodies as humanising. Sometimes, in healthcare, particularly in A&E, it is necessary to look at the human body as separate from its broader context because the focus must be on signs and symptoms. It is exactly the case of restraint practices, mentioned in the literature (Seffo et al. 2020) and by Sarah, which might be considered necessary to prevent immediate physical harm. This, however, represents a reductionist view of the body which can feel dehumanising as it can neglect the implications of *“*being a person in there*”* (Galvin and Todres 2013, p.19).

If looked at through the lens of Embodiment vs Reductionist Body, Sarah’s considerations on touch are extremely significant. When Sarah holds hands or gently strokes a patient’s hair, she is intentionally bringing back the person to a sense of embodiment, showing consideration for the broader context of that human body which is made of relatedness and memories of relatedness (she clearly acknowledges her intention to evoke that primitive sense of safety that patients’ mothers might have conveyed to them when they were children).

Kontos (2004; 2005), writing about older people with dementia argues that body and mind, and body and self, have been constructed as distinct and separate entities in dementia care and that much of the medical literature on older people reflects anxiety about how to manage *"*chaotic bodies in care*"* (Kontos and Martin 2013, p.292). They stress that healthcare professionals are somehow pressured into creating docile *"*dementing bodies*"* (p.292) through rigorous containment of body fluids and wastes, focusing on policing and disciplining those objectified bodies which are looked at as disruptive entities rather than human, reflecting a broader culture which denies the selfhood of the body in people with dementia (Kontos and Martin 2013). Taking all this into consideration, it is possible to see how Sarah's relationship to older people's corporeality helps to shift the focus of care from dysfunction and control to the support of intentional and meaningful ways for the person with dementia to feel connected and to express themselves through the body. When Sarah helps clinical staff assess pain, for example, she knows that there is a richness and significance of behaviour that might go unrecognized if we don't pay attention and by intentionally doing so, she broadens opportunities for delivering better and more humanised care.

9.1.3 The ICCI as a unique role in the landscape of older people-friendly A&E initiatives

As well as the older people-friendly initiatives taking place around the world already outlined in Chapter 1 (section 1.4.2 – p. 11) and Chapter 2 (section 2.6 – p. 49), GEDs (Geriatric Emergency Departments) have multiplied in the United States since I started writing this thesis (Schumacker et al. 2018; Kennedy et al. 2021), as well as a number of new older people-friendly initiatives in A&E both in Australia and USA (Wallis et al. 2018; Chodosh et al. 2021). However, in this evolving landscape pointing towards a humanisation of care for older people in such a challenging setting, the ICCI practitioner role, as far as the PhD researcher knows, still stands as unique.

The position by which Sarah operates is the one of an expert by experience: "Experts by experience have lived illness or caring experiences that form the basis of the expertise and which are utilised through different involvement initiatives" (Jones and Pietila 2020, p.810). As a carer of her older mother with dementia, with no formal training to inform her expertise, Sarah engaged on a very personal level and her knowledge and motivation stemmed from her lived experience. Nilsen et al. (2006) argue that experts by experience in healthcare play an invaluable role in informing practice, health policy and the research agenda. Across all our interviews, Sarah's experience of being a carer for her own mother shone like a bright red thread, bringing together the service she offers to the A&E department with her own sense-making process, which in turn led her to develop a sense of mission and purpose and precise ideas/positions about what dignity and respect for older citizens looks like. Eventually, the shape taken by her role seems not only one of a skilled support worker but also that of an activist for older people's rights. If looked at through the lens of compassion and compassionate practices, this comes as no surprise, given that *"it's only when we know our own darkness well that we can be present with the darkness of others"* (Chodron 2001, p.74).

On another side, due to the very identity of her role (non-clinical), she is free from NHS measurable targets and expectations, and, paradoxically, this seems to allow her to step into some degree of vulnerability and courage thus matching those very values that would be expected of nurses and other healthcare professionals. The knowledge she draws upon is embodied and relational: a kind of knowledge which complement the intellectual and clinical one. It is therefore possible that if clinical staff would be allowed a degree of vulnerability, they would be able to access their own embodied relational understanding. By doing so, they might be able to engage in several forms of communication which could bring about connection and an increased sense of safety in A&E, thus contributing to humanising the care of older people. The presence of an ICCI practitioner in A&E might act as a catalyst for this to happen in a multidimensional way, not only through direct relationship with the patients and their relatives, but also through helping and supporting staff in relating to and caring for the patients, and through role-modelling humanising practices for them.

One might argue that – given the high pressure experienced from staff in A&E – by having an ICCI practitioner with them, clinical staff might almost feel allowed to delegate to the practitioner the human aspect of care while focusing solely on technical tasks and on moving patients through the department quickly. I believe that what we know from both social sciences and psychology – including what we know about the experience of healthcare professionals in A&E – suggests otherwise. Human beings are wired for connection and compassion (Martino et al. 2015; Cacioppo 2022; Cohen 2022) and many healthcare professionals in A&E feel frustrated if not distressed when they feel unable to deliver compassionate care (Gallagher 2014; Taylor 2015; Hunter 2017). What emerges is a picture where professionals feel caught-up in a task-orientated system which makes them lose sight of their own embodied and relational knowing. In this picture, I believe that an ICCI practitioner can carry the potential to foster humanising processes and to prompt compassionate approaches among other members of staff. Witnessing their intervention might help other practitioners remember that compassion is still possible and that, often, it does not require additional time. Moreover, by acting as a connector and facilitator – actually helping out staff – the ICCI practitioner might make nurses and other healthcare professionals feel supported and somehow ‘held’ by their caring presence. As a consequence, staff might possibly come to experience less pressure and have more of an opportunity to reconnect to their own embodied relational understanding, allowing more authentic connection with patients and their carers. This, in turn, could improve their wellbeing, which might entail a cascade of positive effects at both individual and systemic levels (i.e.: preventing burnout and increasing staff retention).

The possible risk, therefore, is not so much that staff could ‘lean’ on the presence of an ICCI practitioner to delegate their own responsibility to deliver compassionate care, but rather that a task-focused, efficiency-oriented (Galvin and Todres 2013; Sharp et al. 2018) healthcare system does not recognise the human needs of staff in A&E leading to clinical staff shortages and their dangerous consequences (Francis 2013; The Health Foundation, Nuffield Trust and the King’s Fund 2019; The King’s Fund and Engage Britain 2022).

A focus on humanisation of care shall be even more important when delivering care under the additional pressure and restriction of a pandemic, as we have learned since 2020. Older people were possibly the most threatened by the COVID-19 virus itself and on top of increased fear of mortality, they had to deal

– in A&E and in the wider hospital environment – with severe restrictions to visits which triggered a sense of isolation and with very confusing interactions - healthcare professionals often wearing invasive personal protective equipment – which have made communication unclear and highly impersonal also impinging on sharing decision-making (Pel-I et al. 2022) and therefore on their sense of agency over their own care. In addition to this, focus should also be on humanising the experience of clinical staff who, with the additional stressors arising from the pandemic, have seen an increase and intensification of burn-out (Chor et al. 2020).

Finally, this study's findings also suggest that older people who received the ICCI in A&E, while sharing most of the negative experiences older patients have reported to have experienced in that setting, also experienced a sense of safety: some felt safe when they felt involved in decisions about their care, or when they felt welcomed, or looked after, or reassured. This happened for some when with the ICCI practitioner, but not necessarily, and this was not always remembered. Eventually, I would argue that it is possible that the presence of an ICCI practitioner in A&E might catalyse a process of humanisation, facilitating interaction, saving time, and role-modelling for other team members those relational possibilities which would contribute to humanise the care they deliver to older people.

9.1.4 Strengths and Limitations

9.1.4.1 Strengths

This study represents a contribution towards a more humanising healthcare delivery for older, potentially disorientated people and their families in A&E.

Using a qualitative, phenomenological approach allowed me to access lived experiences of both older patients and a member of staff, and this is of extreme value if the NHS wants to improve those experiences: as Beames et al. (2021) point out, lived experience perspectives in healthcare must be used alongside quantitative data to help form a judgment about the worthiness of pursuing a future research topic.

Looking at the experience of the ICCI practitioner, this research offers a unique, insider perspective of what it feels like to be in their role and of the values which move their intervention which, to my knowledge, had not been done in a study before.

Including patients living with dementia or other cognitive impairments in the study opened the possibility for people who are too often excluded from research for ethical reasons (see section 4.3.1 – p.103) to have their voice heard. The Global Institute for Research in Humanising Care Contexts has produced a document that notes that the attempt to humanise healthcare requires a dedicated research focus (Morse 2007), and both the UK Government (2015) and Alzheimer's Disease International (2018) have called for a doubling of world-wide research on dementia by 2025: this study is also a response to that.

Discussing the findings against the eight dimensions of the Humanisation of Healthcare Framework has offered the opportunity to appreciate examples of specific ways the experience of older patients could be moved towards humanisation for each dimension.

9.1.4.2 Limitations

The most relevant limitation of this study is the small sample size. This, as already articulated in Chapter 1 Chapter 4 Chapter 6 and Chapter 7 , happened because of the COVID-19 pandemic restrictions during the data collection period, which prevented me from accessing more older people, and online interviews were not seen to be appropriate.

COVID-19 pandemic restrictions also affected the interviews with the ICCI practitioner as, although in her case, using an online platform, communication could still happen at a deep level and offer rich data, nonetheless, as already mentioned in Chapter 4 , online interactions will never offer the same richness of nonverbal cues human beings use to decode and interpret information.

As also already mentioned in Chapter 4 , it would have been ideal to also involve people lacking capacity by gaining proxy consent, however, as a novice researcher, that could be something I do in future research.

Older people interviewed were almost always interviewed at the bedside, with the curtains closed and, although we were not in A&E anymore, and the setting felt quiet, they could be aware of the possibility of being overheard, which might have changed the way they spoke to me.

The importance of co-creation with patients has risen to the awareness of clinical research dramatically since I planned this study in 2017/2018. If I was planning this study now, I would ideally seek advice from representatives of the participants' group (older people, included people with dementia) for designing the study, possibly resourcing them through the Patient and Public Involvement and Engagement in Research (PPIE) team of the Hospital site.

9.2 Implications for practice

Todres et al. (2007) have pointed at the increasing evidence that the human dimension of care can be obscured by a sometimes necessary technological specialised focus. Relentless positivism and extreme reductionism can be damaging (Charon 2006), possibly translating into a *"*refusal to take into account the human dimensions of illness and healing*"* (Charon 2006, p.193). Despite the presence of a number of international and national guidelines and recommendations (American College of Emergency Physicians, The American Geriatrics Society, Emergency Nurses Association, and the Society for Academic Emergency Medicine 2014; Buurman et al. 2021), a profound and widespread lack of confidence of HCPs in delivering compassionate care to older people in A&E emerges from the literature and from this study. However, this study offers a way forward and suggestions for practice which are listed below.

Both healthcare education curricula and NHS organisations ought to find appropriate ways to address this issue and support healthcare practices with older people in A&E:

- Healthcare education should further enhance the integration of embodied and relational ways of learning also focused on *being* rather than only on *doing* (Ellis Hill et al. 2021), allowing students to stay connected or re-connect to their felt sense and their capacity for empathy and compassion while learning and practicing clinical skills. Practicing self-awareness and developing emotional intelligence – the ability to recognise emotions in oneself and in others, to express them and to regulate them and co-regulate them with others (Salovey and Mayer 1990) – being key to this, and the areas of experiential and simulated learning being particularly fertile settings in this respect.

- In view of fostering a more humanised healthcare culture, there is a need to integrate embodied relational knowledge with evidence-based technical competencies (Todres 2008; Ellis Hill 2021) in NHS organisations. Introducing ICCI practitioners for supporting the care of older people could potentially facilitate this process in A&E opening up a number of humanising opportunities, particularly in virtue of their possible role as a catalyst force for empathy and compassion through role-modelling compassionate communication in the department.
  The ICCI practitioner role, in virtue of her function of support to staff, also holds the potential to save the extended time needed to carry on clinical tasks when a patient is unsettled and displays agitated behaviours (therefore possibly cutting care costs), support staff in detecting symptoms of delirium of the hypoactive kind, and in assessing pain, as well as the potential to prevent staff burnout, therefore positively affecting staff retention. Resourcing such roles should prioritise individuals with an ability to appreciate Insiderness (how something feels from the inside, as articulated by Todres et al. 2009) as being an expert by experience for Sarah (having been carer for her own mother with dementia) seemed to contribute to a great extent to the passion and commitment of her intervention, and should aim for this role to be paid rather than volunteer based, as, on top of endorsing its legitimacy (and therefore its potentiality to positively role model and influence culture), it would enhance the building of relationships over time not only with clinical staff, ambulance staff and nursing homes, but also with patients and families, as many older patients are frequent attenders of their local A&E (Greenfield et al. 2020).

On an individual level, healthcare professionals working with older people in A&E can:

- Strive to be relationally intentional in their interaction with older people in A&E: this study confirms the importance of focusing on establishing a warm human connection with patients before any intention to carry out strictly clinical tasks is acted upon (at least every time this is practically possible);
- Carry on their reflexive practice assessing it against the eight dimensions of the Humanisation for Healthcare Framework. The ICCI practitioner role represents an example of the relevance of the framework to the actual experience of older people in A&E.

9.3 Future research

While not every older participant could state what the ICCI meant to them, overall, the account of older patients aligns very much with what Sarah talks about when describing her role. For this very reason:

- further research (ideally through Appreciative Inquiry or Participatory Action Research) into the experience of nurses and healthcare professionals working alongside the ICCI practitioner should be undertaken to shed more light on the phenomena, looking at how they experienced the ICCI practitioner’s presence (with a further focus on understanding if and how the ICCI has influenced the culture of compassion of the A&E team) and also to understand whether nurses and other HCPs in A&E, by sharing the responsibility of care for older people with the ICCI practitioner, can possibly feel reconnected to their own embodied relational knowing, experience being ‘good healthcare professionals’ again, and see their compassion fatigue and moral angst dissipated;
- More research on the experience of older patients who received the ICCI in A&E should be carried on in order to collect rich enough data to get a sense of their experience both in relation to A&E in general and to the ICCI in the specific, as well as interviewing family members of older patients who have received the ICCI to get to an understanding of their own lived experience of the intervention.

- Finally, given the correlation found in the literature between a long and stressful A&E stay and emergence of delirium symptoms in older patients (Cunningham and MacLullich 2013; Bo et al. 2016, see Chapter 1), it would be of value to investigate whether rates of delirium decrease in patients who receive the ICCI.

9.4 Conclusion

In conclusion: older patients, particularly those presenting with dementia or other cognitive impairments, represent one of the most vulnerable patient groups presenting to A&E with very complex issues. For this reason, looking at their difficult experiences feels almost like looking at the challenges of our emergency healthcare service through a magnifying glass. It is imperative to humanise their experience, but this is not possible if we do not humanise the experience of nurses and other healthcare professionals working with them first. While I am writing, the Royal College of Nursing called an action for strike for the first time in 106 years. Thousands of nurses are protesting along the streets, asking not only for better pay and better working conditions for themselves but also to be put in the condition to preserve patients' safety and being able to deliver good enough care. This study shows how patients' physical and emotional safety are not necessarily separable from the experience of staff. The NHS asks their clinical staff to put patients first and to always be compassionate, though compassion fatigue is widespread among healthcare professionals. Staff – especially in high pressure settings like A&E – needs better systemic support if they are to reconnect with their embodied and relational awareness in order to deliver compassionate care to their most vulnerable patients thus humanising their experience.

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Appendix 1 - Clinical study documentation journey table

Table 22 - Clinical Study Documentation Journey Table

Protocol Version	Version Date	Rationale
Protocol 1	6th Dec. 2018	Initial Protocol submitted to IRAS to run the study
Protocol 2	11th Feb. 2019	Protocol eventually approved by HRA after the REC had requested a rewording to a paragraph of Protocol 1
Protocol 3	19th Jun. 2019	After changes in the supervisory team the study aims were refined, and sample size were also modified accordingly through official amendment submission to IRAS
Protocol 4	20th Jan. 2020	Minor changes to wording requested an official minor amendment submission to IRAS
Protocol 5	28th Apr. 2020	Official amendment to the study end-date submitted as a response to the halt to research studies imposed by Covid19 pandemic
Protocol 6	25th Sep. 2020	Official amendments to study procedures submitted, to include health and safety measures related to Covid19 pandemic in the hope to be able to resume interviews with older patients
Protocol 7	15th Dec. 2020	Official amendments to the protocol submitted to include a further objective - phase B of the study- in order to investigate the ICCI phenomena from the point of view of the ICCI practitioner

Appendix 2 - Literature review table phase A

Author/s Year Country	**Aim/s**	**Approach**	**Participants where and when**	**Findings**	**Overall strengths**	**Overall limitations**
Baraff et al. 1992, USA	To determine the older patients' perceptions of emergency care and to identify specific problems and solutions	Qualitative, Using Focus Groups as a method.	Five groups of older patients (over 65 years old) ranging between five and 13 participants each + two carers.	Participants overall satisfied with their medical care. Complaints: long waits, feeling frightened, anxious, uncomfortable, and confused.	Aim clearly stated; method appropriate to answer the research question; results outlined clearly; fairly large number of participants; multiple sites in different geographic locations.	The specific methodology used is not articulated clearly; Focus groups were run up to one year after participants' experience of A&E, so clear recall of experiences might be affected; participants were all "non-smoking, ambulatory, and articulated"; Healthcare system in United States present many differences to UK.
Hedges et al. 1992, U.S.A	To assess the perceived emergency needs of the older patient and potential problems that may interfere with optimal emergency care.	Quantitative approach using a telephone administered survey.	A systematic sample, stratified by age, of 100 patients for each site. For each site, the 70 % was 65 years and over and the 30% was 21 to 64 years old.	Most common problem in all age groups: waiting time. Differences across the groups for other reported problems: staff being too busy, expenses of the visit, pain and confusion. Both groups were generally satisfied with the care provided.	Large and varied sample size; comparison with a different age group:	Telephone interviews may affect the process because communication flows less smoothly; Data have limited generalisability as the USA healthcare system is very different from the UK one; It does not state how long after the A&E experience they have been interviewed.
Majerovitz et al. 1997, U.S.A.	To determine how well older patients and their caregivers understand	Quantitative (Exploratory study, using interviews)	71 older patients aged between 60 and 91 years old and	Older patients wanted to be active participants in their	Aims clearly stated; results outlined clearly;	Patients were interviewed at bedside, thus it is possible that

	medical information they receive in A&E; how satisfied they both are with the information they receive; what information they both want in Accident and Emergency department; how older patients and their caregivers differ in the information they want, and in their understanding and satisfaction with the information received.		32 of their caregivers in one emergency department.	medical care; however, majority of them displayed limited understanding of their condition and treatment. Patients reluctant to voice specific complaints regarding the amount of information they had received. They ended to report that they understood what was happening to them even when understanding was not complete.	two researchers ran the interviews.	their responses –given that they were still receiving treatment- were influenced by the presence of other patients and staff during the interviews; The timing of the interviews also may have affected the generalisability of the data; Patients were only interviewed after they had been waiting in the emergency department for at least three hours. This probably contributed to the high percentage of patients in this sample that were admitted to the hospital. Thus, less seriously ill patients may have been excluded from the sample. Data were collected in only one emergency department, in a predominantly white, middle-class suburban area: different communication issues may arise in other settings; By excluding non-English speakers and patients

						with dementia, the more serious communication problems that these patients might experience were missed.
Spilsbury et al. 1999, UK	To explore older patients' and their carers' experiences of A&E care in a large UK NHS Trust.	Qualitative approach in form of case studies (part of a larger Action Research study) using observation, informal interviews and follow-up-interviews as methods.	12 older patients aged 75 years and older and their carers.	Patients arrived in A&E with low expectations of care and appeared to understand many of the constraints which staff were working under, nonetheless, they were able to identify small improvements in care which would make considerable difference to their experience.	There are interviews at two different points in time + observation, all of which might increase the credibility of the findings; -It is part of a larger action research study Bridges and Meyer 1998) so findings can be contextualised	Methodology is not clearly stated. It let us assume it might be Phenomenology, but it does not state it.
Watson et al. 1999, U.S.A	To describe older patients' perceptions of care in the emergency department.	Qualitative Descriptive design using Interviews as method	12 older patients between 66 and 86 years old from three A&Es in the west of United States, interviewed at home 72 hours after discharge.	Patients needed to feel well informed, waiting time was a critical factor and was always noticed. Professional competence and courtesy was important; Participants commented specifically on the discomfort of beds and carts;	Aim clearly stated; Methodology appropriate to answer the research question; Results outlined clearly; Interviews were carried out within 72 hours of the A&E experience; Patients came from three different	All patients interviewed had been discharged within two hours of their A&E arrival and were interviewed at home. This must have affected their perceptions of the A&E experience and of the interview itself. The specific methodology is not articulated clearly. This study examined a small population of older adults from the western

				They showed a high degree of personal tolerance.	Emergency Departments.	United States: a sample with different demographics or from a different geographical area might offer different perceptions and results.
Nerney et al. 2001, U.S.A.	to assess older patients' satisfaction with care in the emergency department and to identify factors associated with global satisfaction with care.	Quantitative (prospective cohort study using questionnaires).	778 older patients aged 65 years old and over, Mainly African American who have been in an inner-city emergency department. Questionnaires administered in the ward or at home after discharge.	Patients felt more satisfied when time spent in the A&E felt as not "too long," when the emergency physicians and nurses clearly answered their questions, when they felt they could trust an A&E staff member, when they felt kept informed and involved in decisions about their care, when their pain was addressed fully.	Aims clearly stated; Results outlined clearly; Very large sample size; Methodology and methods consistent with the aims.	The study was limited to one urban academic A&E with a predominantly black population; Not all variables that might affect satisfaction rates were studied; USA has different – private- healthcare may not be relevant to public NHS; Many patients refused the Initial A&E survey, were too ill to participate, or were busy with physicians and missed by research assistants in the A&E. These eligible non-participants may have contributed to a selection bias, with an unknown effect.
Nyden et al. 2003, Sweden	To analyse older people's basic needs in the emergency care environment	Qualitative (Life-world interpretative approach using interviews as a method)	Seven older patients between 65 and 88 years old	Older patients' basic needs at the lower levels of Maslow's hierarchy were well represented in the data. Higher needs, such as desire to know	Aims clearly stated; Results outlined clearly; Methodology appropriate to	Maslow's humanistic psychology represents a fairly outdated theoretical framework; The recruitment process is not completely clear;

				and understand, appeared to be totally neglected. Safety needs dominated the whole situation.	answer the research question;	The sample include only patients who had been patients at this A&E on several occasions, but none was a regular attendee, and they had not made any formal complaints.
Kihlgren et al. 2004, Sweden	To describe the conditions at the emergency department (ED) and the events that took place during the waiting period.	Qualitative (Grounded Theory) using non-participant observation and interviews.	18 older patients aged 75 years and older (or in cases where the older patient was not capable of answering the interview questions, from the relatives who accompanied them to the A&E). They were observed along all their journey in A&E and then interviewed.	Six core-variables emerged: unpleasant waiting, unnecessary waiting, lack of good routines during the waiting stage, suffering during the waiting stage, bad feelings during the waiting stage and nursing care during the waiting stage.	Aim clearly stated; Results outlined clearly; Four different researches ran the observations independently; The four observers in the pilot study discussed which categories and core-variables were seen; The two observers that continued, had discussions with each other throughout the whole collection of data and the analysis process.	In the results section the difference between "Suffering during the waiting stage" and "bad feelings during the waiting stage" is not clear; The study does not explore the experience of older people aged 75 years and below; In the findings, it is not always clear when something is an impression of the observer or it is also validated by the interview with the participant; The observer's presence in the actual situation might have Influenced it.
Guttman et al. 2004, U.S.A.	To evaluate the impact of an emergency department-based nurse discharge plan coordinator (NDPC) on unscheduled return visits	Quantitative. Intervention study which compared two groups (intervention and control groups) through interviews at	The sample consisted of 905 patients in the control phase and 819 patients in the intervention phase.	Patients in the intervention group were significantly more satisfied with the information received than the control group	Aim clearly stated; Method appropriate to answer the research question;	Healthcare system in United States present many differences to UK.

	within 14 days of discharge.	different point in time after A&E discharge, and demographic data	All 75 years and over interviewed in A&E at day one, day eight and day 14 after the A&E visit.	(standard care). They had less unscheduled return visit to the A&E, reported a higher perception of wellbeing after discharge and reported more adherence to medication.	Results outlined clearly; Fairly large number of participants;	
McLeod and Olson, 2006, Sweden and UK	A comparative account of older frequent emergency department attenders' evaluation of A&E social work in Sweden and the UK.	Qualitative, using semi structured interviews	Two small groups of older patients (over 65 years old) -one in UK -10 people-and one in Sweden- five people- all were frequent attenders of A&E who had recently been in receipt of social work care in A&E. Interviewed at home after two- three weeks from the experience. Only one hospital x Country was involved	The practical and psychological benefits of the A&E social workers' role in communicating important information, which had otherwise been neglected was evidenced. -both in the UK and Swedish settings- A&E social work acted as a key contact point for social services	Results outlined clearly; Comparative element; Long interviews.	The specific methodology used is not articulated clearly; Interviews took place up to 3 weeks after discharge; There is almost no ethnic difference in the sample.

