"No decision about me without me." Do people with an acquired communication disability think that they can influence strategic healthcare decision-making?

Deborah Herrick Slate

Doctor of Professional Practice

Bournemouth University

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Copyright statement

Abstract

This thesis presents my Professional Doctorate research and practice development concerning the extent to which public participation leads to influence in strategic healthcare planning. The decision to undertake this study was informed by my observations of practice as a Speech and Language Therapist and my personal experiences as a citizen of the United Kingdom.

My personal narrative is used to show how integral my own beliefs and understandings are to the topic of my study and my embodiment in the role of researcher.

The context for my research was the National Health Service (NHS) public engagement agenda and of specific focus within this context were the views of Dorset residents who are living with an acquired communication disability (ACD). In particular, I have sought to discover how this group of people frame their thoughts regarding their ability to influence NHS strategic decision-making. This is an aspect of NHS public engagement activity which has not been previously investigated. As a counter-perspective, the views of NHS commissioners in Dorset regarding their ability to be open to the influence of others were also gathered.

Influence mapping activities were used with both sets of participants and the resultant associated conversations were recorded. An ethnomethodological ethnographic framework was chosen to analyse the conversations and explore the 'ethno-methods' or taken-for-granted practical reasoning which each participant used to situate their views. This analytical approach is one which has been little used to investigate participatory constructs and one which I found merits further development.

My research findings indicate that participants with ACD used their knowledge of the world as members of UK society to frame their understanding of their power to influence and that their communication disability was not necessarily the most salient determinant within this. The ability of the NHS commissioning structure to accommodate citizen input was seen to be limited by participant groups.

Each of us deploys our stock of common-sense knowledge and understanding to organise our approach to situations and because it is taken for granted by each of us it is very rarely interrogated. Further research is needed to explore how a better understanding of these hidden methods might be used to improve the NHS participatory environment and to grow public confidence in the purpose of participation.

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Chapter 1 Personal Narrative

"Little do ye know your own blessedness; for to travel hopefully is a better thing than to arrive, and the true success is to labour?" (Stevenson 1896, p.178)

1.1 Introduction

This chapter sets out the progress I have made during the course of my studies. It serves to place me in the context of my research and my research in the context of me. I will use the Humanisation Framework developed by Todres et al. (2009) to capture the changes I have experienced. Finally, I will reflect upon the range, nature and impact of my learning and establish my ambition for the research that I have undertaken.

1.2 The Humanisation of me

In my opinion, one of the key attributes of a Professional Doctorate (D.Prof) is the value it places upon the interaction between the person, their experience and the creation of knowledge and understanding (Fulton et al. 2013).The D.Prof provides the opportunity to create a space where one can reflect upon the way things are and then challenge *why* they are that way.

Over the course of the last six years I have explored how I might fit into the role of postgraduate researcher and it has been a process of self-discovery and development which has been both painful and exciting in equal measure. I have learned as much about myself as I have learned about the academic fields of study I have pursued. In my personal narrative I will take the opportunity to evaluate what has happened to my understanding of me. As with many of my life experiences, the route by which I arrived at Bournemouth University (BU) has owed as much to serendipity as it has to planning, however I have found that the nature of the BU Professional Doctorate has turned out to be remarkably suited to my learning style. In fact, I did not know that I had a learning style when I started but through supervision, both group and personal, and through my self-directed learning and reflection I have realised my strengths and weaknesses and discovered that I can be a "scholarly professional" (Gregory 1997, p.19). It is

important to me that the D.Prof format allows *me* to be part of my research. Whilst the Bournemouth University Code of Practice for Research Degrees (2014 p.60) describes the D.Prof as requiring "in-depth research related to activities performed in the workplace", in my case much of what I have done has been inwardly focussed on me as a learning adult and the changes which I have observed in myself and in my relationships with others. The power of the D.Prof lies in situating personal development within a professional context and this has enabled me to view the experience I have through the lens of academic enquiry and, by return, view academic enquiry through the lens of me, both the personal and the professional me. The unfolding of this two-way scrutiny will be explored in detail in the remainder of this chapter.

The Faculty of Health and Social Science at Bournemouth University has made a rich contribution to the development of ideas on the humanisation of healthcare (e.g. Todres et al. 2009; Hemmingway et al. 2012). Humanisation describes a philosophic approach which values the person as an individual and places them at the centre of focus. In their 2009 paper Todres et al. defined the concepts contained within their eight-dimensional framework (*see* Table 1.1) and how they could be used to describe and evaluate aspects of healthcare delivery in order to highlight the person at the centre of care.

Forms of Humanisation	Forms of Dehumanisation
Insiderness	Objectification
Agency	Passivity
Uniqueness	Homogenisation
Togetherness	Isolation
Sense–making	Loss of meaning
Personal journey	Loss of personal journey
Sense of Place	Dislocation
Embodiment	Reductionist body

Table 1.1:　　　**Conceptual Framework of the Dimensions of Humanisation**

(Todres et al. 2009.)

The model of humanisation which Todres et al. (2009) present is one which appeals to me because it offers a way of examining the complex, interdependent aspects of dynamic human relationship behaviours. Whilst reading their paper I began to consider the possibility of using the eight dimensions of humanisation value framework as a mechanism for exploring my personal development throughout the D.Prof process. The more I thought about using the dimensions, the more they seemed to fit with the way I had been thinking about my experiences. I believe that they are as capable of supporting reflective practice on one's relationship with one's self as they are to reflective practice on one's relationships with others. I am therefore going to proceed by using the framework to value my own experience through the humanising dimensions.

1.2.1 Insiderness/ Objectification

Insiderness relates to the association between who I am and how I feel - my sense of myself.

I have worked in the National Health Service (NHS) as a Speech and Language Therapist (SLT) since 1980. I realised how closely I identified with my chosen profession when I spent a short time, still within the NHS, working as a General Manager. This was a role which I hated and felt lost in; I did not know how to value myself if I was not being a Speech and Language Therapist and I left the general management role as soon as I could.

I have had a career-long interest in how relationships affect how people communicate and relate to each other and what it means to be valued; it is this instinctive interest that has matured into my current research endeavour. I have found the process of becoming a postgraduate researcher revealing. I have always thought myself to be a trudging student, long-hauling it through whatever educational or academic undertaking I was engaged upon. However, in parallel with that, I know I have a lively imagination and an eternally enquiring mind. I am very, very, fond of ideas and I love words, particularly unusual ones. I am creative, flexible and, more often than not, slapdash. During the first year of the D.Prof each member of our cohort was tasked to produce a PowerPoint presentation on our personal progress. I chose to show my progress, à la Jules Verne, as a journey to the centre of my mind. At the beginning of the D.Prof I was

feeling that I had lost my ability to think independently, lost my sense of autonomy and that I had become a cog in the NHS machine. I have always hated feeling obliged to do something which makes me feel invisible. I do not mean that I need to be noticed, in fact I am very uncomfortable in the spotlight, but I need to be visible to myself and to feel satisfied with myself (not in a smug way but in a noticing way) and what I am doing. In my opinion, the power that feeling pleased with one's self releases energises how one relates to the rest of the world. However, whether feeling pleased with myself is the same as feeling at one with myself is another matter. I suspect not because I can feel pleased about tiny things or big things which exist like islands in the sea of me but the overall sea can still be choppy and uncertain.

Insiderness is a term used to define a feeling of identity that comes from congruence between one's feelings of self-worth and one's external relationships with the world (Todres et al. 2009). The contrasting concept of objectification describes experiences where others define the parameters of self-worth and relationships. My time as a General Manager represents an instance of objectification but I feel that I am probably very fortunate not to have had much personal experience of being, or rather feeling, objectified. However, in my work life I have been exposed to situations where others have been. These situations have arisen in both clinical and managerial contexts and my perception is that these circumstances often relate to the expression of power relationships. Power is a theme in my Doctoral research and one that has presented rich opportunities for thinking. For my personal narrative my reflections regarding the nature of my own power have instigated the recognition that I have a strong sense of my own insiderness and that it is this that has driven me through my D.Prof to date; I am doing this degree for me. In acknowledging this I must also recognise that my sense of insiderness will shape my research, the way it is experienced by others and the notions of power that this may introduce.

I am also an insider as a researching professional investigating an aspect of my own professional environment. By its very nature the D.Prof expects that the student will be bringing their professional knowledge and experience to bear in their chosen research context. The concept of social situatedness (Vygotsky 1986) was applied to the field of learning and research by Lave and Wenger (1991) to explore the relationship which exists between the researcher and the

situation and the context in which the research event or action occurs. Researching one's own field of practice creates a type of insiderness that can bring challenges arising from familiarity or complacency and which may lead to ethical dilemmas. For example, a method which requires the researcher to act as the interviewer could create a situation where the combined role of both researcher and interviewer may influence the nature of the information given by the participant (Kvale 1996) or vice versa (Monroe and Obidah, 2004). Awareness of the potential for the insider's taken-for-granted knowledge, viewpoints or beliefs to affect the findings, either during data gathering or analysis, is important in order to protect the trustworthiness of the conclusions produced (Poggenpoel and Myburgh 2003). My intention to work with people who have some difficulty in communicating means that I must make particular effort to be aware of my taken-for-granted assumptions about my research, as this may reduce my ability to be objective or to be open to different possibilities or explanations. I will address this point further in my research methodology chapter.

1.2.2 Agency/ Passivity

Agency relates to what choices I have and what responsibilities they bring.

I think that I have enjoyed a remarkable degree of autonomy in my life and this has extended to my experience of the D.Prof. The degree of latitude which the BU D.Prof format has allowed has created a wonderful feeling of ownership of the product I have made. I have been able to direct my learning and devise my own outcomes. In group discussion sessions this freedom has been likened to being given a lump of clay and being allowed to make it into whatever one felt it needed to be. The stereotypical image of a passive student receiving knowledge from the educators has not matched my particular experience. I have felt engaged with and empowered by the process and supported and encouraged by my educators. Any passivity which I may have displayed has been entirely self-generated.

In my career, from the outset, I felt able to implement my own ideas independently. In my first year of working I set up a Speech and Language Therapy service to adults in the locality in which I worked. I continued to follow

my own instincts in this vein until, in 2008, I found myself in a place where I was feeling trapped by obligations to organisational systems. Fortunately, in 2009 I saw a chance to step sideways into a secondment with the Dorset Stroke Network and I spent a year working on their communication disability project for which I was given the freedom to design and the responsibility to deliver. It was the product of this project which led me to decide to pursue my current postgraduate study. Having made the decision to return to studying as a consequence of opinions I had formulated during the Stroke Network project, I found that I was actually very bad at making choices when the choice concerned deciding on detail. I could determine the grand plan but not the execution of it. Lee-Ann Fenge, one of my personal supervisors, frequently used the analogy of a station platform during our early supervision sessions when referring to my seeming inability to get going on the detail of my project and particularly with respect to my lack of ability to put anything down on paper. She described her own experience in the early stages of her D.Prof as being like a person on the station platform who could not commit to getting on the train. On my platform I just couldn't assimilate the new information I was acquiring into a journey plan that made sense to me. This experience of inaction rather than action was quite unsettling but I knew that I did not have the skills to get myself moving at that time. I have learned that passivity can, sometimes, be an essential element in achieving growth. Part of my personal development during the course of my studies has been to acknowledge that stillness is as important as movement.

One of the barriers to action has been commitment to the act of writing. I continue to find writing very difficult because I have to choose what to say and how to say it in a way which conforms to academic expectations. It was initially very disempowering to be held to account for choices in vocabulary that I was using from my generic understanding but which were, it turned out, somebody else's and therefore required referencing. Losing trust in my vocabulary and mode of expression had an associated impact on my ability to think, I became uncertain of how to integrate old thinking patterns with new ones. I lost my voice. This unexpected aspect of the process has emphasised the importance of voice in agency. When my confidence in my ability to express myself was reduced I found that I could say nothing and felt powerless to change things because of that. I have been able to reflect on the insight this has provided into the world of

someone who has lost their ability to use their familiar language patterns because of stroke and perhaps better understand how this might feel.

1.2.3 Uniqueness/ Homogenisation

Uniqueness relates to what I am as an individual.

Recently I took part in some research by Dr Carole Pound and Dr Caroline Ellis-Hill at BU (June 2015) which concerned exploration of "lifeworld" (Husserl 1936 in Galvin and Todres 2012) approaches to rehabilitation. Participation in this project opened up a conversation about "what it means to be human" (Galvin and Todres 2012, p.22). Each contributor was asked to arrange, from a selection of craft items, a collection which they felt represented them as a person. The sharing of histories and perspectives during the creation of the representations allowed for insights to be revealed and understood. I chose a scrambled ball of multi-coloured threads which I placed on top of a shiny turquoise stone.

Figure 1.1:   Lifeworld image

This image (Figure 1.1) represents how I experience myself because I think that I am outwardly quite disorganised. However, this external appearance is made of

distinct, consistent elements which all have a relationship with each other. I am a mass of separate colours, not a homogenised brown. I have a capacity to manage a large number of different activities at the same time and to make sense of them to myself, although admittedly I do not always find the end of what I am doing. On the several occasions when I have completed personality style questionnaires for work I have always been categorised in the same way- as someone who is creative and initiates ideas but who is less good (in fact really quite bad) at doing the detail and finishing things. I like the overall effect to be satisfying. My approach to what I do could be captioned "what the blind man on the galloping horse cannot see does not matter". This is perhaps not the best set of innate attributes for a scholarly professional but they are all I have.

The turquoise, which is my birthstone, represents the centre of me which I try to keep hidden from most. I was not sure what the centre of me was when I started the D.Prof but, because of the direction my studies have taken, I find that I am more passionately motivated by ideas of justice and equality than I thought and I have discovered opinions that have come into being from deeply held but previously unrecognised beliefs. I find my inner constructs to be inter-related and compatible on a level that I have never explored before and perhaps this is what life experience creates when you are not looking. What I have found completely entrancing and exciting is that I can find writings from eminent thinkers which chime exactly with what I feel about things myself. The themes I have pursued have brought Bourdieu and Goffman and Garfinkel to my door and what they express makes me feel like I could belong in their world. It is a remarkable process to discover that what makes you tick as "you" and defines you as an individual and unique person also enables you to join a group.

My chosen topic for research expresses my beliefs in justice and equality in the context of NHS participation and seeks to establish whether what I perceive through application of my own experience and values is substantiated by the experience of others. Valuing one's own uniqueness is important but it is just as important to value the uniqueness of others. The temptation to use assumption about the nature of others based purely on one's own preferences and drivers is huge. Reflecting on this I recognise that society requires there to be some overarching assumptions made which the majority are happy to accept but equally nobody wants to be whitewashed out of the picture. I had direct

experience of the product of assumption as a result of arranging to meet my constituency MP. In 2012, in an effort to achieve some personal experience of civic participation as preparation for my research project, I took advantage of the opportunity offered by the political process and attended a constituency surgery of my local MP, Mr (now Sir) Oliver Letwin. I found the encounter completely extraordinary as, having been greeted and offered a seat; I then sat for a good ten minutes while Mr Letwin told me why I was there. I was at that moment truly voiceless. Eventually, I was given an opportunity to correct his assumptions but I felt no assurance that I was being listened to. It drew my attention to the dynamic of such encounters and to the fact that expectation and assumption had led to my disappointment in the experience. It showed me the power of un-met expectation in shaping one's appreciation of an event. Or perhaps, more accurately, mismatched expectation. I realised that I had formed my views of what might be achieved by seeking an interview with Mr Letwin on the basis of little knowledge about or experience of MP's surgeries and no information, other than the various media representations, about Mr Letwin himself. However, I fully anticipated that I would be listened to and conversed with on an equal adult-to-adult basis and, foolishly or naively, I now see that I expected him to be interested in what I had to say. Mr Letwin on the other hand, were he to be asked, would probably have a very different set of expectations and assumptions. Neither of us thought it necessary to check this possibility out prior to embarking on our exchange. We had already categorised each other. Schutz (1967) would describe this in phenomenological terms as typification, whereby unknown others are assigned a "type" based on previous knowledge or experience. On reflection I can see that I was cast in the role of "constituent". For Mr Letwin, as he told me in his opening peroration, people only come to see him when they want something and in this context the descriptive term "oik" was used. Constituents it would seem are one of life's inconveniences. Once he had given me my turn to explain why I was there, which was to ask him how he managed to conduct constituency meetings with people who had a communication disability should they wish to see him, Mr Letwin assured me that people like that didn't come to see him and, in his opinion, should not be given the opportunity to make any decisions anyway. For me, in every way, this was a truly homogenising experience. I felt that I was not being seen as an individual with a unique point of view but rather as a constituent. As a constituent I felt that I

was being cast as something bothersome, ill-informed and demanding. In addition to my personal reaction to this encounter I also was left thinking that Mr Letwin's response to difference, whether that was of opinion or of ability, was one which was designed to deny the value of any individualised perspective.

1.2.4 Togetherness/ Isolation

Togetherness relates to how connected I am and what communities I belong to.

I am a connected person. I create and use networks which are expressed through interpersonal contact but I am poor at managing modern social connectedness through the likes of Twitter, Facebook or Linkedin where the relationships can be more remote. I like belonging but I do not like not being in control. I join things, for example from my past, the Parish Council and the School Governing body. I have a sense of needing to contribute but I also hate being tied in or feeling obliged to do things. I feel that I am a member of my profession, a colleague, a boss, a student, a wife, a mum, a friend and there is no sense of hierarchy intended in that list. I would say that I am someone who reaches out, however I am aware that my communities have become much smaller over the last few years as my outward focus has diminished.

Within the D.Prof I am a member of a group of women who all started their D. Prof in 2010. We have all participated in a group supervision forum from the very beginning of our studentship. Group Supervision has been a safe harbour to return to throughout the D.Prof voyage. From the outset we found ourselves to be a likeminded group of women of a certain age. The monthly meetings have provided a place for sharing and discovery and we have been ably supported in doing this by our team of group supervisors. Each of our mentors has showed us how to be independent in our thinking, to take time to develop our thoughts and explore the various models and meanings of scholarly development (Holloway and Todres 2003).

It was interesting to learn how we each approached the challenge of realising our postgraduate ambitions. Some of us were there because of career pathway and some because of purely personal motivations. The back stories which unfolded during the first two years set the nature of our relationships – relationships which

have become strong and caring, but not close. The greatest feature of our cohort bond is that of respect. We have learned about each other's fears and frailties but we have also learned about each other's strengths. There has never, in my perception, been a spirit of competition between us and when along the way two of our number left the group it was felt as a significant loss. The sense of belonging to this group has been very important to me. I have discovered, as a result of being in my cohort group, that I can be part of something which, because it is neither work nor family related, has afforded me the chance to create a different expression of me and this has been liberating. I have been able to find a part of my personality that I had hoped, but did not know, was there. I have found that I have been able to challenge my own perceptions of myself and to see what my answers might be. I have created a different me from the work and family me.

Part of the magic that has happened in the group supervision sessions has been conjured from the creation of a common context within which we have all been able to find a place to learn and grow. Our like-mindedness in terms of our expressions of belief in social justice, equality and person centeredness has enabled our individually distinctive perspectives to be shared and understood. The discussion and debate has certainly developed my ability to appreciate new ways of thinking and to think in new ways myself. Etienne Wenger (1998) defined this phenomenon within his concept of Communities of Practice through which he locates human learning within a social context. He suggests that the complexity of social engagement creates potential for the creation of meaning through participation and co-creation. I feel very strongly that this is what I have experienced through the group supervision sessions. I also feel that the Communities of Practice concept relates closely to my research interest in terms of offering a bringing together of ideas concerning the development of shared purpose and understanding.

Lack of membership can feel like isolation and, as a personal illustration of a struggle to achieve membership of a community, I would select my cultural challenges to re-calibrate from work culture to academic ways. It has been a struggle sometimes to understand and accept that the way people work and think in a University setting is not the same as the way it happens in my work setting. It has taken time for me to accept that the "right way" is a construct which can

constantly be open to debate and that questions do not always need to have answers. In fact, in my experience to date, questions are more often than not answered with another question. So, one must learn to swing confidently from one to the next, Tarzan-like amongst the academic lianas, and try not to dangle trepidatiously around the edge of the jungle for too long. I could have helped myself by seeking a closer relationship with my postgraduate peers through participating in the wider student community. I am obviously registered with the University and as a part-time student I have access to all the benefits that a full-time student would have. However, I have never felt that I have developed a relationship with the University as an institution nor with the Faculty in which I belong nor with the other postgraduate students - other than those in my cohort. I have found it too difficult from a geographical and a time point of view to sustain the effort to become connected despite the open and welcoming invitations from others in the Faculty to join in with things. I think that this has given me a very different experience of being a student and it has meant that I have been self-reliant in terms of my studying. I feel very much that my D.Prof is **MY** D.Prof. The freedom of independent studentship can also bring the potential for isolation. Discussion with both my group and my personal supervisors has brought to light research which they and others have done on the experiences of D.Prof students (Hutchings 2015; Fenge 2012; Carr, Galvin and Todres 2010) and what they also reveal is the potential loneliness of part-time postgraduate study. Whilst I can fully understand how the process can create a feeling of isolation when the desire is to belong, I have been very conscious that I have actively chosen not to belong to the wider institution and the freedom to choose this option has suited me just fine.

1.2.5 Sense-making/Loss of meaning

Sense-making relates to how I create meaning.

I create meaning through reflection. I am naturally good at it and spend a lot of time doing it. This is not to say that the products of my reflections are always helpful in creating sense or meaning. I find that very often they become a source of worry and anxiety because I can construct a whole range of "senses" from what I perceive and then how does one choose which sense to connect to? This

links, I think, to my preference for rules. Rules help define sense for me because they provide a recipe to which one can add one's own ingredients but still get a recognisable product at the end. I am, possibly contrarily in the light of other parts of this narrative, an obedient person. I do not always like the obedience that I construe the rules to be requiring but I still find it very hard to break them. Perhaps this is the origin of my constant internal dialogue?

My D.Prof study path has taken me into areas of knowledge which I have had absolutely no familiarity with. It has been challenging to assimilate all the information into a body of knowledge which means something to me. Initially I found the experience strangely alienating, rather like looking at some things you really want through a plate glass shop window, being able to admire their colour, shape and size but not being able to feel them or try them on. After a while, I found that I had accumulated enough academic currency to acquire the items but wearing them felt awkward and vaguely fraudulent, a case of imposter syndrome (Clance and Imes 1978) perhaps. Through my personal supervision sessions, I have been able to ask for style advice and have been given frank opinions about what suits me and what does not. I have now reached the point where I am confident to choose for myself and be happy about my choices.

Making sense of what I have learned has been an episodic process - long periods of nothing apparently going in and then suddenly something shifts and finds a place to fit. I have come to just accept and be grateful for this; it must be me who is doing it and it is not necessary to know how! There is a new wave of appreciation for the "slow" in life - slow food, slow living and now, slow scholarship (Muller 2014; Berg and Seeber 2013). In their paper embracing "Unspecialisation" Galvin and Todres (2007) explore the importance of contemplative thinking in the construction of knowledge. Significance lies in accepting that time is part of sense-making and the skill in doing this comes from not fighting and wrestling to make things fit but just taking what comes and enjoying things for what they are. The resulting discoveries from connections made are where the "eureka" moments come from, when insight about a solution provides more clarity than can be achieved through analytical thinking on the same subject; "knowledge can hinder discovery" as Knoblich and Oerllinger (2006, p.38) wrote.

1.2.6 Personal journey/ Loss of personal journey

Personal journey relates to my past, present and future.

I will be 59 when I submit my thesis for consideration of the award of Doctor of Professional Practice. A sense of age, or perhaps more specifically time, is something which I have not been particularly conscious of before now. But being nearly 60 is a very strange feeling. My life experience to date has given me a nice journey on the whole but, reflecting for this narrative, I realise that I have self-determined much of my journey according to my perceptions of the needs and expectations of others. Not that I think that this is necessarily unusual, for it is part of socialisation, but I have never particularly thought of it in this way before. I want and probably need people to be pleased with me but I now see that I also want to be pleased with myself. By and large so far, I have succeeded in both aspects of this endeavour.

I have absolutely loved being a Speech and Language Therapist in every way. After I graduated in 1980 I considered applying for a PhD position but I was offered a job and so took that instead as I thought I ought to earn some money. My career progressed swiftly and by 29 I was the youngest Speech and Language Therapy Service Manager in the country. During this time I continued to study, completing a Diploma in Management Studies and an MSc in Human Communication between 1988 and 1992.

Alongside my professional development during this period I became a wife and then a mother. These aspects of my journey are as important to me as the external professional but are not for sharing. My personal journey has certainly been hugely influenced by my family and they are very relevant to me being who I am but they are not for exposure in this context. This decision however has made me reflect upon the capacity to choose what parts of ourselves we reveal. Some of it is conscious but other aspects are not and I have to assume that everybody makes similar conscious editing decisions all the time, although maybe not those who are constantly posting clips on YouTube. To be allowed to be human is to be allowed to do your own editing. However, it is often the unconscious editing which acts as the life journey sat nav. and determines the route you follow. I think that this is where the interesting stuff happens but no-one

ever talks about it, perhaps because it's not part of conscious thought. I believe it is this realisation which has made me receptive to the charms of ethnomethodology as my qualitative methodology of choice. To be able to understand the methods others use to achieve decisions would be very illuminating, to be not just in their shoes but in their feet.

Returning to work after having children was like starting my career again but with less of the confidence of youth and more of the risk aversion of parenthood. I was lucky to be able to get a small part-time job as a Speech and Language Therapist in Dorset and, over time, I took on more management responsibilities. By the end of the 1990's was once again managing a service. No drama to be had here as ten years pass by and then there I am in 2010 signing up for a D.Prof. Initially I applied and was interviewed for a place at University College London (UCL) and received an offer. I applied to UCL because I saw an advert in the Royal College of Speech and Language Therapists Journal for their D.Prof and because I was feeling the need for change, it was a spur of the moment thing. Having been offered the place I subsequently realised that the logistics necessary to attend would be too challenging. The programme at UCL was part-time, two days a week, for four years. The first two years were a taught programme and the second two years was for the research project and write-up. I realised that, as a self-funder, adding the two day-return train journeys a week was not going to be affordable. So, I looked to my local provider and applied at the eleventh hour to Bournemouth University (BU). I have to confess I was hugely snobbish in my perception of the value of BU as an institution. My motivation to attend was purely logistical. However, as is often the case with my serendipitous decisions, the BU programme has been a truly inspirational experience and an intellectual life saver. I have met some amazing people. I have had the privilege of being mentored by a diverse, complex and challenging group of academics and to be partnered in the journey by some dedicated, motivated and supportive peers. I have been able to set my own agenda and I have grown into a self-believer from the point of view of my ability to cope with this level of studying. I have absolutely no doubt that the BU model has been the right thing for me and I value everything about it (apart maybe from the IT processes). I am glad to have been part of the original programme format as I see the new programme being more process-focussed and therefore more

"owned" by the University. I can understand the institution's motivation to take this direction but I remain glad that I am on the old pathway.

Incidentally, and again on the spur of the moment so to speak, in 2012/13 I signed up for and completed an MSc module in Service Improvement which was also delivered by BU. This was funded and driven by my work needs and, although I would not advocate trying to achieve two different academic programmes at the same time as working, I credit the managed drive to meet short-term targets which came with the Service Improvement module for my precipitation into writing for my D.Prof transfer. Having achieved the required standard to pass the MSc module I was then "in the groove", or as near to it as I was ever going to get, for meeting some D.Prof deadlines. At the same time as this was happening I struck upon the format that I wanted to use for my D.Prof research. Being in control of my journey has meant that I have been able to accept and eventually act upon the ideas that have occurred to me. I find that I have been able to become open to just accepting that something feels right without having to question my decisions or over think things. This is a good place to be; serendipity is one of my favourite words!

1.2.7 Sense of place/ Dislocation

Sense of place relates to where I flourish and feel at home.

I am a "nest" maker of the magpie persuasion. I collect and keep around me a vast range of objects which I like. I very much enjoy and spend a lot of time in the hunting and gathering of my objects of curiosity. My husband has learned to tolerate and now possibly even accept that there will be an unstoppable amount of "tat" entering the house for as long as I am around to acquire it. I have approached my D.Prof information-gathering in much the same way. I have hunted and gathered my literature from a wide range of sources and by using an eclectic and occasionally eureka approach to the defining of search terms. The joy of the lucky dip when you pull out something which is so right and fits so well is not to be missed. I found Bourdieu in a lucky dip moment. The downside of being a constant gatherer is that, and it pains me to admit it, you can end up with quite a lot of stuff which you do not really need. Sadly, I have very weak powers of critical evaluation when it comes to rejecting things collected; I collect what

interests me and therefore it always remains interesting. Whilst this less than helpful attribute has accompanied me into my D.Prof it has enabled me to practice my skills as an academic curator. Initially it was difficult to discriminate in areas where I did not have confidence in my depth of understanding and did not feel that I had the right to criticise. With encouragement, I grew more trusting of my approach to my research context and became able to discard information which did not develop the arguments relevant to my study.

I have experienced challenge during my D.Prof progress which has helped me to define my own sense of place. Most notably I found that the addition of a third supervisor to my personal supervision team created an unexpected de-stabilisation. It has taken me a while to re-create my sense of place in the new supervisory arrangement. My original supervisors, Professor Jonathan Parker and Professor Lee-Ann Fenge, and I had constructed a way of interacting which enabled me to find my place as a supervisee. I feel that we learned each other's styles and preferences and the context was one of nurturing and guiding. When my third supervisor, Dr Vanessa Heaslip, joined in 2014 she brought a very different, much more direct approach to the process of supervision which has changed the dynamic of the sessions. This development has demonstrated to me that her more explicit, holding-to-account style of supervision, whilst difficult at times, has made me clearer about my own beliefs and better prepared to defend my chosen position. The relationship that I hold with each of my supervisors is one which exists to give me the best possible chance of achieving my Doctorate. So, the place where we all meet is still my space.

I am not good at making my sense of place in someone else's sense of place. As part of my information-gathering phase I made contact with the team who were in the process of creating NHS Citizen. The premise behind this NHS England initiative was that everyone should be able to contribute to the creation of the values which provide the framework for National Health Service strategic decision-making. I made arrangements to attend a meeting being held in Exeter and then to meet with the organisers afterwards to talk about how people with acquired communication disabilities were being included and enabled in their plans. The premise of NHS Citizen was, and indeed still is, one which aligns closely with the beliefs I have developed during my D.Prof but my experience of meeting the organisers was not enriching in the way that I had hoped.

Admittedly, in the time we had available not much was going to happen but I did not feel that I was likely to become involved with NHS Citizen despite the fact that they were interested in my take on things. I got the impression that they would be happy to adopt any suggestions I may have provided that they fitted with what they were already doing. This feeling of not belonging or not being welcomed to belong is one which I believe will be seminal to my thesis. Once a ball has begun rolling it is quite hard to stick to its surface and I can completely understand why people are put off by what they perceive as a clique. It takes a lot of energy to create a place in a new environment.

1.2.8 Embodiment/ Reductionism

Embodiment relates to how I experience the world holistically.

In discussing my thoughts on using the Humanising Dimensions as the framework for my reflections with Caroline Ellis-Hill she explained that she related the humanising dimensions to the facets of a cut diamond. Each facet giving a different reflection of the consistent core so, in the same way, each of the humanising dimensions shows a different perspective of what is a unified whole.

In 1985, just after I got engaged, I went to see Sir Anthony Sher perform Richard the Third at the National Theatre. He gave an amazing, now renowned, tour de force performance. What I can more vividly remember from this event though is the fact that the stage lights were reflecting in the diamonds of my engagement ring; little patches of refracted and also white light were being scattered around me and, if I moved my hand then, kaleidoscope-like, the motes of light moved and changed. At the time I was purely admiring the beauty of my ring but now Caroline's analogy has recalled the experience for me with a different purpose. My sense of being a whole person is solid like the materials making my ring, and like the ring this solidity has been wrought both through force and through skill into something which contains more meaning than that represented by its constituent parts. I have described in my narrative some of the different elements of me, many of them well-worn and familiar and others, like Livermorium, only

recently found. Through the course of my D.Prof I have found myself in the presence of academic luminaries and, whilst cognisant of the importance of their command of their field, I have to confess to not always having paid them the attention they deserve through letting myself be distracted by more personally significant things. I know, think, feel, believe that life is about appreciating one's context and being present in the bigger picture but also about not missing the small things.

Without over-working this theme (I hope) if I now pay attention to the lights my ring created I would like to think that all my experiences can be represented similarly. I have had many which have been pure white light and an equal number in all the colours of the rainbow. There have also been a few non-sparkly ones and a couple of dead flat black spots but if you turn your mental hand you can change the pattern. I am very fortunate in the fact that I have felt empowered to change my pattern when it did not reflect the being of me. I am totally aware of how privileged I am in this regard and actually I now believe that my D.Prof is indeed all about me. Even the subject of my research is more about me than it is about the people who have kindly given their time in order to participate. My focus of interest originally was diffuse but inspired by my perception of injustice on behalf of people with acquired communication disability. The clarification of purpose came to me as a result of something which happened to me not them. The whole enterprise has enabled me to pursue something which I, not them, am interested in. How lucky am I that as a result of this I have been able to see a bigger picture?

On a coaching training course I did in 2007 we had to choose a picture postcard to represent where we felt we were now and another postcard to represent where we wanted to be. For the "where I wanted to be" I chose a postcard of the painting by Stubbs of the racehorse Whistlejacket (see Figure 1.2) which hangs in the National Gallery. I first saw this painting some time before 2007 and it completely took my breath away. It was visually and emotionally awe-inspiring not just because of its size but because of its simplicity and yet simultaneously, it's exquisite and profound detail. I chose the picture in the coaching exercise because I wanted to aspire to being capable of producing something which, in my personal universe, felt as complete, as masterful (and finished) and yet as apparently effortless in its accomplishment as Stubbs' painting. In completing my

Professional Doctorate I am not suggesting that I have achieved my expressed aim in the coaching session – all who have accompanied me on my journey will know that I have embodied none of those desired parameters. However, my feeling now is that I can pull together all my disparate parts and be confident that I know who I am. From here, maybe, I can imagine that there is a Whistlejacket in me somewhere.

Figure 1.2: Whistlejacket, George Stubbs

1.3 Humanisation and my research

I have found the Humanisation Framework to be useful mechanism for structuring reflective consideration of my own development as both a professional and a scholar. The themes and ideas that have emerged through its use are also ones which have salience when I look outwards to my research interests. I embrace the interests in equality, justice, individuality and opportunity which reflective use of the Humanisation Framework has identified as core to me as a person and a practitioner. It is important to me that my research holds true to these concepts in my chosen context of current NHS public and patient engagement. I hope to understand what impact a very particular group of citizens think they have on collective participatory activities. My motivation to focus on the experiences of people who have an acquired communication disability (ACD) has arisen as a result of my conversations with people with ACD who have expressed views about the inclusiveness and responsiveness of the offers of participation. From a Humanisation Framework perspective (Todres et al. 2009) what they seemed to be expressing were feelings of isolation, passivity and homogenisation.

A particular example of where NHS service planning processes did not facilitate public involvement occurred in 2012. At this time, the Dorset Clinical Commissioning Group (CCG) together with the Stroke Association decided to restructure the County-wide communication support service which was being provided by the Stroke Association. The decision-making leading up to this change had not formally included the users of the communication support services and when the decision was announced there was considerable upset amongst the service users. A complaint was made to Dorset HealthCare University Foundation Trust, the local community health service provider, via a public engagement event. I was involved in a meeting which was set up in response to this complaint which both those with ACD and their carers attended. Several of the contributors at the meeting had significant communication disabilities but nonetheless made the considerable effort to express their views. All contributors were motivated by a desire to retain a model of service which they valued personally but also wanted preserved for others who might find themselves in similar circumstances in the future.

The outcome of the meeting was that no changes were made to the original decision to change the structure, and the participants with ACD and their carers felt that no regard had been paid to their views as they had still not been given sufficient rationale to justify the, to them, unnecessary changes. This experience served to highlight to me the disparity between the expressed desire to involve people in the planning of healthcare provision and the reality for this particular group of people.

In my professional career I have been fortunate to encounter some extraordinary people who have taught me much about fortitude, grace and flexibility in the face of difficulty. People do not stop wanting to be participators because they have lost some ability to communicate. They may need more time and social space to be able to understand others and to express themselves but they remain competent members of society who want to be as engaged in the world as much (or as little) as any other person. The people with ACD who have participated in my research, some of whom took part in the meeting described above, have expressed thoughts and opinions which reflect their whole life experience and not solely those experiences derived through their loss of communication ability. They have emphasised the importance of preserving their whole identity and not being reduced to being defined by what they cannot do.

In acknowledging the resources I have drawn upon as groundwork for my research I must include a range of other contributors in addition to those with ACD and their families. As I have developed my purpose as a researcher I have found many other generous people who were willing to support, guide and advise me. The impact of their presence in my journey has been significant and I have changed as a result of it. I have made use of opportunities to access their knowledge, skill, experience and tools as they have come my way.

1.4 Impact of my learning on the development of my thesis

I have selected an image of a beehive (see Figure 1.3) to symbolise my approach to learning during the course of my D.Prof.

Figure 1.3: A visual metaphor for my learning approach

In Hebrew my name, Deborah, means a bee. Bees are hard-working and collaborative but also independent in their behaviour when searching for nectar and pollen. They travel far and wide in their foraging and when they find a good source of nectar they share this information with their co-workers. The nectar they bring back to the hive is used to create the honey which sustains the hive.

My approach to creating an intellectual equivalent of a honeycomb for myself has been similar to that of a honey bee. My foraging behaviours have been purposeful but eclectic. In seeking what I needed I have covered many academic fields and the richness of information that this strategy has brought has been both illuminating and challenging. Throughout the humanisation section of my narrative I referred to instances where the experiences I have had have influenced my understanding of myself. In this section of my narrative I will evaluate the process of assembly and explore how what I have learned has changed my thinking in respect of my study.

1.4.1 Bee or Bricoleur?

I have described my information-gathering methods as being bee-like. Although the eclectic methods I used to source information were instinctive to me, I have discovered that the approach is not unique to me. The term Bricolage is now used to refer to the same foraging process (Wibberley 2012). Wibberley references the heritage of the researching bricoleur as stemming back to the writings of Levi-Strauss (1966, 1972) and he captures the value of the term as a "metaphor for the ways in which people construct and make sense of their "knowing" "(Wibberley 2012, p.3). It has been recognised that practical knowledge is often accrued through the process of making do with "whatever is at hand" (Levi-Strauss1972, p.17). In the world of research, bricolage is a way of enabling experiences and/or knowledge from many different arenas to mingle and blend (O'Reagan 2015) and in this way pragmatic solutions can be embraced equally with other more academically accepted sense-making approaches (Kincheloe 2001). This problem-solving, outcome-achieving, eclectic approach is becoming better recognised as a method within academic research (Basten 2014) although still viewed as being a recipe for chaos by others (Hammersley 2005). I can fully appreciate that the lack of a pre-defined, methodically applied search strategy may lead to gaps and/or oversights in the information gained. In circumstances where the subject area is completely unfamiliar it risks the assemblage of an inaccurate understanding of the "found known's" and a blissful ignorance of the "un-found known's" to misuse Donald Rumsfeld's words. However, in my opinion the definition of the term, as set out above, accurately represents what I have done and I stand by my belief in its relevance to both me and my study.

Wibberley (2012) suggests that bricolage is a technique which is particularly applicable to the part-time postgraduate student who may bring the world of work into their development as a student researcher. A bricolage approach acknowledges that sense can be created "on the hoof" so to speak, and can be flexible in encompassing hindsight as well as "in the moment" analysis. Bricolage has been suggested as being methodologically innovative (O'Reagan 2015). It describes a method which is responsive to the way in which the research situation is developing (Denzin and Lincoln 2005). Whether this is a method driven by life experience or by study-related expediency, it is one that accurately

reflects my approach to both life and study. In my experience, the synthesis of new knowledge with old is a creative place where understanding slowly transforms from mirage to oasis and sometimes back again. Being able to "brick-up" and also to "un-brick" has been an important part of the process of knowledge construction. However, Hammersley's (1999) view that danger can lie in a researcher becoming too responsive to their own subjective whims is an important one and I can quite readily see that without the insight which reflexivity offers the potential for indulgence rather than erudition is great. However, I feel that I have learned to use my capacity to reflect as a reflexive tool within my research and to respond to the challenge of "and so what?" The approach which I am now able to call Bricolage has given me the permission to mix things up. If I had felt constrained to continue on a path pre-ordained by my initial ignorance I would not have a finished thesis now.

Looking back at where I have come from, the timeline below (see Table 1.2) illustrates some significant features along the route I have taken to achieving my thesis.

	2010	2011	2012	2013	2014	2015	2016	2017
Group and personal supervision								
Targeted conversations								
Workshops and courses								

Table 1.2: My learning activity over the course of my D.Prof

The table shown above illustrates how I have progressed as a postgraduate learner. It took me two years to adjust to the reality of study. During this time I disassembled the constructs I had brought with me into my D.Prof including the topic of focus for my study. Then I began the process of reassembly.

1.4.2 Supervision

Firstly I must acknowledge the significance of the supervisory input I have had. My supervisors have been my constant companions throughout my D.Prof and I thank them for their patience. I have learned to trust my academic instincts because they have trusted me to have academic instincts. Academic instincts, I have discovered, are closely related to confidence, and as I have gradually grown in confidence I have found it easier to acknowledge and then own the ideas which have come to me. Without this growth nothing else would have been possible.

The BU Code of Practice (BU 2016) outlines the role of the supervisor. Included in the list of supervisory responsibilities is the requirement to ensure that the research a postgraduate student undertakes attains the standards expected by external scrutiny bodies such as the Quality Assurance Agency for Higher Education. With the benefit of my supervisors input I can be confident that research motivated by personal inclination and interest can merit presentation at doctoral level. Their belief in me has been immensely motivating and has enabled me to change my thinking process from an internal and unchallenged activity to one which is open to scrutiny and debate.

In addition to my supervisory conversations which have been a constant influence, I have also had other significant exchanges which have informed and developed my academic persona. I have referred to these as targeted conversations because they represent episodic bursts of development which have contributed to my progress.

1.4.3 Targeted Conversations

As I identified in the humanisation section of my narrative (p.9), I had a very influential conversation in 2012 which marked the beginning of my transformation as a critical commentator. The meeting with Mr Letwin showed me that I had opinions that I was capable of defending objectively in the face of contradictory points of view held by another. Prior to this my willingness to hold my own beliefs as worthy of being defended was not strong. I was always prepared to believe that the other point of view was more valid. This development I see as being

crucial to my being able to grow into an academically critical thinker. The conversation with Mr Letwin also distilled my focus on the role of influence in civic participatory activity and began the journey towards my research activity.

Once I had identified my research focus I was then able to more purposefully gather knowledge about what practical activities might enable my research aims to be met. This more targeted activity began with an exploration of methods which were capable of assessing influence.

Sal Hampson, Jill Bedford and Sue Gorbing of Changes UK generously agreed to give me a three-to-one masterclass on their community development toolkit. They showed me how their work helping members of urban communities to understand influence had created opportunities for the growth of local citizenship. Their work illustrated how simple techniques could create structures within which people could find common ground with civic organisations. The purpose of these techniques, they said, was to achieve a better understanding of the distribution of power in decision-making. It was their exploration of the real-life relationship between power and influence which excited my growing interest in the individual's experience of participatory behaviour. Key to all, in the view of the Changes UK team, was enabling discussion and debate to happen. My interaction with Mr Oliver Letwin had given me direct exposure to the impact of unrealised opportunities for discussion and sharing of opinion. I subsequently chose to use elements from the Changes UK toolkit in my research method because I believed that their simplicity of application would be compatible with my desire to have as accessible and equitable a way of gathering information from my participants as possible.

The way in which I formulated my research approach was informed by my personal, specific and professional, general beliefs about inclusion. In doing so I was using both inductive and deductive reasoning seemingly simultaneously. This intertwining of specific and general, top and bottom, at the same time took a considerable amount of effort to clarify and organise. My bricolage process meant that I developed my research methods as I explored my methodological approach. This process was iterative, with refinement being driven by my growing understanding of my chosen methodological perspective. As this process took

place I was able to interrogate my decision-making regarding methodology by exposing myself to a range of academic opinions both within and external to BU.

Bournemouth University is highly-regarded for its qualitative research portfolio and I have been fortunate in being able to access other researchers in addition to my own supervisors. The diversity of methodological approaches espoused, each of them appearing to be formed by and suited to the individual academic, illuminated for me the fittingness of a beehive metaphor for academic learning. Knowledge is the product of individual endeavour brought to shared purpose. The ways in which knowledge and understanding can be drawn from diverse sources and perspectives showed me the value of reflexive enquiry. Each conversation revealed how the interaction between the researcher and their research was integral to the creation of knowledge and therefore part of the essence of academic pursuit. My concerns regarding my own research focus being as a result of personally held values and beliefs were set to rest. The views of these academics also helped me to develop my own reflections on the nature and purpose of person-centred research. I could see that the pressure I was experiencing to produce some research for my thesis was affecting how I was undertaking the role of researcher. The challenge of valuing the individual, including myself, within a process is one I am still wrestling with.

In parallel with the more intimate conversations described above I have also gained from exposure to conversations and discussions with academics from other Universities. This has enabled me to frame my developing knowledge within a wider academic environment. In particular, in 2014 I had an opportunity to both listen to and speak with Professor Jonathan Tritter on the subject of participatory activity within the NHS. His stance, which emphasised the importance of clarity with regard to the purpose of participation, resonated very powerfully with my own developing assessment of the function of participation. His contribution highlighted for me the importance of understanding what participants, both public and professional, think is required of them. Almost exactly three years after the conference at which Professor Tritter spoke, a workshop about empowered and connected communities run by Public Health England also addressed the challenges perceived to be pertinent to achieving active public engagement and participation in NHS planning. The conclusions drawn at both events were that problems with participation have been created as

a result of the lack of a common understanding and vocabulary, and that change was needed. In order for the general public to be able to be co-creators of the participatory vocabulary, they have to be allowed to speak with their own words.

Through the process of reflecting on my research purpose and in the light of the insights gained from others, I have questioned what the product of participation is expected to be. A recent Massive Open Online Course (MOOC) (London School of Economics (LSE) 2015) on citizen engagement suggested that the need for change was in the eye of the beholder. In the case of the NHS I wonder whether the political eye is looking at the same things as the public eye. From the point of view of my own study the fact that debate and discussion about how to better enable effective participation is ongoing leads me to believe that achieving change in NHS participatory behaviour is a process of evolution rather than revolution. Contextually the participatory environment is dynamic and the ecology of participation is responsive to the threats and opportunities which are created by our society and culture in the UK. This makes it important to notice where we are now so that we can recognise when the situation becomes different. My research aims to understand where people think they are now and what knowledge they are using to inform those views.

1.4.4 Methodology conversations

In addition to developing my appreciation of my research context I also gathered information relating to my methodological approach. Here the same bricolage methods were instrumental in assembling the finished product.

Through the act of engaging in conversation with other, much more seasoned researchers the importance of stopping and noticing as part of sense-making has been highlighted for me. In carrying out research the process should not be allowed to over-ride the opportunities to stand and stare. Qualitative enquiry must open and not close the mind to the presence of difference. Appreciation of this in turn influenced my pursuit of an ethnomethodologically informed methodology. My exposure to a number of debates and discussions between experienced practitioners of ethnomethodologically informed research has led to my finding a methodological approach which I feel fits my purpose. The benefit I have derived from listening to rather than participating in conversations has been inestimable.

During these periods of listening I may have seemed passive to others but I was not passive in myself. I have reflected that engagement need not be an externally manifested state of being and I have realised that this represented an important insight for my own research. My purpose in investigating people's estimation of their own power in a participatory context focuses on the externally manifested outcomes, but from a humanisation perspective I need to remain aware that these may not be the only outcomes. Each participant may be changed through their participation in ways which are unpredictable and hard to measure. Participatory action which represents individual contributions as a collective output cannot be sensitive to each unique input.

Ethnomethodology embraces the individual instances within the collective behaviour, it allows for uniqueness and idiosynchronicity to be recognised. To paraphrase Wes Anderson (2016), ethnomethodology is a not a technique but more a way of framing the motivations for one's enquiry. Particularly, ethnomethodology encourages consideration of the complexity of context, because human beings don't just react to stimuli they respond to meanings. Therefore the creation of meaning is a contextual process which must be subject to personal bias because we all live our own lives according to our individual experiences. The focus on the value of the person and the view that our differences don't make us wrong they just make us different is as powerful as it is illuminating. In the context of my study, this underlined for me the importance of understanding what each of us brings to situations which ask for individual experience but not for the context.