Richardson et al. 2007, New Zealand	To examine the experience of the older patient (aged 80 years or over) admitted to an inpatient bed via the A&E of a major tertiary level teaching hospital.	Mixed Methods – face-to-face interviews and follow-up telephone interviews after discharge + Descriptive statistics-	13 older patients aged between 80 and 102 years old (for the qualitative part).	Patients reluctant to criticise any of the hospital processes and in general expressed satisfaction with their time spent in-hospital. Descriptive statistics around admission timing and procedures were obtained, together with workload and acuity indicators. Potential barriers to seamless care were identified.	Aim clearly stated; Results outlined clearly; Large sample group.	During the data collection there was an unanticipated increase in service workload which impacted on data capture. The study was limited to patients who were admitted to medical wards, which restricted the potential population, and also served as a source of confusion for staff carrying out the data collection; Data collection was further compromised by not having dedicated data collectors employed specifically for this purpose; The 'follow-up' telephone interviews occurred two weeks after discharge. Participants might have found it difficult to recollect perceptions; Authors state that participants found it more difficult to communicate this way and were less likely to expand on answers; The study leave uncovered the experience of older

						people aged 80 years and below; The methodology used in the qualitative part is not articulated clearly.
Way et al. 2008, UK	To describe the experience of older people receiving Emergency Care	Qualitative (Discovery Interviews)	69 older patients over 75 years old and 27 of their caregivers	Some older people were reluctant to call ambulances or attend A&Es. Many of them thought that their significance was less than that of other patients. Felt passive. Fear and anxiety about treatment. Staff's interpersonal skills exerted a strong influence on these emotions. They valued the roles of their caregivers, for their company and support. They displayed different levels of knowledge about their conditions. Expressed frustration at being asked the same	Aim clearly stated; Results outlined clearly; The sample group was large and recruited at multiple sites; Methodology appropriate to answer the research question.	The study leave uncovered the view of older patients aged under 75 years old; The specific methodology is not articulated clearly.

				questions several times by different staff.		
Bridges and Nugus, 2009, UK	In this paper the authors report the role that a sense of significance plays in the experiences of older patients in urgent care settings and explore the factors that influence those experiences.	Qualitative, Using Discovery Interviews.	69 older people (75+) and 27 of their relatives interviewed across 31 NHS trusts in England; 68.75 % of participants came from A&E. The rest of them had accessed other urgent care settings like urgent care centre (5,5%) and walk-in centre (5,5%). Other accounts (8,9%) covered out-of-hours GP visits, a GP admission to an in-patient unit and an ambulance journey; The mean time of interview lengths was 12 minutes.	Older patients experienced a diminished sense of their individual significance. Some questioned the legitimacy of their presence in the urgent care setting and believed that they mattered little in relation to other patients and the other tasks which health professionals were undertaking.	Aim clearly stated; Method appropriate to answer the research question; Results outlined clearly; Large sample, across many sites, thus much reliable.	The specific methodology used is not articulated clearly; Interviews were run at different stages of the patient care journey, so not all recall was fresh; Participants were all over 75; Not everyone was from A&E; It is not acknowledged where patients were interviewed; People with cognitive impairment were excluded; Some patients and relatives may have felt constrained by the relationship of the interviewer to the service in question, and by the desire to not get staff into trouble; Most patients included in the study were White British, aged 75–79, living in their own home; The study specified the exclusion of individuals who were seriously ill or unable to cope psychologically or who

						were confused, thus findings may be limited to older patients who share specific characteristics.
Lyons and Paterson, 2009, UK	To explore the aspects of emergency care that are important to the older patients who received treatment at the Royal Infirmary of Edinburgh and to establish whether their specific needs were met.	Qualitative (Grounded Theory) Using in-depth semi-structured interviews	20 older patients between 66 and 90 years old from one emergency department, interviewed in their in-patient bed (it does not say how long after the experience)	Patients had two distinct sets of needs: for information, clarification and physical care for their health-related problems, and for empathy reassurance, concern and understanding.	Aim clearly stated; Methodology appropriate to answer the research question; Results outlined clearly; -The primary researcher was not a nurse or medical practitioner and so has had little experience of emergency care environments. She therefore had few preconceived ideas about older people's experiences in such environments.	It is possible that the responses of participants, many of whom were still receiving treatment, were influenced by the presence of other patients and staff during the interviews.
Kelley et Al. 2011, Canada	To understand how the physical environment, the social climate, the hospital policies and procedures, and the healthcare system promote or impede the capacity of the hospital	Qualitative. Focused Ethnography using semi-structured interviews and observation.	Patients aged 75 and over, relatives, staff. Participants were interviewed at the A&E site. Some older people also had a follow-up telephone interview at home. A&E observation was	The physical space of the A&E was problematic. Participants noted overcrowding, noise and limited space. Orientation and wayfinding cues represented	Aims clearly stated; Results outlined clearly; Methodology appropriate to answer the research question;	On-site interviews generally lacked privacy, which may have influenced interviewees comments; The final number of participants is not stated (and how many of them

	to provide ‘senior-friendly’ care in the A&E.		carried out at different times of the day during the week to cover all possible timeslots.	challenges. Older people specifically spoke about being cold, hungry, thirsty and about noise, lack of privacy and interrupted sleep; Described the A&E as ‘busy’ and ‘chaotic’. Reported coming to the A&E because they believed their needs would be met quickly. They were fearful and seeking reassurance. Their expectations were inconsistently met. Need for enhanced communication. Participants viewed the A&E as ‘under-staffed’ and staff as ‘overworked’.	Observations and interviews carried out at different times and days of the week to cover all possible time slots; Triangulation through the use of different methods and deepening of the point of view of older people through the use of follow-up telephone interviews; Analysis of data carried out by multiple researchers and compared.	were patients, relatives, or staff); Not everyone identified as a potential participant was interviewed; Some individuals declined participation; Seniors’ proxies were approached for an interview if the senior was deemed incapable, however, it cannot be assumed that proxies accurately represented patient experience; The study was carries on at a single A&E
Considine et al. 2010, Australia	To describe older people’s perspectives of accessing A&E care with a focus on older peoples’ experience of the circumstances leading up to A&E attendance, transport to the A&E and the triage process	Qualitative. Descriptive approach using interviews.	30 older patients over 65 years old from three different A&E’s and some of their caregivers.	Some participants expressed frustration for having to wait for prolonged periods of time. Others described relatively short waiting times and a smooth transition through the triage process. Views on access to emergency care: some described feelings of	Results outlined clearly; Large and varied sample size; Each participant was recruited as close as possible to their presentation to A&E; Strong reliability: different	Focuses specifically on older peoples’ experience of the circumstances leading up to A&E attendance, transport to the A&E and the triage process, without covering the rest of the A&E stay experience; The specific methodology is not articulated clearly.

				equity, others attributed factors such as arriving by ambulance, personal characteristics or behaviours, socio-economic status and age as influencing waiting times and access to care.	researchers collected and analysed the data and then agreed on analysis theme.	
Olofsson et al. 2012, Sweden	To explore and describe the experiences of a group of chronically ill older patients during their triage encounter and subsequent A&E stay.	Qualitative (Giorgi's descriptive phenomenology using a Life-World approach. Open-ended—semi structured-Interviews as a method).	14 older patients with a chronic illness between 71 and 90 years old in their clinical setting. Interviews lasted between 30 and 60 minutes.	The visit to the A&E was experienced as contradictory. Initially, the triage encounter fostered confidence and set promising expectations, but during the rest of the visit, the patient felt abandoned and considered the staff uncommitted and reluctant. Inattentive attitude and indifferent behaviour caused a feeling of exclusion, lack of interest in the patient contributed to a feeling of being neglected and ignored, and failure to listen contributed to frustration and disappointment.	Aim clearly stated; Methodology appropriate to answer the research question; Results outlined clearly.	The study was limited to a single site; Patients presenting to A&E with chronic illnesses are normally lower in triage and need to wait more. This must have affected participants experience in a specific way; Results are also limited to Swedish speaking, older than 70 years of age diagnosed with at least three different clinical conditions, wo had visited the A&E three times or more during the past 12 months, and were prioritised as yellow (60 min) or green (120 min); No mention of at what point in time they were interviewed after the A&E stay.

Parke et al. 2013, Canada	To identify factors that facilitate or impede safe transitional care for community dwelling older adults with dementia in two Canadian emergency departments, and to identify practice solutions for nurses.	Qualitative interpretive, descriptive exploratory design with three iterative, interrelated phases and photo elicitation focus groups. The methodological approach is informed by a social ecological perspective. Interviews, Photographic Narrative Journal and photographic focus groups were the methods used.	10 dyads of older patients (60 years+) and caregivers, four Registered Nurses, and four Nurses Practitioner, from two Canadian A&Es. Participants were interviewed in the community within six months of the A&E experience.	Four interconnected themes emerged: being under-triaged; waiting and worrying about what was wrong; time pressure with lack of attention to basic needs; and relationships and interactions leading to feeling ignored, forgotten and unimportant. Together these issues stem from a triage system that does not recognize atypical presentation of disease and illness. This potentiated a cascade of vulnerability in older people with dementia and their caregivers.	Aims clearly stated; Results outlined clearly; Triangulation using different methods, thus higher reliability; Methodology and methods consistent with the aims; Strong discussion re: the implications of the findings for practice and policies needing to change.	Caregivers in the study described their experiences emphasizing problems rather than positive encounters: it may be that older adult-caregiver dyads who encountered problems were more likely to volunteer for the study; Only English-speaking patients; Only patients with dementia; Only interviewed together with their caregivers; Interviewed up till 6 months after the A&E experience.
Stein Parbury et al. 2015, Australia	- To explore the expectations and experiences of older people and their carers leading up to and following presentation to the A&E; -To discover and disseminate information that will improve the patient/ carer experience	Qualitative. Interpretive design using semi-structured interviews.	10 older patients between 65 and 94 years old (with a chronic condition) and their caregivers, one month after the A&E experience, in their homes. Interviews lasted between 23 and 58 minutes. Participants were interviewed	Participants felt uninformed about A&E procedures; therefore, families/carers felt the need to advocate for information and basic services. Participants were grateful for the care received and mindful of the busy environment. To meet	Aims clearly stated; Three researchers independently assessed themes emerging from the analysis; Strong ethics considerations such as interviewing older people one	The study was limited to a single site; Study interviews occurred a month following the ED presentation which may have resulted in a decreased ability to recall perceptions; The specific methodology is not articulated clearly;

	through enhanced practice delivery.		twice: once with the caregiver and once on their own.	the expectations of older people, nurses need to provide timely information and advice carers how they can assist.	months after to allow full recovery, and participants interviewed both with their caregiver and alone to allow them freedom of expression.	Only patients accompanied to ED by a caregiver were included; People with impaired cognition were not included.
Goncalvezet al. 2015, Brazil	To assess practices of embracement (triage) at the patient intake area of the emergency department of Porto Alegre Clinical Hospital from the perspective of older adults.	Qualitative. Using semi-structured interviews.	30 older patients over 60 who had been through the A&E and who had been initially triaged between intermediate and high risk (no low risk), interviewed in the hospital ward or at home. Interviews lasted on average 28 minutes	The elderly classified as intermediate risk said that they waited for about three hours to be seen by a doctor but understood that the waiting time was related to the severity of the health problem. They expressed both resignation to long wait and trust in the service. They highlighted that during their long wait they should have their basic needs attended to, such as being fed, pain relieved and have the right to a companion. In terms of waiting time, communication and satisfaction with the service, results varied.	Interviews were helped by visual prompts, such as pictures; Data were analysed independently by two researchers and then themes compared.	The paper does not address issues of mental capacity and dementia; Methodology is not clearly explained; It is not clear at what point in time patients were interviewed.

Liu et al. 2016, Australia	To determine the non-medical needs of older patients in the emergency department.	Quantitative Cross-sectional study using a self administered questionnaire	548 patients between 50 and 80+ without dementia or other communication difficulties, Monday to Friday between 8 and 17 in one A&E. They were given assistance in filling the survey if needed.	The older the patient, the less likely they were to know how to call for assistance, to know how the A&E works and to be concerned about the A&E lights. The 65–79 age group had higher proportions who agreed/strongly agreed that their illness and treatment had been clearly explained to them. Older patients were significantly less likely to be frightened by their illness. There were trends towards older patients feeling less scared and feeling less ignored.	Aim clearly stated; Results outlined clearly; Fairly large number of participants.	Selection bias may have been introduced by convenience sampling mainly during office hours, as it has been reported that staff attentiveness is less during night shift; The study entry criteria may have excluded subsets of patients who, by nature of their illness or condition, may have responded differently: for example, patients with cognitive impairment and delirium are common in the A&E and may perceive their A&E care differently; The study questionnaire was designed for self - administration and this may have been difficult, especially for the older patients. Although assistance was available, this may have introduced a Hawthorne effect by precluding anonymity for some patients. The study was undertaken in a single A&E.

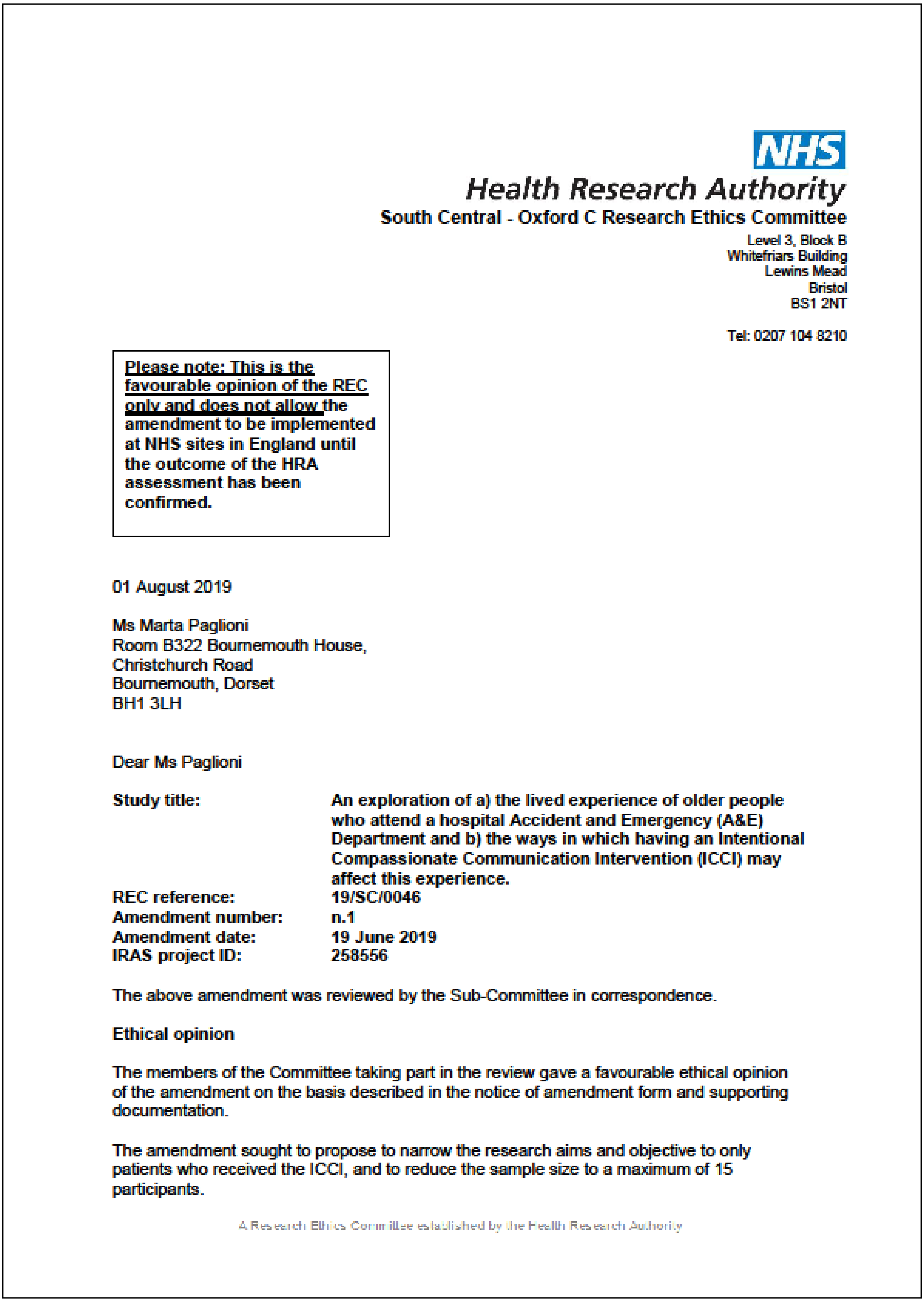
Palonen et al. 2016, Finland	To describe the experiences of older A&E service users and nurses regarding family involvement in older people's discharge education.	Qualitative descriptive using thematic interviews as a method.	Seven older people between 76 and 84 years old, five family members and 15 nurses. The mean length of the interviews was 30 minutes, interviews took place approximately two weeks after A&E discharge. In the participants' home.	A&E service users (older people and their families) felt ostracised with regard to the families' involvement. Older patients' need for family involvement was not considered, and family members were not contacted to receive discharge education. They felt that families were cut out from the whole discharge process. A&E service users felt that family members did not receive the same information as the older patients did. The ostracism made A&E service users angry and appalled.	-Results were outlined clearly.	The specific methodology used is not articulated clearly; Despite the inclusion of patients, nurses and family members, the point of view of nurses is much more prevalent in the results chapter; Finland emergency care system is very different from the NHS: for example, for acute illness during office hours, people do not go to the A&E but to local health centres, thus most acute illnesses in A&E are treated during out of office hours. The paper however, does not specify at what time the interviewed patients had been admitted to A&E; The paper does not acknowledge whether any patient with dementia or cognitive impairment was excluded; Patients and caregivers findings are blended together and reported at one as "service users"; Participants were interviewed indistinctively

						as a peer of patient-caregiver or individually; The results can only be applied in the context of older A&E patients; Data were collected from only one A&E.
Hunold et al. 2016, U.S.A.	Describe and rank priorities of care among older adults receiving care in the A&E.	Quantitative. Cross-sectional study using a single open-ended question.	185 patients aged 65 years and older. Participants were recruited from two U.S. A&Es. Consecutive patients aged 65 years and older presenting to the A&E between 9 A.M. and 9 P.M. seven days a week. Interviewed during the A&E visit.	Of the 185 participants, 114 identified at least one of the reported priorities within the “evaluation, treatment, and outcomes” metacategory; 67 (prioritized the “timely care” metacategory; and 38 prioritized the “service” metacategory. Other metacategories included “physical environment” “communication” and “disposition” 19 patients prioritized being discharged home; only one patient identified hospital admission as a top priority. Few patients identified the cost of care as a priority.	Aim clearly stated; Fairly large number of participants; Two A&E sites.	Healthcare system in United States presents many differences to UK; Patients were interviewed only during their A&E visit without restricting when during the visit the interview occurred: priorities almost certainly evolve over the course of the visit.
Blackwell et al. 2017, UK	Critique the use of Experience Based Co-Design in an A&E	Qualitative.	10 patients 65 years and older with palliative needs who	Feelings of panic and uncertainty were reported on admission	Aims clearly stated;	

	setting, and present evidence specifically about palliative care needs in the A&E from older patients and staff.	Experience-Based Co-Design using narrative video-taped interviews	had received care in A&E, and their carers. Interviewed few weeks after the A&E stay	to A&E. Waiting time was a significant issue, and knowing what was happening and understanding how the A&E system and processes work emerged as very important too. Patients became fearful if they were left alone, and they reported that how they are acknowledged and validated by the healthcare professionals impacts on their experience, as well as the reason for the visit: for some the A&E is a port of safety, for others it is the result of deterioration, lack of support or a catastrophic event.	Methodology explained in-depth; Methods appropriate to answer the research question; Results outlined clearly; Results reviewed and approved by participants after being analysed; Significant impact on practice and quality improvement.	
Han et al. 2017, Taiwan	To explore the experiences of older patients during A&E return visits, with a view toward identifying factors that contribute to return visits.	Qualitative Phenomenography Using Semi-structured interviews as a method	30 patients aged between 65 and 82 years old from one A&E in Taiwan who were having their return visit in a time range of max 72 hours after their first visit interviewed in the observation room. Interviews	Some patients directly linked the return A&E visit to their experience during the first visit. They felt they had been "tricked" into returning home before they were ready. To address that, they returned to the A&E to seek another opinion	Methodology clearly described; Methods suitable to answer the research question; Results outlined clearly;	Interviews were conducted behind curtains to protect patients' privacy, but were sometimes interrupted by environmental noises; All the study participants were non-trauma patients. Results from this study cannot be

			lasted between 52 and 75 minutes.	in the hope that the “new” doctor would be able to identify the “real problem”. Participants expressed their fears of death and dying as exacerbated with each self-identified need to visit the A&E and the subsequent confirmation from medical staff that there is some problem.		extrapolated to the experience of trauma patients; Focuses a lot on the reason leading them to return and less on their experience when there.
Goodridge et al. 2018, UK	To describe the patient experience of older adults in the A&E and generate recommendations for enhancing their experience.	Qualitative. Descriptive design using focus groups and interviews as a method	41 older adults between 65 and 95 years old and 15 caregivers. Focus groups were conducted in public meeting rooms up until two years after the participants A&E experience. Each group included between three and 10 participants	Older adults attending the A&E are at risk for health care-related emotional harm unrelated to their entrance complaint. Participants (both patients and carers) highlighted an overall lack of responsiveness within the A&E to both the experience and agency needs of older adults. They articulated a list of key recommendations they believed would foster a better experience.	A large and varied group of participants was recruited; Results outlined clearly.	Focus groups took place until two years after the A&E experience which may have resulted in a decreased ability to recall perceptions; The specific methodology is not articulated clearly; Focus group participants were recruited on the basis of interest in this topic, raising the possibility that older adults with positive experiences in the A&E did not volunteer to participate; It is not clear if people with dementia or other cognitive impairments were included.

Appendix 3 - REC approval for Study Phase A



NHS
Health Research Authority
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Lewins Mead
Bristol
BS1 2NT

Tel: 0207 104 8210

<u>Please note: This is the favourable opinion of the REC only and does not allow</u> the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

01 August 2019

Ms Marta Paglioni
Room B322 Bournemouth House,
Christchurch Road
Bournemouth, Dorset
BH1 3LH

Dear Ms Paglioni

Study title:	**An exploration of a) the lived experience of older people who attend a hospital Accident and Emergency (A&E) Department and b) the ways in which having an Intentional Compassionate Communication Intervention (ICCI) may affect this experience.**
REC reference:	**19/SC/0046**
Amendment number:	**n.1**
Amendment date:	**19 June 2019**
IRAS project ID:	**258556**

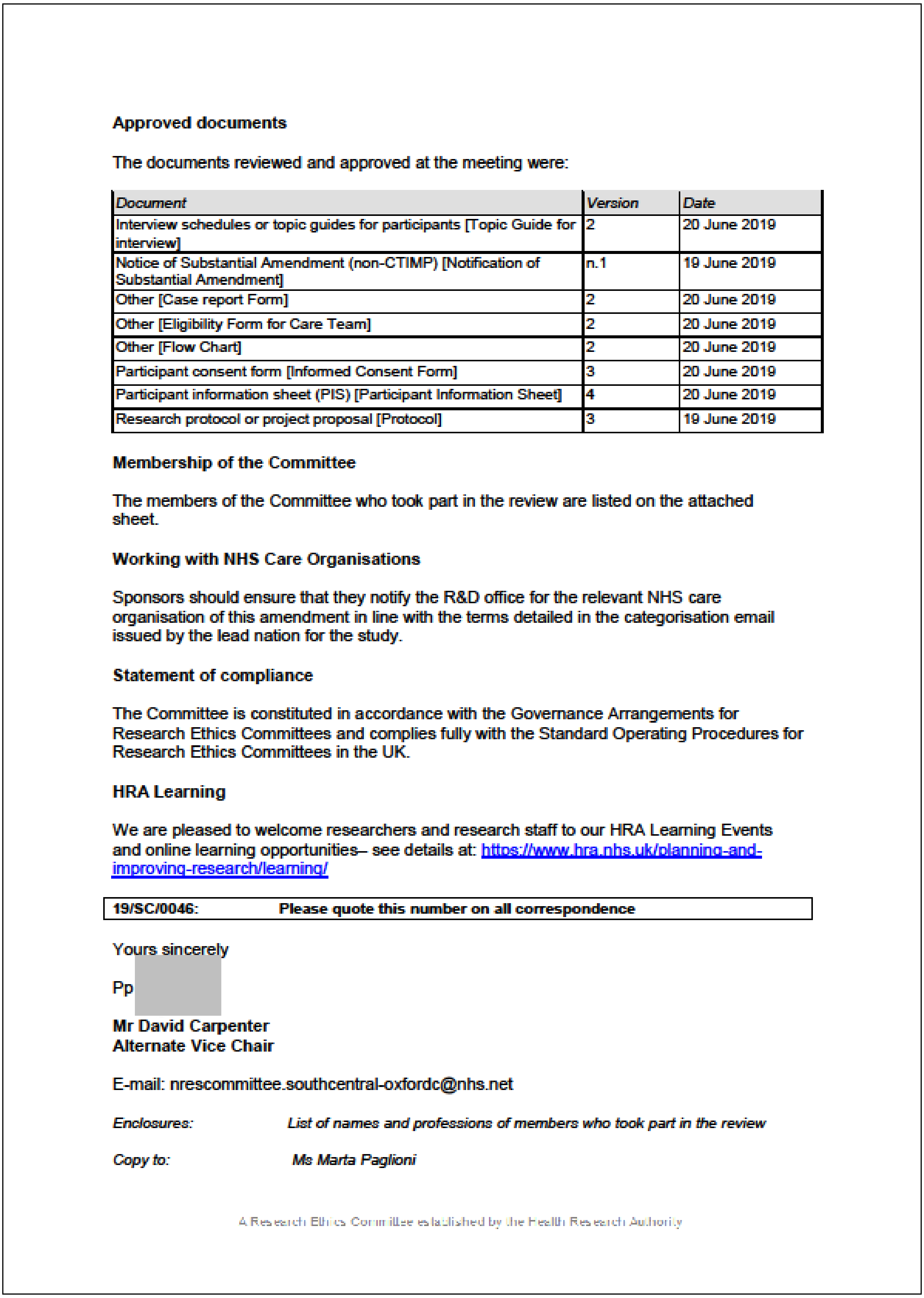
The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The amendment sought to propose to narrow the research aims and objective to only patients who received the ICCI, and to reduce the sample size to a maximum of 15 participants.

A Research Ethics Committee established by the Health Research Authority



Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Interview schedules or topic guides for participants [Topic Guide for interview]	2	20 June 2019
Notice of Substantial Amendment (non-CTIMP) [Notification of Substantial Amendment]	n.1	19 June 2019
Other [Case report Form]	2	20 June 2019
Other [Eligibility Form for Care Team]	2	20 June 2019
Other [Flow Chart]	2	20 June 2019
Participant consent form [Informed Consent Form]	3	20 June 2019
Participant information sheet (PIS) [Participant Information Sheet]	4	20 June 2019
Research protocol or project proposal [Protocol]	3	19 June 2019

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

19/SC/0046:	**Please quote this number on all correspondence**

Yours sincerely

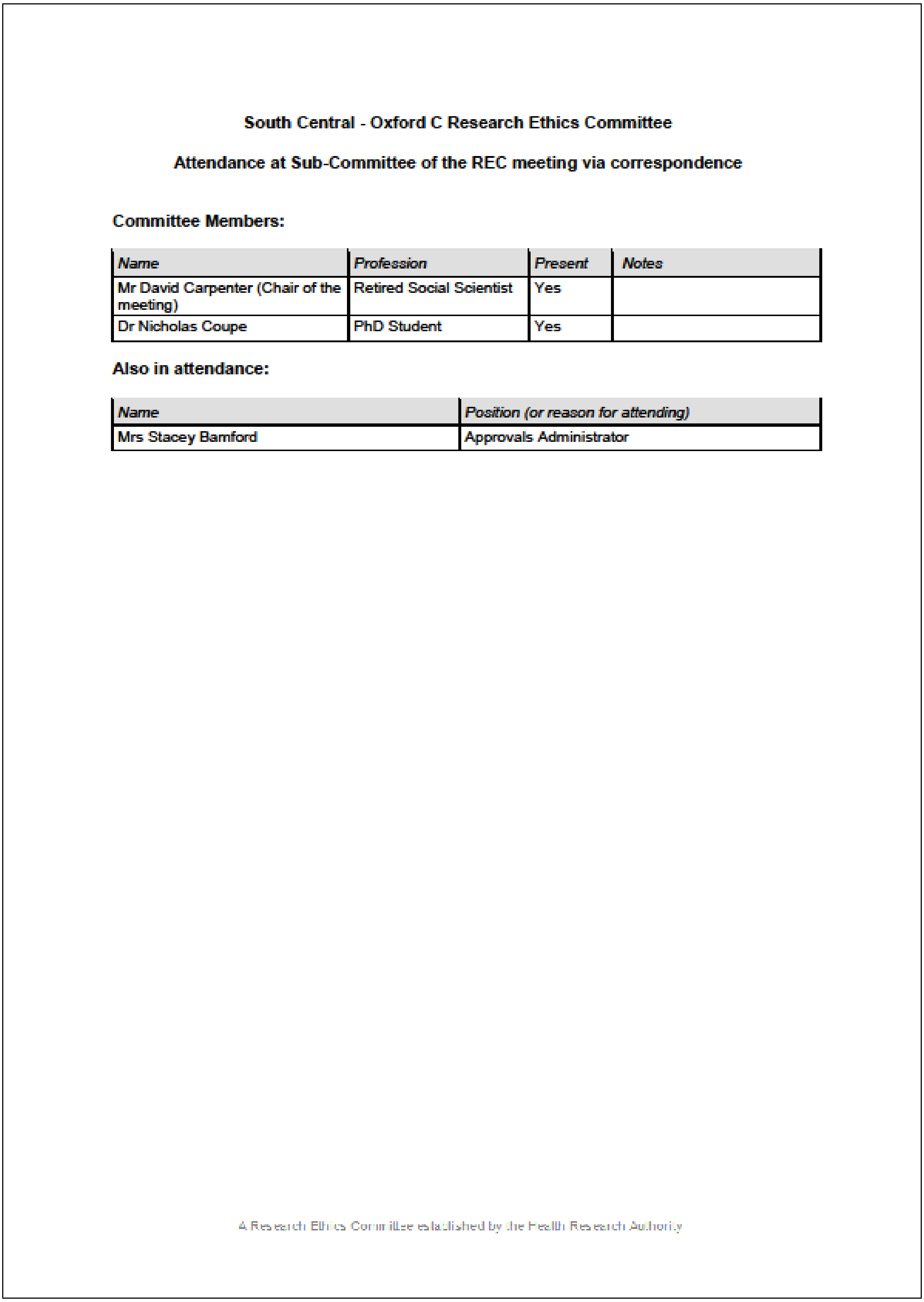
Pp [redacted]

Mr David Carpenter
Alternate Vice Chair

E-mail: nrescommittee.southcentral-oxfordc@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Ms Marta Paglioni*



South Central - Oxford C Research Ethics Committee

Attendance at Sub-Committee of the REC meeting via correspondence

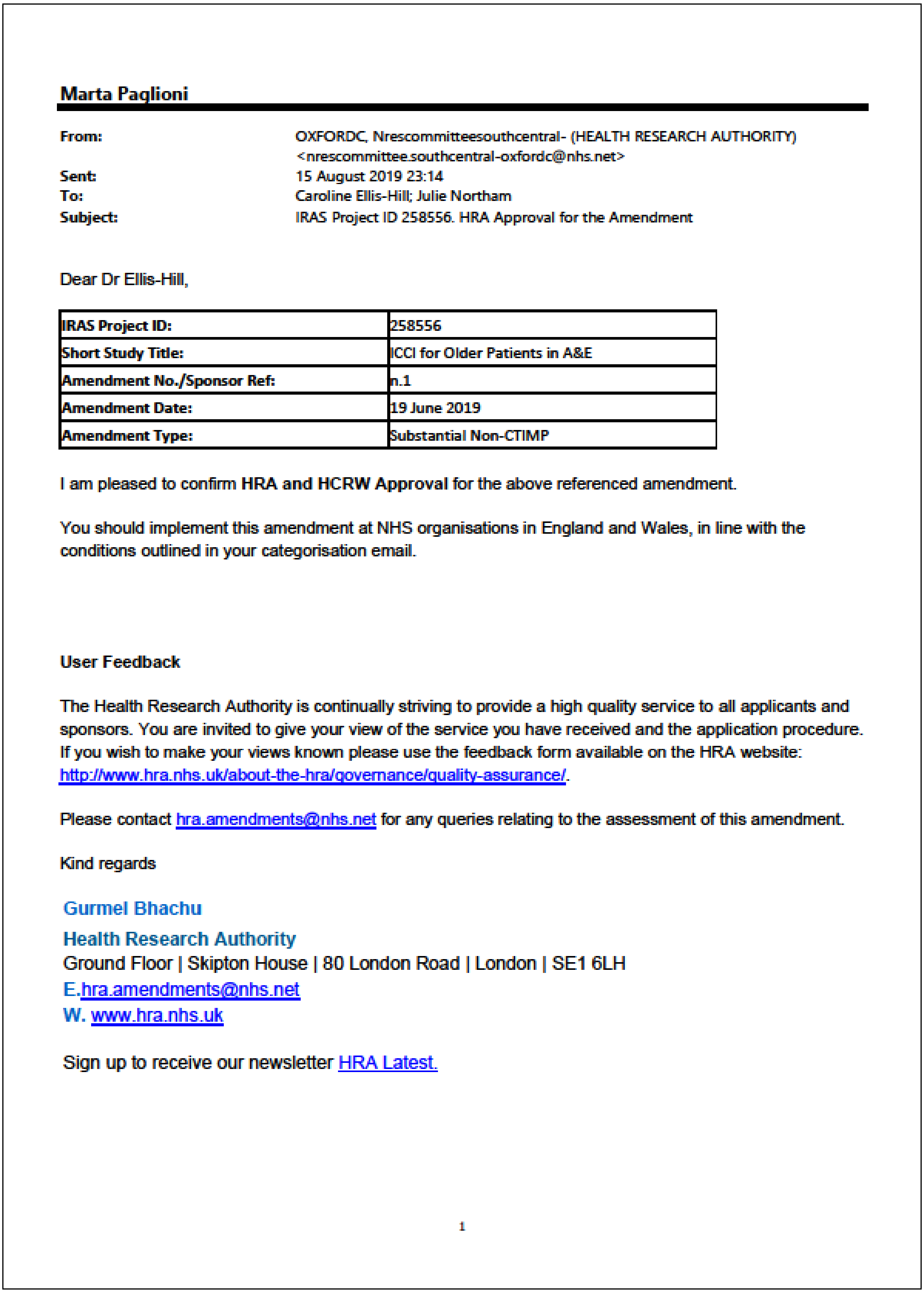
Committee Members:

Name	*Profession*	*Present*	*Notes*
Mr David Carpenter (Chair of the meeting)	Retired Social Scientist	Yes	
Dr Nicholas Coupe	PhD Student	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Mrs Stacey Bamford	Approvals Administrator

Appendix 4 - HRA approval for Study Phase A



Marta Paglioni

From:	OXFORDC, Nrescommitteesouthcentral- (HEALTH RESEARCH AUTHORITY) <nrescommittee.southcentral-oxfordc@nhs.net>
Sent:	15 August 2019 23:14
To:	Caroline Ellis-Hill; Julie Northam
Subject:	IRAS Project ID 258556. HRA Approval for the Amendment

Dear Dr Ellis-Hill,

IRAS Project ID:	258556
Short Study Title:	ICCI for Older Patients in A&E
Amendment No./Sponsor Ref:	n.1
Amendment Date:	19 June 2019
Amendment Type:	Substantial Non-CTIMP

I am pleased to confirm **HRA and HCRW Approval** for the above referenced amendment.

You should implement this amendment at NHS organisations in England and Wales, in line with the conditions outlined in your categorisation email.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/.

Please contact hra.amendments@nhs.net for any queries relating to the assessment of this amendment.

Kind regards

Gurmel Bhachu

Health Research Authority
Ground Floor | Skipton House | 80 London Road | London | SE1 6LH
E.hra.amendments@nhs.net
W. www.hra.nhs.uk

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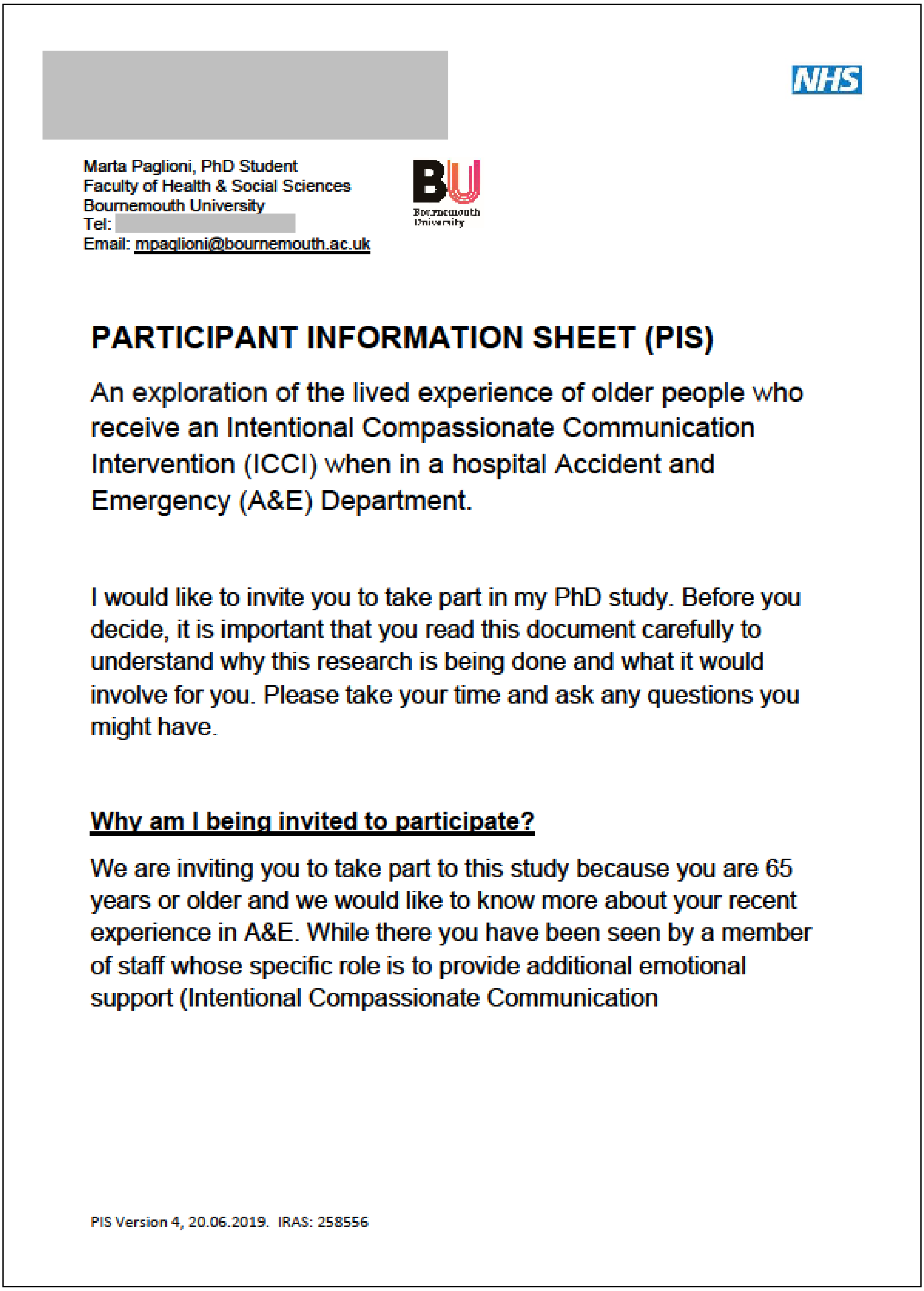
Appendix 5 – PIS for patient participants



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NHS

Marta Paglioni, PhD Student
Faculty of Health & Social Sciences
Bournemouth University
Tel: [redacted]
Email: mpaglioni@bournemouth.ac.uk

BU
Bournemouth University

PARTICIPANT INFORMATION SHEET (PIS)

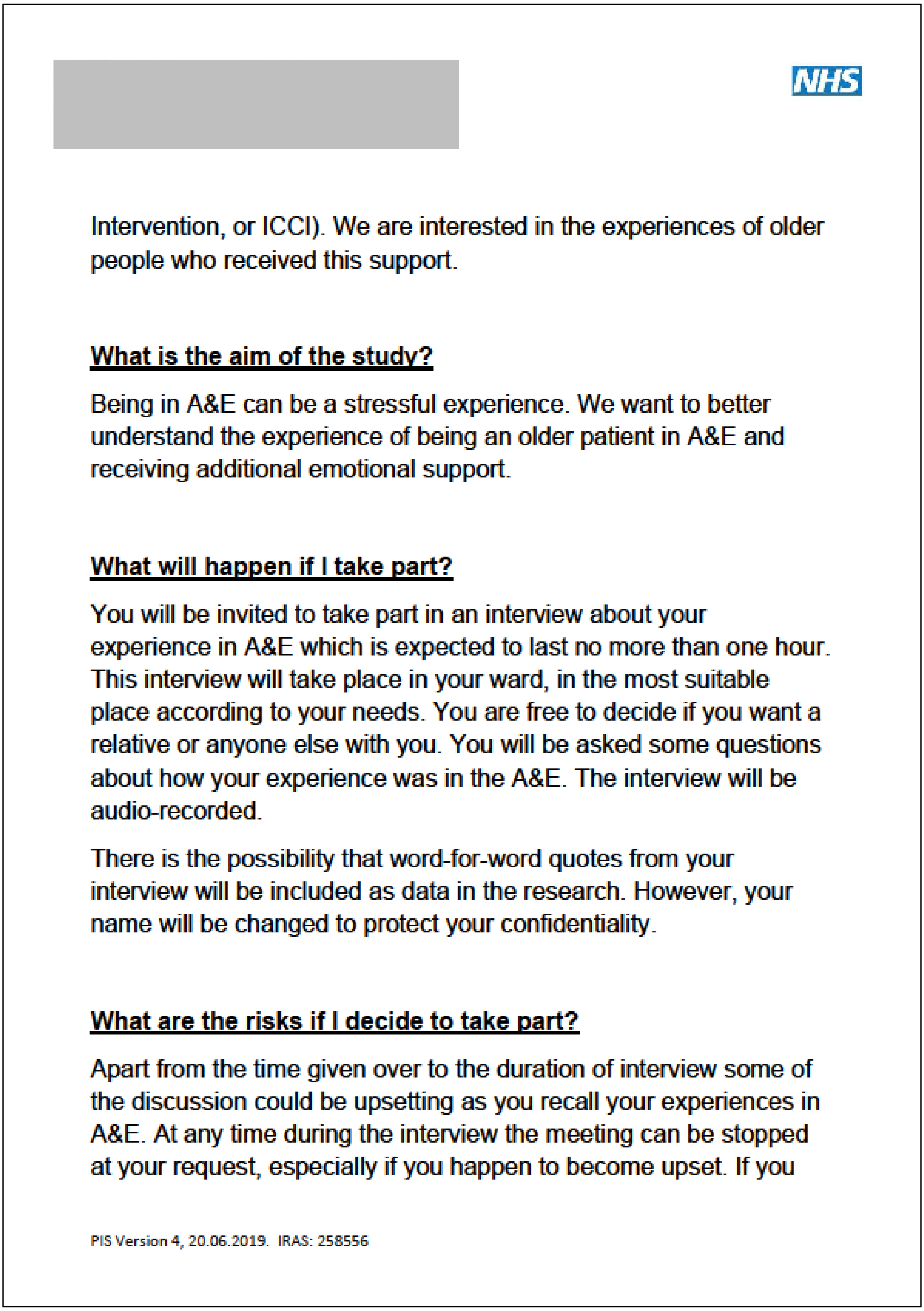
An exploration of the lived experience of older people who receive an Intentional Compassionate Communication Intervention (ICCI) when in a hospital Accident and Emergency (A&E) Department.

I would like to invite you to take part in my PhD study. Before you decide, it is important that you read this document carefully to understand why this research is being done and what it would involve for you. Please take your time and ask any questions you might have.

Why am I being invited to participate?

We are inviting you to take part to this study because you are 65 years or older and we would like to know more about your recent experience in A&E. While there you have been seen by a member of staff whose specific role is to provide additional emotional support (Intentional Compassionate Communication

PIS Version 4, 20.06.2019. IRAS: 258556



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NHS

Intervention, or ICCI). We are interested in the experiences of older people who received this support.

What is the aim of the study?

Being in A&E can be a stressful experience. We want to better understand the experience of being an older patient in A&E and receiving additional emotional support.

What will happen if I take part?

You will be invited to take part in an interview about your experience in A&E which is expected to last no more than one hour. This interview will take place in your ward, in the most suitable place according to your needs. You are free to decide if you want a relative or anyone else with you. You will be asked some questions about how your experience was in the A&E. The interview will be audio-recorded.

There is the possibility that word-for-word quotes from your interview will be included as data in the research. However, your name will be changed to protect your confidentiality.

What are the risks if I decide to take part?

Apart from the time given over to the duration of interview some of the discussion could be upsetting as you recall your experiences in A&E. At any time during the interview the meeting can be stopped at your request, especially if you happen to become upset. If you

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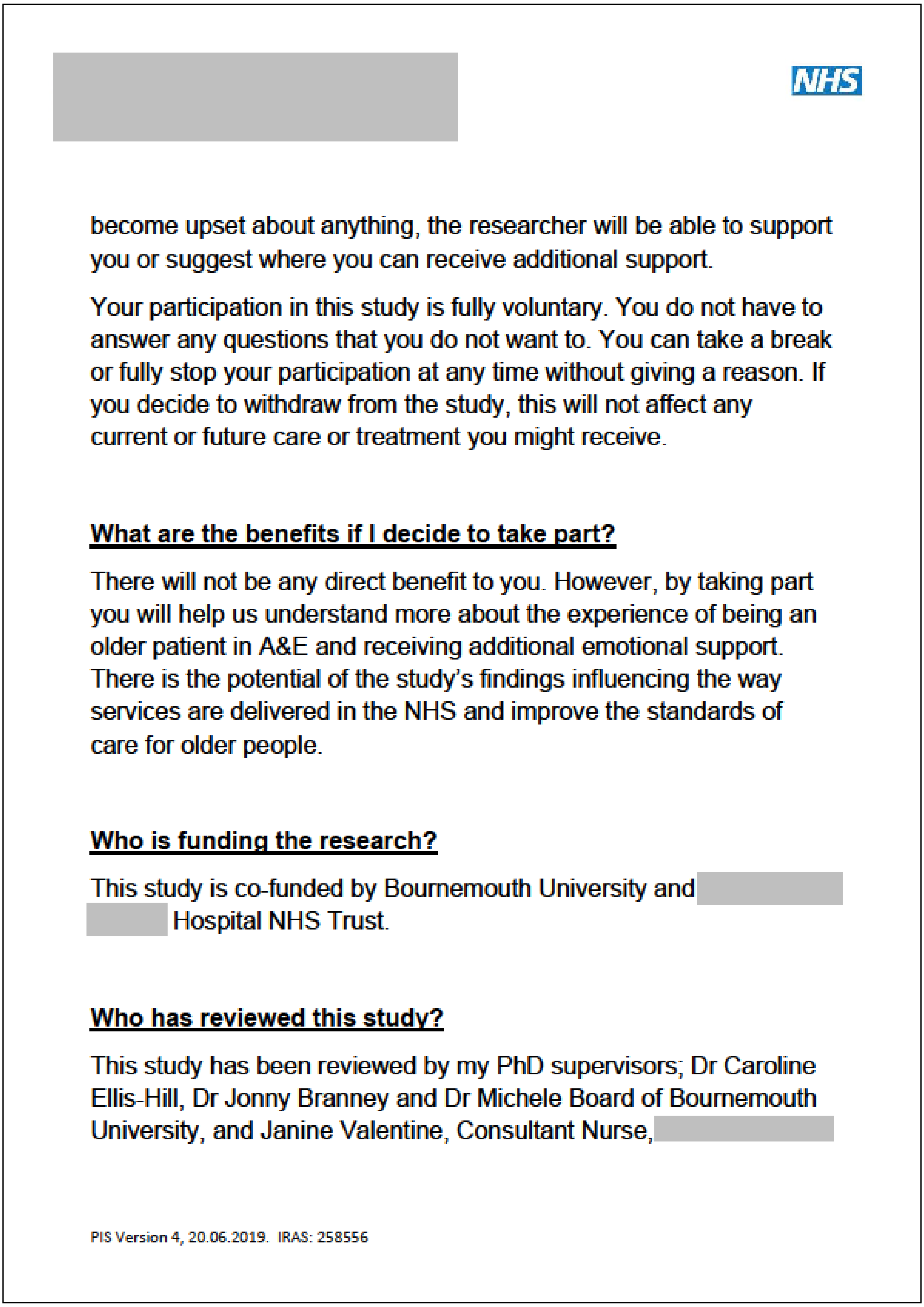

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become upset about anything, the researcher will be able to support you or suggest where you can receive additional support.

Your participation in this study is fully voluntary. You do not have to answer any questions that you do not want to. You can take a break or fully stop your participation at any time without giving a reason. If you decide to withdraw from the study, this will not affect any current or future care or treatment you might receive.

What are the benefits if I decide to take part?