1.4.5 Practice Development conversations

My interest in Asset Based Community Development (ABCD) (Kretzman and McKnight 1996) has emerged as a result of my investigations relating to the practice development strand of my thesis. I believe that an ABCD approach may address the questions raised in my research regarding achieving agency, togetherness and uniqueness and thereby enabling meaningful participation. In pursuit of examples of the use of ABCD approaches I visited Sally Byng, Chief Executive of the Barnwood Trust in Gloucestershire. The Barnwood Trust is a charitable organisation which focuses solely on the county of Gloucestershire

and is dedicated to creating the potential for people with disabilities to make the most of their lives. They fund projects which aim to create welcoming communities and/or promote citizenship and their "You're Welcome" (Barnwood Trust 2015) project was designed to better understand what drove people's feelings of wellbeing and whether those who were living with a disability had equal access to those things. One of the outcomes of the project was that the Trust went on to introduce an ABCD approach as a way for people/communities to create their own interpretations of openness and inclusivity which were driven by their own values and personal resources. One such project was the Cirencester Sofa Month where a sofa was placed at various outdoor locations around the town and people were able to sit and chat with volunteer "Sofa Sitters" about what they thought made Cirencester welcoming and what more they would like to have available as community resources to help people connect. This project brought people together, both able and disabled, in order that they might collectively achieve common community goals.

My conversation with Sally reinforced my belief that an ABCD model could stimulate a participant-led response to the findings in my research. Sally emphasised that ABCD in its purest form was perhaps not the easiest thing to initiate and sustain but the ABCD principle of using a strengths-based approach was certainly a good place to start. I have taken her advice to heart and recognise the imperative, if an ABCD approach is to be used, of ensuring that care is taken to co-produce the project from the outset.

1.5   Learning Conclusions

The product of the investment and input I have described above will, superficially, be definable through the existence of a thesis. My thesis will be the tangible evidence of seven years of learning, change and development in me. I have come to understand that this achievement has only been possible thanks to a process of humanisation which has enabled me to better understand myself and the systems within which I and others exist. I have explored boundaries both real and imagined and the research I have undertaken has answered some questions but posed many more.

Undertaking the D.Prof has created a new sense of place for me and for this I credit my peers and my supervisors. I have been allowed to create a new nest in a new environment which has been built from new and different materials. From this nest I can see a different landscape and forage for different nourishment but I am the same bird.

1.6   Outline of future chapters

In this first chapter I have set out the context of me, locating myself within my new academic persona. The D. Prof provides an environment where professional, personal and academic influences come together to form a "scholarly professional" (Gregory 1997 p. 19) and it has been important to establish the nature of my particular landscape. The subsequent chapters of my thesis will continue to present my development as a researching practitioner within qualitative research as the core theme. In chapter two I set out the academic literature and professional "grey" literature which has informed the development of the study, identifying the themes from which my research questions have emerged. Chapter three expands to explore my choice of methodology and method, establishing why I feel it has the best fit both with my research purpose and with me as a researcher. Following the presentation of my findings in chapter four, chapter five discusses how these findings relate to both the original thematic perspectives as well as exploring how my perspectives have changed in the light of this new information. This analysis serves to highlight the impact of the relational processes which have occurred between me as researcher and my topic of research. These then, in turn, informed my practice development which I have set out in chapter six. My practice development identifies how my learning over the course of my D.Prof has informed and influenced my clinical practice in the "real world". Chapter six also contains my conclusions and recommendations for future research. Finally then, I return to reflect on my personal narrative approach and identify how the experience of learning and researching has changed my view of myself as a researching professional.

Chapter 2 Literature Review

"The problems are solved, not by giving new information, but by arranging what we have known since long."
Ludwig Wittgenstein Philosophical Investigations (2010 p 59)

2.1 Introduction

In this chapter I will establish the contextual landscape for my study. I will present key themes relevant to the understanding of participatory behaviour in strategic NHS decision-making arenas which I will structure under the following headings; Participation and Policy; Communication Disability and Inclusion, and finally Power and Influence. This chapter will show how consideration of the views of people with acquired communication disability have been overlooked in the development of NHS public-participatory relationships to date and identify why this oversight is worthy of further investigation. In addition I have included in my literature review an exploration of the background to and context for my chosen methodology and how this fits with my research purpose. Finally, I will present the aims and objectives of my study.

2.2 Search Strategy

At face value my research question is seeking to explore a seemingly straightforward question about whether, through civic participation, a particular section of the public think they can influence strategic healthcare planning decisions. My personal inclinations, as I outlined in chapter one, naturally lead me to be informal in my approach to identifying and searching for information. However, as soon as I began to reflect on the nature and purpose of my question, I realised that I had a potentially enormous task on my hands. I recognised that the knowledge that I had identified as necessary for underpinning my research objective needed to be derived from a wide range of academic disciplines. Without the benefit of confidence and the legitimacy of a label for the search process I favoured, I perceived that a more methodical and systematic approach might be necessary to establish my key concepts with more academic

rigor and credibility. Therefore, I selected a standard PEO (**P**atient/Population/Problem; **E**xposure; **O**utcomes)-based search model (Coughlan and Cronin 2016). This approach is considered best suited to qualitative research enquiry and I found it helpful in capturing my search terms. My searches used the Bournemouth University library database and the National Institute for Health and Care Excellence (NICE) Healthcare Databases Advanced Search (HDAS). I excluded any publications not printed in English as I do not speak any other languages and I identified 1990-2016 as the date range to be searched as this represented the period most relevant to the development of the current NHS participatory policy and practice in which my study is situated. I selected search terms directly related to my key areas of research focus: acquired communication disability, stroke, healthcare service planning, policy, participation, power and influence. I found that including acquired communication disability in combination with any of the other terms significantly reduced the number of relevant returns. This was an early indication that my study could provide new perspectives but also that a more eclectic search process may be justified. Therefore, in order to further develop my information resource, I also turned to the Royal College of Speech and Language Therapists research network database, my local NHS library service and made wide-ranging forays into the internet using a variety of search engines.

In addition to the literature searches described above I also made targeted literature searches to support my understanding of "new to me" academic disciplines such as philosophy, sociology, politics and behavioural economics. This activity in turn stimulated additional episodic forays into the literature as I hit upon lines of enquiry which caught my interest and my new-found identity as bricoleur became fully realised. In addition, for many of my trains of thought, I owe debts of gratitude to my supervisors and my D.Prof peer group who have been generous in the sharing of their own knowledge resources and ideas.

As a result of my experience of implementing the PEO searching process I have confirmed to myself that a bee is what I am best at being but I can acknowledge that structure is helpful for containing and defining the target. The benefit, to me, of pursuing both structured and unstructured searches lay in my melding of formal academic systems with organic and informal gathering. By taking this approach I was able to manage the pressure of new information which otherwise

would have overwhelmed me. The disadvantages were apparent in the early stages of my literature review when, with little confidence in the credibility of a more eclectic method, I struggled to make my search needs fit with more prescribed search formats. Confidence has given me "permission" to be comfortable with the final product which is a literature review informed by a search system which has suited me but which has also felt academically legitimate.

2.3 Participation and Policy

Sir John Garnett of the Industrial Society once told me his pig and chicken story which he employed to illustrate the difference between participation and involvement. He said, in the making of a full English breakfast the chicken participated but the pig was involved. This may be variation on the original story which is said to have originated in the 1950's (whereby the pig was said to be "committed" to the breakfast project rather than being involved in it) but Sir John obviously felt the variation suited his point at the time.

The clarity of application personally expressed by Sir John during our conversation in the 1980's is perhaps no longer appropriate in the twenty-first century climate of citizenship but an appreciation of what is intended by the use of the terms would be helpful. The terminology used today to describe the activities undertaken in the pursuit of a shared role in decision-making, namely participation, involvement and engagement; is open to a variety of interpretations dependent upon one's perspective (Wistow and Davey 2011). The context for this study is specifically civic participation.

Civic participation, as opposed to political participation, has been defined by Zukin et al. (2006 cited Zani and Barrett (2012 p.2)) as "voluntary activity focussed on helping others, achieving public good or solving community problems". Further, Zani and Barrett helpfully go on to provide a differentiation of purpose between participation and engagement. For them participation refers to a behavioural response to a situation which requires action whereas engagement they see as being psychological in nature as it involves the individual paying attention to or having interest/knowledge in a topic or situation. States of participation and/or engagement are related but not necessarily dependent upon

each other. In my view, these more recent definitions sit better with the modern constructs of citizenship which appears more fluid in its application.

The NHS currently favours the use of both the terms "participation" and "involvement" to describe the relationship at the level of the individual whereby patients or service users are involved in planning and decision-making around the delivery of care relevant to their own specific healthcare needs (my health), (NHS England 2013). Participation is also used to define the act of the coming together of NHS professionals and the people who use its services for the purposes of collective thinking. This is a more democratic level of involvement through which people/citizens can influence the decision-making for more strategic healthcare provision which will affect the local population in general including themselves (our health), (NHS England 2013). Engagement then tends to be used to define the range of activity undertaken by providers of services which is directed towards promoting participation (NICE 2008; DoH. 2011; NHS England 2014).

The challenges currently being faced by the NHS in redefining what the NHS does in the twenty-first century in order that public health needs might be effectively met, have been acknowledged in NHS England's Call to Action (NHS England 2013), which emphasised the importance of the public and the professionals talking to each other about what was important. The value of incorporating public views in a way which demonstrates the impact of these views on decision-making had previously been emphasised in a guide document from the Royal College of General Practitioners (RCGP 2011, p.2) where it is stated that effective PPI requires "...systems and a culture that reach out to the populations that you serve and allow you to alter commissioning plans to meet their expressed need". A significant purpose of public and patient participation is to enable those who have received healthcare interventions to inform and advise professional health service commissioners from the standpoint of their personal experience, which in turn affords the service commissioners the opportunity to see the services they commission from the perspective of a service user. In my view it is a natural, common-sense consequence of this relationship that the contributions of those with lived experience are seen and/or felt to have made a difference.

In my study I am specifically focusing upon the participation of people at the strategic level of NHS service planning, known as Commissioning. Woodin (2006 p.203) defined commissioning as "a proactive strategic role in planning, designing and implementing the range of services required". He also defined the role of Commissioner as:"decid[ing] which services or healthcare interventions should be provided, who should provide them and how they should be paid for".

Commissioners are required to work with the public who may use the services which they commission in order to ensure that the commissioning interpretation of healthcare needs is valid and accurate. The ways in which this requirement is met are largely at the discretion of the commissioning organisation. The CCG in Dorset, which is one of the largest CCG's in England (Dorset CCG 2014), offers a spectrum of opportunities for the public to share their views on current and proposed services and service changes (Dorset CCG 2017).

In choosing to become involved in activities such as NHS service -planning and decision-making, people are exercising their citizenship through civic participation. Over the last 20 years there has been a re-emergence of the concept of "citizenship" culminating in the "Big Society", an initiative launched by the coalition government in 2010 and designed to "take power away from politicians and give it to people" (David Cameron 2010). Encouraging civic participation was seen as a way of empowering communities and increasing social action. There was evidence that public belief in the ability of the "people" to actually effect change had decreased in the 5 years prior to the launch of the Big Society initiative (Hilton et al. 2010), which was perceived politically to have created a culture of dependency and a lack of civic responsibility. The results of an Ipsos MORI survey for the 2020 Public Services Trust, also published in 2010, showed that respondents valued the knowledge that there were opportunities to become involved but that they did not feel it necessary to actively take those opportunities up. The authors of the report described this as a "passive yet consultative relationship" (IPSOS Mori 2010, p.24). In a similar vein, Hilton et al. (2010, p.5) also identified this phenomenon in their paper and described these relationships as "cheque book" participation whereby the responsibility to

contribute was viewed as having been met through a financial rather than an intellectual or emotional investment.

This calls into question whether "the man in the street" really wants the bother and, if this is the case, then it also calls into question how representative those who do choose to actively participate are. The creation of a "usual suspects" phenomenon has been investigated by Skidmore et al. (2006) who identified the likelihood of a co-dependency developing whereby the participatory few de-motivate the passive many from considering becoming involved because the passive many come to assume that the same few people will always be the ones to participate. Compounding this, Skidmore et al. (2006) also found that the organisation in which the active participants participate becomes dependent on a known band of familiar people who can be relied upon to fit with the organisational culture, the outcome of this being that new views, opinions and/or perspectives are lost to the decision-making process. A further consequence of this is that there is potential for the established group appearing to be, or indeed actually being, a clique which can be a disincentive for new, otherwise motivated participants to pursue involvement. The incentive for the man in the street to persist in making a contribution is further eroded according to the findings of a systematic review by Conklin et al. (2015) which showed that there was actually little evidence of the impact of having public involvement in service planning. So perhaps the passive relationship between the public and service providers is not surprising.

That there should have been room for confusion regarding the purpose and practice of participatory activity in the NHS in England and Wales could be seen as surprising given that there has been no shortage of advice on how to do "involvement" and what the outcome of such endeavours should be (DoH 2004, 2005, 2006, 2007, 2008 and 2013). From 2008, following the passing of the NHS Act in 2006, it became a legal requirement to involve the users of health services in the planning and design of the services provided, updating the previous formal specification in the 1990 NHS and Community Care Act. The expectations set out in the 2006 Act were originally established in the NHS Plan (DoH 2000). The requirement to involve was encapsulated in Section 242 (1B) of the Act; which required that users "are involved (whether by being consulted or provided with information, or in other ways)" (DoH 2008, p.60). The main intention of the new

Act was to make involvement, whatever that meant, mandatory. Most healthcare organisations were already using patient feedback and other inputs to inform their service development and provision but there was no consistency regarding the interpretation of the need to involve patients or people in general. The suggestion that the duty to involve might be discharged by users only being provided with information, seems unambitious when viewed from where we are now. However, in 2008 the expectation of being informed as part of being involved in one's own care let alone for the purpose of strategic planning was not always realised.

During 2007-8 Dorset residents took part in a Joseph Rowntree Foundation initiated study which captured the extent to which older people in the county were involved in the commissioning of health and social care services (Wistow and Davey 2011). The fieldwork which took place in 2007 found that, although Dorset was leading good practice in some aspects, specifically in social care domains, there was still a propensity to perpetuate existing models of service delivery based on existing usage or on what the service providers themselves defined as being needed (Wistow and Davey 2011). Dorset commissioners had identified that their own involvement infrastructures were "insufficiently integrated with strategic decision-making" (Wistow and Davey 2011, p.57).

Unfortunately, the consequences of failure to adequately take account of patient and or public involvement in service planning and delivery became tragically apparent with the findings of the Francis Inquiry Report published in 2013. In reaction to such events the NHS's desire to create a background for decision-making that had some basis in actual user experience was intensified and coupled with a willingness to invest the product of this activity in creating better services in the future. However, the landscape within which public/patient participation in decision-making was to take place had become increasingly complex. Now, not only was there a requirement to engage the public as service users in the decision-making of NHS Trusts but also in that of NHS Commissioning bodies as evidenced in the NHS Commissioning Board document, "Everyone Counts: Planning for patients 2013/14". In addition, the Health and Social Care Act of 2012 introduced, alongside a significant organisational reform, a reformed method for enabling formalised community input which was intended to take place via independent scrutiny bodies. At a

local level, this formal process would be represented by the creation of an organisation called Healthwatch. The expressed purpose of Healthwatch, as laid down by the DoH (2012, p.175), is to give "citizens a greater say in how the NHS is run" through "strengthening the collective voice of local people".

Achieving citizen involvement in either provider or commissioner planning activity is proving to be no mean challenge. Florin and Dixon (2004) explored the purpose of public involvement in healthcare and concluded that the aims for public involvement needed to be more clearly thought out so that all involved could be enabled to achieve the best, most appropriate outcomes. Some expressed concern about the ground-level willingness within NHS organisations to accommodate greater openness to the public voice (Milewa 2004, Sang 2004, Martin 2009). Whilst there is now little argument that involvement is of benefit to both the public and the organisations (Crawford et al. 2002, Da Silva 2012), more recent systematic reviews (Nilsen et al. 2006 and Conklin et al. 2012) have shown that there is still limited evidence of public participation having an impact on service design. Critical scrutiny by Tritter and Kouvusalo (2013) of the Department of Health 2012 policy changes caused them to suggest that the introduction of Healthwatch would serve to distance the public from the NHS as an organisation by placing more layers between it and the public. Tritter and Kouvusalo (2013) go on to take issue with the Department of Health perspective on how local voice may be strengthened and how the authenticity of user voice may be preserved. How voices are heard is key to the success of public participation. A difference in perception of the role and purpose of the public in decision-making between the public on the one hand and the NHS professionals on the other has potential to lead to the disappointment of one or other party, or possibly both parties, in terms of what the product of participation is (Boswell et al. 2015).

2.3.1 Public Opinion

Whilst it is possible to locate published evidence on the products of public participation in healthcare planning, it is hard to find any evidence of what the public's opinion is about this Recent Canadian research (Pomey et al. 2015) however shows that participation in decision-making can be felt to be a very

positive experience by both the users of the service and the provider organisation, with the products of participatory activity being mutually valued and respected. In the UK it is clear that healthcare providers are still striving to achieve the right formula (HQIP 2016) but are beginning to recognise some successes. Unfortunately, outside the more formal channels of involvement, it is more common to see anecdotal reports of public dissatisfaction relating to circumstances where services are being withdrawn or hospitals closed against the public wish, as illustrated by the postings on nhspublicvoice.wordpress.com (2016) or by more local protests in Dorset initiated by CCG proposals to cut services (Webster 2016). A comedienne whom I heard on Radio Four (News Quiz, November 2015) said engagement happens when people are sufficiently provoked to become involved and participate. Sometimes individuals can be bothered and sometimes not. If each individual has a threshold of initiation then it is plausible that their threshold could be, in part, determined by their appreciation of the structure within which the participation activity occurs and this dynamic will vary from instance to instance. If enough people bother then it perhaps becomes more appealing for those with higher thresholds to join in because they perceive that the structure is changing.

The development of the concept of involvement in the NHS has demonstrated how the purpose of patient/user involvement has followed both social and political trends (Fudge et al. 2008). These trends have influenced how the processes have been implemented and how they have also determined the value placed upon the contributions made by participants (Hogg 2007). Later Coe (2011, p.266) referred to the "democratic deficit" in reference to the continuing gap between those in control and the public. In fact, the modern ambition to create a more engaged relationship between healthcare providers and recipients has a forty-year history of changing culture which has culminated in the concept of a Patient-Consumer (Mold 2010). The use of the term consumer in relation to healthcare gained momentum during the 1980's and 1990's and still continues (Maxwell and Weaver 1984; Beresford and Croft 2004; Hogg 2009). As consumers of healthcare, the public express their preferences as a way of influencing the range and nature of future service provision. In a consumerist model the relationship between service recipient and service provider is one based on economic principles (Rowe and Shepherd 2002). As an alternative,

Rowe and Shepherd (2002) contrast the consumer model with a democratic model which draws on the power of the public to challenge the decision-makers in terms of their justifications for choices made. Litva et al. (2002) endorsed the need for people to understand the rationales regarding the decisions made and can accept those which conflict with their own views if they appear to have been arrived at legitimately. Litva et al. (2002) also concluded that the public were quite capable of differentiating circumstances where it was appropriate for their views and experiences to be taken into account and those where it was not. The potential for both consumerist and democratic participatory activity to be occurring simultaneously with no differentiation of purpose Rowe and Shepherd (2002) proposed was, in part, responsible for some of the perceived confusion in the development of participatory activity.

Whilst there is no doubt that the term consumerism has entered the healthcare arena there is less certainty about the NHS' capacity for democracy and I am inclined to agree with Mold's (2010) ultimate conclusion that the definition of a Patient-Consumer would differ depending upon whom you asked, the organisation or the individual. Traditionally NHS organisations have had control of the participatory environment and Barnes et al. (2007) commented that the voice of service users can lose its distinctiveness when it is "invited into the spaces of governance" and that this closes down diversity. Seeking involvement from the public to fulfil a consumer function by providing feedback may provide evidence of an interaction between provider and user but there is little evidence of impact (Mockford et al. 2011, Conklin et al. 2012) which may suggest that, from the perspective of the organisation, participation has limited purpose. It could be that the relationship between the NHS and the public is dependent upon the trust the organisation has in the public to behave appropriately. Litva et al. (2002) explored the validity of the view that the public were too subjective and emotional to make sensible decisions. Both terms emphasise the cultural dominance of the organisation in framing the access to the healthcare decision-making arenas. The "Dr knows best" culture has a lasting heritage which is proving difficult to escape and recognising this Andrew Lansley, Secretary of State for Health (2010), said "too many patients feel talked at rather than listened to". The structure of the system determines the type of relationships which can be created. The importance of both public and organisational participants knowing

and understanding each other in order that engagement can be "intelligent and productive for both parties" (National Council of Volunteer Organisations (NCVO) 2011, p.9) has been recognised. The current published evidence regarding perceptions of purpose in public participation is largely framed from the point of view of the NHS professional participants. The impact of professionalism on the culture of participation is significant not only from the point of view of the aforementioned salaried NHS professionals but also from the point of view of the professionalization of some of the "lay" roles which exist within the participatory structures. Increasingly, members of the public who participate on formal boards are referred to as "experts by experience" which denotes a professionalization (Evetts 2012) of their credentials for membership. Hoggett (1996) identified the desirability of transition from "old" to "new" professionalism which would value knowledge in a different way. More recent work by the King's Fund (2013) suggests that the individual patient/healthcare provider relationship is changing to allow better balance between the two. It is hard to demonstrate a similar degree of shift at the public/provider level. Reports such as that from the NCVO (2011) identify that very little has been published concerning the views of citizen participants in strategic healthcare planning contexts. My study specifically seeks to explore what progress has been made towards achieving a more integrated participatory process from the point of view of people with ACD. It is hoped that this will help to open up a dialogue on how participants' points of view, if expressed and understood, can contribute to a shared understanding of purpose.

2.3.2 Consumer Customer or Partner?

The concept of the healthcare service user as a consumer or customer has developed with the growth of choice-making opportunities and the drive to achieve efficiency through market forces. It could be said that this approach stems from the Griffith's Report produced in 1983 which introduced a business concept previously unthought of in the NHS. At the time, the report chimed with the free market economy culture of the Conservative Government under Margaret Thatcher when the "nanny state" (McCleod 1965, p.11) was in the process of being dismembered. Whatever one's political view, the development of consumer consciousness within the NHS took a step forward during this era and this momentum was not lost during the New Labour years in the 1990's

where the desire to create a culture of individualisation and self-reliance continued. David Cameron was keen to reinforce this shift in the balance when, as Leader of the Opposition he said:

"the public become, not the passive recipients of state services but the active agents of their own life. They are trusted to make the right choices for themselves and their families. They become doers not the done-for" (2007 cited in Boyle and Harris 2009).

The apogee of user participation is co-production. The term co-production was coined by Elinor Ostrom in the 1970's. It is, fundamentally, an economic concept. However, it has become well used in healthcare think-tanks over the last fifteen years as the new culture of involvement has been emerging. Co-production in health embraces the social value of broadening the perspective on what good looks like in healthcare and emphasises the benefit of utilising the skills and abilities of the service users to build new relationships (Boyle and Harris 2009). This thinking had begun to challenge the traditional "Dr knows best" philosophy and to explore the value of knowledge in a different way. Systems within the NHS were gradually becoming better developed in their capacity to respond to patient choice, from a pre-determined range of what care option they might prefer and to react to patient feedback with respect to individual experiences of care. However, equivalent systems were perhaps not so well placed to embrace the involvement of people in the strategic planning, design and development of services. There was concern, from this point of view, that "people" may not know how to behave as potential co-producers of services. Sutcliffe, in her report from the Patient and Public Involvement Learning and Development Project (2007) pointed out that patients, who were accustomed to being passive recipients of healthcare services, may not easily take up the role or the responsibility of being a service designer. Coulter (2006) identified a potential for dissonance in the role of co-producer as service users may respond differently depending on whether they were considering decisions on behalf of general society or decisions based on their own personal circumstances. Both authors highlighted a need to differentiate between the democratic and the consumerist approaches to involvement. Still today the tension between individual experience and professionally derived evidence remains "the elephant in the room" of co-production.