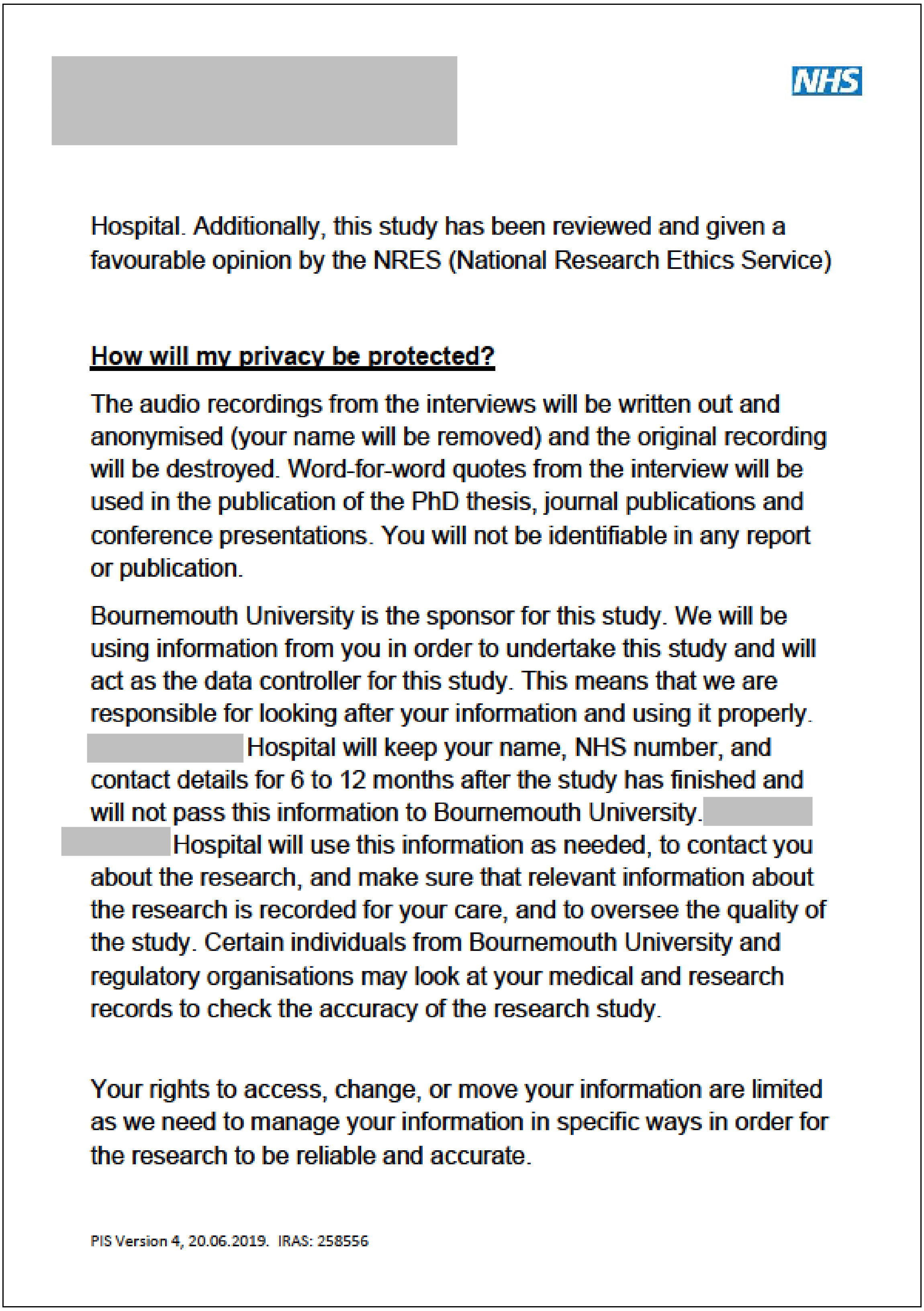
There will not be any direct benefit to you. However, by taking part you will help us understand more about the experience of being an older patient in A&E and receiving additional emotional support. There is the potential of the study's findings influencing the way services are delivered in the NHS and improve the standards of care for older people.

Who is funding the research?

This study is co-funded by Bournemouth University and [redacted] [redacted] Hospital NHS Trust.

Who has reviewed this study?

This study has been reviewed by my PhD supervisors; Dr Caroline Ellis-Hill, Dr Jonny Branney and Dr Michele Board of Bournemouth University, and Janine Valentine, Consultant Nurse, [redacted]



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Hospital. Additionally, this study has been reviewed and given a favourable opinion by the NRES (National Research Ethics Service)

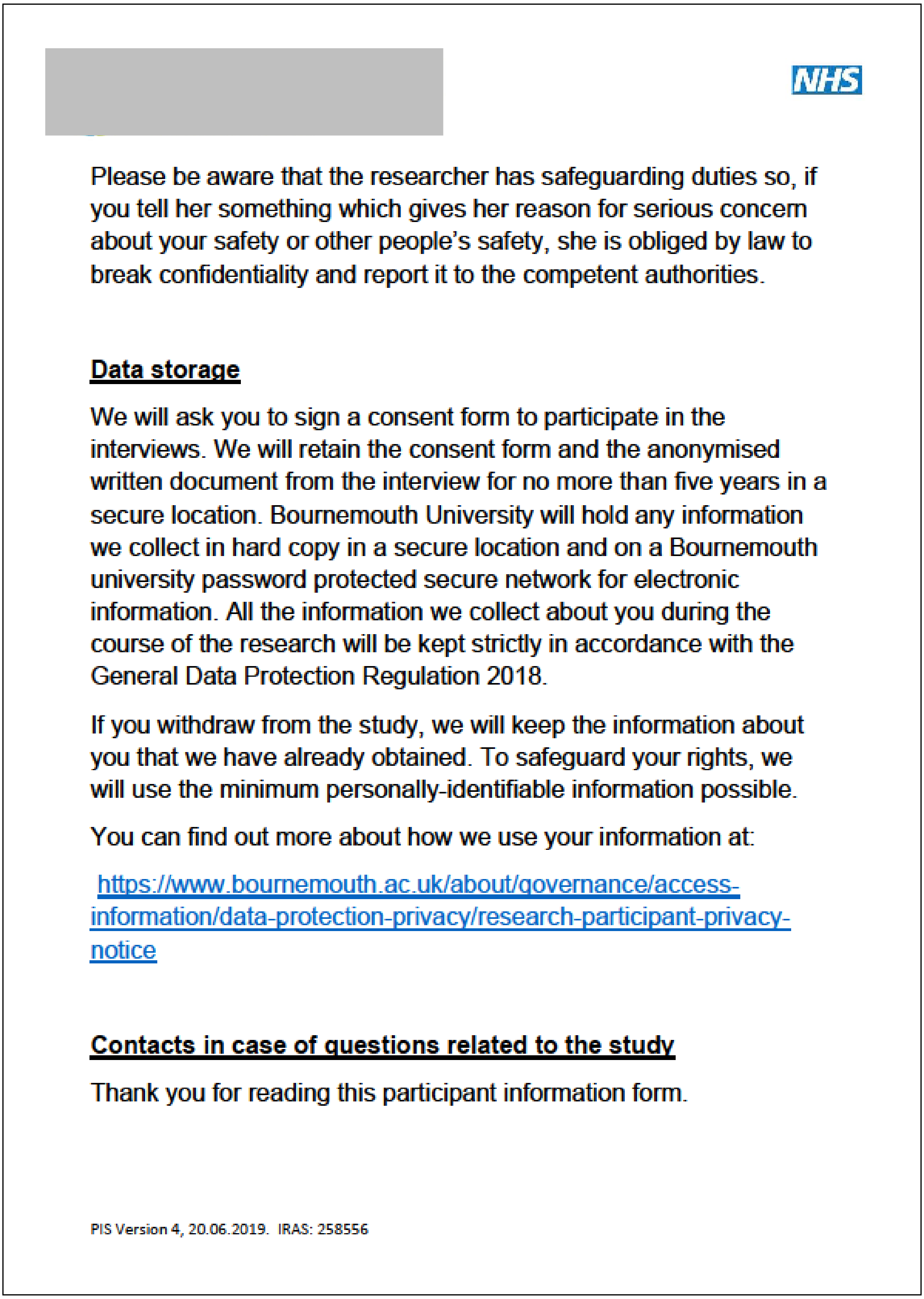
How will my privacy be protected?

The audio recordings from the interviews will be written out and anonymised (your name will be removed) and the original recording will be destroyed. Word-for-word quotes from the interview will be used in the publication of the PhD thesis, journal publications and conference presentations. You will not be identifiable in any report or publication.

Bournemouth University is the sponsor for this study. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. [redacted] Hospital will keep your name, NHS number, and contact details for 6 to 12 months after the study has finished and will not pass this information to Bournemouth University. [redacted] [redacted] Hospital will use this information as needed, to contact you about the research, and make sure that relevant information about the research is recorded for your care, and to oversee the quality of the study. Certain individuals from Bournemouth University and regulatory organisations may look at your medical and research records to check the accuracy of the research study.

Your rights to access, change, or move your information are limited as we need to manage your information in specific ways in order for the research to be reliable and accurate.

PIS Version 4, 20.06.2019. IRAS: 258556



[redacted]

Please be aware that the researcher has safeguarding duties so, if you tell her something which gives her reason for serious concern about your safety or other people's safety, she is obliged by law to break confidentiality and report it to the competent authorities.

Data storage

We will ask you to sign a consent form to participate in the interviews. We will retain the consent form and the anonymised written document from the interview for no more than five years in a secure location. Bournemouth University will hold any information we collect in hard copy in a secure location and on a Bournemouth university password protected secure network for electronic information. All the information we collect about you during the course of the research will be kept strictly in accordance with the General Data Protection Regulation 2018.

If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

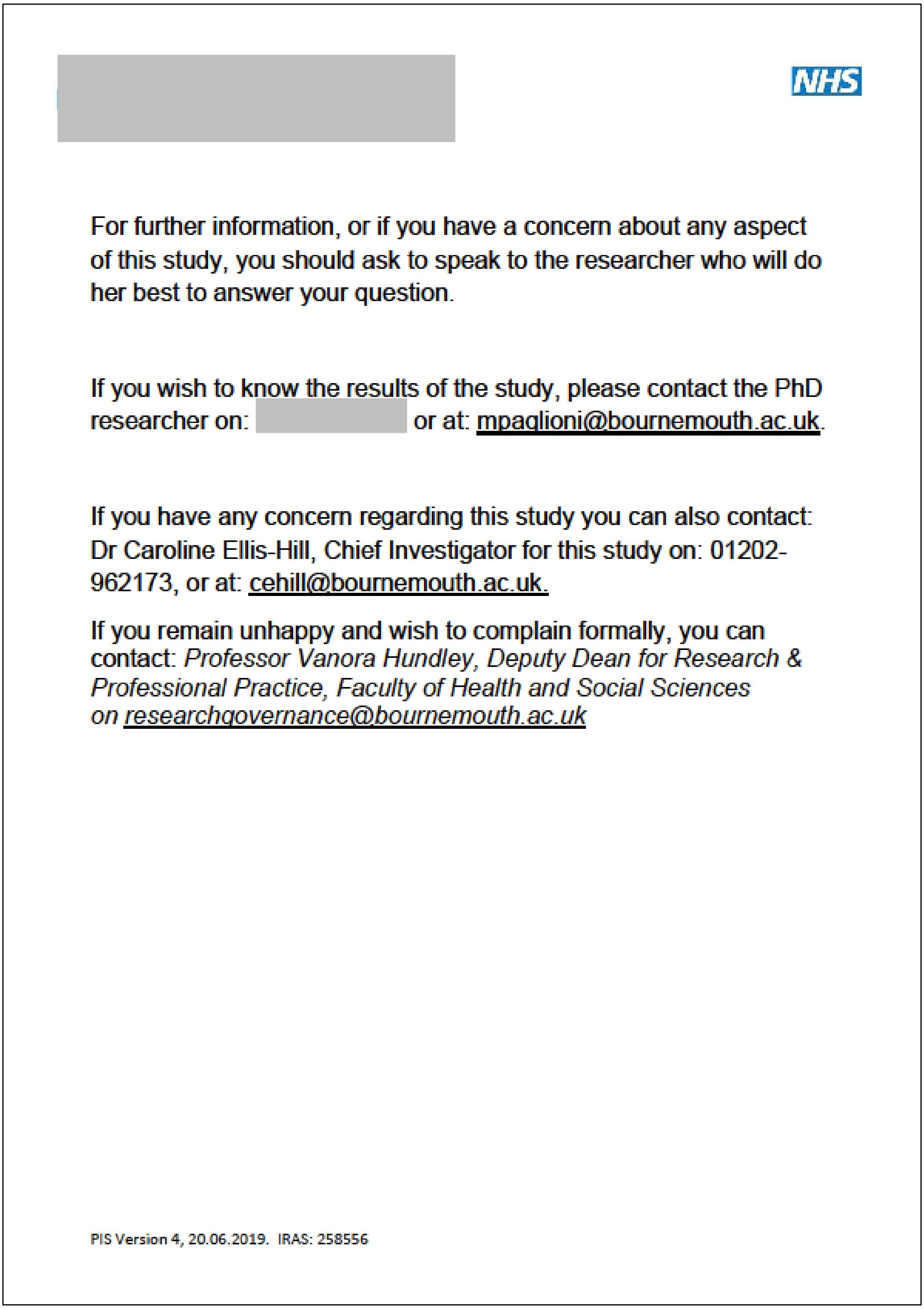
You can find out more about how we use your information at:

https://www.bournemouth.ac.uk/about/governance/access-information/data-protection-privacy/research-participant-privacy-notice

Contacts in case of questions related to the study

Thank you for reading this participant information form.

PIS Version 4, 20.06.2019. IRAS: 258556



[redacted]

For further information, or if you have a concern about any aspect of this study, you should ask to speak to the researcher who will do her best to answer your question.

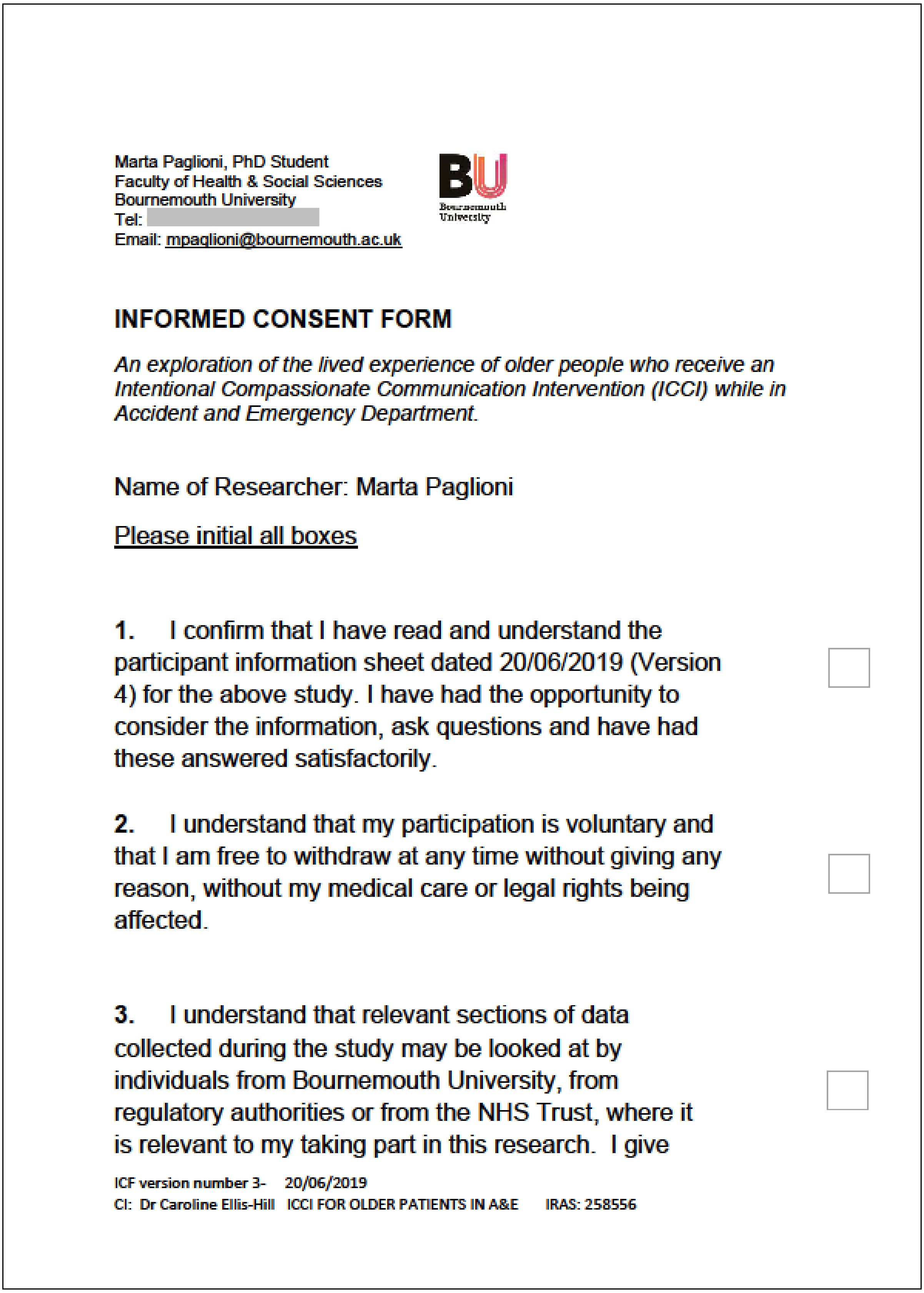
If you wish to know the results of the study, please contact the PhD researcher on: [redacted] or at: mpaglioni@bournemouth.ac.uk.

If you have any concern regarding this study you can also contact: Dr Caroline Ellis-Hill, Chief Investigator for this study on: 01202-962173, or at: cehill@bournemouth.ac.uk.

If you remain unhappy and wish to complain formally, you can contact: *Professor Vanora Hundley, Deputy Dean for Research & Professional Practice, Faculty of Health and Social Sciences on researchgovernance@bournemouth.ac.uk*

PIS Version 4, 20.06.2019. IRAS: 258556

Appendix 6 – ICF for patient participants



Marta Paglioni, PhD Student
Faculty of Health & Social Sciences
Bournemouth University
Tel: [redacted]
Email: mpaglioni@bournemouth.ac.uk

INFORMED CONSENT FORM

An exploration of the lived experience of older people who receive an Intentional Compassionate Communication Intervention (ICCI) while in Accident and Emergency Department.

Name of Researcher: Marta Paglioni

<u>Please initial all boxes</u>

1. I confirm that I have read and understand the participant information sheet dated 20/06/2019 (Version 4) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that relevant sections of data collected during the study may be looked at by individuals from Bournemouth University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give ☐

permission for these individuals to have access to that data.

4. I understand interviews will be audio recorded and word-for-word quotes from the interviews might be published anonymously. ☐

5. I agree to take part in the above study. ☐

6. I understand this project is part of a PhD study ☐

Name of Participant: ....

Signature: ....

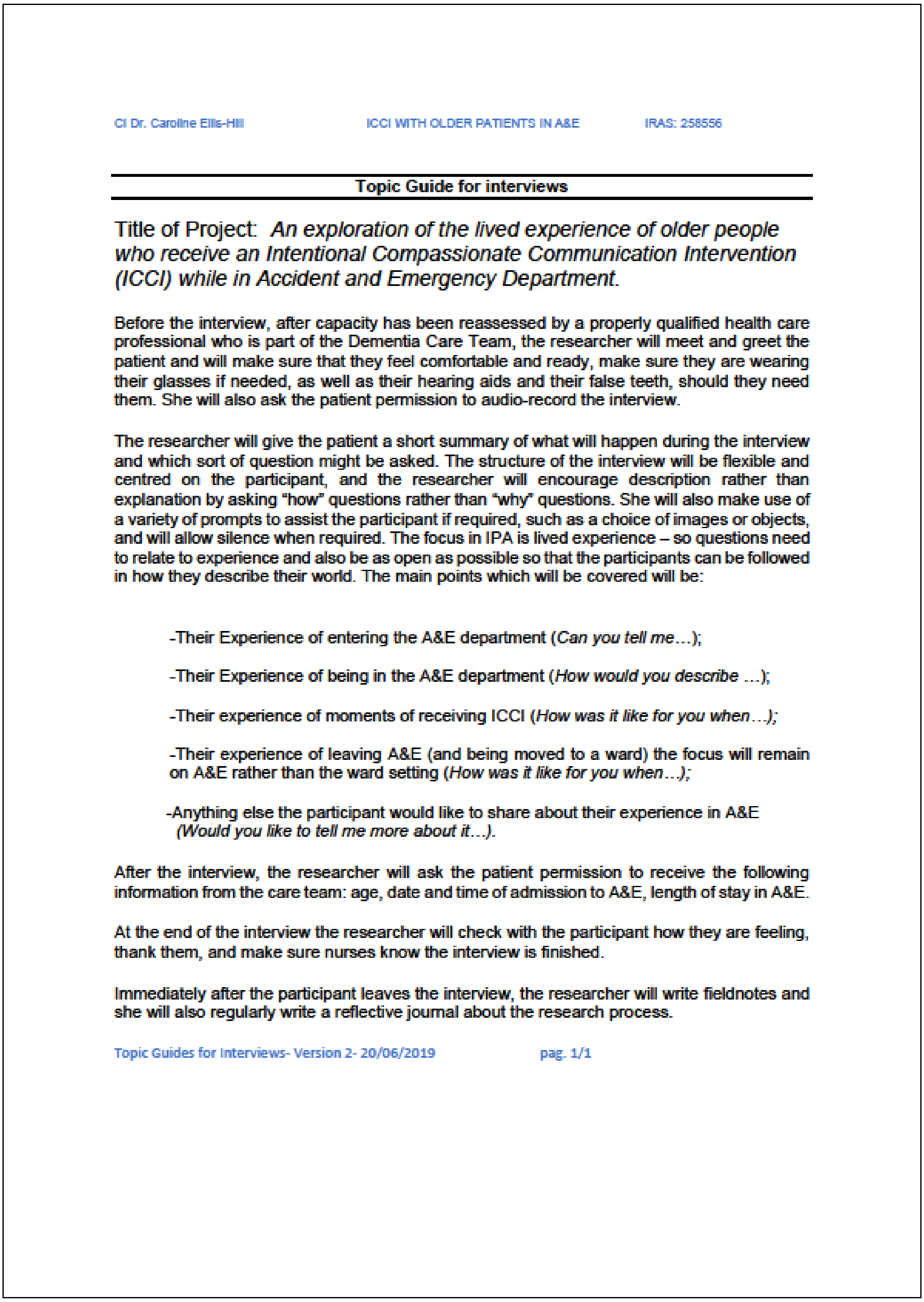
Date: ....

Name of Person taking consent: ....

Signature: ....

Date: ....

Appendix 7 - Topic guide for interviews patient participants



CI Dr. Caroline Ellis-Hill ICCI WITH OLDER PATIENTS IN A&E IRAS: 258556

Topic Guide for interviews

Title of Project: *An exploration of the lived experience of older people who receive an Intentional Compassionate Communication Intervention (ICCI) while in Accident and Emergency Department.*

Before the interview, after capacity has been reassessed by a properly qualified health care professional who is part of the Dementia Care Team, the researcher will meet and greet the patient and will make sure that they feel comfortable and ready, make sure they are wearing their glasses if needed, as well as their hearing aids and their false teeth, should they need them. She will also ask the patient permission to audio-record the interview.

The researcher will give the patient a short summary of what will happen during the interview and which sort of question might be asked. The structure of the interview will be flexible and centred on the participant, and the researcher will encourage description rather than explanation by asking "how" questions rather than "why" questions. She will also make use of a variety of prompts to assist the participant if required, such as a choice of images or objects, and will allow silence when required. The focus in IPA is lived experience – so questions need to relate to experience and also be as open as possible so that the participants can be followed in how they describe their world. The main points which will be covered will be:

-Their Experience of entering the A&E department (*Can you tell me…*);

-Their Experience of being in the A&E department (*How would you describe …*);

-Their experience of moments of receiving ICCI (*How was it like for you when…);*

-Their experience of leaving A&E (and being moved to a ward) the focus will remain on A&E rather than the ward setting (*How was it like for you when…);*

-Anything else the participant would like to share about their experience in A&E *(Would you like to tell me more about it…).*

After the interview, the researcher will ask the patient permission to receive the following information from the care team: age, date and time of admission to A&E, length of stay in A&E.

At the end of the interview the researcher will check with the participant how they are feeling, thank them, and make sure nurses know the interview is finished.

Immediately after the participant leaves the interview, the researcher will write fieldnotes and she will also regularly write a reflective journal about the research process.

Topic Guides for Interviews- Version 2- 20/06/2019 pag. 1/1

Appendix 8 - Encounters with patient participants vignettes

For each participant I will now present a short vignette outlining their individual experience of being in A&E as it emerges from the interview. To allow the reader to get as close as possible to the lifeworld of each one of them, I will write the vignettes in first person (Italics font): this should result in a number of short, evocative, monologues.

At the bottom of each vignette, I will also include my experience of the participant while interviewing them, trying to convey it through description.

These vignettes reflect the phenomenological approach used in the study, representing a way to add “texture” as opposed to just “structure” (Todres 2007, p.46) to the communication of findings. This difference between structure and texture has already been mentioned in chapter 3 when describing the choice of an interpretative phenomenological framework rather than a descriptive one. The *structure*, which Todres talks about, is that *distancing* in which themes can be expressed and explained through the revelation of their inner logic and inner relationships, while the *texture* refers to that *closeness* which gives readers access not just to explanations and conclusion, but to the possibility of an intuitive, empathetic understanding, so that the understanding of a phenomenon can be taken alive, present not just as a theory, but as an intuitive essence, or, as Gendlin names it, *felt sense* (1984). The following vignettes, therefore, will assist in providing context to the personal world of the participants and to the phenomena represented by our encounter, allowing the reader to more fully understand - or more intuitively feel - the verbatim quotes used in the rest of the chapter.

Walter
When I arrived at A&E yesterday, I felt immediately relieved. It was the third time I was brought there, which is kind of funny. I got there by ambulance, and the chaps who took me were very friendly and chatty. They said that they wouldn’t leave me alone on the ambulance, and that they would stay with me all the time.
When we got to the hospital, we got out, walked around, then turn left, turn right and we got to A&E. Once there, waiting to be seen by a doctor was so long! I think I spent three or four hours in that tiny room. Luckily, my daughter was with me all the time…but what can you do? Once you are there, you have to wait and that’s it!