If it is accepted that co-production is to become the new gold standard for the design and development of healthcare services then planners must also recognise the challenge to the co-production approach in terms of achieving representation. Guidance issued by the NHS Commissioning Board document "Everyone Counts" (NHS 2013) emphasised that no community should be left behind or disadvantaged in the new patient-centred, strategic service planning process. Whilst the power of a different perspective is acknowledged it is equally recognised that there remains potential for the exclusion or abandonment of those who are not able to become involved on the same terms as the "ordinary" public because of their particular support needs. Ironically, in contrast, when no view was considered other than that of the professionals the discrimination against certain groups of citizen participants on account of their disability was not apparent because all service recipients were excluded from the decision-making arena. The fact that society can exclude some people from being able to have a say in how things are done to or for them, for a range of reasons too great to enumerate here, has undoubtedly existed for as long as humankind.

2.3.3 Ladder of Participation

For modern purposes one of the seminal texts to establish the potential for the exclusion of people from civil society decision-making was the paper by Sherry Arnstein published in 1969. Working in the context of the civil rights struggle in America in the 1960's, Arnstein proposed the notion of a set of hierarchal relationships through which she identified the stages of involvement as she saw them. The eight stages she described began with manipulation and concluded with citizen control. This process she realised simplistically as an 8-step ladder (see Figure 2.1) containing three zones of citizen experience.
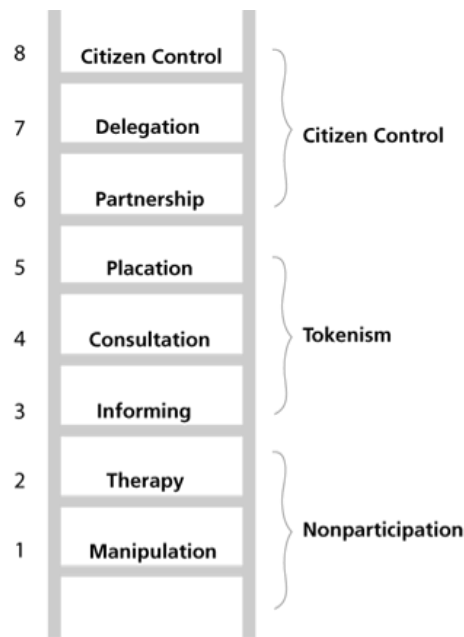
Figure 2.1:   Arnstein's Ladder of Participation (1969)

In Arnstein's terms, step six, that of partnership, was the first which represented a true opportunity for the citizen to have some degree of influence over the decisions being made. In Arnstein's view, only step eight, participation, gave citizens the power to take the decisions.

Tritter and McCallum (2006) have challenged the linear and simplistic ladder concept, updating it in their view to better represent the culture and practice of 21st century Europe. Both models have a hierarchical structure whereby the most meaningful involvement sits at the top but Tritter and McCallum (2006 p.157) tried to capture the complexity of today's involvement culture where, in their view, "user involvement requires dynamic structures and processes legitimised by both participants and non-participants". They suggested that legitimization of the process of participation would be produced not by the act of participation alone but by the impact of what is produced, thereby transforming the culture of healthcare through mutually derived outcomes. So, for them, success should not lie in the power to make the decision but in the realisation of the change produced by the decision, a comment which shows foresight in the light of the findings of the review by Conklin et al. (2015) mentioned earlier. Not only was the model proposed by Tritter et al. (2006) a more complex model but it was also one that embraced the belief that participation should result in visible change which all participants would recognise as the product of their joint efforts. This would truly change the culture of healthcare if it were to be achieved. However, it was

an earlier and less complex concept of a pathway or progression for involvement from "choice to voice" (Hickey 2014) which was adapted by NHS England to create their own version of the ladder of participation, thereby returning to the more simplistic, linear representation created by Arnstein. In truth, I would argue that the manner of representation illustrated in the various models merely serves as a vehicle for the concepts attached to each level of participation, and whilst the complex and dynamic model favoured by Tritter and McCallum (2006) is probably nearer to the modern aspiration it does not have the pragmatic simplicity which facilitates the communication of the basic principles. Simple communication of basic principles is needed if greater involvement is to be promoted to the general public who, research has shown, are not naturally inclined to believe their view matters or makes a difference in the arena of healthcare provision.

In 2013, as part of the Open Government initiative, NHS England instigated an involvement project which they entitled NHS Citizen. The brief was to create a mechanism for citizen involvement in the service design and planning activities undertaken by NHS England and the creation of the entity was itself to be an example of citizen co-production from the outset. The intention of NHS Citizen was to create a platform for the production of co-solutions, with citizens being actively involved in previously hidden aspects of decision-making (OPM 2014). This initiative could therefore represent the beginning of the shared context culture change so desired by Tritter et al. (2006). The drive to have civic/public engagement in the functions of organisations which have previously been "behind closed doors" in terms of how decisions were made is not without danger to the parties on both sides of the equation however. The rules for how this new transparent people-powered relationship should work are not immediately clear so the intention to afford opportunities to influence decision-making could result in a "too many chiefs" scenario where the final decisions are still made by a select few with no reference to the origins of or inputs to the debate. Learning how to have a dialogue, therefore, could be the biggest challenge. It could be argued that the reason why tensions such as those suggested above might arise is because the new involvement expectations are being grafted on to the old organisational culture rather than a change in culture taking place from the roots. In a report for the Joseph Rowntree Trust the authors argue that civic

participation cannot be satisfactorily achieved through the existing structures and pathways (Skidmore et al. 2006). They point out that doing the wrong thing better will not create the desired objective of true citizen participation regardless of the degree of user involvement through the old structures.

2.3.4 NHS Commissioning

In striving to achieve more transparent procurement of services in the here and now the NHS has changed its methods. A more open process of commissioning through which the commissioners assess and define the health needs of the population, determine priorities and buy appropriate services has been introduced. A pattern of activity known as The Commissioning Cycle (NHS 2008) has been implemented which identifies the phases which must be accomplished in order to demonstrate the relationship between what is identified as needed and what is subsequently provided. The diagram depicting the cycle (see Figure 2.2 below) shows that patients and the public are the hub of the cycle. Whether their central position serves merely as a focus for professional attention or implies that they are the controllers of the cycle is not clear. The only obviously active role for patients and the public is indicated in the monitoring and evaluation section where they function as the providers of views, where sought. Clearly, there is scope for latitude in interpretation and in the intervening years since 2008 commissioning custom and practice has evolved but, in my view, the cycle gives little encouragement to commissioners to embrace a more pro-active approach for patient and public participation and involvement. If this is the case, whether the Commissioning Cycle approach is capable of producing the type of culture change which will result in the systemic co-production of commissioning decisions still remains to be seen. But perhaps this interpretation smacks of paranoia.

Figure 2.2:   The Commissioning Cycle (NHS 2008)

The guidance produced by NHS England specifically for creating a culture of involvement following the implementation of the NHS Act of 2006 (DoH 2008) may be the document to scotch such suspicions. It serves as a toolkit of suggestions for achieving involvement and identifies an "involvement continuum" (DoH 2008, p.70) which moves through 4 levels from the giving of information to passive recipients through to participation in co-production. This guidance is, however, for NHS staff and not for the public and the ultimate objective of this continuum process is to enable the participants to arrive at commissioning decisions which are "affordable, clinically safe and acceptable to the users" (DoH 2008, p. 84). The use of the phrase "acceptable to users" shows that there

remains a recognition that decisions, whether co-produced or not, will be mediated through financial and clinical constraints which will have defined the range of the choices available. This realisation of the reality of the act of involvement implies that the final decision-making is likely to remain the province of the professionals and the so called "tyranny of professional discourse" (Gillman et al. 1997, p 675) will be perpetuated.

2.3.5   NHS Commissioning in Dorset

The previous section set out the national framework for commissioning and the role the public and patients were expected to play in this process. The guidance provided by NHS England is subsequently interpreted and implemented locally and is where the rhetoric becomes reality. To establish the commissioning context for Dorset I gathered information from the Dorset CCG website (Dorset CCG 2016) which provided the following demographic summary.

Dorset is a county in which 754,000 people live. The county contains both rural and urban populations and in both there are pockets of deprivation. There are proportionally more residents over the age of fifty than under it; this is the reverse of the demographic trend in England as a whole. The number of people over seventy in Dorset is expected to increase fourfold in the next ten years and the older and aging population means that the health issues associated with age are more prevalent. The number of people anticipated to be living in Dorset with a long-term disability is also expected to rise from the nineteen percent recorded in 2011. Within this overarching statistic, stroke, together with cancer, is identified as one of the major causes of death in the county and is one of the conditions which is expected to increase in incidence because of the demographic profile of the county. In addition, the CCG acknowledges that the impact of the health challenges is compounded by issues such as public transport and availability of community services, particularly for residents living in the more rural parts of the county.

Over the last eight years, in accordance with Department of Health guidance and policy, much effort has been made by the current CCG and its antecedents in Dorset to secure public and patient input into and feedback on strategic health provision decisions. In 2013 the CCG embarked upon a countywide Clinical

Service Review (CSR) and specific patient and public engagement events such as "The BIG Ask" (Dorset CCG 2013) were focused upon generating the views of the general public on the strategic direction of healthcare delivery in Dorset. The products of this and other "views-seeking events" have been communicated back to the people of Dorset through CCG information tools such as "Feedback" which can be accessed via the CCG website and also via various mainstream media platforms such as local newspapers. As a result of these and other, more service specific, communications, a level of dialogue has been achieved between the CCG and the public which has never been experienced before. Opportunities for ongoing involvement in the various public and patient forums established by the CCG and other bodies such as Healthwatch are available for those who wish to use them. General public debates about the proposals which the CCG have highlighted for consideration during the CSR have been regularly initiated however, public reaction, as recorded by Healthwatch in their recent evaluation of the CSR process (Healthwatch 2017), indicates that public opinions have not been in short supply but the public have not felt listened to As a backdrop to my research into participation in strategic healthcare decision-making this current context could not have been more ideally crafted.

Whilst the CSR is addressing the complexion of healthcare provision in Dorset across the whole spectrum of services, my research has a specific focus on stroke care. The percentage of the population in Dorset who have experienced stroke or Transient Ischemic Attack (TIA) is higher than the national average and this is expected to continue to rise (Dorset CCG 2013). NHS stroke services in Dorset have been commissioned following Department of Health guidance and therefore the National Stroke Strategy (DoH 2007) has been the most recent commissioning template. Patients have been actively engaged in stroke service planning in Dorset since 2009 and a general culture of participation is now well established in this area. The pathway of care for stroke which is now in place contains well-defined steps which serve to carry a person from first suspected signs and acute stroke care through to being re-established in their community as a stroke survivor. The work completed in Dorset to date has ensured that high quality care is available throughout the stroke care pathway and feedback on the performance of the services in Dorset has generally been good (RCP 2016) However, there is no readily available evidence to show how the input of patients

has informed or influenced the decisions about stroke care provision that have been made by the CCG to date.

In my opinion the status of any participatory activity lies in its function as a dialogue, with stimulus being followed by some sort of response. It is this view that has determined that the setting for my research should embrace not only the landscape from the point of view of the public/patients but also the landscape from the point of view of the commissioners responsible for stroke service commissioning at the CCG. It is the application of this commissioning process in its current state in Dorset, from the perspective of its inclusiveness to people with acquired communication disabilities who represent a potentially "hard to reach" group, which is under scrutiny in my research.

2.4   Hard to reach

"Hard to reach" is a term which is often used in health and social care contexts as a label for many different groups of people (Freimuth and Mettger 1990; Flanagan and Hancock 2010; Roger 2015) and is attached for many different reasons. Generally, it is a term applied by those with power to those who do not respond to the rules of their game and it implies inequality (Flanagan and Hancock 2010). However, as Flanagan and Hancock (2010) go on to point out, "hard to reach" could be a label equally applied to social processes as to individual participants. In 2009 a report for Ipsos MORI Social Research Institute (McLean and Andersson 2009) concluded with a suggestion that more work was necessary to deliver meaningful citizen empowerment. They went on to emphasise the significance of including the seldom heard and the hard to reach within the empowerment agenda. In their view meeting this key test should constitute evidence of true citizen empowerment. A review of literature by Beadle-Brown et al. (2012) emphasised the way in which the assumptions of health and social care researchers often served to create barriers to inclusion which would not have been identified as necessary by the potential participants. Whether individually or socially attributed, the outcome of some being labelled "hard to reach" is that their particular perspectives or experiences may remain unheard and therefore unaccounted for. Hodges et al. (2014) in their Seen but Seldom Heard project draw attention to the impact of being unheard and

challenge the way in which the current participatory culture excludes alternative voices.

The absence of voice can be both metaphorical concept and real-life experience. For those who have an acquired communication disability it is likely that both interpretations apply. In the context of strategic healthcare decision-making there is very little published research to indicate how people who are living with a communication disability view their place and purpose in contributing to local NHS decision-making forums.

2.5   Communication Disability and Inclusion

For my study I am particularly focussing upon people whose communication disabilities have arisen from a neurological event known as Stroke. Stroke describes a circulatory malfunction whereby the delivery of oxygenated blood to the brain is interrupted resulting in damage to brain cells and therefore to brain function (Lincoln et al. 2012 in Kneebone 2016). If this damage occurs in certain specific areas of the brain it can affect communication by impairing the brain's ability to process communication (aphasia), be it incoming, i.e. listening or reading (receptive aphasia) and/or outgoing, i.e. speech or writing (expressive aphasia). It may also affect the coordination of speech (dysarthria) which can make otherwise intact communication attempts difficult for the listener to understand because the production of the communication is slurred or distorted. I shall refer to both the impairments of the internal processing of language and the external production of speech which can be experienced by people following stroke as acquired communication disabilities (ACD).

2.5.1   What is Stroke?

Generally, Stroke is the most common cause of long-term disability in the developed world and there are currently 1.1 million Stroke survivors living in the UK. In 2014/15 in the South West region, Dorset was recorded as the county with the largest number of stroke survivors. At that time there were 18,000 residents

recorded as having had a stroke (Tyrell et al. 2016) this represents approximately 2.5% of the county's population.

In the early days after Stroke a third of survivors will have communication impairments. However, long-term (more than one-year duration), approximately 15% of all people will experience a lasting impairment of their communication as a result of the initial event (McKevitt et al. 2011, Stroke Association 2013). Many who have a Stroke will also experience cognitive changes whilst in the acute phase of post-Stroke recovery. Most commonly these are disorders of attention, executive function and memory but, by one year post-Stroke, problems with attention and concentration are the main residual cognitive difficulties (Lesniak et al. 2008). The resultant loss of confidence in being able to keep up with and follow complex conversations that these combined long-term cognitive and communication impairments bring is significant. Investigation of the impact of an acquired communication disability on previously communication competent adults has shown that there is a profound change in their perceptions of their quality of life and their ability to participate in social life, together with a marked increase in the experience of depression (Parr 2007; Hilari 2011; Spaccavento et al. 2013).

2.5.2 Acquired Communication Disability

It is a common experience that people with ACD often have their communication taken over by others who speak on their behalf. Whilst this is a natural rescue reaction on the part of carers, who perceive the person with ACD to be struggling, it represents a dynamic and delicate balance of roles and it can also serve to render the spoken-for voiceless. Research by Cruice et al. (2005) and Gillespie et al. (2010) has shown that, whilst proxy speakers can represent the views of the person being spoken on behalf of for up to fifty percent of the time, the views expressed by the proxy are equally frequently **not** the same as those of the person with ACD. The experience of being spoken for can be affirming if the spokesperson eloquently and accurately expresses the views of the person with ACD. This can serve to reduce any social anxiety however, perhaps not surprisingly, people with ACD have also reported that their sense of themselves is significantly affected by their communication disability (Howe et al. 2008) and is something which Shadden (2005) referred to as identity theft .The impact

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which reliance on a proxy has on the confidence of the person with ACD to engage in social activities, even with familiar others, is considerable. Research has highlighted how the person with aphasia and their caregiver differentially rated issues such as independence and over-protection and how relationships have been put under strain by the changes within those relationships (Gillespie et al. 2010; Vickers 2010; Babbitt and Cherney 2010; Brady et al. 2011; Stroke Association 2013; Musser et al. 2015). Stroke survivors with ACD perceive their aphasia as a serious social disability (Law et al. 2007a;Johansson et al. 2012), the consequence of which is often self-imposed social isolation (LeDorze and Brassard 1995; Parr et al. 1997; Lyon 2000 and Simmons-Mackie 2000; Parr et al. 2004; Palmer and Paterson 2013).

2.5.3 Self-exclusion

Such decisions to self-exclude have been framed as being in part a consequence of self-referent thought processes through which each individual gauges their belief in their own ability to be effective (Bandura 1982). This internal evaluation is common, to a lesser or greater degree, to all people as they make continuous assessment of their capabilities in relation to the context in which they find themselves. The sudden acquisition of ACD, where such significant changes in the ability to be independent in communication and thereby in control of one's own life in the same ways as were possible prior to the stroke, necessitate a reconstruction of a new self, the result of which may contribute to the decision to withdraw from situations requiring communicative contact. These people are at once removed from the opportunity to participate and, thereby the opportunity to introduce into any social situation the perspective which having a communication disability brings is lost (Simmons-Mackie and Damico 1995, 2007; Dalemans et al. 2010; Fromm et al. 2011).

Being a person with ACD does not mean however, that in addition to losing your ability to communicate easily you have also lost your ability to formulate an opinion or to hold a view. Kagan (1998) describes this as the aphasia masking the individual's competence and Johansson et al. (2012) showed that people with ACD, even when their communication was severely affected, preferred to take part in conversations if they could. So where is it that the disability lays?

2.5.4 Social impact

Human beings are social animals living in a highly socialised world dependent on communication in all its forms to maintain their connectivity as Goffman (2009, p.5) asserts, "every person lives in a world of social encounters, involving him in either face-to-face or mediated contact with others". Despite this, the ability to self-impose a state of social isolation is not exclusive to people with ACD as evidence from the work of sociologists such as Goffman (1983), Giddens (1976) and Emirbayer and Mische (1998) for example has shown. Indeed, the sense of self, the role of the self in conducting interpersonal relationships and the expression of self-agency or the belief in ones' ability to control one's own life through decision-making (Bilton et al. 1996; Williams 2003) are central facets of human social behaviour in general and are therefore key concepts in the examination of the potential for individuals to contribute in a social world. The inter-relationship of the self, the belief in one's self-agency and the efficacy of the eternally manifested behaviours which result is subject to lifelong change as a reaction to the contexts or structures in which the behaviours take place.

Work conducted by Garcia and Connor (2011) demonstrated that people with ACD were not only affected by the change in their social role due to the loss of their communication but were also affected by environmental factors such as noise and style of communication. The participants in this study strongly preferred face-to-face interactions over remote or mediated methods of communication. The significance of situated talk where the participants could detect and respond to the full gamut of communicatory effort was great (Garcia and Connor 2011). Therefore, opportunities to participate which are not able to offer a conducive and supportive approach that is flexible to the needs of individuals with ACD are likely to foster feelings of exclusion. The views of people with ACD with regard to their own social isolation may well be reinforced through their experience of attempting to communicate with a general public whose lack of awareness of what skills and techniques are potentially valuable (and also acceptable) in maintaining social discourse with someone who has an acquired communication disability. Although the media coverage of the consequences of stroke in general has increased in recent years (Sherratt 2011) it still remains the case that lack of awareness of how to offer appropriate communication support

creates barriers to participation in community life for people with ACD (Cruice 2007; Howe et al. 2008; Mackensie et al. 2011; Code et al. 2016). This is, in part, due to the fact that ACD is an invisible disability which gives no clue to the potential conversationalist that different communication strategies may be necessary, thus the potential for embarrassment and communication breakdown is constantly present outside the immediate social circle of the person with ACD.

2.5.5   Enabling structures

Early research in Scotland (Hartley 2003) provided evidence to show that small changes in the customs and practices of primary care-giving organisations could significantly improve the experiences of those with communication or literacy support needs. In 2007, a proposed Charter for Communication was drawn up which was based upon the Communication Bill of Rights published in America in 1992. This document set out what rights people with communication disabilities in the UK should expect to have been met with regard to their being included in community life (Communications Forum 2009). The draft Charter contained 6 sections namely:

- Information

- Support and Training

- Time to Communicate

- Access to Services

- Inclusion in Social Networks

- Services from Employers.

Each section clearly established what rights and responsibilities were to be achieved if inclusion was to be effectively accomplished. There is no evidence that this Charter was ever issued as an agreed document but it's key messages were summarised for use in work by the Aphasia in Scotland Project (Law et al. 2007b) and also in the Communication Charter published by Speakability (an aphasia charity) in 2013. Both documents emphasised the importance of facilitatory environments and flexible approaches in enabling participation. The

need for education in how to achieve such good practice was addressed by Connect, the Communication Disability Network, who produced a training toolkit which embraced the Charter's fundamental principles and which was designed to raise the awareness of the communication support needs of people with ACD (Parr et al. 2008). The Toolkit was co-designed by Speech and Language Therapists together with people with ACD and served to address the need for information about what may help people with ACD participate in all aspects of life. The impact of this training product, which was extensively used by Stroke Networks in Primary Care Trusts throughout England, has not been evaluated nationally but locally in Dorset the training programme ran for a year from 2009-2010 and trained over 600 people who were working in health and in social care contexts. The Dorset project evaluation showed that direct improvements in the communication environment could be made which both increased the communication confidence of NHS staff and enhanced the experience of inclusion for people with ACD, but it also highlighted the barriers too (Slate 2010). The successes emphasised that people with ACD could participate in decision-making about proposed improvements to services, whilst the barriers identified that the NHS organisations were not able to be flexible enough to accommodate some of the proposed good practice. One example of such a lack of flexibility concerned the proposal to restructure the stroke follow-up appointments. The staff involved in this service had identified that it would be desirable to increase the length of appointment for the stroke survivors who had ACD to give them time to get their questions across and to understand the answers given by the Consultant. This was presented to the panel of people with ACD who participated in the project and they agreed that this move would be helpful. The proposal was then tabled to the hospital management team who said that it would not be possible because it would make the out-patient clinic last too long. Many other proposals concerned small changes such as the creation of aphasia-friendly leaflets and the introduction of communication support techniques such as readily available pencils and paper, and where these were implemented they enabled better communication. Sadly, over the last five years, organisational reforms have removed not only the implemented changes but also the body of knowledge and skill in the staff as no new training has been delivered since the end of the project.

2.5.6 Sustaining Change

The ongoing importance of sustaining such changes must not be under estimated if culture change is to be embedded. A working paper by Garcia and Conner (2011) looking at communication access in the USA emphasised the significance of the communication environment on the perceptions of inclusion held by people with ACD. Their research indicated that even after many years of living with ACD the participants in their study still considered themselves excluded from participation in activities and roles that they found valuable to their sense of well-being on account of the lack of an inclusive communication environment. These reported experiences were regardless of the adjustments to a change in social role which the participants had made and also regardless of their general personality and social inclinations. The importance of both culture **and** environment in the facilitation of participatory behaviour has not been explicitly highlighted within the policy guidance for the NHS in England and Wales.

However, over the last ten years the Scottish Government has taken a more concerted and sustained approach to the inclusion of people with ACD in social life, both domestic and civic. Research undertaken by Mackensie et al. (2011) showed that even people with ACD who were motivated and active participants in civic life were frustrated by the lack of understanding about their communication support needs. The Aphasia Scotland project (Law et al. 2007b) has demonstrated that the participation of people with ACD can be achieved in a real and meaningful way when the context and environment in which the participation occurs is made consistently and robustly appropriate (MacKellaig et al. 2014). Though the implementation of such initiatives it has been shown that an aphasia friendly approach does not just improve things for those with ACD (Swinburn et al. 2007). Even the smaller Dorset project showed that the measures taken to improve communication access for people with ACD also benefitted participants who did not have any identified communication impairment (Slate 2010) which might indicate that in complex or newly emerging contexts everybody benefits from clearly communicated rules and processes which they are given time to understand and use.

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2.5.7 Models of disability

Both Connect and Aphasia Scotland have focussed attention on the impact of communication disability on an individual's ability to take part in life and made suggestions on how this impact might be reduced. There have been many models of disability (Finkelstein in Swain et al. 1993) most of which have presented the social exclusion of people with disability as being the result of their impairment and not as a consequence of the inability of the societal structure to enable the inclusion of the disabled person. From the 1970's onwards the developing concept of a social model of disability, a term coined by Mike Oliver in 1983 (cited in Swain and French 2004), rather reframed the context in which disability was viewed. Now in the 21st century, disability is much more accepted in terms of there being an ability rather than a *dis*ability spectrum (Shakespeare and Watson 2002, Swain and French 2004) and some argue that the social model fails to account for the needs of people with communication disability (Swain et al. 2003) and is therefore not fully representative. What the social model of disability does do however is raise the level of debate generally with regard to inclusionary practice. This is a positive direction of travel which the mainstreaming of events such as the Paralympics has helped to embed, although many might feel that the successes of elite athletes are not a natural reflection of normal life - with or without a disability. More prosaically, national initiatives which started with the passing of the Disability Discrimination Act in 1995 (later to become the Equality Act in 2010) were mirrored globally by initiatives such as The World Health Organisation's (WHO) framework known as the International Classification of Functioning, Disability and Health (ICF). The ICF serves to provide a standard terminology and language with which the impact of disability in all its guises can be identified and therefore recognised (WHO 2002). Through the ICF the WHO aimed to embrace the social model of disability by introducing and encouraging a more holistic approach to the assessment of disability which broadened the societal perspective beyond the impairment to embrace an appreciation of the impact of the impairment on an individual's functional ability to live a fulfilling life. The ICF categorisation recognises the importance to wellbeing of being able to be part of a larger social group. Activity and participation which constitutes a theme within the domain of Functioning has community, social and

civic life specifically included as a chapter within it. In addition to establishing that having a disability should not exclude one from opportunities available to non-disabled people, the ICF also serves to identify what considerations need to be taken into account and what measures should be taken in order for people with disabilities to successfully access life and society. There is no intimation that difficulties will not have an acceptable solution found for them in order to achieve an inclusive society. Since its publication the framework has informed the development of thinking with regard to inclusion and enablement generally but also specifically with regard to ACD (Threats 2007). In respect of post-stroke experience, most aphasic stroke survivors will return to living their lives as best they can once the initial healthcare activity has concluded and the acute phase of the stroke has passed (van der Gaag et al. 2005). All will have views and opinions about the services they have received. The expectation should be that these views and opinions will be sought and captured by the NHS involvement process.

2.5.8 Making policy real

Returning to the guidance for the NHS on the implementation of Section 242 (1B) of the NHS Act, it states that "as commissioners, PCTs have a particularly important role in gathering and acting on the views of users, including those who are easy to overlook" (DoH 2008, p.10). Research in Australia has shown that, for people with ACD, interaction with formal governmental institutions and agencies presents particular barriers which can be difficult to overcome and that there is no evidence of a universal willingness to create an inclusive-to-all approach (Booth 2012). In the UK the explicit recognition of the need to embrace more than the "usual suspects" as well as the requirement to facilitate participation has excited much debate and deliberation but has this resulted in any change to the experience of people with ACD? The product of the change in thinking about inclusion that has taken place during the years since the WHO framework has certainly led to more improvements in the general legislation which exists to protect the rights of those in society whose circumstances potentially stand them out of the mainstream and admittedly these developments have also contributed to the involvement agenda. NHS Commissioning Board document, "Everyone Counts: Planning for patients 2013/14" contains the

following statements: "We need to know more about what our patients think of the services we commission and act on that information in designing and delivering services." and "We recognise a particular responsibility to ensure that the voice and views of currently disadvantaged groups are sought out and listened to" (DoH 2012, p.8). This expressed intent to enable the participation of all and not just the easy to reach or most vociferous is both significant and encouraging. The challenges lie in recognising that for people with ACD the mechanisms of involvement need to be sensitive, flexible and informed by best practice so that involvement feels accessible, inclusive and worthwhile. Although, a review by Dalemans (2010) indicated that even now very little published evidence is available on the participation of people with aphasia in civic life, so we could be experiencing a "Catch 22" situation. If the profile of inclusionary needs of people with ACD in civic activities is to be raised then more work needs to be done and it is only right and proper that it should be so, as people with ACD are, first and foremost, **people** who have as much right as the next person to exercise their civic prerogative if they choose to. This would be a true realisation of the NHS motto "no decision about me without me" in strategic planning as well as in individual care contexts.

2.6   Power and Influence

Power and influence are, I believe, central constructs underpinning my research topic. In exercising power and/or influence individuals are using a range of skills which are highly complex and can be very diverse in nature (Gaventa 2006). In order to explore the roles which power and influence play and why I believe that they might be central to my study I have reviewed the literature on both through the prism of public participation.

2.6.1 Power

The Oxford English Dictionary (OED) defines the noun "power" firstly as "the ability or capacity to do something or act in a particular way" and secondly as "the capacity or ability to direct or influence the behaviour of others" (OED 2015). The definition thus defines power as existing both intrinsically within an individual and

at the same time having the potential to be part of a dynamic relationship beyond the individual. The consequences of the ability and/or capacity to exercise power are fundamental to our social lives.

In the previous section on Policy and Participation I discussed the evidence relating to participation and the impact of professionalism on the potential for successful interactions between NHS staff and patients or the public in general. Lipman (2000) interprets concepts of power and influence in healthcare contexts using classifications derived from Handy (1993). Lipman (2000) acknowledges the impact of the power structures within healthcare settings, particularly the power and influence of medical professionals, and suggests that the introduction of social science approaches might assist in changing the balance. It is widely acknowledged that the degree to which the levels of culture in the NHS preserve historical hierarchical relationships may actively undermine the development of non-professional influence and that wholesale change in power relationships, whilst desirable, will be difficult to achieve (Davies et al. 2000).

The intricacies of the interactions which bring about the experiences of power have been subject to a range of theoretical perspectives as it is an aspect of human behaviour which significantly sculpts individual experience. Philosophers from Machiavelli onwards have sought to explain and define power but for the purposes of my review it is Foucault's interpretation that I will carry forward to apply to my area of study. In his later writings in particular, Foucault saw power as ubiquitous, as a manifestation of a collective behavioural practice rather than something exercised by individuals and therefore, as a practice, power was not reducible to "types" as such. The emphasis lay in achievement through societal accomplishment. He proposed that power produced "domains of objects and rituals of truth" (Foucault 1991, p.194) which were arrived at through accepted knowledge and scientific understanding. The concept of truth is central to this theory as the process by which truth is established is the arena where power is enacted. He saw the achievement of this as a dynamic, but rule-based, culturally derived and socially constructed process accomplished through interactions which were framed by the knowledge and beliefs of the interlocutors. Instinctively, I feel that Foucault's interpretation with its emphasis on achievement through socially dynamic processes offers a valid perspective. His emphasis on the potential for fluidity in the creation of power relationships opens an

opportunity to investigate how this process may influence social behaviour and to explicitly explore the knowledge and beliefs of participants in relation to the understanding of domains. Foucault's assessment that the nature of power was ubiquitous and that its realisation, through the enactment of relationships, was possible because of its ubiquitousness relates compatibly with the principles of ethnomethodology. A methodology which enables one to focus on the methods which individuals use to make sense of their place in their social environment and to predict the place of others may enable transparency where none has previously been afforded. By exposing the perceptions of individual participants to ethnomethodologically informed analysis, one might illuminate the workings of power as expressed by the experience of influence. Once an appreciation of the significance of the unspoken "understandings" of such relationships has been reached it becomes important to establish whether all participants possess and use these "understandings" similarly. In practice, the experience of power behaviour is not always derived through a constantly mutually agreed exploration of knowledge and belief. Similarly, the theoretical landscape of power is one which accommodates a spectrum of academic viewpoint. I have expanded on why I feel that the Foucauldian view has salience but that is not to say that other approaches are discounted. Therefore, I feel that value is also added through consideration of the conceptual structure provided by other, possibly more concrete models.

Like Foucault, Max Weber similarly analysed social structures and the interactions between them. His focus however was on structure, power and the realisation of authority and therefore his conclusions were considerably more hierarchical in nature. For Weber, bureaucracy represented the mechanism through which social structure was achieved (Weber 2006). Weber's types of power and authority are used by Charles Handy (1993) to explore the function of power and influence in organisations and the Weberian concept of authority applies well to an organisation such as the NHS which so enthusiastically embraces hierarchically driven structures. Rudolph (2006) suggests that although seeming to be diametrically opposed to each other in theoretical perspective, both Foucault and Weber hold as central to their theories the notion that the expressions of power are created through a routinisation of learned behaviours, otherwise referred to by both as "discipline". The fundamental socialising effects

of such learned behaviours enable us to create a dependable, predictable routine environment within which to operate but, from the point of view of culture change, this is not a desirable state. If the NHS is to embed a set of new relationships through which patients, and more broadly the public, will have greater influence over how healthcare is designed and delivered then understanding how individuals process their part to play is key to understanding what needs to change.

In 1959 psychologists French and Raven developed theories on social power which provided a springboard for future thinking and study on the subject. They proposed a model which distinguished five distinct iterations of the expression of power by people, namely, coercive power, reward power, legitimate power, referent power and expert power. Each type describes a behaviour pattern which, whilst it can be framed within the broad OED definition, also reveals the contextual complexity associated with the expression of power. Whilst French and Raven's model suggests distinction derived through the psychological purpose of power, it is clear from everyday experience that power behaviours are not expressed according to their academically convenient categorisation. The infinite range of possible behaviour combinations which can be generated in attempting to describe what may be happening in relationships where power is enacted makes other interpretations attractive. This is particularly so when considering the relationship dynamics between individuals and organisations.

Academics such as Lukes (Lorenzi 2005), Gaventa (1980), Clegg (1989) and Giddens (1984) all argued the dimensionality and subtlety of power perspectives from their particular intellectual viewpoints which were framed by the political milieu of the day. Giddens' work on structuration and agency was particularly embraced by the Labour government of the 1990's for example. Structuration theory followed the Foucauldian view that social practices, as they happened in space and time, constituted the arena of power. Individuals, through their capacity to choose were the agents who enacted the social practices and either perpetuated them or changed them. To understand the context in which the choice was to be made, each individual must have knowledge and understanding of the "rules", which Giddens defined as "techniques or generalisable procedures applied in the enactment of social practices" (Giddens.1984, p.21).

In response to Lukes' work Bourdieu conceptualised power along similar dimensional lines but construed it as a set of interconnecting constructs through which struggles over resources could be described. In Bourdieu's analytical model, power exists in three domains, habitus, capital and field which overlap but remain distinct, and the relational processes which operate between the domains hold the "sociosymbolic alchemy" (Wacquant 2013, p.2) of social behaviours. Bourdieu sees power as being socially and culturally created through a process of continual interaction between individual agency and the structure in which it exists. The relational dynamic which Bourdieu names habitus and which Wacquant later described as 'the way society becomes deposited in persons in the form of lasting dispositions, or trained capacities and structured propensities to think, feel and act in determinant ways, which then guide them' (Wacquant 2005, p.316). It is habitus which defines and structures individual actions and gives a sense of place or stratification or hierarchy to participants. Capital represents the assets which are available to each individual and which can be brought to bear in social arenas in order to gain the individual status and/or power. Capital, which Bourdieu further differentiated into economic, cultural and social forms, can be possessed in differing quantities according to the environments or fields in which the individual is socially active. Capital is transferrable between fields. Fields are the spheres of struggle within which capital resources are deployed according to the objective positions which people occupy, and as such they define or constrain participants perceptions of possible action (Wacquant 2013) .Fields are therefore networks of structures which can determine the validity of the various forms of capital held by an individual. To enable these three elements to function successfully Bourdieu postulated a fourth feature, Doxa, which operates throughout all the domains because it represents the collectively understood, underlying taken-for-grantedness of the rules according to which individuals can operate in the relationships between habitus, capital and field.

On an individual level each person possesses a range of resources or capital. Bourdieu saw social capital as being symbolic in nature because it "is governed by the logic of knowledge and acknowledgement" (1986, p.257). Social capital defines an individual's connectedness to others and operates through their own sense of place or habitus which enables them to feel themselves included or

excluded from fields. Doxa, serves to confirm these constructs by reinforcing the sense of order which is viewed collectively by participants as common sense. At a macro or organisational level, Bourdieu saw the state as representing the formalisation and regulation of symbolic power through rules, rituals and bureaucracy. He went on to suggest that through this process those in society who were not in possession of the power became inured or in Swartz' (2002, p.7) term "practically adapted" to the social inequality and thought of their status as normal and not one to be contested. This outcome of power behaviour is particularly relevant to this study as it permits the acceptance of a status quo which is the product of what Weber and Foucault termed routinisation. Once caught in such routinised structures it can become hard to change.

Further exploration of the consequences of power brings consideration not only of the impact of the players who are present in the power relationships but also the impact of those who are not. Lukes (in Lorenzi 2005) suggested that if individuals do not participate, the absence of their contribution must have an impact on the outcome of the activities being undertaken and this will be the case regardless of the scale of the context. If people are absent from decision-making arenas then the decisions taken will not reflect their views and this may engender a feeling of "being done to" (Leighton, 2010). A Joseph Rowntree Foundation report also produced in 2010 (Hunjan and Keophilavong 2010) concurred with Leighton (2010) in emphasising the importance of power and powerlessness on well-being. The more people feel in control of the things that affect their lives the greater their sense of well-being and consequently the more likely they are to engage in participatory activities.

Of course it is naive to presume that the individual's sole dilemma is to choose between participation and non-participation. Being absent from a decision-making arena may not be as a result of choice but as a result of ignorance of opportunity or as a result of active exclusion by others. Gaventa (1980) developed a "Power Cube" model which used a three-dimensional approach to describing power relationships in an attempt to capture this aspect. Gaventa was particularly interested in organisational power and described visible, hidden, and invisible dimensions of power which reflected the transparency of opportunity to participate. His approach acknowledged that not only perspective but purpose also defined power relationships between people and/or organisations. His model

emphasised the importance of what he termed space. Space is the place where opportunities occur. Gaventa quotes Lefebvre, "space is a social product ...it is not simply "there", a neutral container waiting to be filled, but is a dynamic humanly constructed means of control, and hence, of domination, of power" (Gaventa 2006, p.27) Power is present in spaces but not all participants are able to access all spaces.

In the context of decision- and/or policy-making, power behaviours are exercised to achieve target outcomes and can serve to establish or reinforce the custom and practice. In this regard the relationship between Gaventa's thinking and that of Bourdieu is clear. Like Lukes (Lorenzi 2005) his models recognise that different actions would be provoked according to the players involved and the purpose desired. My research seeks to find out how participants view the power in the space that I have labelled as NHS service planning. I have chosen to adopt the word influence to describe the product of the power relationships experienced by the participants in the context of NHS service planning.

2.6.2 Influence

Influence is a mechanism though which power is identified within a relationship. It is referenced as part of the definition of power where power is defined as being the capacity to change the behaviour of another. Influence itself is defined as the "action of a person or thing on or upon another, perceptible only in its effects" (OED 2015). So, in terms of this definition, the key to the recognition of the presence of influence is that an effect can be perceived. It describes what happens when power is directed outward and these two terms, power and influence, are therefore frequently used interchangeably in the popular literature. This is not surprising if one agrees that influence is the experience of the application of power behaviours. In the context of participation, I suggest that influence is what participants are hoping to have when they perceive that a course of action is not in their interests or to their benefit.

What makes influence possible has been the subject of considerable study. Cialdini (2001), a psychologist and author of popular books on the topic of influence, proposed six principles of influence which map easily onto models of power such as those proposed by other psychologists, French and Raven (1959)

for example. Cialdini's approach has grown from the application of psychology in using influence to sell products and his books are well used in marketing and sales training. The influence behaviours he identifies are described as "click whirr" (Cialdini 2001, p.3). They are automatic response systems governed by subconscious rules and they are the product of our individuality, plus our social identity, plus the context in which we find ourselves. They are "shortcut" learned behaviours to save conscious effort and this is, he suggests, why they can be so successfully exploited. More recently the work of Kahneman has further raised the profile of the salience of thinking mechanisms with his book Thinking Fast and Slow (2011) which reinforces the significance of the automatic processes involved in decision-making.

Research has also shown that individuals are very susceptible to being influenced differently from their personal inclination when they are in group situations and the power of this social influence can produce responses and decisions which are potentially at difference with their individual views (Barnum and Markovsky 2007). This is important to remember when considering the function of influence in group participation. The added complexity of behaviours mediated by factors such as self-categorisation (Turner and Reynolds 2012) and status typification (Fisek et al. 1991) creates a highly complex dynamic whereby each participant is using their assessment of the social value of the others in the group to determine the validity of their own views. This work has its origins in the very early social psychology behavioural publications of Festinger (1954) and Moscovici (1972) for example. The impact on each individual's self-categorisation caused by a change in communicative status or the impact of an acquired communication disability on the assessment of that individual by others has been little researched but is of great significance when considering the topic that I have chosen to study.

In the current NHS change process, influence is recognised as a method of achieving culture change. Politicians and policy makers recognise that behaviours can be triggered and then managed to achieve the desired outcome. The interest in the application of influence tactics as a legitimate way of changing public behaviour has been growing. The terms "nudge" and "think" (John et al. 2009) together with "shove" (DEA/Involve 2010) have entered the vocabulary of those wishing to influence behaviour. Power and the mechanisms by and through

which it can be demonstrated and felt are seminal to understanding why people might behave the way they do. As has already been discussed, the relationship mechanisms through which people enact their self-determined roles have philosophical and sociological explanations as well as psychological. Bourdieu's Theory of Practice (1976) models social and cultural behaviours which are predicated upon subconscious rules and activities for example. From sales to politics, such behaviour frameworks have used these unwritten rules to enable desired results to be achieved.

In a review produced for Government Social Research, Andrew Darnton (2008) has illuminated the way in which an understanding of human behaviour on the individual, meso and macro level, has informed Government policy and practice. Darnton helpfully presents a summary of 60 behaviour change theories and compiles a practical guide to implementation of behaviour change in the service of achieving "positive policy outcomes" (2008, p3). The drivers being explored by the policy research units are evaluated, predominantly from the point of view of how the public may be influenced/manipulated (depending upon your viewpoint) to comply with the desired direction of travel. The required outcome being for the public to be "engaged" in the change process to the extent that their behaviour changes. It is evident that the policy research units are driving the understanding of how government can more successfully package its messages to tap into the basic social psychological functioning of the electorate. This approach is nuanced and subtle using "nudge" tactics, very popular in the political world at the moment, which recognise that a relationship must exist between the influencer and the influencee for change to happen. So the influence here is one way only. Behavioural Economics seems entirely centred on the understanding of social rule application and the analysis of human behaviour in any of the above contexts and the extrapolation into "recipes" for achieving some predetermined desired outcome feels scientific and empirical rather than interactional and pragmatic. In a paper for the Overseas Development Institute, Sutton refers to the term "a chaos of purpose and accidents" first coined by Clay and Schaffer in 1984, to describe the policy development and implementation process (Sutton 1999, p.1). She asserts that the policy process is not rational or linear and that in the transition from policy to implementation unpredictable events occur. This assessment still stands despite considerable investment in achieving control over

events, as evidenced in the Institute for Government document "Policy Making in the Real World" (Hallsworth et al. 2011). The complex systems through which policy decisions are taken are reliant upon a range of both knowing and unknowing actors playing their part. A decision to do something does not reliably result in that exact thing being achieved.

The appreciation of influence as a philosophical or psychological entity must be functional not only from the point of view of the administrators but also from the point of view of the people receiving services. So, consideration of the lived experience of power and influence in the context of the NHS, where so many of the decision-makers are white, middle-class men, will be important. The interaction between the perception of power and the class and/or gender of the participants has been a source of rich debate in the Western world from the beginning of the 20th century onwards (Weber 1998; Hurst 2007; Flemmen 2013) In terms of the focus of my research, the relationship between power and influence must be taken into consideration. These factors become even more relevant when a more inclusive approach to decision-making is being encouraged, for the wider community will contain interest groups whose narrative and groupthink behaviours may be equivalent to those of the policy elite but whose perspectives are quite different. Bringing these viewpoints together in a meaningful and respectful way is the challenge currently faced in the NHS participation context.

In an effort to circumscribe the locus of control and possibly determine outcomes, political attention has been drawn to the production of a considerable number of words on the subject of public and patient involvement/engagement/participation in the doings of the NHS. The themes with regard to participation have remained constant but the regularity and volume of pronouncements containing them indicates that progress toward the desired outcome is perceived to be slow. However, to return to a point made in the section on participation and policy, there may well be a difference in perception between the organisation and the public regarding the desirability and relevance of participating. The various organisations are mandated to involve the users of their services and their performance may well be rated according to the outcomes of these activities. On the other hand the public, as users of the NHS services, may see the purpose of participation in such activities in an entirely different light. The study by Litva et al.

(2002) showed that people wanted to be consulted but not given the responsibility of making the decision. Similarly, a report prepared for the 2020 Public Services Trust by Ipsos MORI (2010) revealed that, by and large, people wanted to feel they could influence if they needed to but did not want to be actively involved all the time. It might be that these findings reflect that the general public have a level of trust in the decision-making abilities of the organisations or a perception that what people think is not sufficiently valid to determine a final outcome. Further evidence on how the relationship between the public and the professional NHS decision-makers works would be valuable in understanding how to enable the relationship to mature. The process through which policy decisions are developed and concluded is a rich cauldron where sociological, political, anthropological, managerial and change management ideologies come together.

In order to manage the inherent complexity and to create a basis for collective understanding a strategy of discourse narrative is often brought to bear. Narratives structure and simplify the context for dialogue in a way which creates a "wisdom" which then illuminates the future discussion contexts. The owners of the narrative are the ones who create the "wisdom" and therefore this is very likely to be affected by their personal views and knowledge base. The way policy communities have formed in the past has tended to reinforce the groupthink (Janis 1972) tendency in narrative formation, as likeminded people have collected to determine policy. Shore and Wright (1997) looked at this aspect from the point of view of the participants' ability to define the decision arena whereby items for discussion could be ruled in or out through the dominance of the collected group wisdom. A group can hold power through the vocabularies they use and so, conversely, legitimate interests can be disenfranchised through the use of language. Foucault (1991) emphasised the power of vocabulary in neutralising the political nature of a discourse by re-couching it in scientific terms which serve to mask the actual purpose of the debate, as the apparent objectivity of technical term usage is perceived to afford a value-free appraisal of the issues. However, for those who have less familiarity with the vocabulary and confidence in the organisational culture, a failure of the organisation to recognise their needs can strengthen the perceptions of elitism. It is recognised that supportive inclusionary practices need to be incorporated in order to overcome such

barriers. Morrison and Dearden (2013) demonstrated that all participants in Patient and Public Involvement (PPI) activities benefitted from supportive techniques which facilitated the use of non-technical vocabulary and signalled permission to participate on equal footing with healthcare professionals. Initiatives such as the "Stronger Voices" campaign launched in Scotland (Alliance 2014) address the need for a more confident and informed public presence in decision-making. The Stronger Voices philosophy was adopted by Dorset CCG (2014) in order to address this issue locally.

These initiatives recognise that participation can require the investment of time and effort in order for the general public to become confident. The drive to develop such strategies has arisen from the top-down policy requirement to "engage and involve" and so the emphasis has tended to remain on activities which "up-skill" the public participants rather than changing the customs, vocabularies and practices of the organisations. This could imply that some vocabularies have more value than others if plain English is not seen as good enough. For those who have difficulty in using their communication skills the experience of exclusion is enhanced (Parr 2001). As previously referenced, Slate (2010) identified that modification of Dorset CCG PPI presentation materials according to the communication access needs of people with aphasia (Connect 2009) helped not only participants with ACD but also those without communication disability to follow and process the information being given. Morrison and Dearden's work (2013) emphasises the value of participatory design that is inclusive to all and enables the potential for tokenism to be avoided.

In this thesis the perception of the value of involvement is evaluated from the point of view of people with ACD. Dorset CCG's adoption of strategies such as "Stronger Voices" indicates that, as an organisation, they are keen to enable meaningful public participation. However, if the organisational response to the drive to include the public recognises that adjustments might be needed but the resultant modifications are based upon assumption of need rather than proof of need, then beginning to understand what potential participants think will be valuable in developing more accessible models of participation.

2.7 Ethnomethodology: Review of background and context

An evolving desire to investigate assumptions people make about the power they may have to influence the decisions of others led me to consider a number of qualitative research methodologies. It became clear to me as a result of this process that the value of my research would lie in capturing the individual contributions as unique experiences. My decision to focus on an ethnomethodologically informed approach was arrived at as a result of my investigatory reading. I saw the principles of an ethnomethodological investigation as being compatible with the personal and professional values which drove me to want to research how people constructed their understandings of civic participatory behaviour. My Ethnomethodology discovery process is important to the setting of my developing thesis and therefore this introduction to ethnomethodology belongs here in my literature review.