A nurse came and then went saying that he would be back in a minute, well: that was the longest minute ever! Ahahahaha!
When the man arrived to tell me where I had to go, they took me up for X-rays and all that: I was left on a side, going up to a room where all people are waiting to get all sorted. In there I waited and when they were ready for me, they came and gave me x-rays, they brought me back there, and then they kept me on the

side, where they all started, you know, “lie there” and, ahem, “raise your arm” they say…and that’s it!

The staff in A&E has always been very nice: they talked to me.
When they moved me to the ward, I felt relieved. In fact, I feel better now than when I arrived there.

I interviewed Walter at his bedside, closing the curtains around us. When I first looked at him, he appeared to me as very weak -I believe I got this impression from his vulnerable gaze and posture, and his thinness-. When we started talking, I sensed he was not verbally very articulate and even if he did not seem to be distressed, he gave me a sense of being bored…or maybe just a bit anxious. I am not sure.
The main struggle for me was to get him to talk about his subjective experience rather than having a report of facts. From his facial expression, tone of voice, words, and utterances he used, I sensed he had felt quite powerless and passive in A&E. There was nothing he could do to improve his situation: he only had to wait. After the waiting, Walter described a series of medical examinations which have been *done to him* and again the use of language suggests to me that he was inhabiting a passive role at that time. Walter did not remember the ICCI professional, but when asked, he recalled the staff having been very nice and *talking to him*.

Anne
I arrived at A&E yesterday around lunch time. I was brought there by an ambulance.
When I first arrived, they said they were very busy… I had to wait in the corridor.
Honestly, I can’t say whether it was for a long time, you know, when you need to go to the toilet it certainly feels too long!
When I got to the little cubicle, I said to the nurse that I needed to go to the loo. They told me to wait and went away. To me, it felt they were gone for ages…that was the worst thing, as I actually thought: “I am not going to last…” that remembered me of two years ago, when I was in hospital after a fall, and I was dying to have a wee…that was a bad experience! This time, when they went back to me, they had brought me a commode, as by then, I would not have made it to the toilet.
I know they are very busy and there are always people who are worse than you, but they tell you: “hang on a minute” and then disappear for ages, and you are dying to go to the toilet!
That was bad, but otherwise, they were very, very good, I have no complaints. After this, I went to X-Rays, then someone came and talked to me, but I can’t remember who… you see so many people in there, they are coming and going, you sort of forget who they are. Also, I don’t remember the time very well. I only know I had to wait again and that was not good either: I was in the corridor waiting without knowing how long it would last, wondering what was going to happen, and when, and I also was a bit cold and not very comfortable in the chair. It was quite an experience! I guess it was around five when I eventually got to the ward. There, they brought me supper, as I had not had anything to eat since breakfast.

They were very good, you know, I have no complaints, but it is not quite the same of being home, isn't it?
Although I mix up in my memory the people I met in A&E, I can remember one lady. She was "dementia and something..." carer, and she is the only one I can remember. She was very nice, she came and chatted to me for a bit. She was quite easy to talk to, and although I don't have dementia myself, I recon she wanted to reassure older people and I think it is very important to have someone like her, because doctor and nurses are very busy and someone like her helps you feel you are not wasting their time. Yesterday I felt so rotten, it was dreadful, I thought: "where is that all going to end?" and just chatting things through with her was very nice. All staff in A&E was nice, I really cannot complain, the only thing I can say is that, sometimes, it is not easy to understand foreign accents, and a lot of staff has it, you know, so I kept asking them to repeat 'cause I could not understand…I have nothing against them, but, you know, it is difficult to understand…other than that, they were all very good.

I interviewed Anne at her bedside -although she was sitting on a chair near her bed- closing the curtains around us. She had just been moved from another ward and had a short nap before talking to me. I perceived her as very weak (very thin, pale, feeble voice) but also very lucid and articulate. I also felt we established some form of personal connection, from the beginning. I did not struggle to understand her speech and I could easily link my questions to her answers. The more we talked the more I felt she relaxed and trusted me: I could see this from her body posture and her smile.
I had a feeling that she had quite several issues about which to complain regarding her A&E experience, but at the same time, it seemed to me that she did not want to sound unfair or ungrateful.

Dave
I arrived at A&E yesterday by an ambulance car…or maybe it was a taxi? I am not sure.
When I got there, I waited some time in a bay. I always felt treated very well by the staff, I would say they were caring and respectful. The waiting time wasn't so long, I think I waited less than I would expect.
I interviewed Dave at his bedside -he was sitting on a chair near his bed- closing the curtains around us. He had arrived at A&E by ambulance, and even if he had spent the first half an hour on his own, his wife had reached him straight after, and had stayed alongside him for the whole time. He did not remember the ICCI professional, but his wife did. Dave decided to be interviewed in presence of his wife, which I feel made the interview process quite difficult for me. While the participant appeared not to remember very much of his A&E experience, his wife tended to answer for him, which made very difficult to gather direct lived experience from him. Despite this, I felt he was sincere in saying that he had felt treated with care and respect by the staff during his A&E stay.

Robert
I came to A&E five days ago by ambulance. I did not know what to expect just before arriving, but I have to admit that, straight from the beginning, I found a

very welcoming atmosphere: the staff was very amicable, very greeting…they even brought me a cup of tea!
When I first arrived, I was a bit scared of the unknown, but I would say that I ended up feeling at home, really. It might be because I felt that nothing worse was going to happen to me at that point…or maybe because I felt that people there were all right, I mean, they were good…I don't remember single professionals or their names, I have seen so many people in there… but they were good! Also, it didn't feel like being in an emergency department…nobody seemed in pain, nobody was crying or screaming. The transition to the ward where I am now was also very smooth.
Robert was interviewed in a room -other than his bay- where there was nobody else present at that time other than me and a nurse (who was very familiar to him, and whom he had wanted to stay with us).
He was sitting in a wheelchair and I was sitting alongside him. He seemed to me very articulate and lucid and we both seemed to hear and understand each other quite well.
Robert did not remember the ICCI professional, although he seemed to remember what she usually does (bringing a cup of tea).

Michael
When I arrived at A&E few days ago, I got to a section where I seated and waited for them to get a bed ready for me. Meanwhile, someone was taking my temperature and was doing all the other things they needed to do, you know, wiring you up all that bloody palaver, making sure you are breathing and all that… and they ask you all the questions: "A,B,C…" to see if you…you know. Staff was good. I mean, I just had my second heart-attack, I was on my own, I was in pain…there was not much anybody could do, really, but in a moment like that, they slightest things they do can help a lot! And they were very good, they were marvellous. They help you in the basic things…do you want to know the personal side of things? Well, this is really bad, ahahah! They taught me how to use a bottle. I couldn't use a bottle, and I could not do it standing so I needed help: they showed me how to use a bottle, and that meant a lot: I am all right with that now.
Before anything else, a lady came to me…I think she did say who she was, but I don't remember now. She didn't stay very long but asked about how things had gone and if I had been treated all right thus far. That attention felt very good. It was like having someone from staff with me at the exact minute I wanted them. Staff was very good indeed, although if I'd have to say something, I will say that they'd need double the staff: they are overworked. They are asked to do too many things at a time.

I interviewed Michael at his bedside closing the curtains around us. His son was present as per this participant's choice, however he remained silent.
Michael displayed a lively sense of humour and a willingness to share, however, I struggled to understand his speech from time to time, which might have affected the quality of the interview I carried out with him.

Pauline
I arrived at the emergency department few days ago, by ambulance. I was alone at the beginning, but my son came in while I was there.

Getting to the emergency department on my own was fine. The staff made me feel at ease and I could feel they were taking care of me and making sure I was safe and looked after.
Initially, I was in the corridor, then, they found a bay where they popped me in to do tests and things…in the bay it was quite easy: I kept feeling that they were taking care of me. They also made sure I was in a place where I could see what was happening around me so that I wouldn't be nervous.
I felt they were making sure that I could see they were working to help me.
Overall, the A&E experience wasn't difficult for me. This might be due to my son being there with me for almost all the time, bless him… but maybe also to the fact that the staff made me feel involved in everything they were doing to me. All of this felt quite reassuring.
The transition to the ward was smooth. If I had to say to a friend what to expect from being in A&E in this hospital, I would say that there is nothing to worry about.

I interviewed Pauline at her bedside closing the curtains around us.
I felt she was very articulate, at the same time, I perceived a sort of reluctance in disclosing the emotional side of her experience.

James
I came to A&E a week ago by ambulance and I was on my own.
I came because I was feeling unwell with shortness of breath and lightheaded.
When I first arrived, it was all right… I remember they did some blood tests... after a while I started to feel a bit nervous…I was alone in the bay…the curtains were closed, but I would have wanted to see people around me…thus I asked the nurse if she could open-up the curtains and she did it. After that, I felt more relaxed.

So, I was lying there when someone came and checked that I was all right and asked if I wanted a tea or a coffee. I said I wanted a tea. She brought me tea. I don't remember if she also brought some biscuits. She was very kind, very good. I loved being treated like that.
Despite this, the waiting felt long.

It was boring to wait in that cubicle on my own, when the only things I could see was the clock on the wall… I started thinking that I might have been forgotten there…and that would have been bad, as I don't like to stay closed, you know, I have early stages dementia. It had already happened to me in another hospital's A&E and even back then I had asked not to be left on my own as I have early stages dementia and I need to be with other patients.
When you are in that, it is a bit like being in a prison, but if you have people around you, it is more like an "open prison", ahaha!
I would say that in A&E the staff is good. They are very nice…even if not so affectionate like in the ward where they all know me so well…you know, I go there often!
If I had to tell a friend what to expect from the A&E here, I would say that they do not have to worry about anything as they will be looked after, and even if it might look like they have been forgotten, they didn't. Even if the waiting time feels long, it is not because they forgot you. You will see that staff will keep

coming in, checking on you, doing the tests, and even when you think that you have been there alone for ages, they will eventually come back to you again.
It is not like in other hospitals that one might hear about on the news where older people wait for much longer time…

If someone needs to go to that A&E they should not worry –even if they are going on foot- as they will be taken care of, so it worth it, even if they come a long way to go there. Staff will do anything, and they will keep you informed: they will tell you what you need to know, and they will listen and ask you if you have questions. They are good. I like them.

I interviewed James at his bedside closing the curtains around us.
He came across as a blunt and self-aware individual, and I felt he was very willing to chat and share his experience with me. Our interview was interrupted by a doctor who came and communicated to him some relevant information about his condition. After the doctor went away James commented with me that he had received some good news -which had made him feel relieved- and some news he did not like instead. This seemed to prompt some anxiety. However, when asked, he said he was keen to keep on going with our interview.
It clearly emerged that he remembered the ICCI professional, even if he did not know who she was.

Barbara
When I first got to the A&E, it was all right, I mean, everybody was nice to me and even if I was in a bit of pain, it wasn't' too much, after all.
I was on my own, which also felt ok, as I am used to be on my own: it doesn't worry me.
The waiting, as I expected, was not too long, and nothing made me feel particularly uncomfortable: the staff was very good.
When I was moved from the A&E to the ward it also was all right.

Interviewing Barbara (at her bedside, with curtains closed around us) made me feel uncomfortable. She seemed to me extremely dismissive of her experience and very resistant when I tried to get few more details from her. On top of this, she stared at me with an interrogative expression on her face and asked me to repeat multiple times a number of questions I asked stating that she could not understand me. I started wondering in myself if that was due to my Italian accent and I guess these feelings and thoughts going on in my head might in turn have affected the interview process. She did not remember the ICCI professional.

Appendix 9 - Literature review table phase B

Author/s Year Country	**Aim/s**	**Approach**	**Participants, where and when**	**Findings**	**Overall Strengths**	**Overall limitations**
Meyer et al. 1999, UK	To explore the organisation of care for older people in a A&E setting	Mixed methods; Action Research; Field notes, observation, interviews with patients, carers and A&E staff, Focus groups and descriptive statistics on data from the hospital's records.	Seven A&E staff nurses and managers interviewed over 10 months.	Staff pointed at Systemic issues affecting their ability to care for older people in A&E and negative attitudes towards older people in A&E (justifying them with those organisational factors). At the core of those negative attitudes, there was often the perception that a provision of the full range of care for older people was not "their" job.	Aims clearly stated; Results clearly Outlined; A number of different dataset and methods of data collection allows for triangulation of findings.	One site only. Findings might not be generalisable.
Kihlgren et al. 2005, Sweden	To use the experiences of emergency nurses to illuminate what constitutes good nursing care for patients 75 years or older transferred to emergency departments.	Qualitative; Semi-structured interviews	10 A&E nurses who had worked at one hospital's A&E for 10–17 years. Interviewed in a quiet hospital setting. The interviews lasted between 30 and 60 minutes.	The study showed that it was necessary to be knowledgeable, to be understanding of the older patients' situation and to take responsibility for them in order to be able to provide good nursing care. The emergency nurses shifted focus from describing the central aspect of good nursing care to	Aims and results stated clearly; Lots of direct quotations.	The sample was limited to one hospital site; Nurses are asked about their experience of caring for over 75 only, younger patients are excluded; Methodology is not clearly articulated.

				describing what hinders the provision of it.		
Robinson and Mercer, 2007, USA	To determine A&E nurses' knowledge and perception of care provided to older adults, and to obtain a profile of older adults seen in the A&E. To examine older adults' length of stay in the A&E and any contributing factors.	Quantitative; Cross-sectional Descriptive statistic using a survey administered to the nurses and a sample of patients' records.	18 A&E nurses of a rural hospital with a mean length of 12 years' experience in the A&E were administered the Geriatric Institutional Assessment Profile (GIAP). Two additional open-ended questions were added to the questionnaire: 'What are the most pressing issues you currently face in caring for elderly patients?' and: 'Do you have any other comments or reactions to a particular issue raised by this questionnaire?	Nurses felt most treatments were used with the right amount of frequency with older people. However, they also felt that pain medication was used too little. Nurses felt somewhat satisfied with the care delivered to older people. Continuity of care across settings was rated the lowest, reflecting less satisfaction. Nurses believed lack of knowledge about older adult care, economic pressures, and communication difficulties, as well as confusion over who was the decision-maker and a lack of bed availability interfered with providing good care. Staff shortages and transportation to return older adults to nursing homes were	Aims and results stated clearly; Methodology clearly articulated.	USA Health system is very different from UK and most European ones; The sample was limited to one hospital site; The problem with return transportation may be unique to the rural area served by the hospital in this study. In this community, medivans do not operate after 5:00 p.m., only ambulance service is available, but patients must meet certain criteria for the ambulance transport to be covered by the insurance.

				the highest rated obstacles to care. They requested in-service education on older adult care and information about management of indwelling urinary catheters in the A&E.		
Kelley et al. 2011, Canada	To assess the environment of an emergency department and its impact on care of adults aged 75 and over, using a 'senior-friendly' conceptual framework that included the physical environment, social climate, hospital policies and procedures, and wider health care system. Generate recommendations for practice	Qualitative; Focused Ethnography; Observation, questionnaire, semi-structured interviews and administrative data with staff, older patients and their proxies and community informants.	61 A&E members of staff of a regional acute care hospital were involved in a survey and one-to-one semi-structured interviews. Staff included physicians (10), nurses (10), support workers (3), diagnostic imaging (12), palliative care (3), rehabilitation (2), support care (2), laboratory (2), community service staff (2), clerical (1), housekeeping (3), dietary (2), pharmacy (2), security (4), and paramedics (3). 7 were management staff responsible for staff providing services to the A&E.	Staff expressed their vision of providing senior-friendly care. The A&E was fast-paced, overcrowded, chaotic and lacked orientation and wayfinding cues, as well as appropriate equipment and furniture, all of which created barriers to providing appropriate care. Seniors' expectations often went unmet, and staff expressed moral angst at recognizing unmet needs.	Aims and results stated clearly; Lots of direct quotations; Methodology clearly articulated; The diversity of participants and variety of methods of data collection allowed for triangulation of findings.	The sample was limited to one hospital site and to the experience of staff with people over 75. Might not be generalisable. Gathering data from very busy staff and very sick patients in an A&E is extremely challenging: authors warns that on-site interviews generally lacked privacy, which may have influenced interviewees' comments.

Parke et al. 2013, Canada	To identify factors that facilitate or impede safe transitional care in the A&E for community dwelling older adults with dementia and to identify solutions that would support Registered Nurses' roles to provide gerontologically sensitive care that could be tested in future studies.	Qualitative; Interpretative, descriptive exploratory design informed by a social ecological perspective; Interviews and photo-elicitation focus groups.	On top of 10 dyads of older patients/family caregiver, 10 Registered Nurses (RN) and 4 Nurses practitioners (NP) took part to interviews. RNs and NPs were recruited from two participating A&Es; RNs and NPs participated in an audio-recorded interview lasting 1–1.5 h, which were conducted by a trained research assistant at a location away from work that was chosen by the nurse. Subsequently, four nurses elected to participate in a photo-elicitation focus group.	Participating nurses distinguished between patients with and without urgent physiological problems. This suggested that if the older adult with dementia had an obvious urgent physiological problem, their priority for care would increase. However, if their presenting problem was not obvious, they were at risk for being under-triaged. RNs and NPs also recognized that the chaotic environment could impede safety for older adults with dementia. RNs described the A&E as noisy and stressful, and lacking normal cues that serve to re-orientate the person with dementia. Time pressure was a reinforcing consequence that impeded safe care because it affected	Aims and results stated clearly; Methodology clearly articulated; A diverse range of datasets allows for triangulation of findings.	Only experiences with patients with dementia were included. It might not be generalisable to experience of staff with older patients without that condition. Authors acknowledge that nurses and dyads were drawing from separate experiences. Conducting triad interviews (nurse, older adult and their caregiver) would ensure shared experiences.

				nurses' approach to care.		
Gallagher et al. 2014, Australia	To investigate emergency department nurses' perceptions and experiences of caring for older people.	Qualitative; Focus groups.	27 A&E nurses - working at least from three years- were interviewed in the context of four focus groups of between six and 12 participants. This happened in the A&E tutorial room of a tertiary referral hospital once per week for four weeks. Each focus group lasted approximately 60 min.	The first theme emerged was the clash of expectations between nurses and family/carers related to safety and quality of nursing care. Older people were perceived to be vulnerable in the emergency department, and nurses were frustrated that competing priorities decreased their ability to ensure them safe and quality care. Nurses felt family/carers were disappointed with care provided and might not empathize with or understand their predicament. The second theme concerned nurses' perception that family/carers could provide a safety net for the older person in the emergency department in times of high workload.	Aims and results stated clearly	Methodology not clearly articulated; Study participants were recruited from one A&E only, so the results might represent site-specific issues. Authors warn that while efforts were made for all focus-group participants to express their views, it is possible that some voices were not heard equally.

Fry et al. 2014, Australia	To explore the experiences and expectations that A&E nurses have of family and carers accompanying the older adult patient.	Qualitative; Focus groups.	27 nurses -working from at least three months in the A&E of a metropolitan referral university hospital interviewed in the context of four focus groups conducted once per week for four weeks during staff change-over in a room that was private and separate from the A&E clinical environment. There were four focus groups of between six and 12 participants, which lasted 45–60 min each.	Three major themes were identified from the data related to nurses' experiences and expectations of the role and behaviours of the family/carers of older people in the A&E as follows: 1. The importance of time. 2. The family/carer as an informant. 3. Getting in the way.	Aims and results outlined clearly; Lots of direct quotations.	Methodology not articulated clearly. Study was conducted at one site only and while the sample group shared many characteristics of A&E nurses in general it is not presumed to be representative of all A&E nurses. The study also did not include senior nurses and it would be valuable to repeat the study in other A&Es that have a different staff mix, demographic proportions and/or models of care and to include senior staff. Authors state that while all attempts were made for the focus group interviews to be inclusive of all participants, it is possible that some voices were not heard.
Taylor et al. 2015, Canada	To explore the experience of caring for the older adult within the A&E.	Qualitative; Focused Ethnography; One-to one semi-structured interviews and non-participants observation.	Seven registered nurses who had worked at least for three years in a mid-size urban centre in one of the oldest census metropolitan areas of Canada, and who had taken care of at least one older	Findings revealed three themes: the culture, which focused on priority setting and throughput of patients, lack of fit between the older adult and the A&E and managing lack of fit. Nurses relied on a	Aims and results clearly articulated; Methodology clearly explained.	Authors warn that the group of nurses who participated in this research may represent nurses who were particularly interested in the care of older adults, therefore findings might not be generalisable to all nurses. Moreover, they alert that this study was

			adult within the previous six months were interviewed in a private place of participant's choice. Brief follow-up interviews (approximately 15 minutes) took place on four occasions for clarification of data. The second part of the study involved 12 hours of non-participant observation of nurse participants during their scheduled shifts in the A&E. Four sessions of between 2 and 4 hours took place during peak activity in the study A&E (i.e., 10:00 am–midnight) The first author was not able to observe direct patient care but debriefed with the nurse participants immediately after	default orientation of priority setting, recognizing this put the older adult at risk of substandard care. Lack of fit was accentuated by the need to 'puzzle through' atypical presentations of many older adults.		conducted in a mid-size tertiary care hospital in a small urban centre therefore results might not be replicable elsewhere. The study A&E was the only A&E in this city and different results may have been obtained in a venue where ambulance diversion could occur.

			care was provided to an older adult.			
Gallagher et al. 2015, Australia.	To determine whom, of older people, emergency nurses perceive as using the most nursing resources and to profile this subgroup from the A&E dataset.	Mixed methods; Focus groups and data from patient medical records.	27 emergency nurses and 13 older patients in a tertiary referral university hospital were interviewed weekly -in the context of focus groups- for four weeks during staff change-over in a private room separate from the A&E between September and October of 2011, with 6–12 participants in each group	Emergency nurses perceived that the highest demand for their resources came from the older persons representing multiple times in short timeframes (cluster presenter). Cluster presenters had a longer length of stay and required intensive nursing time and vigilance because they had one or more chronic illnesses and comorbid conditions such as limited mobility and dementia. Cluster presenters had to have a full assessment each presentation, were usually admitted to the hospital and admitting specialists were reluctant to assume care. Emergency nurses experience frustration and lower job satisfaction relating to care of these older	Aims clearly stated; Results clearly articulated; Lots of direct quotations.	Single centre study: findings might not be generalisable. Methodology not articulated clearly.

				patients and this was evident in the focus groups.		
Fry et al. 2015a, Australia	To understand emergency nurses' perceptions of the role of family/carers in caring for the older cognitively impaired person experiencing pain.	Qualitative; Constructivist approach; Focus groups	80 Emergency Department nurses were interviewed in the context of 16 focus group, over a 12-week period. The average group size was five participants. The interviews lasted between 35 and 60 min. Nurses interviewed came from four different sites: two tertiary referral hospital, and two district hospital.	Three key themes relating to family/ carers emerged from the analysis. The themes included 1) the role of families and carers in building a clinical picture; 2) family and carers as a hidden workforce; and 3) family and carer roles in pain management decision making.	Aims and results stated clearly; Methodology explained;	Only experiences with cognitive impaired older patients were taken into consideration, therefore it might not be generalizable to older patients not presenting a cognitive impairment; Authors acknowledge that the use of group interviews can promote the views of more vocal participants, potentially silencing others, and thus encourage unwarranted group consensus, so the findings may not resonate with all emergency department nurses. Moreover, as the group interview questions were at times framed as a negative question, this may have biased participants towards more negative responses.
Fry et al. 2015b, Australia.	To explore the practice of care among emergency nurses caring for older persons with cognitive impairment and who presented in pain from a long bone fracture, to	Qualitative; Focus groups.	80 A&E nurses with at least one year experience across four emergency departments (including two district hospitals and two tertiary	Four main themes emerged in relation to nurses' confidence and self-efficacy for this specific field of care: (1) confidence and self-efficacy through experience;	Aims and results clearly articulated; Lots of direct quotations.	Methodology is not explained; Only experiences with cognitively impaired older patients who present with a long bone fracture are taken into consideration,

	highlight nurse confidence and self-efficacy in practice.		referral hospitals were interviewed in the context of 16 focus groups for 12 weeks.	(2) confidence and self-efficacy as a balancing act; (3) confidence and self-efficacy as practice; (4) confidence and self-efficacy and interpersonal relations. From the experiences of these A&E nurses we can see that when dealing with older people with a cognitive impairment, having confidence and self-efficacy will influence care practices and drive nursing action. However, confidence and ultimately self-efficacy, are gained through the process of developing positive interpersonal relationships with their patients, which in turn, shapes their pain management practices and their ability and willingness to be a patient advocate. Clinical settings and patient groups provide nurses with		limiting the transferability of findings; Authors acknowledge that the paper did not examine the impact that gender could have had on emergency nurse interpersonal interactions with cognitively impaired older patients, which could have presented various interpersonal and intergenerational issues.

				opportunities for learning and refining practice and behaviour. In this way nursing praxis is built upon clinical experience, knowledge, reflections and confidence.		
Bulut et al. 2015, Turkey	To determine the views of emergency service staff concerning ageing and older patients who present to emergency services with acute or chronic complaints.	Mixed-methods; Questionnaires and Focus groups.	19 physicians and 17 nurses -with at least one year experience- who worked at the adult emergency service of the Gazi University Health Research and Practice Center between July and December 2010 were administered questionnaires and then, following analysis of the questionnaires' data, two focus group interviews (one group of 11 physicians and one group of seven nurses) were conducted to obtain further information.	Four themes were determined: 1. Understanding older patients' situations; 2. Good nursing care and medical treatment; 3. Affecting good nursing care and medical treatment; 4. Emotions experienced. Participants felt that understanding and insight regarding the characteristics of older patients were important. Nurses and physicians described the older patient as a person who is aged over 65 years and in need of care, with limited or altered physical,	Aims and results stated clearly; Lots of direct quotations.	The sample was limited to one hospital site; No Research Ethics committee could authorise the study.