2.7.1 Origins

Ethnomethodology as a discipline grew out of the 1960's reaction to the scientific methods of the 1950's and earlier. It is not an experimental methodology in an empirical scientific way but rather it embraces the qualitative observational and philosophical perspectives in its recognition of the individual instances of "practical reasoning" (Garfinkel 1984) which underpin human behaviours. Whilst ethnomethodology certainly owes its origins to both phenomenology and sociology it maintains a methodological status based in the diversity of expression of human behaviours as accomplishments (Turner 1974) Ethnomethodology differs from the pure phenomenological approach (Psathas 1968) by being concerned with the "how" of experienced behaviours rather than with the description of them. It differs from a sociological approach by being concerned with each instance of the how's of interaction rather than with the labelling of a genre of how's as a theoretical entity. Garfinkel himself was academically nurtured in the context of the phenomenological work of Schutz (1967) and the sociological work of Parsons (1951), but became interested in the application of mundane common-sense knowledge through his Doctoral work with Jurors. He saw that people brought with them a fully functional set of social engagement skills which, in an unfamiliar context such as when being jurors, they

worked on collectively to make sure that they were all operating their skills in a similar way thus revealing that each recognised the others as having the same systems but not necessarily the same interpretations of them. Garfinkel in Coleman and Garfinkel (1968) talks of the jurors explicitly checking common understandings of terms used for example. He used this insight to demonstrate that the interactional behaviour of humans was governed by a set of unacknowledged rules and that these rules were being applied in a "moment-by-moment determination of meaning in social contexts" (Heritage1984, p.34). Garfinkel recognised that importance lay in capturing what the individual/s involved in an interaction defined as happening rather than in the observer imposing an external evaluation of the event in question. His decision to label such an approach as ethnomethodology was arrived at as a result of his understanding that the jurors in his study were using a methodology of commonsense (Garfinkel 1974), their particular social order being created in their minds as social actors rather than social order being an adopted external system derived from the outcome of a consensus of values in society. In this way, social activity has structure but is not determined by its structure which means that it is in a state of constant flux. Each individual member of society measures and interprets their rules against the circumstances in question and the actions taken as a consequence of these individual perceptions then either reinforce or challenge the collective concept of the social structure. Or, to summarise, as postulated by Emibayer and Mische (1998) social agency = habit+ imagination + judgement.

2.7.2 Situating social behavioural concepts

The study and appreciation of the making of meaningful interactions through the interpretation of actions and structure encompasses contributions from a broad spectrum of both sociological and philosophical theorists. Contributors including Bourdieu, Foucault, Wittgenstein, Goffman and Giddens offered theories which incorporated a general appreciation of the role of structure and rules in the governing of human behaviour and practice, "societies everywhere, if they are to be societies, must mobilise their members as self-regulating participants in social encounters" (Goffman 1959, p.42). Later, Goffman went on to state that for society to function successfully, individuals must operate on the assumption that

all other individuals will be operating the same or similar rules of regulation with the ideal being when the accepted signs "mean to the sender what they mean to the recipient" (Goffman 1983, p.5). The complexity here lies in the processes undertaken to achieve the establishment of this agreement. As has been previously discussed, Bourdieu's Theory of Practice (1976) offered an influential explanation of how such agreement might be structurally accomplished. His theory proposed a framework within which behaviours were enacted that was common to all human social activity. His structure of practice, field, habitus and doxa suggested an intricate relationship between internal and external stimuli. Of all the structures, habitus, he suggested, was responsible for governing the actions undertaken by an individual in a given context or setting. Bourdieu proposed that it is each individual's habitus which governs not only their resultant actions in a given situational context but also how the particular action is decided upon. In his view, these selections were made because they were both "sensible and reasonable" for the individual (Bourdieu 1990, p.50). For Bourdieu sensibleness and reasonableness were determined by the appropriateness of the determined action both to the situation in question and to the actor undertaking the action (Bourdieu 1976, p.79; 1990, p.60) However, he also stated that in addition to the action seeming sensible and reasonable to the actor it must also seem sensible and reasonable to other actors in the same context. Therefore, he concluded that it was necessary for all actors to have common access to the understanding of customs and practices for any chosen action to make sense and be considered acceptable (Bourdieu 1990).

2.7.3   Rules and agency

Rules and the notion of a framework within which behaviours are enacted according to an internalised compendium of rules is enticing because it suggests a simple analysis might be achievable. However, I also find it challenging as the use of the word "rules" implies a rigidity which is not easily mapped on to real-life encounters. Wittgenstein (Lamarque 2010) preferred to think in terms of routine practices rather than rules in the same context. Routine practices represented behaviours created at the dynamic interface between societal context and individual experience. In considering the difference which might be perceived between "rule" and "routine practice" I feel semantically the term "routine

practice" affords a suggestion of individual variation and this in turn implies that there might be more scope for difference if individual experience has a greater role in informing resultant behaviours. Garfinkel would see this ability to retain individuality within the system as crucial, the alternative being to become a "judgemental dope" (Garfinkel 1984, p.67). The ability of any individual to operate independently of societal norms and according to their own reality suggests that behaviour is driven by more than just habit. Most of us, if asked, would intuitively say that we have the ability to make our own decisions; that we are in effect free agents (Bilton et al. 1996). Emirbayer and Mische (1998) suggested that the reality of human agency is complex and multi-layered so that individuals can not only carry out actions according to what they have learned from previous experiences and contexts but they can also construct novel contexts and project potential responses from which to choose. In their exploration they referenced Schutz, one of Garfinkel's mentors, amongst others who saw agency as the construction of ends for means which were informed by reflection. So, in this view behaviour was informed through learned experience but remained flexible enough to adapt to anticipated or novel situations. It is usually to be expected, as a criterion of competence, that actors are able to explain what they do and that individual performance in a social context is subject to the application of rules or systems but not necessarily in a formulaic way. The conclusion was therefore that human agency is not completely governed by sets of "taken for granted" (Emibayer and Mische 1998, p.963) practices. Garfinkel himself was clear that whilst there was structure it did not render the individual a judgemental dope because the individual's actions, although mediated by structure, were undertaken in a moment-by-moment process of assessment. The resultant social behaviours were therefore the product of a constant fluid negotiation between what the individual knows and believes and what the individual is actually experiencing in the moment. Giddens (1984) would endorse that the concern of ethnomethodology was the dynamic interaction between the core social structure and the individual experience. He presented the cycle of motive, rationalisation, action, reflection as a framework through which, he suggested, the production of social action could be interrogated. He saw this structure not to be temporally dependent but the actions derived through it as being situated in time and space and it is at this interface where, he suggests, the finely tuned balance between structure and agency might sit.

2.7.4 Action in the making

As ethnomethodology reveals social phenomena "in situ" (Beemer 2006, p.84) it exposes action in the making. Participants are accorded space to account for their own actions which, ethnomethodologically speaking; Lynch (1997) concludes constitutes the legitimation of actions which are already structured and thereby rational. This could call into question the extent to which, in the act of making discursive or explicit any precursor to action, the actor filters and creates *a* structure for the listener/observer rather than *the* structure that they are actually operating. The degree to which the audience affects the account must also be considered. Amongst those who could be defined as "audience" must be the researcher themselves. In exposing the real-time, participant -derived understanding of a procedural process, ethnomethodology imposes a particular regime which allows the investigator the role of recorder rather than interpreter and it is this which marks Garfinkel's departure from his mentor's more sociological approaches to social phenomena.

In attaining an appreciation of the complexity of theories of human social behaviour in the round it became increasingly apparent to me that it is entirely possible to subscribe to several theories at once in the process of determining one's own viewpoint. In developing a working understanding of the subject I can, borrowing from Foucault, begin to create my own reality within which I can undertake my study.

2.8 Summary and research aims

My literature review has identified the complexity of the NHS participatory environment and considered how theories of power and human behaviour might determine the cultural context within which my study is placed. These aspects are relevant to my study because they help to describe the relationships which enable or inhibit purposeful engagement. My particular focus on the perceptions of people with ACD is intended to bring a different perspective on participation which could add value to the developing knowledge base about how to produce a participatory experience which is more inclusive in both involvement practice and outcome. As there is very little evidence of research that has previously taken this approach, this study will offer the opportunity to open up a new dialogue.

To achieve the ambition outlined above I identified the following research aims for my thesis:

1. To understand what a sample of Dorset residents with an acquired communication disability as a result of stroke thought about their ability to influence healthcare commissioners.

2. To explore how open to influence the healthcare commissioners in Dorset believe themselves to be.

3. Through using the local lessons learned from Dorset, to contribute to a wider understanding of the processes which may facilitate better, more meaningful participation for people with ACD.

The following five objectives describe the approach taken:

1. To record the views of the participants with ACD with regard to their ability to influence healthcare commissioners, through the use of an influence-mapping axis tool.

2. To record the views of healthcare commissioners with regard to their openness to being influenced using a mirror influence-mapping axis tool.

3. With both groups of participants, to produce stakeholder influence maps showing the relative positions of influence thought to be held by those stakeholders whom each participant views as being involved in the service design process.

4. To compare and contrast the influence maps and axes produced by the people with ACD with those produced by the healthcare commissioners and identify areas of common understanding and areas of discrepancy.

5. To evaluate the relevance of an ethnomethodological approach to the understanding of how people perceive purpose in participation and to reflect on its potential to contribute to a different way of designing participatory systems.

The relationship between the aims and the objectives of my study clearly define my intention and purpose. My choice of ethnomethodology as an under-pinning

methodological approach presents me with challenges in terms of maintaining the status of the individual participant contributions whilst seeking conclusions about how experience of the participatory process might be improved. In the next chapter I will explore the methodological considerations I have used to enable me to construct an achievable, practical study.

Chapter 3 Methodology and method

"See first, think later, then test. But always see first. Otherwise you will only see what you were expecting." (Adams 2009, p.136)

3.1 Introduction

In this chapter I situate my chosen methodological approach within the wider philosophical and sociological context. I establish how the particular methodological approach used in the study was arrived at and why it was felt to be compatible with the achievement of the research aims and objectives. I then set out how my methodological approach will be realised as a set of practical data-gathering activities.

The transition from theory to practice can be challenging and techniques may appear muddied or compromised by real-life scenarios. Furlong and Oancea (2005) provide reassurance that there is value in the exploration of human experience as it happens. They argue that such applied approaches are not "methodologically depleted" by real life but rather "define quality in terms of wider social robustness" (Furlong and Oancea 2005, p.9). Practice-based research must be capable of responding to the unexpected or unplanned and the influence of the practical environment in the decision-making about both research methodology and research design is acknowledged. As I am part of my research environment I will begin by establishing my own methodological milieu.

3.2 My Own Taken-for-granted Assumptions

My own personality, inclinations and interests are central to my being a researcher. Malterud (2001) acknowledged the inextricable relationship between researcher and investigation, analysis of findings and conclusions drawn. Ellis and Bochner (1996, p.16) refer to Weber's phrase "the webs of significance we spin ourselves" in their appraisal of the relationship between the researcher and her/his research. The quotation from Douglas Adams which I used at the beginning of this chapter speaks to me of the perils of certainty and of fixed views. In chapter one I interrogated my understanding of myself and the "web of

significance" I have woven from my own experiences. Therefore I must strive to be aware of how my own frames of reference may influence what I do. In research, reflexivity describes the process of systematically attending to the way in which the knowledge is being created throughout the research period in order that the researcher can be conscious of the effect they may be having on the product of the activity. My professional persona will be as influential as my personal one. The way in which I interact with my participants and my data will determine the outcomes I produce. From the outset therefore, I must try and instil the discipline of systematically attending to the relationship I have with my research.

In my research I am interested in how my participants use their knowledge and their experiences to assess the context of participation. In my literature review I addressed the significance of "short-cut" thinking processes on people's behaviour. I cannot exclude myself from this instinctive psychological process and I have been clear in my own mind from the very outset that I am making some significant assumptions in my approach to this study. Firstly, I have assumed that all my participants will be competent in their understanding and application of social rule knowledge. Although one group of participants are people for whom the usual methods of communicating are impaired I have assumed that they are, nonetheless fully practiced users of the normal rules of engagement in complex communicative situations. This assumption could of course be challenged because one may think that acquired communication disability could be closely associated with impairment of other social abilities. However, my clinical experience as a speech and language therapist leads me to be confident that the assumption I am making for the communication impaired group is valid. This belief is also supported by research which has shown that regardless of the damage to the communication systems, the underpinning knowledge and practice of how to maintain a communicative social context generally remains unaffected (Goodwin 2004; Simmons-Mackie and Damico 1995). Less remarkably perhaps, I made a similar assumption with regard to their communication competence for the participants who are working in the CCG. Here my everyday appreciation of people in the workplace allowed me to assume that they were equally capable of operating appropriate social rule sets. Finally, I

have made the assumption that both sets of participants will be able to identify the presence or absence of influence in their relationships with each other.

3.3 Why Qualitative Research

In wishing to examine how people perceive what it is to influence or be influenced I knew that my guiding methodology needed to be one which took a societal perspective and a qualitative approach. Qualitative investigations are framed in a naturalistic context and afford the researcher opportunity to use inductive or explorative processes (Bowling 2009). That being said, and notwithstanding the earlier reference to the acceptability of real-life data, any methods used to gather data must aim to provide information that is defendable as being trustworthy. Trustworthiness in regard of qualitative data is determined according to its adherence to four key principles: credibility, transferability, dependability and confirmability (Guba 1981). The challenge must always be to produce data which is derived from transparent and replicable procedures. On the way to achieving external credibility each researcher, according to Miller (1997, p.35) engages in "a creative process which necessarily involves making choices about methods and data on the one hand, and asking analytical questions about the data on the other". The establishment of a theoretical milieu for a study is therefore informed by perceived suitability for the topic in question and researcher preference, together with considerations of the achievability of the research methods within the desired methodology (Holloway and Galvin 2016).

There is no shortage of choice in qualitative research methodologies which range from the mainstream to the niche and esoteric. The process of exploration and selection appears daunting at the outset particularly when research aims are also evolving. As a novice researcher, I began by exploring Critical Theory-based approaches and in the process of doing this I was able to begin to distil my theoretical preferences. I found the ideas of Habermas (1984; Ion 2015) around the understanding of the intuitive processes underlying human behaviour particularly illuminating. This led me to realise that I was not interested in observing and interpreting what people were doing when participating but rather I wanted to know what they themselves thought they were doing and why they felt

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they were being successful or otherwise. What did they see as the reality of the situation for them? Further consideration of this interest drew me to consideration of ethnomethodology as a methodological approach.

3.4   Methodology. The rationale relating to Ethnomethodology

As has been explored in the Literature Review section, Harold Garfinkel, the originator of the term ethnomethodology, described ethnomethodologists as "doing studies of practical activities, of commonsense knowledge, of this and that, and of practical reasoning" (Coleman and Garfinkel 1968, p.23). The work of Theodore Marmor and Rudolf Klein (2012) who themselves were drawing on the work of Oakeshott (1991) helped my translation of ethnomethodological principles into the healthcare environment. I saw that ethnomethodology's particular focus on the subconscious fabric of practical knowledge which each individual person brings to bear in their social interaction would be most compatible with my research intention. Ethnomethodological approaches strive to make the "seen but un-noticed" (Brown 2012, p.4) in human behaviour apparent so that situations can be understood according to each individual who expresses those behaviours or practices. For me the beauty of this definition lay in its lack of pretension and its appreciation of each person's reality. In discovering it I had found a description of what I was interested in but had previously been unable to intelligently articulate.

3.4.1   The "seen but un-noticed"

The motivation for my research interest stems from a desire to understand what a particular group of health service users think about their power to influence healthcare planning decisions. Every individual's decision to act in a socially engaged way is framed by their knowledge and experience as well as their personal inclinations, traits and habits. Papers by De Jeagher and colleagues (2009; 2016) suggest that the complexity of social interaction and the relationship between life and mind is at the crux of understanding behaviour. In my literature review I explored some of the philosophical and sociological theories of behaviour which have been offered as explanation of human social action. How

people behave in social contexts is dependent upon their approach to making sense of the situation they are in, and the experience of being in the situation provides feedback on the appropriateness of their sense-making. Phenomenological work by Merleau-Ponty (1964) and the sociological investigations undertaken by Goffman (1959; 1983) have explored the enactment of sense through self. In Goffman's view socially situated interactions both require and create shared meaning. In her recent work Koubova (2014) discusses the relationship between the visible and the invisible aspects of individual sense-making in human interactions. She describes sense-making as the process of aligning one's knowledge of the world and the way it works, the visible, with one's appreciation of how one's own self works, the invisible.

To me, the motivating or de-motivating factors which determine an individual's decisions to participate are central to the understanding of how participatory activity might be better done. I see the acknowledgement of the person as an individual as being key to appreciating both the differences and the similarities in how people understand the purpose of civic participation. Ethnomethodology focuses on the way in which sense-making is expressed through what are referred to as member's methods or ethno-methods. It illuminates the way in which people might make sense of the actions of others and make themselves sensible in return. The status of ethnomethodology as an academic discipline in its own right has been challenged and is seen by some as "fringe" (Prasad 2005) but it is becoming more a mainstream approach in organisational studies of work, for example (Rouncefield and Tolmie 2013). The application of an ethnomethodological approach to the study of civic participation allows a novel perspective to be taken which may help to emphasise the importance of the shared sense of common context in the creation of a successful social interaction. This perspective will be further developed within the discussion chapter, chapter 5.

3.4.2   Ethnomethodology and its application to this study

In embracing ethnomethodology as the methodological environment for my research I believe that I have chosen a framework within which the activity I have

described as "influencing" can be picked apart. It has already been established in the literature review that the notion of "influence" is open to a variety of interpretations. It is therefore entirely possible that, because the experience and interpretation of influence is heavily embedded within the social framework each person develops as a result of their life experiences, what I have perceived as influence may not be recognised as such by others. Ethnomethodology allows for each individual's experiences to be valued as individual. The dynamic relationship which exists between meaning and experience means that each person will possess their own model for influencing behaviours, which will have been developed in response to the circumstances in which they find themselves exposed to or using influence. As has been previously discussed, the collection of background experiences eventually becomes habituated and exists below the level of consciousness in each of us. Without explicitly checking, it is not possible to verify common understandings and for those participants who are both citizens and commissioners it may be that they have two different sets of practices. In a work role a different set of behaviours may apply where habituated patterns become organisational culture and similarly impose a filter below the level of collective as well as individual consciousness. For those working in the CCG, therefore, there may be a dilemma regarding which behaviours are the more salient to them. For both sets of participants however, the application of an ethnomethodological approach gives value to these individual experiences without the need of external researcher-derived interpretation (this is what Garfinkel termed ethnomethodological indifference). As researcher I would be required to collect and collate – or perhaps curate would be more accurate, as each response is individual - the responses and not attempt to filter them through the prism of my own experience. Ethnomethodologically speaking, this lack of interpretation is important as any pre-supposition of analysis could be seen to risk obscuring the methods actually being used (Lynch 1997). These caveats apply most forcefully when considering in-the-moment data. However, I will not have access to this type of material and therefore, in the context of my study, whilst I like ethnomethodology as an approach because I am interested in trying to understand what each of my participants holds as real, I am conscious that the methods I have identified to gather my data are not ones usually used in pure ethnomethodological circles.

3.4.3 Ethnomethodological challenges

I have captured participant views on a situation which will not be taking place at the time of discussion or even have taken place in the recent past. Potentially, the participants with ACD may never have participated at the level of strategic NHS engagement I am focussing on. I have, therefore, to tap into the opinions the participants have formed through experiences of participation, either in a specific NHS sense or in a more general sense and so the information offered is reflexive and not of the moment. In recent discussions with current practitioners of ethnomethodologically motivated investigations I have taken reassurance from the fact that ethnomethodology is not seen by these proponents as a research technique per se but more as a way of framing the purpose of one's enquiry (Personal communication Dr A. Dennis. April 2016). This has suggested to me that there is potential for a variety of perspectives regarding the application of the frame of ethnomethodological enquiry. In exploring the understanding of participants with regard to the context of participation and the potential for influence, I will be capturing each individual's reflections on their view *of* the context rather than their actual actions *in* the context. I maintain that this does not mean that my study is not ethnomethodological in its purpose.

Reflexivity is integral to the sense-making process as each individual maps new experiences onto their existing knowledge of the world. Giddens (1991) maintained that the reflexivity of modern life in general makes everyone automatically an ethnomethodologist of their own lives. Heritage (1984, p.5) viewed ethnomethodology as having an "open-ended reference to [the study of] any kind of sense-making procedure, the term represents a signpost to a domain of uncharted dimensions rather than a staking out of a clearly delineated territory" and Lynch (1997) held that, for ethnomethodology, there was no mandatory set of data collection methods to achieve the aim, so long as they were adequate to the particular phenomena being studied. Later, Lynch re-examined his views on reflexivity and ethnomethodology and concluded that reflexivity was inherently "part of the infrastructure of objective accounting no less than of self-conscious efforts to be reflexive" (2000, p.47). This view reinforces the methodological flexibility of the approach and in accepting these principles I believe that I can allow for latitude in the application of data-gathering techniques in order to

enable an appropriate method of enquiry. However, despite my allegiance to the principles of an ethnomethodological approach and the reassurance I have drawn from the notion that as a methodology it represents a broad church embracing a range of academic pursuits, I also recognise that my need as an ethnomethodological novice requires the support of an existing academically accepted framework. Further investigation of ethnomethodologically derived methodologies led to the suggestion that the use of an ethnomethodological ethnographic approach would be one most compatible with the achievement of my research objectives.

3.4.4 Ethnomethodological Ethnography

Ethnomethodology and Ethnography have shared interests as disciplines and in Coulon's (1995) opinion ethnomethodology has borrowed methods from ethnography enabling, for example, taken-for-granted assumptions and commonsense knowledge of participants to be revealed. As a distinct methodological approach, ethnomethodological ethnography provides a focus upon the ways in which people make sense of their social environment as revealed through the product of interviews which serve as the primary format for gathering information. The approach has been little used in contemporary healthcare research but I believe that it offers the most appropriate mechanism for the investigation of the topics in question in my study. In both ethnomethodology and ethnography there is an expectation that the researcher has an understanding of and familiarity with the area of study, what Garfinkel termed "unique adequacy" (Wakefield 2000), so that their own values and sense-making structures have congruence with those of the participants and therefore do not disturb or detract from the participants contextual reality. As researcher I have credibility within a healthcare environment, I have worked previously as a commissioner of healthcare services and, whilst I do not have direct personal experience of a communication disability, I have professional insight into the impact of such. In addition to this I am also a citizen and user of the healthcare services provided by Dorset CCG.

In exploring the relevance of an ethnomethodological ethnography approach to my study, a paper by Harper et al. (2007) came to my attention which described

the methodology's application in a way closely aligned with my own purpose. The authors used a set of key investigatory themes which were distilled from the work of Garfinkel and Coulon amongst others, and utilised them to create a framework which was then applied to the analysis of their interview transcripts. The table below sets out the themes as defined by Harper et al.

Key Aspect.	Description
Taken-for-granted assumptions.	Normal everyday routine activities. Expectations of what should happen in a normal day and how members expect others to act.
Commonsense Knowledge and procedures	Corpus of knowledge used by members of a social group to make sense of their world. Collective knowledge all members share.
Typification.	Common ways people classify objects, events and experiences. Process of categorising individuals or events into types.
Accounting	All the diverse activities, mental and overt that are used in sense-making by the group members.
Indexicality	Formal characteristics of any account that communicates different meanings on different occasions. Actions and utterances depend for their meaning on the context in which

	they occur.
Reflexivity	An interdependence between the circumstances members attribute to social events and their descriptions or accounts of what the events themselves are.

Table 3.1:   **Key Aspects of Ethnomethodological Ethnographic enquiry.**

(Harper et al. 2007)

The framework identified in Harper et al. (2007) is an ethnomethodologically aligned way of analysing narrative source material to illustrate how meanings have been ascribed by the study's participants. The intention of my study is to capture conversational reflection as it occurs during a practical, task-based activity. As an example of how insight can be derived from participants who are talking about their perceptions of an activity which they understand rather than actually demonstrating their understanding of the activity by accomplishing it, the approach taken by Harper et al. has provided the structure I was seeking for my own research.