			Each focus group interview lasted approximately 30–45 minutes.	psychological, and social skills.		
Palonen et al. 2016, Finland.	This study aims at describing the experiences of A&E service users and nurses regarding older people's discharge education in A&Es. In particular, it reports findings concerning family involvement in discharge education.	Qualitative; Descriptive approach; Semi-structured interviews.	Participants in this study were older people discharged from centralised A&Es, their family members and A&E nurses. Nurses interviewed were 15. They had two–31 years of work experience in A&Es. The mean length of the interviews was 30 minutes; The nurses' interviews took place in a hospital setting during the nurses' shifts, in a separate, quiet and confidential room.	Family involvement in discharge education was seen as turbulent. The experiences were twofold: family involvement was acknowledged, but there was also a feeling that family members were ostracised. Families were seen as a resource for nurses, but as obliged initiators of their own involvement.	Aims and results stated clearly; Lots of direct quotations; Data were triangulated.	The sample was limited to one hospital site; Methodology is not clearly articulated.
Fry et al. 2017, Australia	To determine emergency nurses' perceptions of the feasibility and utility of Pain Assessment in Advanced Dementia tool in people over 65 with cognitive impairment (CI). The Pain Assessment in	Qualitative; Exploratory approach within a constructivist paradigm; Focus Group.	Focus groups were conducted with 36 nurses from two metropolitan teaching hospital and one district hospital over a 12-week period.	All nurse participants perceived that pain was a clinically important issue. Many reported that older people with CI who were experiencing pain often received suboptimal pain management.	-Aims and results stated clearly.	Authors alert that focus group data can promote the views of only the most vocal participants. This could result in silencing quieter participants. Consequently, focus groups may bring to the surface particular viewpoints and not be

	Advanced Dementia tool was then compared with The Abbey Pain Scale, Doloplus-2 and PACSLAC. The objective was to determine which observational pain assessment tool was the most appropriate for the emergency department		The focus groups occurred within three months of PAINAD testing completion In a private room within the A&E. Lasted between 40 and 60 minutes	Suboptimal pain management often arose from communication barriers between the person with CI. Many reported that the lack of an appropriate tool marginalised the CI older person and delayed analgesia. Nurses recognised the need for a standardised pain assessment tool suitable for use with people with CI in all Australian A&Es. Further, PAINAD enabled the nurses to better communicate with treating physicians about their pain assessment and management concerns for these vulnerable patients PAINAD helped the A&E nurses to convey more accurate information on pain intensity, which was often not possible when relying on a		representative of all participants. Second, despite three A&Es participating in the study, not all nurses who used the PAINAD tool in their practice participated in the focus groups. Further, interview times were organised for the afternoon, which may have limited the opportunity of staff to participate in the study. Therefore, it is possible that the perspectives of some nurses were heard over others and so the findings may not be generalisable. While all nurses had used the PAINAD and were familiar with the other pain assessment tools (The Abbey pain scale, Doloplus-2 and the PACSLAC), unfamiliarity of tool use within clinical practice may have biased their views. Specifically, nurses only tested the PAINAD tool and so their responses and preference for this tool may have led to tool bias in the study. In addition, the lead investigator was involved

				verbal or visual analogue scale. In contrast, in the absence of a tool like PAINAD, information on pain intensity was difficult to convey to medical staff. As a result, many participants reported that if the person seemed settled, despite the presence of significant injuries, only minor analgesics were prescribed by medical staff. The more complicated and busy the tool, the less likely the respondents were to support the tool. Their preference was for a brief, information-rich pain assessment tool for people with CI. Emergency nurses also argued for the need to better engage with medical staff as pain management policies often limited their capacity to initiate analgesics.		in the testing of PAINAD across sites and was known to participants; consequently, there was the potential for acquiescence bias, which needs to be considered when reviewing these findings. The focus is on the experience of staff with older people with CI. Pain assessment with older people without CI might be very different.

Wright et al. 2018, UK.	To collaboratively identify with emergency clinicians' improvement priorities for emergency department–based palliative care for older people.	Qualitative; EBCD (experience-based co-design); Interviews.	In-depth interviews with 15 emergency clinicians (nurses and doctors) at a large teaching hospital emergency department. nine nurses (four junior, two seniors, and three with management or supervisory roles) and six doctors (one junior, two seniors, and three with management roles) between 2013 and 2014 Interviews lasted 40 -60min	Eight challenges emerged: patient age; access to information; communication with patients, family members, and clinicians; understanding of palliative care; role uncertainty; complex systems and processes; time constraints; and limited training and education. Through feedback sessions, clinicians selected four challenges as improvement priorities: time constraints; communication and information; systems and processes; and understanding of palliative care. As resulting improvement plans evolved, "training and education" replaced "time constraints" as a priority.	Aims and methodology outlined clearly. Analysis was particularly robust as they checked back with the clinicians before confirming the findings.	A potential limitation of the findings was the ratio of nurse to doctor participants in feedback sessions. This could have distorted the importance given to some themes over others. The focus is on providing palliative care to older people, therefore not generalisable to provide care to older people without palliative needs.
Hunter et al. 2017, Canada	To understand safety and harm in rural A&E transitional care for community dwelling	Qualitative; Interpretive, descriptive exploratory design	A total of 12 HCPs, seven from one province and five from the other were	Three themes were identified: physical environment (space, design and	Methodology articulated clearly.	Focus on the view of HCP on older people with dementia only, therefore not generalisable to older

	older adults with dementia from the perspective of healthcare professionals (HCPs).	from a social ecological perspective. Interviews.	interviewed using semi-structured interviews. Interviews lasted one to one hour and a half. Participants were from nursing, social work, occupational therapy, physical therapy and medicine.	equipment), work environment (pressure to perform) and practice environment (family, knowledge and processes). A conceptual model was developed to illustrate how HCPs worked to balance safety and harm for older patients with dementia within a milieu created by the overlapping and synergistically interacting environments.		people without that condition. Findings may be not generalisable to non-rural A&Es. While moral distress among staff was present in the data, it was not explored in depth.
Gorawara-Bhat et al. 2017, USA.	To identify themes arising from nurses' perceptions of assessing older patients' pain, and to use those themes to guide development of optimal interventions to improve quality of pain assessment in the emergency department.	Qualitative; In-depth, semi-structured Interviews.	In an urban adult A&E in Midwest US, a convenience sample representing the A&E nurse population, (n = 20), comprising approximately 30% of nurses employed at that A&E was interviewed during their shift hours at a quiet A&E location. Interviews lasted between 20 and 40 minutes.	A framework was developed to conceptualize challenges, strategies, subthemes, and their classifications, yielding four typologies, comprising challenge types matched with appropriate strategy types. Major sub-themes included: A) Reported pain of patients: subjective in nature;	Aims stated clearly, Results exposed eloquently. Lots of direct quotations. Data triangulation by using participant observations, improves the likelihood that the emergent themes are reliable and valid.	Authors warn that this study was undertaken at one single academic medical center in Midwest United States, and results may not be generalizable to other regions.

				B) Pain reporting in elderly: multi-faceted and complex; C) Reported pain and observed patient behaviour: mismatch; D) Pain rating scale: oversimplifies assessment/treatment of pain; E) Protocol/guidelines: difficult to implement; F) Over-medication in the A&E: rampant; Major sub-themes to surface under "strategies" included: A) Assess the whole patient including their nonverbal behaviour; B) Document reported pain and observed behaviour in the same patient; C) Modify: 1) pain assessment scripts 2) medication dosages 3) protocols to be detailed and patient-centred 4) use nursing judgement (also often coded as any		

				combination of two or all of 1, 2 or 3 above). D) Enhance communication with patients/physicians: compassion with patients E) Be mindful of patient safety; F) Develop electronic programs, e.g. "Reassess Reminder"; G) Use nonpharmacological measures; H) Promote educational interventions in geriatric pain.		
Parks et al. 2019, Canada	To gather information about barriers and enablers that influence guideline-based care of geriatric fall patients presenting to the emergency department, from the point of view of emergency staff	Qualitative Using a Theoretical Domains framework (TDF) approach In-depth semi-structured interviews	11 emergency physicians from five ED sites interviewed. Each interview lasted between 37 and 56 minutes.	Participants felt they lacked knowledge of current evidence and guidelines related to the care of older people presenting with a fall. In addition, expressed concern regarding those same guidelines which they saw primarily as expert opinion based without sufficient data. They unanimously felt the need for training prior	Results stated clearly; Methodology stated clearly (TDF) Interviewed physicians from multiple ED sites; Analysis carried on simultaneously by 2 researchers with a third involved to resolve disagreement	Only included physicians; Only including reflections on care provided to older patients presenting with a fall; Authors state that since the study's interviewer was a current FRCPC resident, social desirability could influence interviewees' reported knowledge level and behaviours

				to implementation of these guideline-based recommendations. A widespread concern was that providing guideline-based care would increase time and workload for them within the ED, and, as a consequence, would ultimately result in less time spent with other departmental responsibilities, including patients. The majority of physicians felt that the ideal ED workup for these patients would be multidisciplinary, with many of the current guideline recommendations possibly being carried out by allied health providers. Important barriers identified to the implementation of this guidelines were also the lack of tangible positive reinforcement when providing comprehensive care		

				to these patients, and prior negative experiences with older patients. They were also concerned they may forget to consider and implement all the guideline recommendations It was frequently mentioned that emotions negatively impacted the level of care provided to older patients presenting with a fall (whether it be negative emotions induced by patient interactions, other interactions or external pressures within the ED). Lastly, physicians felt that the area of the ED to which the patient is triaged has an effect on extent of workup and evaluation, along with patient characteristics, poor availability of physical equipment such as mobility aids and poor availability of collateral historians.		

				Many physicians stated they required additional financial support and departmental buy-in to properly implement these guideline recommendations.		
Wolf et al. 2019, USA, Canada and Hong Kong	To understand: which emergency department resources and services are available to facilitate the care of geriatric patients; What screening practices are in place to facilitate the care of geriatric patients; Which community resources are available to facilitate the care of geriatric patients, and what is the experience of emergency nurses in caring for the geriatric population?	Mixed-methods Quantitative survey Qualitative focus group	1610 emergency nurses were surveyed 23 emergency nurses took part to two focus groups Focus groups lasted 1 hour each	Less than half of respondents reported that resources such as ambulatory aids, bed alarms, colour-contrast décor, non-skid, non-glare flooring pressure-reducing mattresses, railings on walls in rooms or hallways, safety mats and hearing or vision aids were always available in their departments. Less than one third reported that human resources, such as a dedicated pharmacists or social workers, were always available. Hospice-evaluation services, physical therapy evaluation, and palliative care were also noted to be always available by	Aims and results stated clearly Large sample size with data collected using different methods/methodologies In addition to member-checking (PI and 6 members of the research team) the qualitative findings by focus-group participants, the final manuscript was reviewed by all authors and by 3 members of the Institute for Emergency Nursing Research Advisory Council who were not involved in data collection or analysis. Three more experts in emergency nursing also reviewed the manuscript.	Methodologies not stated – Authors warn that this study sample comprised emergency nurses working in the United States, Canada, and Hong Kong. Both the survey and focus-group samples were self-selected and may not represent all the responses available. The differences between nurses who chose to participate and those who chose not to participate cannot be determined, and thus potentially important differences between the groups cannot be ascertained.

				fewer than 25% of respondents. Psychiatric evaluation services were reported as being always available by 57.8% of respondents. Fewer than 50% respondents reported that older patients are screened for risk for malnutrition, sexually transmitted diseases, potentially inappropriate medications, and activities of daily living. Fewer than 50% reported that it was easy or somewhat easy to communicate with home-based services; hospice agencies; nursing facilities (about a received patient or a returning patient); primary care physicians; specialists, palliative care, or rehabilitation; respite or nursing facilities when the patient is being admitted directly from		

				the emergency department. Nurses thought that older patients are often not recognized as being quite ill and are under-triaged, their vague complaints mistaken for anxiety, depression, or loneliness. Keeping patients safe was discussed almost entirely in the context of fall prevention. Interventions were targeted at the patient such as special floor mats to aid in depth perception, and at providers, such as identifying patients at risk for falls via visual cues Higher workload emerged as a theme. Participants acknowledged that the cognitive impairments and physical limitations common in the older patient resulted in a significantly longer process of not only initial assessment and		

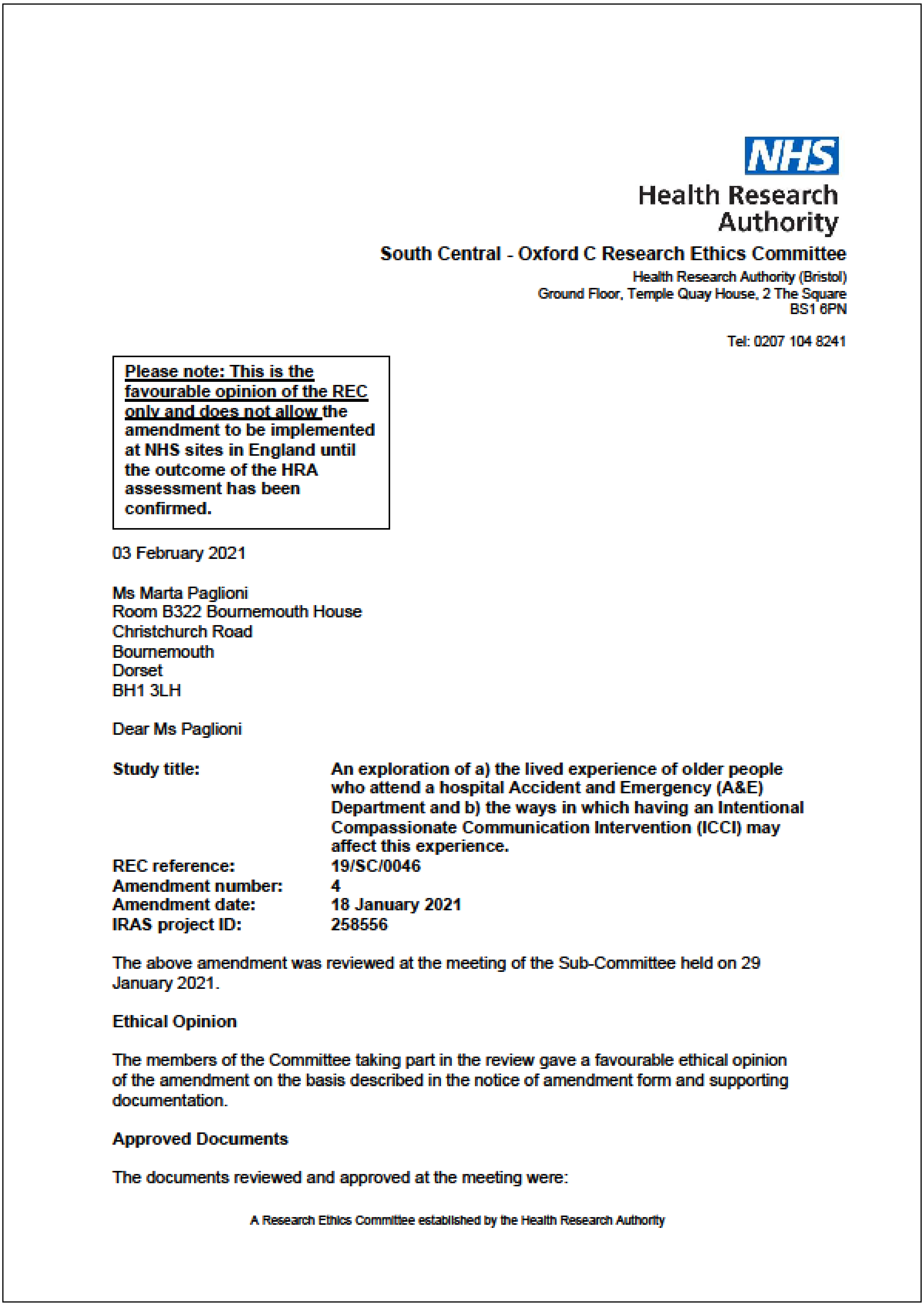
				determination of acuity but also routine preparatory care such as getting the patient undressed or getting a urine sample. Participants reported that the extended care time could result in older patients waiting longer to be seen and voiced concern that there were often inadequate resources for this care to be provided safely and with dignity. In addition, the higher workload also refers to the need for social intervention, leading to frustration for nurses who see huge gaps in the social fabric that leaves patients unable to be cared for at home. Our participants made a connection between the higher workload and the need to maintain dignity for the older patient recognizing that the lack of autonomy		

				inherent in a health care setting and the frustration of the prolonged care needs time could result in a lack of respect for older patients. The focus of discharge planning was to prevent repeated visits, so participants stressed the need for careful assessment and intervention to address logistical needs such as rides home, meal planning, and access to pharmacies Another barrier noted by participants was interest in the care of the geriatric patient. They reported that, owing to the vague complaints of older patients and the extended time required to assist them with ADLs, newer nurses who had not received training as certified nurse assistants (CNAs) had lower		

				interest and comfort levels with older patients, whereas nurses who had received that training were reported as being excellent nurses for older patients.		
Lennox et al. 2019, Australia	To explore health professionals' perspectives of caring for community-dwelling older patients in the A&E.	Qualitative; Focus groups and interviews.	54 nursing staff and allied health clinicians and seven medical staff participated in nine focus groups and seven interviews, respectively, in a private space nearby the A&E. Focus groups and interviews took place between November 2013 and January 2014, each lasting 30–60 min.	Health professionals described tailoring their approach when caring for older patients, including adopting a specific communication approach (i.e. increased voice volume, slower rate of speech). Caring for older patients was perceived as challenging given the need to balance the expectations of family members to deal with associated complex needs and limited time for transitional care planning in the A&E. The environment and equipment were perceived as unsuitable, alongside a lack of geriatric-	Aims stated clearly; Results articulated clearly.	The study was restricted to a single A&E. Also, it was focused on community dwelling older patients and therefore does not highlight the experiences of caring for those living in aged care facilities. Finally, authors state that while efforts were made to ensure that all participants were able to voice their opinions in the focus groups, they may not have been heard equally. Different modes of data collection can give different depth of data: physicians were administered one-to-one semi-structured interviews, while nurses and Allied Health professionals took part to focus groups.

				specific knowledge; contributing to what health professionals described as a poor fit between the A&E system and older patients' needs.		
Seffo et al. 2020, Sweden	To describe the experience of healthcare professionals in assessing pain and communication in patients with both hip fractures and dementia in an emergency department.	Qualitative Focus groups and Content Analysis.	Twenty-one registered nurses experienced in treating people with dementia and a hip fracture were interviewed in five focus groups between November 2018 and May 2019 in an emergency ward. Each focus group lasted between 55 and 90 minutes.	All nurses reported that the assessment of pain and communication with patients with dementia and hip fractures was a complex process. A great deal of stress, fast and brief communication, quick decisions and quick treatments in assessment of pain were only some of the difficulties the nurses emphasized. They also suggested a whole series of improvements for those patients.	Aims stated clearly; Results articulated clearly; Expands on implication for practice;	Data collected at one single research site; Methodology is not articulated clearly; Only experiences with patients with dementia were included. It might not be generalisable to experience of staff with older patients without that condition.

Appendix 10 - REC approval to Study Phase B



NHS
Health Research
Authority
South Central - Oxford C Research Ethics Committee
Health Research Authority (Bristol)
Ground Floor, Temple Quay House, 2 The Square
BS1 6PN

Tel: 0207 104 8241

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

03 February 2021

Ms Marta Paglioni
Room B322 Bournemouth House
Christchurch Road
Bournemouth
Dorset
BH1 3LH

Dear Ms Paglioni

Study title:	**An exploration of a) the lived experience of older people who attend a hospital Accident and Emergency (A&E) Department and b) the ways in which having an Intentional Compassionate Communication Intervention (ICCI) may affect this experience.**
REC reference:	**19/SC/0046**
Amendment number:	**4**
Amendment date:	**18 January 2021**
IRAS project ID:	**258556**

The above amendment was reviewed at the meeting of the Sub-Committee held on 29 January 2021.

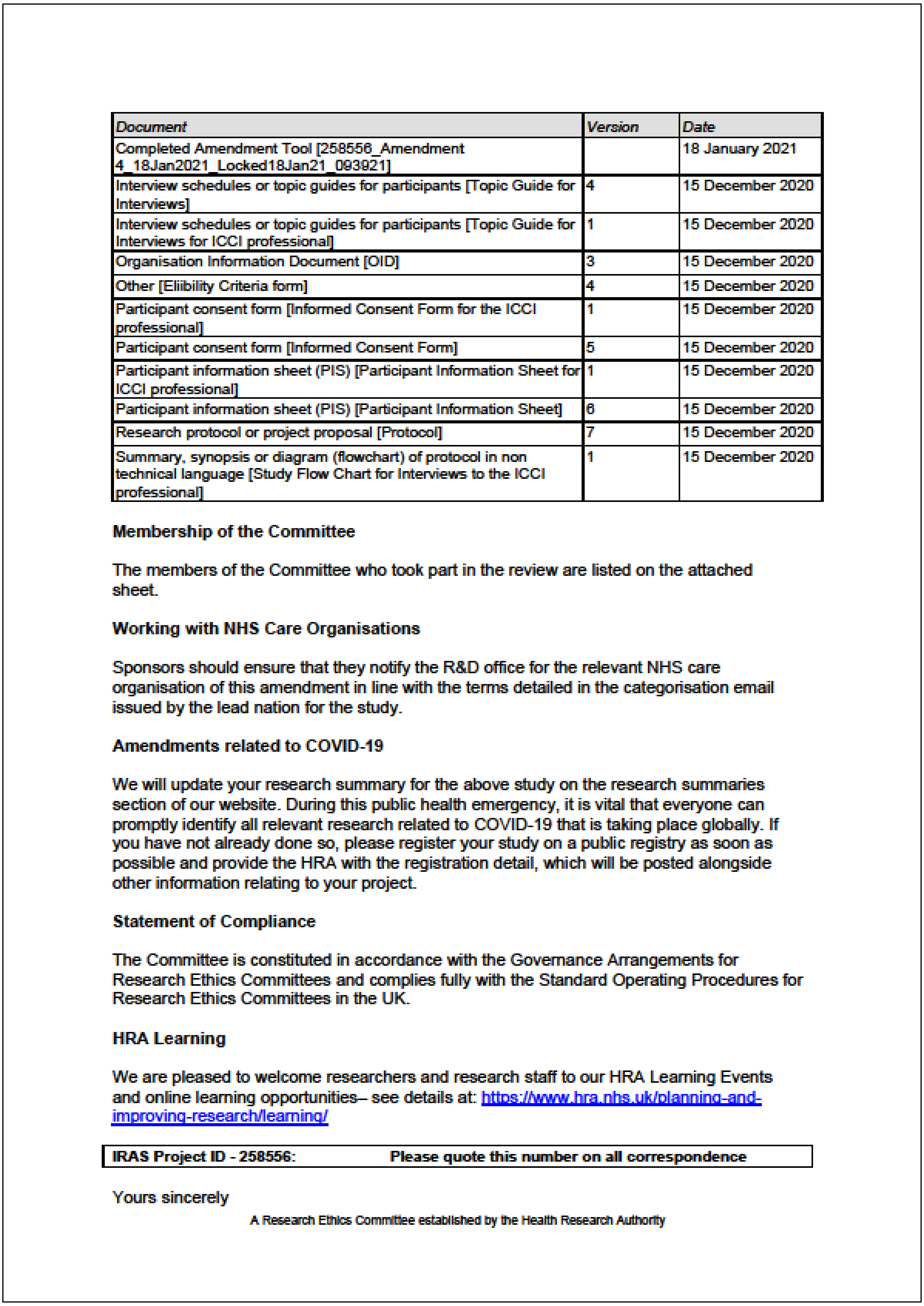
Ethical Opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved Documents

The documents reviewed and approved at the meeting were:

A Research Ethics Committee established by the Health Research Authority



Document	*Version*	*Date*
Completed Amendment Tool [258556_Amendment 4_18Jan2021_Locked18Jan21_093921]		18 January 2021
Interview schedules or topic guides for participants [Topic Guide for Interviews]	4	15 December 2020
Interview schedules or topic guides for participants [Topic Guide for Interviews for ICCI professional]	1	15 December 2020
Organisation Information Document [OID]	3	15 December 2020
Other [Eliibility Criteria form]	4	15 December 2020
Participant consent form [Informed Consent Form for the ICCI professional]	1	15 December 2020
Participant consent form [Informed Consent Form]	5	15 December 2020
Participant information sheet (PIS) [Participant Information Sheet for ICCI professional]	1	15 December 2020
Participant information sheet (PIS) [Participant Information Sheet]	6	15 December 2020
Research protocol or project proposal [Protocol]	7	15 December 2020
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Study Flow Chart for Interviews to the ICCI professional]	1	15 December 2020

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Amendments related to COVID-19

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

Statement of Compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS Project ID - 258556: Please quote this number on all correspondence

Yours sincerely

A Research Ethics Committee established by the Health Research Authority

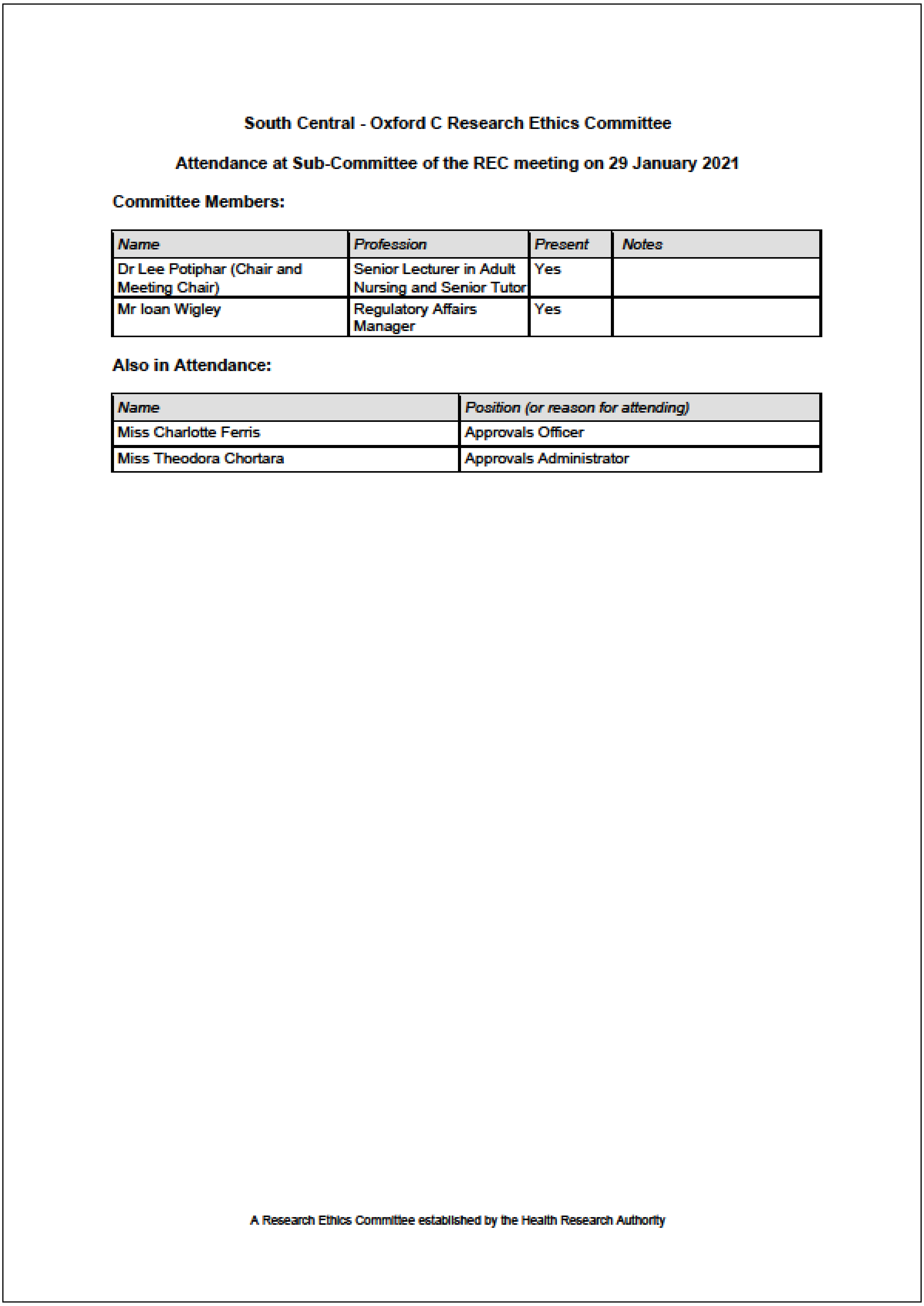
[redacted]

PP
Dr Lee Potiphar
Chair

E-mail: oxfordc.rec@hra.nhs.uk

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Ms Marta Paglioni*



South Central - Oxford C Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 29 January 2021

Committee Members:

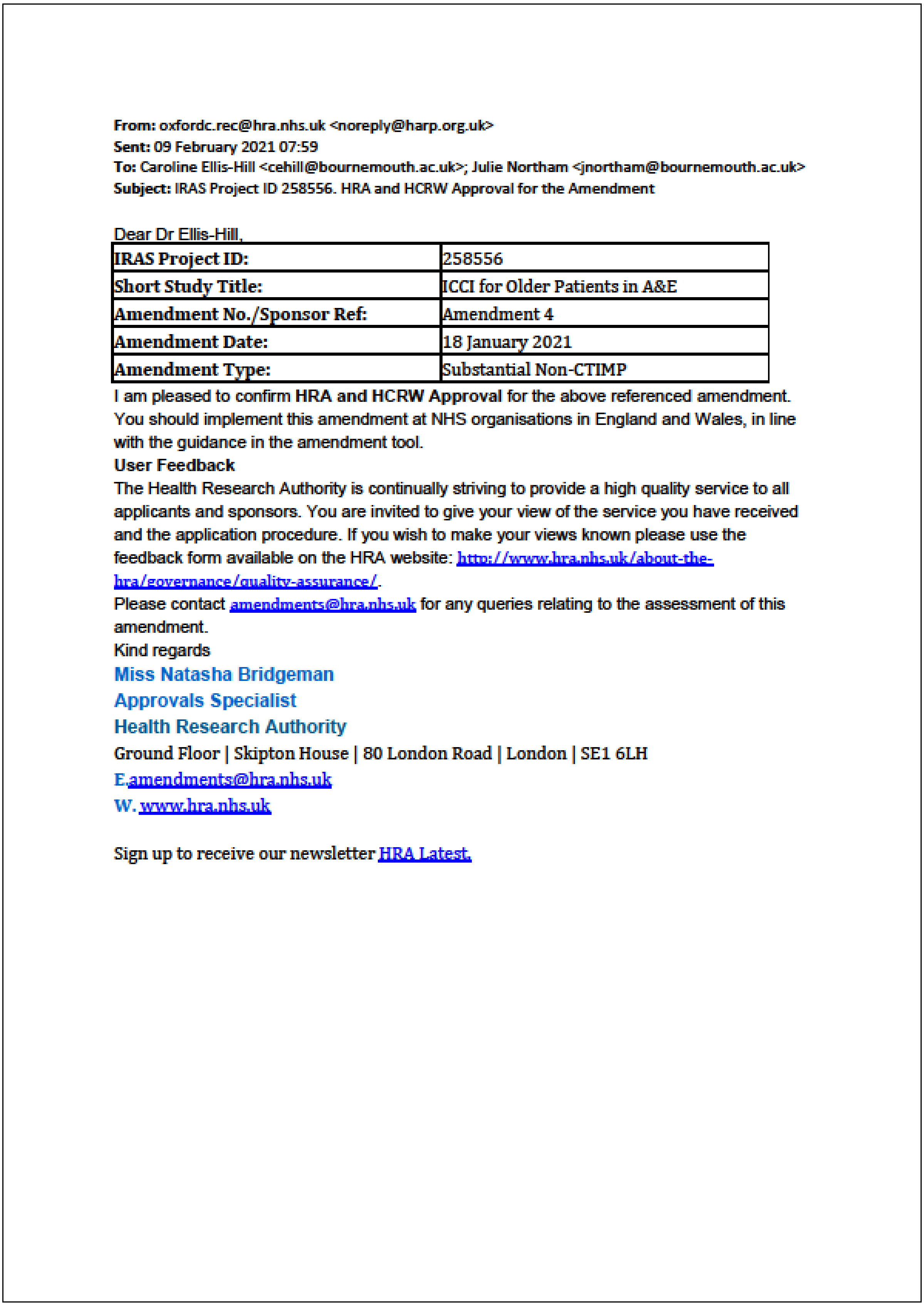
Name	*Profession*	*Present*	*Notes*
Dr Lee Potiphar (Chair and Meeting Chair)	Senior Lecturer in Adult Nursing and Senior Tutor	Yes	
Mr Ioan Wigley	Regulatory Affairs Manager	Yes	

Also in Attendance:

Name	*Position (or reason for attending)*
Miss Charlotte Ferris	Approvals Officer
Miss Theodora Chortara	Approvals Administrator

A Research Ethics Committee established by the Health Research Authority

Appendix 11 - HRA approval to Study Phase B



From: oxfordc.rec@hra.nhs.uk <noreply@harp.org.uk>
Sent: 09 February 2021 07:59
To: Caroline Ellis-Hill <cehill@bournemouth.ac.uk>; Julie Northam <jnortham@bournemouth.ac.uk>
Subject: IRAS Project ID 258556. HRA and HCRW Approval for the Amendment

Dear Dr Ellis-Hill,

IRAS Project ID:	258556
Short Study Title:	ICCI for Older Patients in A&E
Amendment No./Sponsor Ref:	Amendment 4
Amendment Date:	18 January 2021
Amendment Type:	Substantial Non-CTIMP

I am pleased to confirm **HRA and HCRW Approval** for the above referenced amendment.
You should implement this amendment at NHS organisations in England and Wales, in line with the guidance in the amendment tool.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/.

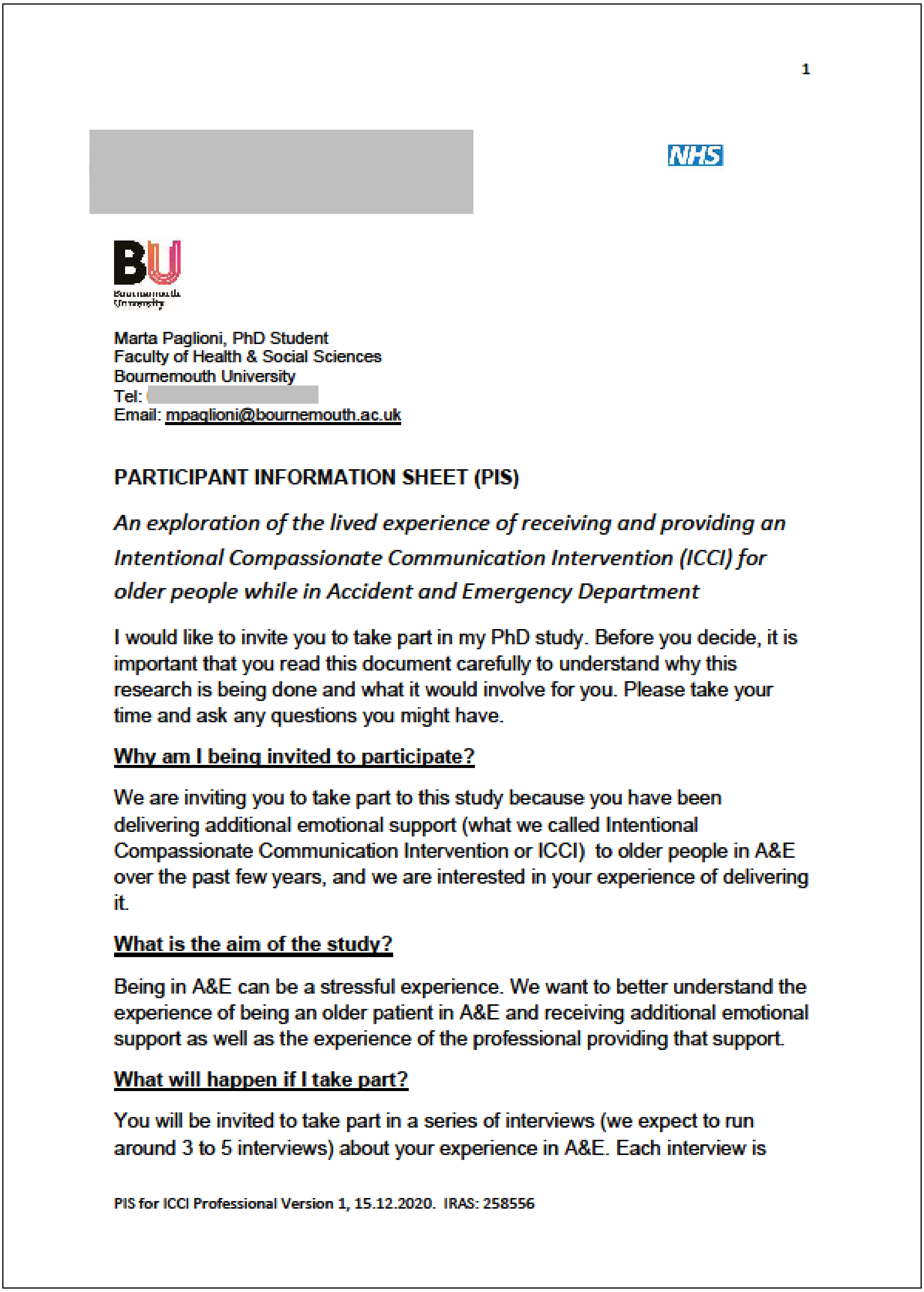
Please contact amendments@hra.nhs.uk for any queries relating to the assessment of this amendment.

Kind regards

Miss Natasha Bridgeman
Approvals Specialist
Health Research Authority
Ground Floor | Skipton House | 80 London Road | London | SE1 6LH
E. amendments@hra.nhs.uk
W. www.hra.nhs.uk

Sign up to receive our newsletter HRA Latest.

Appendix 12 - PIS for ICCI practitioner



[redacted]

Marta Paglioni, PhD Student
Faculty of Health & Social Sciences
Bournemouth University
Tel: [redacted]
Email: mpaglioni@bournemouth.ac.uk

PARTICIPANT INFORMATION SHEET (PIS)

An exploration of the lived experience of receiving and providing an Intentional Compassionate Communication Intervention (ICCI) for older people while in Accident and Emergency Department

I would like to invite you to take part in my PhD study. Before you decide, it is important that you read this document carefully to understand why this research is being done and what it would involve for you. Please take your time and ask any questions you might have.

Why am I being invited to participate?

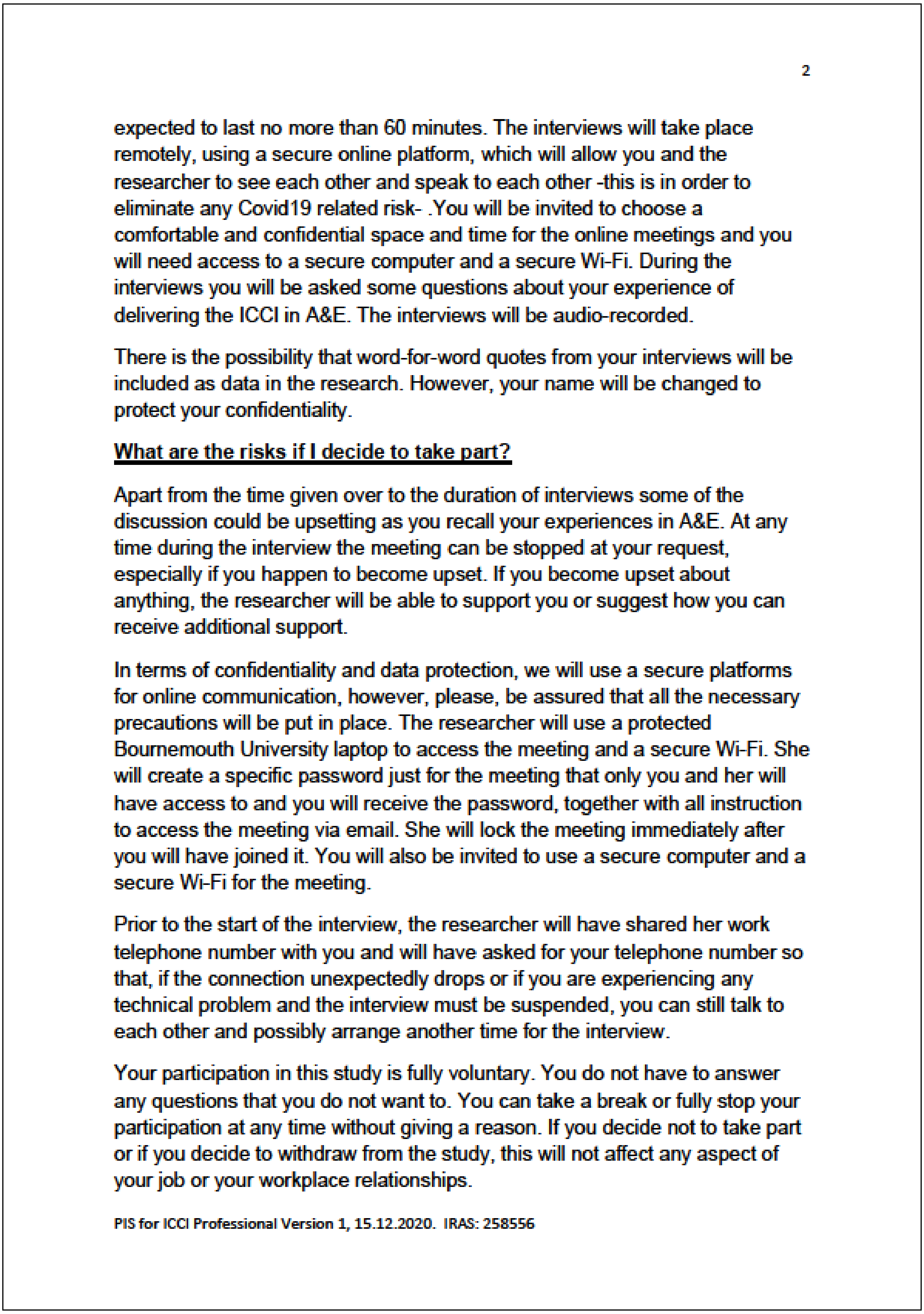
We are inviting you to take part to this study because you have been delivering additional emotional support (what we called Intentional Compassionate Communication Intervention or ICCI) to older people in A&E over the past few years, and we are interested in your experience of delivering it.

What is the aim of the study?

Being in A&E can be a stressful experience. We want to better understand the experience of being an older patient in A&E and receiving additional emotional support as well as the experience of the professional providing that support.

What will happen if I take part?

You will be invited to take part in a series of interviews (we expect to run around 3 to 5 interviews) about your experience in A&E. Each interview is



expected to last no more than 60 minutes. The interviews will take place remotely, using a secure online platform, which will allow you and the researcher to see each other and speak to each other -this is in order to eliminate any Covid19 related risk- .You will be invited to choose a comfortable and confidential space and time for the online meetings and you will need access to a secure computer and a secure Wi-Fi. During the interviews you will be asked some questions about your experience of delivering the ICCI in A&E. The interviews will be audio-recorded.

There is the possibility that word-for-word quotes from your interviews will be included as data in the research. However, your name will be changed to protect your confidentiality.

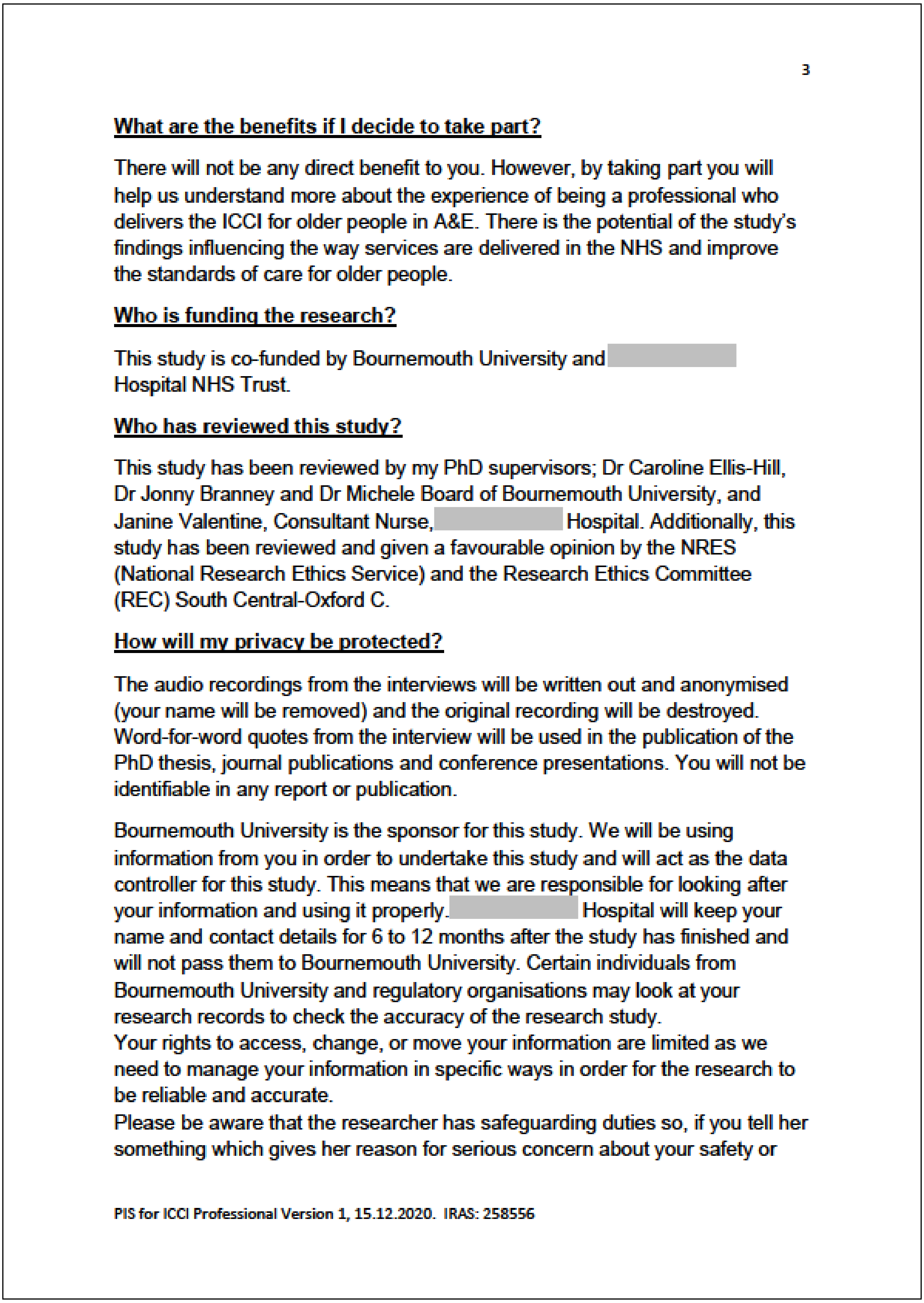
What are the risks if I decide to take part?

Apart from the time given over to the duration of interviews some of the discussion could be upsetting as you recall your experiences in A&E. At any time during the interview the meeting can be stopped at your request, especially if you happen to become upset. If you become upset about anything, the researcher will be able to support you or suggest how you can receive additional support.

In terms of confidentiality and data protection, we will use a secure platforms for online communication, however, please, be assured that all the necessary precautions will be put in place. The researcher will use a protected Bournemouth University laptop to access the meeting and a secure Wi-Fi. She will create a specific password just for the meeting that only you and her will have access to and you will receive the password, together with all instruction to access the meeting via email. She will lock the meeting immediately after you will have joined it. You will also be invited to use a secure computer and a secure Wi-Fi for the meeting.

Prior to the start of the interview, the researcher will have shared her work telephone number with you and will have asked for your telephone number so that, if the connection unexpectedly drops or if you are experiencing any technical problem and the interview must be suspended, you can still talk to each other and possibly arrange another time for the interview.

Your participation in this study is fully voluntary. You do not have to answer any questions that you do not want to. You can take a break or fully stop your participation at any time without giving a reason. If you decide not to take part or if you decide to withdraw from the study, this will not affect any aspect of your job or your workplace relationships.



What are the benefits if I decide to take part?

There will not be any direct benefit to you. However, by taking part you will help us understand more about the experience of being a professional who delivers the ICCI for older people in A&E. There is the potential of the study's findings influencing the way services are delivered in the NHS and improve the standards of care for older people.

Who is funding the research?

This study is co-funded by Bournemouth University and [redacted] Hospital NHS Trust.