3.5   Methods

In this section I will begin by defining my particular research context. I will establish the steps I took in the journey which culminated in the collection of my findings. This journey began with the requirements of the ethics process and the various ethical considerations which contributed to the structure of my study. The achievement of personally satisfactory solutions to the ethical challenges raised was important to me as it enabled me to stay true to my beliefs and my research purpose.

I will then set out how I accessed my study participants and finally I will explain what my participants were asked to do during their session with me.

3.5.1 Ethics Approval

Ethics approval for the study was sought from Bournemouth University only. The National Institute for Health Research (NIHR) ethics checklist was completed to determine whether ethical approval was also required from this body. The checklist result confirmed that, as the participants would not be recruited from any NHS institutions, NHIR approval was not needed (Appendix 1).

The Bournemouth University Ethics Committee asked for confirmation that the ethics submission clearly demonstrated that full consideration had been given regarding the potential for participants recruited for the ACD cohort to be considered vulnerable. The specific issues which had been raised relating to communication vulnerability, mental capacity and consent were addressed to the satisfaction of the Ethics Committee and ethics approval was awarded in 2014 (Appendix 2)

3.5.2 Mental capacity and vulnerability

The term "vulnerable" is generally used to describe a person or a situation perceived as being at risk of physical and or emotional harm (OED 2017). This definition places the control of the term in the hands of the person doing the perceiving and suggests a paternalistic approach whereby the vulnerable are required to be protected. However, as L'Engle (1990, p.139) wrote, "to be alive is to be vulnerable" and therefore vulnerability is the experience of all of us.

Heaslip (2013) identifies vulnerability as being multi-factorial and as requiring contextual interpretation, identifying that perception of vulnerability is therefore, subjective. This subjectivity therefore creates potential for a difference of opinion with regard to the degree of risk which may be present. It is clear that vulnerability as a concept is in itself vulnerable to inconsistent interpretation (Loue and Loff 2013). It is important to be clear whether the identification of vulnerability comes from the individual themselves or from the systems within which they exist. Questions concerning the presence or absence of vulnerability can therefore create the challenge of difference of opinion where individuals can be identified as vulnerable by others when they do not, themselves, feel so.

Current opinion in social care contexts is turning towards a re-definition of the concepts of vulnerability and risk.

In situations where organisational determinants of vulnerability are applied unilaterally, people can be disempowered. Ethically, it is right that care must be taken not to put people in harm's way but there is also an equal responsibility to allow individuals to own their own decision-making. Generally, there is a fear that people suspected of being vulnerable in terms of consenting to participation are not given opportunities to even consider being a participant. Fisher (2012) suggests that this approach may well infringe rights of citizenship from already marginalised members of society. She quotes (2012, p.3) Green's opinion that qualitative research should not exclude vulnerable participants as by including them it "can effectively give voice to the normally silenced and poignantly illuminate what is typically masked" (Green 1994, p.541). Overall, it is the view of both Fisher and Green that people in possession of attributes which mark them out as vulnerable from the point of view of wider society are not routinely given the dignity and respect of being accorded the chance to make their own decisions about participation in research. Recent developments by organisations such as INVOLVE have sought to address this (INVOLVE 2004).

Further, it could be argued that as a registered NHS professional my personal moral and ethical code would lead me to be more conscious of and protective about the overall wellbeing of my participants. As a speech and language therapist my working life has been focussed upon the creation and maintenance of holistic, respectful, trusting relationships with my patients. These qualities bring responsibility and Floyd et al. (2010) suggest that this dynamic brings about a far greater level of protection than would be provided by any ethics committee compliance. Of course, one should not be complacent but I think it is important to acknowledge and value the human qualities which may not be easily represented on a form.

I recognised, despite the intention to create a level playing field common to both sets of participants, that there remained potential for ethical challenge to my chosen approach as the participants with ACD could be exposed to a pressure to participate which they were unable to deny due to their mental capacity or communicative vulnerability. Mental capacity refers to the power to make

informed and independent decisions about one's actions. The fundamental premise of my study was that the participants with ACD would have presumed capacity as, in everyday life as citizens, they would be offered opportunities to participate in many things which they could choose to accept or not regardless of whether they fully understood the implications of doing so. The CCG participation arena does not exclude any potential participant on the grounds of mental capacity and therefore I wanted to replicate this openness for the purpose of the study.

The presence of a neurologically acquired communication disability does not necessitate the presupposition that cognitive functioning is similarly or equally affected as the two are not necessarily linked. However, it is the case that people who experience difficulty in processing incoming verbal and or visual language-based information would need support in accessing the information such communication contained. Communicative vulnerability may therefore concern the likelihood of the participants being coerced into a course of action despite their capacity to act independently because of their language impairment and/or the potential for the contribution they make, if it is mediated through the researcher, to be misconstrued or manipulated by the researcher to comply with their desired outcome.

Although mindful of the potential for criticism I remained certain that any offer made to potential participants should not exclude people from participating on grounds of age, gender or social background. The only defining inclusionary characteristic for both groups were that they were adults living in Dorset who were either stroke survivors with ACD or working as commissioners in Dorset CCG. In short, my study was open to citizens of Dorset.

In addition, my approach assumed that the participants with ACD should not automatically be considered to be vulnerable on account of their communication status. Evidence from my findings, which will be further explored in the discussion chapter, confirmed this stance as valid because these participants demonstrated that they did not identify their communication disability as being central to their self-perception of agency or as a specific impediment to their capacity to influence. In considering the particular circumstances pertaining to people with ACD it is without doubt possible to create a communication

environment which disenfranchises the individual with ACD and renders them vulnerable in both regards expressed in the paragraph above. However, it has been formally recognised through the Convention on the Rights of Persons with Disabilities (CRPD 2009) that deliberate barriers to participation must be avoided and that all reasonable steps should be taken to accommodate any specific needs in order to enable participation on an equal basis. Habilitation or adaptations in support of access on the grounds of communication disability can relate to conversations, documents and environments and all should be considered in partnership with the person with ACD. In this regard my own professional attributes as a registered Speech and Language Therapist who has worked with adults with ACD in accordance with the standards expected by the Health and Care Professions Council (HCPC) and the Royal College of Speech and Language Therapists (RCSLT) for over 30 years provided assurance that every care would be taken to ensure that known communication access needs can be met and that the voice of the participant would be preserved.

3.5.3 Informed consent

Principle two of the Economic and Social Research Council states that:

'Research subjects must be informed fully about the purpose, methods and intended possible uses of the research, what their participation in the research entails and what risks, if any, are involved.' (ESRC 2017)

The process through which potential participants in research studies are advised of the purpose, methods, risks and possible uses of the research commonly involves the use of written information sheets which can be supported by face-to-face interaction if need be. All information relating to the giving of consent should be accessible to the potential participants in terms of the vocabulary used and the presentation or format. General standards for communicating with the public and patients have now been produced by NHS England (NHS 2016) but at the time of this study care was taken to ensure that all information, both written and verbal, was available in an aphasia-friendly format in compliance with the guidelines provided by Connect UK (2008).

Prior to embarking upon the actual research activities each participant was asked to sign a consent form in accordance with Bournemouth University ethics practice

(Appendix 3). The basis of consent to participation in my study was that participants could withdraw their consent at any time. This approach was not considered desirable by the Bournemouth University Ethics Committee as they felt that the research would be fatally compromised if participants withdrew after their data had been collected. Although withdrawal of consent after the data had been gathered would have provided a very different range of issues to discuss, in my view my chosen approach was entirely compatible with the context and ethos of my area of study. In everyday life people can retract their agreement to participate in activities at any time and whilst there may well be some informal consequences arising from this, there is usually no formal sanction incurred. In the event, none of the participants withdrew.

3.5.4   Participants

In seeking to explore my area of interest I have elected to look at the participatory experiences of stroke survivors who have an acquired communication disability (ACD), with a specific focus on their views about the potential for influence in decision-making. Thirty percent of stroke survivors will be living with some degree of communication impairment (Stroke Association 2013) so it is important that any NHS stroke care planning participatory activity should seek to capture their views. However, as examined in the literature review, the impact of ACD on a person's ability to engage in social situations has been well documented (Simmons-Mackie et al. 2007; Parr 2007). Therefore, participation in a public event could represent a situation which is particularly difficult for those with ACD because of the demands such a situation makes on both verbal and visual communication channels. However, I firmly believe that there is much to learn about the experience of this particular group of people who are often overlooked or thought of by service planners as "hard to reach" or "seldom heard" (Flanagan and Hancock 2010; Rowntree 2012) and who frequently become observers rather than participants in life (Parr 2004). The right to function as engaged and contributing citizens, should individuals wish to do so, requires the offer to participate to be received and acted upon. It requires someone to ask people what they think rather than assume things on their behalf and finally, and perhaps most importantly for those people with ACD, it requires them to think that the consequence of their contributing is worth the cost to them of doing so.

For my study I chose to involve participants who were living their lives with ACD and who were no longer in receipt of healthcare relating directly to their stroke. This was because of my interest in their views as people with a particular set of life experiences. I identified them because they were citizens in society and not because they were patients who may be defined by their being recipients of care from a particular healthcare system.

In order to provide the counterpoint to the views of the participants with ACD and to reflect the concept of dialogue which has been construed as central to the accomplishment of meaningful Public and Patient Involvement (PPI). I also determined that I would have a second set of participants who would be recruited from the commissioning arm of the CCG. Commissioners are employed to secure healthcare services for Dorset which are relevant to the needs of the population and which are affordable and equitable. They are required to incorporate the views of the public and patients in their decision-making and to be transparent about how decisions are reached. The role of commissioner in its current guise has been in place since 2011 and the context of commissioning in general is now established but in terms of implementation the process of commissioning is still evolving. This group of participants were therefore defined by the activities which they undertook at work.

3.5.5 Access to Participants

The participants with ACD were purposively sampled though their registration with the Stroke Association Communication Support service. The planners and commissioners were also a purposive sample of people defined by their working role within a specific organisation. For each group, permission to approach the potential participants was sought respectively, from the regional Stroke Association Manager for those with ACD and from the Chief Executive of Dorset CCG for the commissioners. Once the respective permissions had been secured invitations to participate were sent. In the case of people with ACD it had been my original intention to visit all relevant communication groups and present, in person, the opportunity to participate in my study. However, the Stroke Association preferred that initial contact was made with the target group by letter. Consequently, an invitation letter was created in accordance with the principles of

aphasia-friendly written material (Parr et al.2008) (Appendix 4), and was sent by the Stroke Association administration team to all those registered as having a communication disability on the Stroke Association Dorset database. In the case of the Dorset CCG participants, direct approach by telephone was made by me to holders of appropriate commissioning positions within the CCG.

The approach to the potential CCG participants yielded five positive responses. There was no response however from potential participants with ACD as a result of the letter sent to the people on the Stroke Association database. Therefore, following further consultation with the Stroke Association Regional Manager, it was agreed that my attendance at group meetings could be offered so that the project could be explained in person. This proposal was made to all the directly funded and the affiliated Stroke Association communication groups run in Dorset and was taken up by four different groups. After a more personal, face-to-face explanation of the project and invitation to consider taking part at these groups, fifteen people offered to take part and nine actually completed the tasks. There was an option for both sets of participants to participate as part of a group activity but this was not taken up and therefore all participants undertook the data-gathering tasks on a one-to-one basis.

3.5.6 Data Gathering

It was very important to me to create a data-gathering process that was equally accessible for both sets of participants and that would generate comparable end products. A focus on exclusively verbal activities would potentially disadvantage the participants with ACD and perpetuate any view that participation was not achievable if you had difficulty communicating verbally. My aim to explore how experiences of civic participation might be improved for people with ACD by finding out what they thought about the current culture of participation would be fatally flawed if I disempowered their voice through my research design. Whilst the methods chosen for this study have not been previously used in the specific research context of participation in healthcare planning, they have all been well practiced in other arenas of socially oriented investigation (e.g. Bedford et al. 2009; ODI 2009; Just Associates 2002; Meyer and Muller 2006;) and represent robust and straightforward models.

Visually based methods of data gathering are familiar tools in stakeholder analysis and are routinely used to plot and understand the relationships between users and organisations. I could see that they provided the common-to-all participatory activity I was seeking. The utilisation of a paper, pen and picture-based mapping approach enabled each participant to place themselves in the context being considered without the need to rely solely on verbal description or the ability to self-generate a model. A mapping exercise represented a practical and focussed activity which was easy to demonstrate and provided a common and permanent record of the process which could then be interrogated, if necessary, to find out why participants had created the profile they had. Such approaches are frequently used in project management to create visual representation of abstract relationships whether in terms of thoughts, as in mind-mapping, or in relationships, as in stakeholder analysis (Mayers and Vermuelen. 2005). I believed that this method would be appropriate for making explicit the hidden part of the engagement relationship which I have referred to as 'influence' and it also had the potential to reveal the influence dynamics as perceived by each side. I liked the apparent concreteness of the approach for the capture of an abstract concept.

3.5.7 Data-gathering tools

To provide the task-based focus for my data gathering I chose to use two forms of mapping. For the first I used linear axis mapping tools (see Figure 3.1) created by Changes UK and published in their Voice (2009) and Echo (2010) toolkits for community involvement facilitation.

Linear Axis Mapping

1	2	3	4	5	6	7	8	9	10
Least									Most.
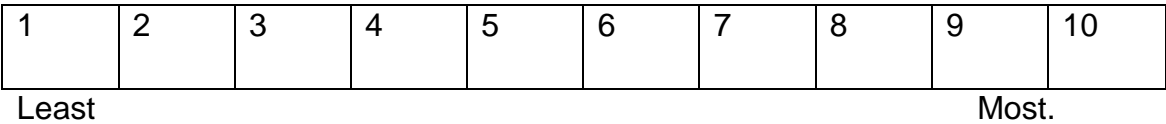
Figure 3.1: **Changes UK Linear Axis used for both Voice and Echo.**

The Changes UK tools both use a horizontal axis along which equal gradations are marked representing a spectrum of influence from none to full. The Voice axis was used by the participants with ACD and they were free to place themselves according to their assessment of their ability to influence the healthcare provision decisions made by the CCG. They used the scale of one to ten, with one representing least influence and ten being most influence. Each participant used their own judgement to assign an axis value to their view.

The Echo axis was used by the CCG participants and was similarly arranged on a scale of one to ten. However, in the Echo exercise, given attributes were assigned to each value on the scale. These attributes had been generated by the Changes UK team based on their preparatory work with local community groups in the Midlands (Appendix 5). The CCG participants reviewed the axis value descriptions and chose the description and therefore the value which most closely reflected their personal experience of how open to influence they felt they were able to be in their role as a CCG commissioner.

The question asked of both groups prior to undertaking the axis mapping exercise specifically used the word "think" in respect of their views on their power to influence and openness to influence. "Think" was used rather than the word "feel", which might be more likely to lead to responses based in emotion or perception, or the word "believe", which might reveal conviction or principles; in order to encourage the process of considering the question in an intellectual rather than an emotional way. In making the exercise deliberative it was hoped that more of the mechanism of decision-making might be revealed as discussion about the process of arriving at a final conclusion took place.

3.5.8 Influence Mapping

For the second mapping activity I used a model based on a stakeholder mapping tool developed by Just Associates (2002). The influence-mapping exercises were designed to elicit views on who the participants thought did influence the healthcare planning decisions taken by the CCG. This process involved the generation of a collection of influencing agents which were then arranged on a sheet of paper which showed the CCG (for the participants with ACD) or themselves as an individual commissioner (for the CCG participants) at the top of

the page. Each participant then positioned the influencing agents from their self-generated lists either closer to or further away from the top of the page depending on whether they thought that particular agent had more or less influence.

The mapping exercise used with the participants with ACD was designed to be sensitive to the users' potential communication support needs and offered a pre-generated range of possible NHS stakeholders represented both pictorially and by their written names. The pre-generated selection was created by me but validated as a representative selection by colleagues working in the NHS. This is a weakness in the design as there could be many other influencers perceived by the participants which I had not included. Therefore, the selection was presented as a comprehensive but not exhaustive range of potential influencing agents from which, in addition to any self-generated items, participants could compile their own individual set of influencing agents. They could then arrange their self-selected agents closer to or further away from the healthcare decision-making function dependent on their perception of the agent's ability to influence the activity. During this task I supported the participants as needed to enable them to create their desired selection of influencing agents. In the examples below the participants have been assigned pseudonyms. The map generated by "Joe" is shown below (see Figure 3.2).

Figure 3.2: Influence map created by "Joe" September 2015

The participants from the CCG were asked to generate their own list of influencers. They were not given any instruction on how this should be accomplished but they were provided with Post-it notes and a pen to capture each item once they had thought of it. Very little input other than task clarification was needed from me. Once they had generated a collection which they felt fulfilled the brief they were then asked to place each of their influencing agents on their map according to how much influence they felt that agent had on them in their role. As an example the map generated by "Chris" is shown below (see Figure 3.3).
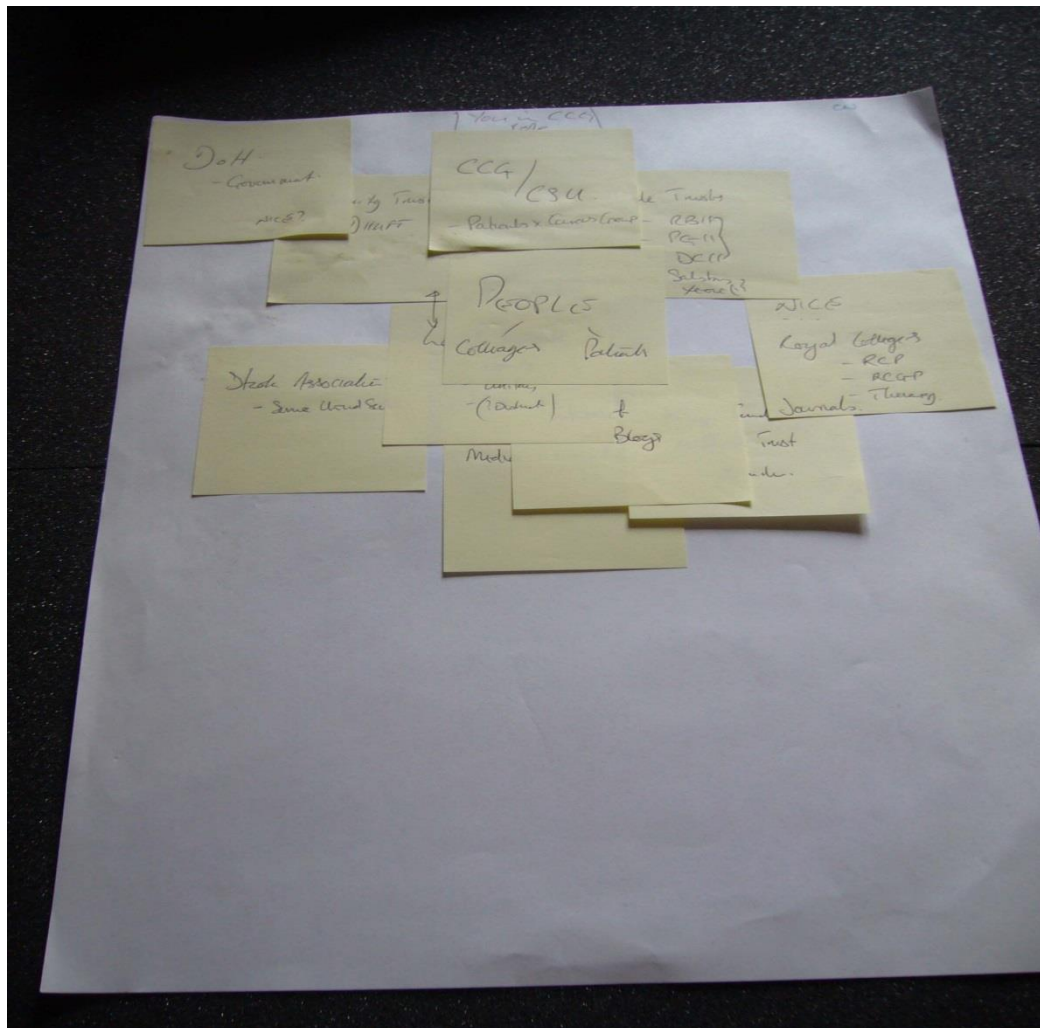
Figure 3.3:.   Influence map created by "Chris" October 2015.

3.5.9 Audio recording

The task focus of the data gathering for both the Voice and Echo processes and the influence mapping activities involved physical activity to produce the required outcome of the exercise but conversation and discussion activity was an essential and inevitable by-product which, whilst not part of the expressed purpose of the session, was crucial to understanding the thought processes being used by each participant. Therefore, during the data gathering with both sets of participants, recordings were made of the sessions so that the accompanying conversation could be captured and transcribed and later serve to illuminate and enrich the eventual interpretation of the visual products. In the case of the participants with ACD this was achieved as part of a digital audio-visual recording in order to also gather non-verbal/vocal but nonetheless

communicative contributions to any discussion that took place. I am not aware of any similar study which has used an equivalent approach.

I recognised that my role in the information-gathering process, as a Speech and Language Therapist, as an NHS worker and as the researcher, could potentially compromise or influence the responses I captured. Qualitative research explores experiences through a range of techniques including interviewing and in an interview scenario the researcher is the research instrument (Denzin and Lincoln 2000) and the outcome of the research enterprise is therefore dependent upon the researcher providing and maintaining the openings through which the participant can offer their particular perspective (Chenail 2011). It is a skill to be able to create a conversational ambience which, although dependent upon questions, is not constrained by them. Although my research method involves conversational questioning, it is not an interview-based method per se. However, the information provided by my participants during conversation is crucial to the achievement of understanding about their individual methods through the use of an ethnomethodological ethnographic approach. It is clear therefore that it would be incumbent upon me not to influence what is contributed through my questions.

3.5.10 Interview training

In 2009 prior to starting my D.Prof, and as training for my role in the Dorset Stroke network project, I undertook Discovery Interview (DI) training (Machin 2003). The DI techniques are designed to enable the interviewee to recount their own story in their own words and emphasise the supportive role of the interviewer as listener. This training supported me to develop my ability to manage an interview in a way which facilitated the interviewee to be in charge of their contributions. The DI approach is very compatible with the range of communication techniques used by a speech and language therapist in a clinical setting and the training highlighted the transferability of my clinical skill to the qualitative research interview setting.

Although particularly compatible with my clinical conversation support skills, I used the DI training to create an open and supportive environment with all the participants which I feel enabled them to use their personal experiences to inform their responses without interference from me. I endeavoured to ask only open

questions and to allow the participant to lead the narrative during the mapping sessions, thereby allowing each participant to describe and define their thinking processes in their own words. As an insider researcher (Carter 2004; Labree 2002) I remained aware of the potential that my participant's perception of my status or role may affect what information they disclosed and the emphasis they assigned to things. Where it was apparent that there was an impact from previous relationships upon the context of the interview this was acknowledged within the context of the interview conversation. This happened twice; on both occasions the participants were commissioners.

3.6   Timeline of Research Activities

Both the participants with ACD and the CCG participants chose the venue, date and time most convenient to them for our meeting. I was keen to facilitate this degree of choice in order to preserve the sense of the participant being in control of their participation. In all cases I travelled to the participant and was able to meet their requests in terms of date and time of meeting. Meeting on the participant's "home turf" could have created an environment which was not conducive to data collection because of distractions or difficulties arranging the materials to be used but I felt that it was important to maintain as open an approach as possible. In the event, only two of the sessions were affected by extraneous noise. From my point of view this did not impact on the interactions or the accomplishment of the tasks and neither participant indicated that they were bothered by it. It did however affect the audibility of the sound recordings which later made transcription difficult.

The data from both groups of participants was gathered over the period May 2015 - September 2015. For all participants the activities took between an hour and an hour and a half in total to complete. This included the preliminary and concluding chat and consumption of tea/ coffee and biscuits where offered.

3.6.1   Participants with ACD

Each participant with ACD was visited at home at a pre-arranged time at their convenience. The purpose of the research was explained including details of how

the information supplied would be managed and used and the fact that participants were free to withdraw from the research at any time. Once satisfied with the general format, each participant signed a consent form prior to embarking on the research activities. Then the digital video camera and digital audio recorder were set up and tested and the task in hand was explained to the participant using as much or as little communication support as the participant needed. In some cases it was established at the outset what kind of communication support was preferred by the participant but the majority took things as they came and we negotiated any stumbling blocks collaboratively, with support strategies being devised spontaneously and intuitively by both of us. The communication support provided by me entailed using active listening, slowed speech or shorter sentence structures and/or using written words or pictures to supplement the spoken word. Communication auto-support techniques used by the participants included self-cueing, repetition and writing and drawing. In deploying these strategies the meaning of the term influence and the context in which influence was to be considered was discussed and considered. After this had been established, the participant's first activity was to indicate on the Voice influence axis how much influence they thought they had over stroke service planning decisions by marking the axis with a cross at the value they thought matched their view.