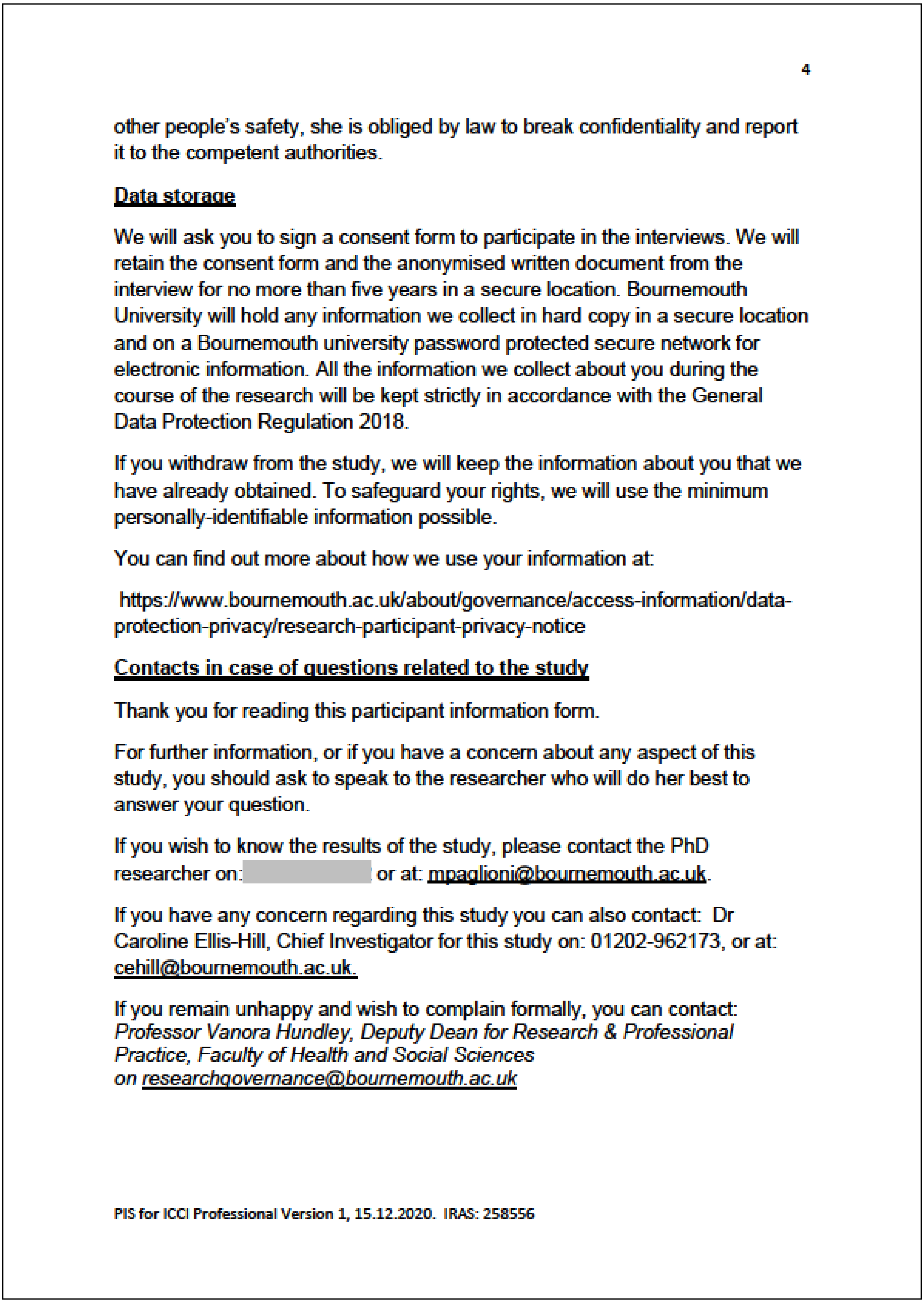
Who has reviewed this study?

This study has been reviewed by my PhD supervisors; Dr Caroline Ellis-Hill, Dr Jonny Branney and Dr Michele Board of Bournemouth University, and Janine Valentine, Consultant Nurse, [redacted] Hospital. Additionally, this study has been reviewed and given a favourable opinion by the NRES (National Research Ethics Service) and the Research Ethics Committee (REC) South Central-Oxford C.

How will my privacy be protected?

The audio recordings from the interviews will be written out and anonymised (your name will be removed) and the original recording will be destroyed. Word-for-word quotes from the interview will be used in the publication of the PhD thesis, journal publications and conference presentations. You will not be identifiable in any report or publication.

Bournemouth University is the sponsor for this study. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. [redacted] Hospital will keep your name and contact details for 6 to 12 months after the study has finished and will not pass them to Bournemouth University. Certain individuals from Bournemouth University and regulatory organisations may look at your research records to check the accuracy of the research study.
Your rights to access, change, or move your information are limited as we need to manage your information in specific ways in order for the research to be reliable and accurate.
Please be aware that the researcher has safeguarding duties so, if you tell her something which gives her reason for serious concern about your safety or



other people's safety, she is obliged by law to break confidentiality and report it to the competent authorities.

Data storage

We will ask you to sign a consent form to participate in the interviews. We will retain the consent form and the anonymised written document from the interview for no more than five years in a secure location. Bournemouth University will hold any information we collect in hard copy in a secure location and on a Bournemouth university password protected secure network for electronic information. All the information we collect about you during the course of the research will be kept strictly in accordance with the General Data Protection Regulation 2018.

If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information at:

https://www.bournemouth.ac.uk/about/governance/access-information/data-protection-privacy/research-participant-privacy-notice

Contacts in case of questions related to the study

Thank you for reading this participant information form.

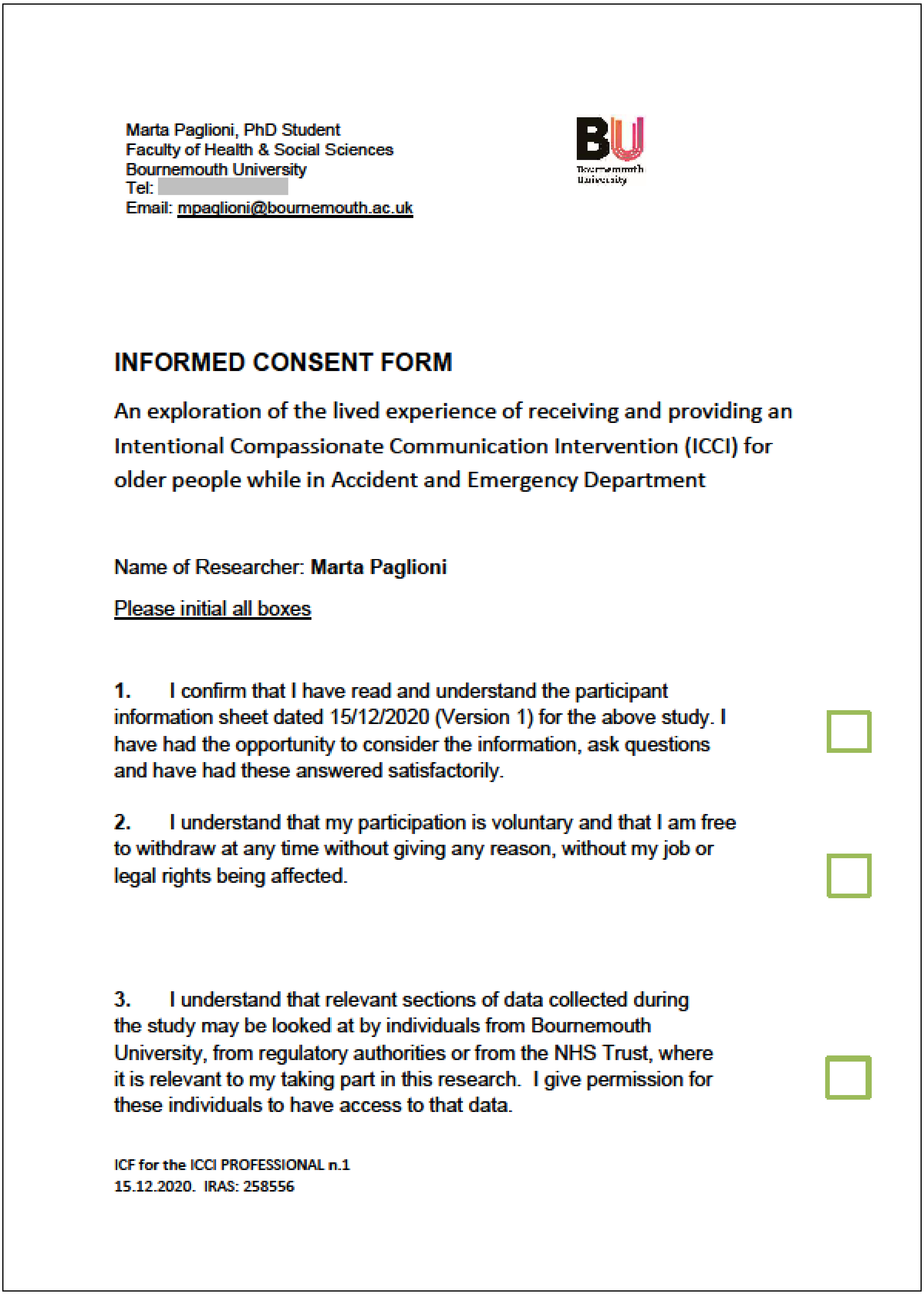
For further information, or if you have a concern about any aspect of this study, you should ask to speak to the researcher who will do her best to answer your question.

If you wish to know the results of the study, please contact the PhD researcher on: [redacted] or at: mpaglioni@bournemouth.ac.uk.

If you have any concern regarding this study you can also contact: Dr Caroline Ellis-Hill, Chief Investigator for this study on: 01202-962173, or at: cehill@bournemouth.ac.uk.

If you remain unhappy and wish to complain formally, you can contact:
Professor Vanora Hundley, Deputy Dean for Research & Professional Practice, Faculty of Health and Social Sciences
on researchgovernance@bournemouth.ac.uk

Appendix 13 - ICF for ICCI practitioner



Marta Paglioni, PhD Student
Faculty of Health & Social Sciences
Bournemouth University
Tel: [redacted]
Email: mpaglioni@bournemouth.ac.uk

INFORMED CONSENT FORM

An exploration of the lived experience of receiving and providing an Intentional Compassionate Communication Intervention (ICCI) for older people while in Accident and Emergency Department

Name of Researcher: **Marta Paglioni**

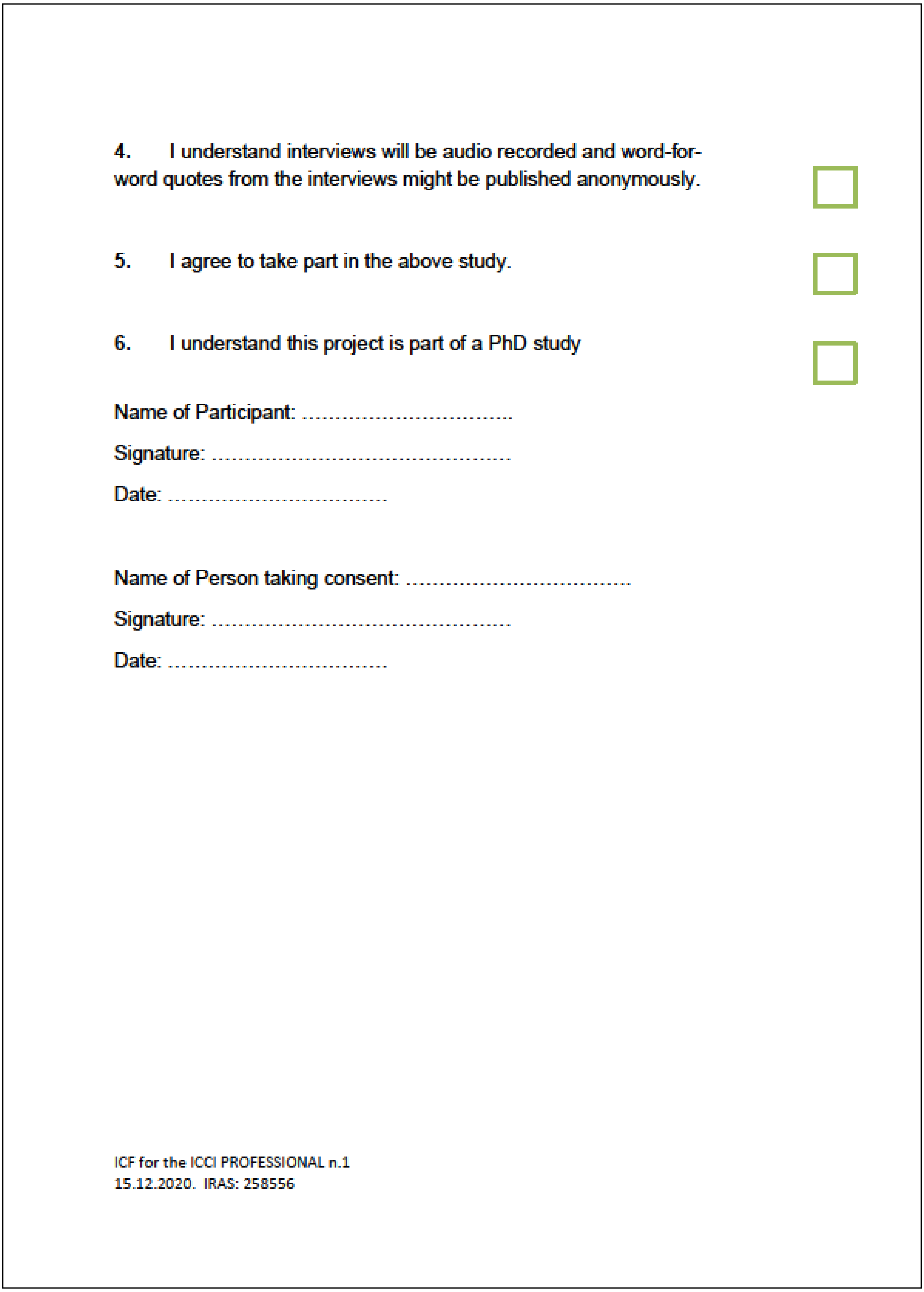
Please initial all boxes

1. I confirm that I have read and understand the participant information sheet dated 15/12/2020 (Version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my job or legal rights being affected. ☐

3. I understand that relevant sections of data collected during the study may be looked at by individuals from Bournemouth University, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to that data. ☐

ICF for the ICCI PROFESSIONAL n.1
15.12.2020. IRAS: 258556



4. I understand interviews will be audio recorded and word-for-word quotes from the interviews might be published anonymously. ☐

5. I agree to take part in the above study. ☐

6. I understand this project is part of a PhD study ☐

Name of Participant: ....

Signature: ....

Date: ....

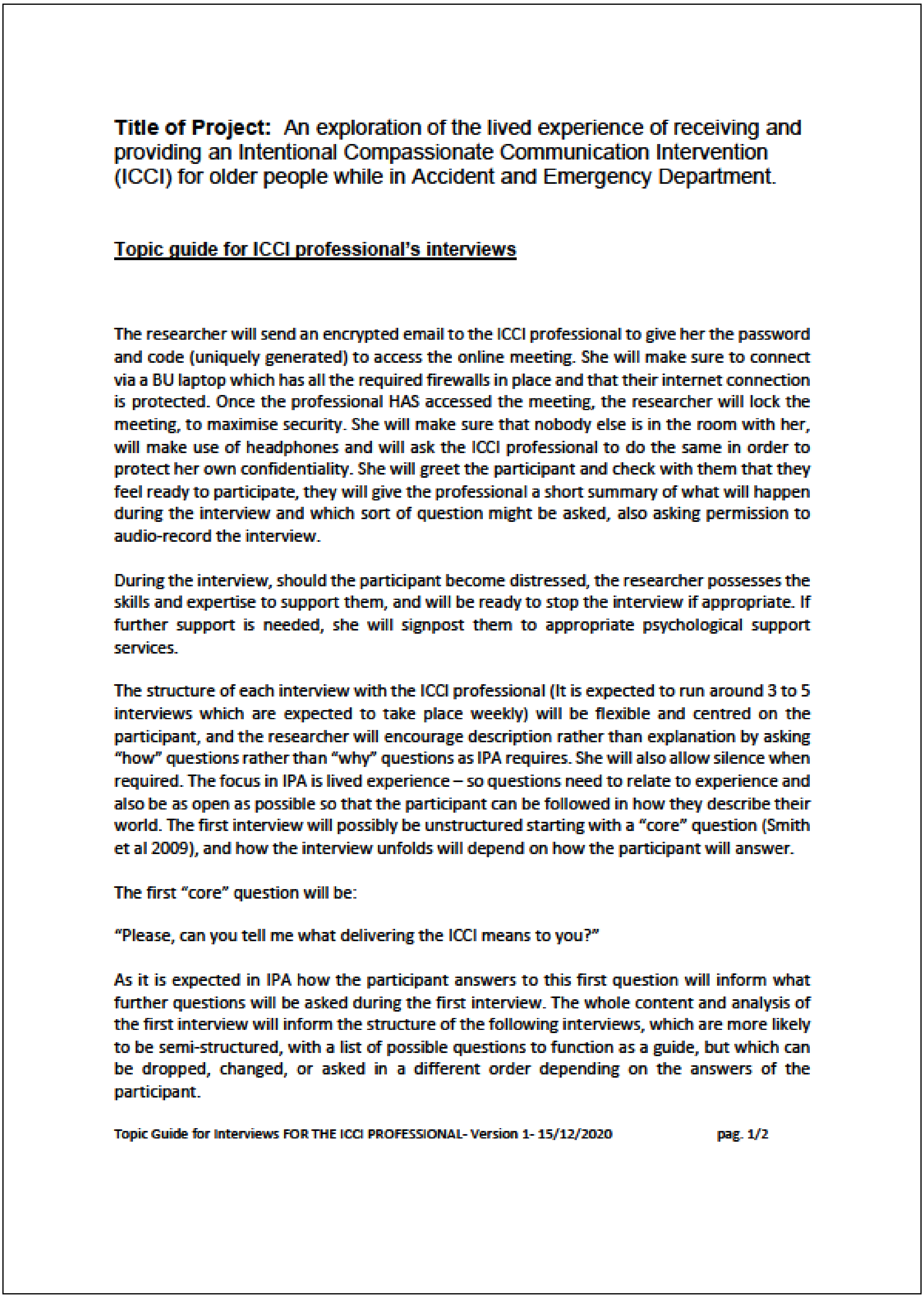
Name of Person taking consent: ....

Signature: ....

Date: ....

ICF for the ICCI PROFESSIONAL n.1
15.12.2020. IRAS: 258556

Appendix 14 - Topic guide for interviews ICCI practitioner



Title of Project: An exploration of the lived experience of receiving and providing an Intentional Compassionate Communication Intervention (ICCI) for older people while in Accident and Emergency Department.

Topic guide for ICCI professional's interviews

The researcher will send an encrypted email to the ICCI professional to give her the password and code (uniquely generated) to access the online meeting. She will make sure to connect via a BU laptop which has all the required firewalls in place and that their internet connection is protected. Once the professional HAS accessed the meeting, the researcher will lock the meeting, to maximise security. She will make sure that nobody else is in the room with her, will make use of headphones and will ask the ICCI professional to do the same in order to protect her own confidentiality. She will greet the participant and check with them that they feel ready to participate, they will give the professional a short summary of what will happen during the interview and which sort of question might be asked, also asking permission to audio-record the interview.

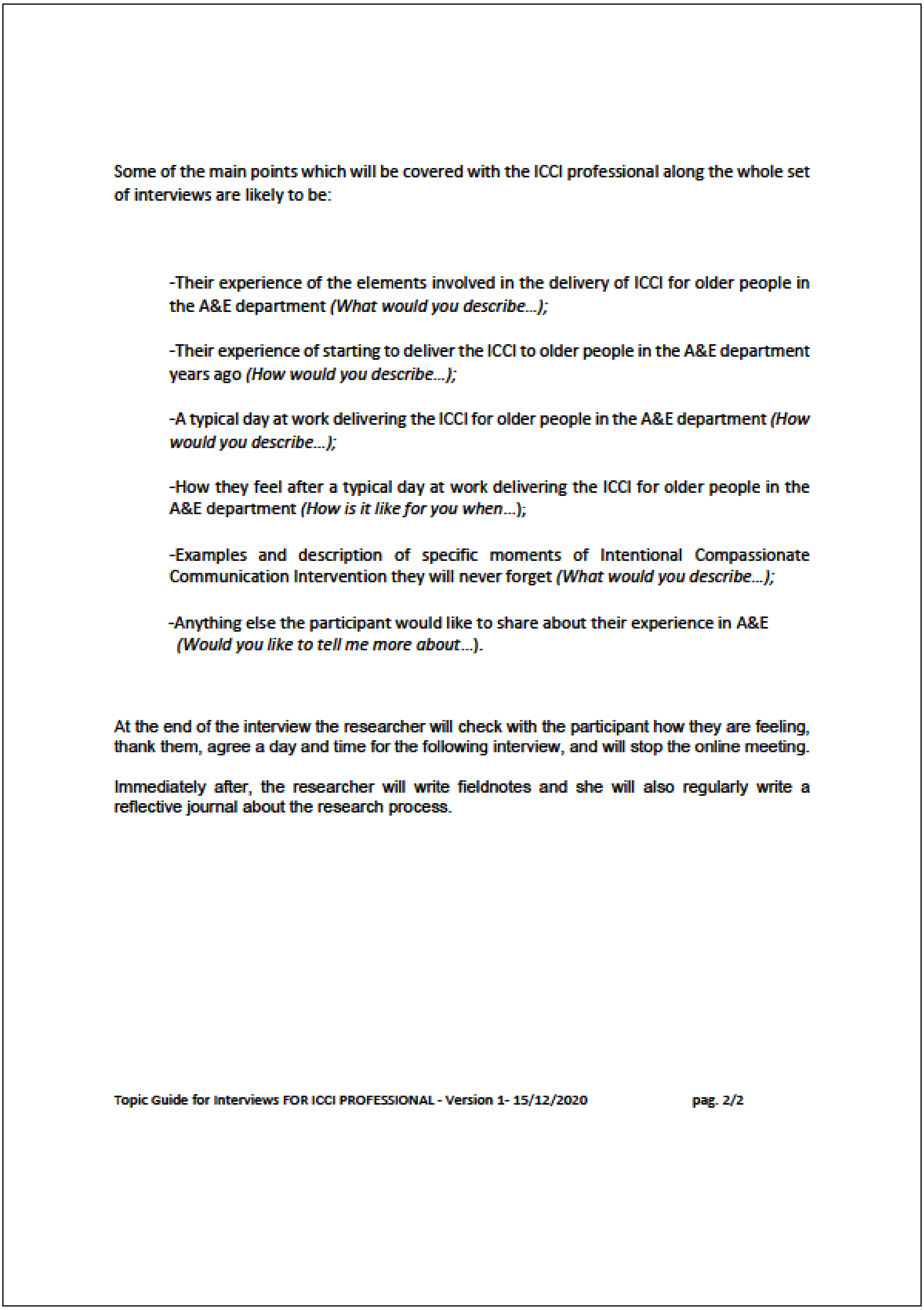
During the interview, should the participant become distressed, the researcher possesses the skills and expertise to support them, and will be ready to stop the interview if appropriate. If further support is needed, she will signpost them to appropriate psychological support services.

The structure of each interview with the ICCI professional (It is expected to run around 3 to 5 interviews which are expected to take place weekly) will be flexible and centred on the participant, and the researcher will encourage description rather than explanation by asking "how" questions rather than "why" questions as IPA requires. She will also allow silence when required. The focus in IPA is lived experience – so questions need to relate to experience and also be as open as possible so that the participant can be followed in how they describe their world. The first interview will possibly be unstructured starting with a "core" question (Smith et al 2009), and how the interview unfolds will depend on how the participant will answer.

The first "core" question will be:

"Please, can you tell me what delivering the ICCI means to you?"

As it is expected in IPA how the participant answers to this first question will inform what further questions will be asked during the first interview. The whole content and analysis of the first interview will inform the structure of the following interviews, which are more likely to be semi-structured, with a list of possible questions to function as a guide, but which can be dropped, changed, or asked in a different order depending on the answers of the participant.



Some of the main points which will be covered with the ICCI professional along the whole set of interviews are likely to be:

-Their experience of the elements involved in the delivery of ICCI for older people in the A&E department *(What would you describe…);*

-Their experience of starting to deliver the ICCI to older people in the A&E department years ago *(How would you describe…);*

-A typical day at work delivering the ICCI for older people in the A&E department *(How would you describe…);*

-How they feel after a typical day at work delivering the ICCI for older people in the A&E department *(How is it like for you when*…);

-Examples and description of specific moments of Intentional Compassionate Communication Intervention they will never forget *(What would you describe…);*

-Anything else the participant would like to share about their experience in A&E *(Would you like to tell me more about*…).

At the end of the interview the researcher will check with the participant how they are feeling, thank them, agree a day and time for the following interview, and will stop the online meeting.

Immediately after, the researcher will write fieldnotes and she will also regularly write a reflective journal about the research process.

Glossary

A&E	Accidents and emergencies hospital department
ACCU	Acute Cardiovascular Care Unit
AXIS	Appraisal Tool for Cross-Sectional Studies
BADth	British Association of Dramatherapists
BU	Bournemouth University
CARE	Care and Respect for the Elderly
CASP	Critical Appraisal Skills Programme
CIOMS	Council for International Organizations of Medical Sciences
CSD	Cognitive Spectrum Disorders
COVID-19	Coronavirus disease
DEEP	Dementia Engagement and Empowerment Project
EAU	Early Assessment Unit
ERU	Embodied Relational Understanding
GBD	Global Burden of Disease
GCP	Good Clinical Practice
GDPR	General Data Protection Regulation
HCPC	Health and Care Professions Council
HRA	Health Research Authority
ICCI	Intentional Compassionate Communication Intervention
ICF	Informed Consent Form
ICU	Intensive Care Unit
IHME	Institute for Health Metrics and Evaluation
IPA	Interpretative Phenomenological Analysis
IRAS	Integrated Research Application System
MCA	Mental Capacity Act
MHRA	Medicines and Healthcare Products Regulatory Agency
MMSE	Mini Mental State Examination
NDPC	Nurse Discharge Plan Coordinator
NHS	National Healthcare System

NICE	National Institute of Care Excellence
NMC	Nursing and Midwifery Council
PEO	Population, Exposure, Outcome
PIS	Participant Information Sheet
PPIE	Patient and Public Involvement and Engagement in Research
OPED	Older People Emergency Department
OPTA	Older Person Technical Assistant
REC	Research Ethics Committee
R&D	Research and Development
RCN	Royal College of Nursing
TAKs	Therapeutic Activities Kits
WHO	World Health Organisation