The second activity required each participant to consider who they thought might be able to influence the CCG decision-makers in their stroke service planning. To assist them in doing this a pre-prepared selection of pictures showing potential influencers was available (examples shown in Appendix 8). All participants used this pack and the process of deciding whether the person or persons, or organisation depicted was firstly, known to the participant and secondly, thought to have influence, generated a great deal of thought and conversation. Participants talked themselves through their decision-making process and this content formed part of the data set gathered. Participants were also able to add any additional influencers they wanted to who were not represented on the picture card selection. Post-it notes, a blank card and a pen were provided to facilitate this. Once the selection of influencers had been arrived at, each participant was asked to arrange them according to the strength of influence they were thought to have. An A3-sized piece of card was used to create the map field

with the CCG as the object to be influenced positioned at the top of the card. Those thought to have the greatest influence were placed nearest to the top of the card and those with least influence further towards the bottom of the card.

Once the map had been created a photograph was taken to record the result. This concluded the data-gathering exercise.

Examples of the influence maps created by Fiona and Dan, which have been standardised from the original photographs, are shown in Appendix 6. An example of a transcript of the audio recording made during a mapping session with Ray is shown in Appendix 8.

3.6.2   CCG Participants

Each CCG participant was visited at their place of work at a pre-arranged time to suit them and a quiet space was identified in which to carry out the research activity. The purpose of the research was explained together with the information management protocols and withdrawal terms. Once each participant was satisfied, consent forms were offered and signed and the digital audio recording device was set up.

For the CCG participants, the first activity was to create their Influence Map (Just Associates, 2002). They were asked to think about who influenced them in their commissioning decisions and then to write each influencing agent as they thought of them on a separate Post-It note. The talk which this activity generated was important as most participants coached themselves through the brainstorming of items to be recorded on the Post-It notes. During this time I was largely quiet unless asked for clarification about the task or asked to confirm or otherwise whether I understood what they were saying. Occasionally, I did have to initiate questions for clarification or to ask if they could expand on their thought processes but at no time did I suggest any potential influencing agents for them to include. Once all the items generated had been recorded on individual Post-It notes each participant was asked to arrange the Post-Its on a sheet of A3 paper, putting those with most influence over them in their role at the top of the page and those with least at the bottom. Once completed the maps were stabilised by fixing each Post-It notes in its position with sticky tape.

Following completion of this activity, participants were asked to look at the Echo influence axis and to read the accompanying axis values. Once they had studied the accompanying information, they were asked to choose which axis value description most closely matched what they felt about their openness to influence in their role. They then marked that value on the axis with a cross. This concluded the data-gathering activity.

As with the participants with ACD, I recognised that my background as an NHS employee and previous involvement with the Dorset Stroke Network (no longer in existence) represented potential for an "insider" dilemma. I acknowledged this in my opening explanation of purpose at the start of each information-gathering session. My intention was to reassure each participant that they could respond to the tasks as they chose and also to remind myself that my role was not to constrain their responses within the object of the task.

Examples of the Influence Maps created by Fran and Felicity are shown in Appendix 7 and the transcript of the audio recording made with Fran is presented in Appendix 9. One of the CCG participants was unable to complete the Echo axis at the time of the interview and then subsequently became seriously ill. Therefore there are only 4 Echo axes included in the data set.

Chapter 4 Findings

"For there is nothing lost, that may be found, if sought." (Spenser 1590)

4.1 Introduction

In this chapter I will present my analysis of findings. All participants have been given pseudonyms. Firstly, the data provided by the influence rating and mapping exercises will be presented and discussed. Following this, the analysis of the conversation transcripts will be set out. In both sections the responses from the participants with ACD and the participants from the CCG will be addressed as separate bodies of data. This approach is adopted because throughout my research I have identified the participants as belonging to either, the group of people with ACD or the group of people who are CCG commissioners. In my treatment of findings, I wish to maintain this distinction between the two groups in order to preserve the context of the individual responses. Examples used will be attributed and analysed as relevant only to that particular participant. Where the participant has offered biographical information in support of their decision-making this will be added to provide contextual background, although not all participants volunteered this. Finally, this chapter will conclude with a summary of findings and identification of themes for further discussion in the following chapter.

4.2 Influence rating outcomes

I have presented the ratings of influence provided by each group of participants in table form in order that individual responses in each participant group can be viewed together. My analysis of the data focuses on the relationship between the position chosen and the accompanying contextual narrative that each participant supplied whilst making their decisions. I have used the narrative to illuminate the participant's decision-making processes.

The participants with ACD freely rated on a scale of one (least) to ten (most) how able they thought they were to influence the decisions made by the CCG on matters of healthcare provision (see Table 4.1). Two participants, Len and Dan, gave split ratings.

Participant	Ray	Len	Joan	Joe	Dan	Pam	Tom	Barbara	Fiona
Rating	1	1 / 4	4	4	4 / 5	5	5	5	6

Table 4.1:   Influence rating responses given by participants with ACD.

The outcome of this activity showed that each participant with ACD was able to consider himself or herself as an influencing agent. Although the majority chose the middle values on the scale as representative of their capacity to influence CCG decision-making, two people identified themselves as having no power to influence at all in this context.

Most forceful in his estimation of having no influence was Ray. He was emphatic that his power to influence was nil. He communicated that, in his view, no-one listened to what he had to say.

> "It's the- oh you, blah, blah, blah. You've done this then now, this, this oh-when- oh no. To myself so and so, oh no you're there, you're finished."

I reflected back what I had understood by his comment which he confirmed as correct.

> "..and it didn't really matter, you think, what you felt that you might have wanted?" Deb.
>
> "No." Ray.
>
> "No?" Deb.
>
> "They don't want to know." Ray.

Two people, Len and Dan, nuanced their response and gave split ratings. Len indicated that currently he makes no effort to have influence and therefore scored himself as a one but thought if he wanted to influence he would rate his chance of influencing as a four. Dan, who has a significant communication disability thought his chances of influence were somewhere between a four and a five. Dan's wife said that he was by nature someone who had always got involved and spoken his mind.

Fiona, who placed herself at six on the scale, also added the following comment

> "I think I am very good at voicing my opinion – I'm not convinced it makes any difference."

When this was explored she said that as she had never had feedback from the CCG following participation she had no evidence to indicate that her contribution had made a difference.

Tom who identified himself as a five on the axis indicated that this was because it was so much more difficult for him to become and remain involved following his stroke.

> "Ahh, well the er the lack of ability to communicate. Erm, getting better all the time but I think – well some days it is some days it isn't but erm, erm. That's the first thing maybe, lack of being able to speak on the phone. I can speak on the phone but not well. I can't use, you can't use the computer erm, can't erm. I can't go to meet somebody without A (his partner). Erm, just general things make me, not cross, but makes me, make me, erm. I don't know the word – erm, (sigh) frustrated. Yes, yes."

Similarly, Pam, rated herself as a five but qualified this by saying that her ability to influence was very dependent on both how she felt in herself and on the environment within which the participation event was being held. Big groups and unfamiliar people made it harder for her to contribute as she became nervous and this then impacted on her communication.

Joan who rated herself as a four indicated that this was because she preferred to rely on others to comment on her behalf. She indicated that she considered the organiser of the stroke group she attended to be a most effective influencer but

she did not score this person on her axis because I failed to ask her to do so, which on reflection was an error on my part.

In summary, the responses of the participants with ACD show that the range of experiences identified as being significant in their self-evaluation of influence were not exclusively derived from their communication disability. Communication disability was an aspect of their experience which they felt was not addressed well by the organisers of NHS views-seeking opportunities but it did not deter them from wanting to share their views and be heard.

The CCG participants rated their openness to being influenced in their role as Commissioners according to specific rating criteria which used a scale of one (least open) to ten (most open) and also provided a self-generated influence map which represented who they thought they were influenced by and how strong an influence that entity had over their CCG role decision-making (see Table 4.2).

The results of these activities showed that the CCG participants all considered that their ability to be open to influence was towards the more open end of the scale. Most chose a rating of six or seven from the scale of one (most closed) to ten (most open).

Participant	Chris	Naomi	Lorna	Felicity	Fran
"Real" rating	Not given	4	6	6	7
"Desired" rating	Not given.	6/7	7 or more.	8	10

Table 4.2: **Showing the "openness to influence" rating responses given by the CCG participants**

However, as evidenced by their conversation whilst undertaking the task, some felt that their personal willingness to be open did not accord with their professional, in role, capacity to be open. They also showed that they recognised that the CCG's aspiration to be open to influence was not matched by the reality.

Fran commented:

> "I think my Team is here (8) and yet we are doing this as well with the community groups. See, this is where the CCG aspires to be (10) but some of that will be because they should aspire to that rather than at the time, do. Whereas me, as an individual working with patient leader chair and PPEG, are absolutely up here (10)"

With a final decision made as:

> "So, we are definitely a 7. I am able to be definitely 7 in my role."

Felicity, in her rating acknowledged that the ability to be open to influence depended on what it was she was engaged in at that moment in time.

For example:

> "I think, for some things- like when we went out for glucose meters. We went out- what's the easiest product to use, you know if you are going to use it- it just has to value for money. So tell us which one to use so that is very open. But other things, it's um, you know, you have to say- how representative, you have to come back and say how representative are some people or we have got a population verses an individual the tensions between that and even, you know, the people who get involved in

national groups; how representative are they of the majority of our population and the people who have the greatest needs may be the most silent and who talks the loudest isn't actually – it's getting that balance."

I did not ask them how much influence they thought they themselves might have on the CCG as a citizen and this is something which would be interesting to explore in future to ascertain whether their citizen's views accorded at all with those of the participants with ACD.

The CCG participants who completed this activity all chose to give two different evaluations, the first representing their assessment of their actual ability to be open to influence in their role and the second representing where they thought the CCG aspired to enable them to be. For some there was a third assessment of where they believed themselves to be as people rather than employees. These self-evaluations suggest that each individual's response is governed by a complex process which combines personal, organisational and cultural drivers. How this might impact on the experiences of the citizen participants with ACD will be examined in the discussion chapter.

4.3   Influence mapping outcomes

Like the influence rating exercise, the influence mapping activity provided visual and verbal data. My analysis again uses both sources of information to enable conclusions to be drawn.

The influence mapping activity required each group of participants to undertake similar but not identical tasks. The talk which accompanied the influence mapping activity revealed something of how each participant made sense of the task of deciding about the question of influence. For both sets of participants it was clear to me from their conversations that they had an understanding of the context I was asking them to think about and were able to place themselves within that context. I judged this by the nature of the clarifying questions which they asked before and during the tasks.

"So, can I just clarify because my role has changed so much, so dramatically that the way I would answer it would be different depending on what I was working on." Fran. (CCG)

"OK. And, influence in the context of my decision-making? Lorna. (CCG)

"Where would they go or where would I want them to be?" Fiona (person with ACD)

"I don't know, umm----- difficult um, where is it, in the house or outs—when does it apply?" Tom (person with ACD)

The selection of potential influencing agents that was offered to the participants with ACD was accepted as sufficient by all but three of them. Fiona and Barbara added "the public" and "patients" to their selection but subsequently neither mapped the public or patients as being highly influential. Pam added "Help and Care", a social services organisation, but then similarly did not map it as particularly influential. The general acceptance of the pre-prepared selection provided may be accounted for by the task design and presentation and I accept that this is a potential flaw in my study design. If I were to repeat the same activity in the future I would allow for the co-production of the full pack of potential influencers so that it was representative of the participants' knowledge and experience rather than mine. This conclusion is not without irony in a study which aims to examine what the individual experience of participation is.

The role of the cards was to provoke thought. In each session the cards represented the tools for the activity and were therefore part of the task. All participants subsequently created their own set of cards from the pack and so were able to individualise the tools according to their experiences. During the mapping task it was noticeable that those with whom the participants had experienced a clinical or caring relationship during their period of post-stroke care assumed a position of greater potential for influence than those for whom the participants had knowledge of but had had no relationship with. The influence maps which were produced showed a highly nuanced understanding of influence on the part of each participant. There was clearly critical assessment of stratification or hierarchy made as the resultant visual mapping representations illustrate. Participants showed that they saw a key set of professional clinicians

as being most influential but that they did not view all professionals within the health and social care environment as belonging to this set.

Most frequently represented as being most influential were the GP and the Medical Consultant. Second most frequently mentioned as being influential were the Dorset Echo and the constituency MP. Allied Health Professionals and Nurses generally were thought to be of moderate influence along with friends and family members. Also thought to be of varied, but never high, influence were the third sector organisations such as the Stroke Association and Age UK. Of equal interest to me were the cards which were infrequently or never selected to be part of the map. In this group were the Department of Health, Social Workers, the local Councils, POPP's and Healthwatch.

The individual influence maps produced by each CCG participant showed how each person drew from their own unique set of identified influencers. Some had highly complex systems with numerous, carefully differentiated elements whilst others produced much simpler, less stratified maps. The differences in approach seemed to depend on what the map creators' particular area of responsibility was as a commissioner but their personal networking inclinations also played a role. It became clear through the mapping exercises that these intimate aspects of work-related association would be very hard to anticipate or imagine for someone who was outside of the organisation.

Three of the participants had direct involvement with commissioning stroke care across the county, one had a locality focussed role and the final participant was responsible for undertaking the patient and public engagement activity relating to all CCG activity. Each of the CCG participants identified patients and/or the public as being one of their strongest influencing factors but in fact the public and patients featured less in their narrative than did other more organisationally or personally derived influences. Again, like the participants with ACD, the Commissioners appeared to focus on those with whom they had a working relationship and therefore about whom they could form opinions. The influencing agents seen as having most significance were wide-ranging but broadly represented an equal number of agents both internal and external to the CCG as an organisation. In terms of the service user representation in the maps, whilst

one person gave the general public a place in the "most significant" group, the primary focus for the majority of the participants was placed on formal public, patient and carer representatives and groups. Like the participants with ACD, the CCG participants saw Allied Health Professionals and nurses as being moderately influential.

4.4   Analysis of conversational data

Each participant was audio-recorded as part of the research process and these recordings were subsequently transcribed, examples can be found in Appendix 8 for participant with ACD and 9 for CCG participant. The conversations between participants and myself provided additional information about how each participant constructed their approach to completion of the tasks in hand and also provided insight as to what methods they were using to guide or arrive at their conclusions, and thereby illuminating their sense-making procedures. To begin my analysis I have applied the framework supplied by Ethnomethodological Ethnography (Harper et al. 2007) and this has enabled me to frame each person's contributions within a common structure and has aided me to see the workings of my participants' thought processes.

I have found it a challenging endeavour because there has been a significant time period between data collection and transcription and final analysis. However, the discipline this circumstance has imposed by necessitating my listening to each individual contribution has been invaluable. If as a consequence I have made errors of attribution this, perhaps perversely, underlines the principle of holding as paramount the impact of the individual sense-making process. I have fed back to my participants the conclusions I have drawn from their contributions and all were satisfied that they had been represented accurately.

The Ethnomethodological Ethnography framework supplies the following elements for analysis of the methods individuals use to create and maintain their sense of meaning.

- Taken-for-granted assumptions

- Commonsense knowledge and procedures

- Typification

- Indexicality

- Accounting

- Reflexivity.

I will use each element as a heading under which each group's responses will be analysed.

4.4.1 Taken-for-granted assumptions: how participants anticipate what "normally" happens

Although the participants with ACD were all able to indicate how influential they thought that they were able to be, only three of the nine actually had any recent experience of participating in a CCG mediated views-seeking activity. All the participants, regardless of experience, indicated that they thought that the CCG would not be receptive to their (the participants) views. Their comments demonstrated assumptions about the openness of the CCG decision-makers to accommodate the views of the public. In expressing these opinions the participants with ACD made no reference to their communication disability as being a cause for the perceived lack of openness. Responding as citizens of Dorset, their assumptions were based on presumptions that the decisions had already been made anyway:

> "Even a group of us, if we all went en-block it wouldn't make any difference to what they have already decided" Barbara.

Barbara went on to qualify this assertion:

> "It's a question of money. It's always a question of money"

There were also views expressed which indicated that the participants thought influence was possible, but not by them as members of the public:

> "if you have someone at the top who has a favourite then that will influence them" Fiona.

These assumptions were consistently held across the group. There was no contribution that suggested that anyone thought any other alternative "normal" was possible in the current climate. Their individual assumptions appeared firmly fixed in a context where decisions were determined by other people or forces external to and unconnected to them.

In the case of the Commissioner participants they instinctively identified themselves and their assumptions both within a work context and also within a personal context. The trigger question I asked had not indicated that a differential response was expected but all gave multi-layered answers in reply. This indicates to me that they operate differential sets of taken-for-granted assumptions which are categorised by the role or purpose they see themselves as having. This realisation led me to understand how compartmentalised it was possible to be in the application of assumed norms. Unlike the participants with ACD, the CCG participants demonstrated their capacity to differentiate between accepted versions of "normal".

They defined the work context by what boundaries and strictures they perceived to be created by the role they were in. These rules produced conflict between required and desired sets of assumptions. In recognition of this, they made reference to how their own personal assumptions were occasionally at odds with what their work role required and they were able to identify these incidences and apply the work appropriate mind set:

> "Because the biggest influence should be the people" Fran.
>
> "And is it?" Deb
>
> "No, because I am told what to do and that influences how I work with the people" Fran.

The dissonance was most evident when they were tasked with identifying how open to influence they thought they were able to be in their work roles, which is illustrated by the following response:

> "Tricky in terms of how wide you are thinking - cos if you are thinking CCG as a whole I think that is where we are (4). But, if you are thinking of me as an individual person - where I am (7)... and then there is a professional person working (6). So there are three different "me's" in this." Naomi.

If each individual commissioner is subject to similar conflicts regarding which set of assumptions can be used then it becomes possible to see that there is potential for inconsistency and therefore potential lack of clarity in relationships with the public.

4.4.2 Commonsense knowledge and procedures: participant's stock of knowledge

Both sets of participants sought to align their knowledge and understanding of the context with my task requirements by asking clarification questions which enabled them to feel confident about using the knowledge they had in the particular context in hand:

> I've put patients there haven't I, Can I put in-patients? Naomi (CCG)

> "Can I voice my opinions or can I persuade?" Fiona. (Person with ACD)

These examples show how these particular participants needed to establish explicit agreement about what the task in hand needed them to achieve. They gave examples of their understanding in order that I could confirm or deny the appropriateness of their potential responses. Although not all participants did this it was clear to me from the responses given that both sets of participants were able to use their stock of knowledge as best suited them to support their decision-making during the tasks.

The participants with ACD, whilst all having their experiences of acquired communication disability in common, were a diverse group of individuals. Their life experiences prior to their stroke and the length of time which had elapsed since their stroke were very different. However, the task of mapping who or what each participant thought might wield influence over CCG decision-making did reveal some interesting similarities which might indicate that each participant was using general commonsense knowledge about how the Health Service worked rather than specific knowledge about how the CCG worked or how the new NHS was organised.

They then also brought to bear information gained from their particular knowledge about and experiences of healthcare since their stroke but thought this was not considered valid currency in CCG participatory activity terms:

> "They are wanting it to be wider than that but I can't, I am just talking from my experience" Barbara.

> "Don't say- they say oi don't you this- this is you, what can we do now. They say this is what we are doing. Now how you saying, you haven't comment ? anything you?" Ray.

Ray's comment relates to his experience of being told what he should think rather than being asked what he thought. He was very reluctant to adjust his "knowledge" to fit with what he saw as being expected from someone with such severe communication disability. He was determined to continue to draw on the knowledge and skill he possessed as a competent adult and not to be confined by his current circumstances. He demonstrated the frustration of being constrained by the taken-for-granted assumptions of others about what a person with communication disability can or cannot do.

In the light of the CCG participants representing themselves differently depending on which "me" they were answering as, the information they gave when responding as a CCG commissioner was supplemented with comments that related to them as themselves outside of work.

 As they talked about themselves as workers it became clear to me that both the "commonsense" knowledge and the procedures used as reference involved some very specific vocabularies which made it difficult for an outsider to understand:

> "That's the PPEG (Patient Participation and Engagement Group) for the CSR (Clinical Services Review). SSV (Supporting Stronger Voices), HIN (Health Involvement Network) - someone would have a heart attack to come and see this, they would be like, don't use any acronyms!!" Fran

> "We had a workshop and there was one of the newer locality GP's and he said, look I'm new to this and it's all a complete mystery to me. So I chirped up and said, well I've been in it ten years and I have just learned to accept it as a mystery and run with that " Chris.

Contributions showed how the processes and mechanisms of the CCG organisation created specialist knowledge. It was accepted that this would make it very hard for the general public to understand how to interact with the CCG at a public participatory level and to feel that they had any recognisable influence over how things might happen. The desire to engage people in commissioning activity in a meaningful way was not easily satisfied because of the mechanisms inherent in the system:

> " (the general public will) listen but then they will say, fine, but what I want to tell you about... and therefore they will see decisions being made, um, when they are made, and they might feel – well my views didn't inform that and yet, actually, they will." Fran

> "I have tried to get that message over but - when we have done all the public meetings to say that engagement is very much a process and that it is made up of lots of different elements and they are all vitally important and that they are all important at different times and that they are interconnected and that, you know, information giving is a very important part of engagement and that on-going dialogue is a very important part of engagement but people's views when they give them won't necessarily inform stuff *there* but it might inform stuff *there*" Fran.

There was common background between the commissioner participants from the point of view of a work history of employment within the NHS. Three had been providers of NHS services prior to becoming employed by the CCG, one was still a provider of NHS services in addition to their work in the CCG and the fifth participant had always worked in the NHS but as a public engagement officer rather than as a clinician. The influence maps which they each created showed how prior knowledge and experience contributed to their interpretations of current relationships:

> "School, they tell me quite a lot of things." Felicity

> "Why? Because of school gate conversations?" Deb

> "No, because I am a Chair of Governors so teachers tell me things; parents tell me things. Children talk about – you hear all sorts of things at school that you wouldn't necessarily hear in other ways." Felicity.

It is clear that, like the participants with ACD, the CCG participants source their knowledge about the context of participation from a wide range of experiences

but, unlike Ray who felt constrained in his use of his knowledge and skills by the presence of his communication disability, the CCG participants are free to import knowledge as necessary to suit their requirements at the time. Of course transferrable knowledge and experience are essential to be able to function successfully in any environment and the NHS participation agenda requires the application of transferrable knowledge to inform and shape decision-making. In my discussion I will further explore how the participants with ACD might be able to illustrate the benefit of being facilitated in order to bring more than just their experience of stroke.

4.4.3   Typification: how participant's experiences are classified

In examining examples of typification I can see that for the participants with ACD the responses that gave indication of how they classified their experiences showed that change had taken place as a result of their stroke.

Each individual generalised their experiences of being unable to effectively communicate as impactful upon how they perceived their life experience post-stroke and most indicated that they had particularly re-classified themselves as "non-contributors" in any unfamiliar or formalised settings. They described how their lack of confidence to communicate affected how they assessed opportunities for engagement now. They also recognised that it was more than just their communication disability which determined their approach to life. This did not mean, however, that the participants thought they had nothing to contribute but that the impact of living with stroke made contributing a challenge:

> "Sometimes, after stroke - it's, just today I just need to get out of bed. You might be really passionate but today is not the day" Fiona.
>
> "Dan would have spoken up before his stroke" Margaret. (wife).

In Dan's case, Margaret described how, prior to his stroke, he was someone who was very motivated to speak his mind and to contribute but now she did much of the talking on his behalf. In our interview Dan made some verbal contributions but most of the narrative was provided by Margaret. Dan did have power of veto if what Margaret said did not reflect his opinion but the way in which the views were expressed was hers and not his.

This insight is valuable when considering how the existing participatory mechanisms work. In an environment where the communicative medium is verbal, Dan and those with a similar level of expressive communication disability are reliant on others to communicate on their behalf and to identify what these experiences mean to them.

In creating their individual influence maps the commissioner participants all demonstrated their own knowledge of their role and purpose within the CCG. They showed in detail how each commissioner networked their experiences in the world of work. It suggests that the role they inhabit as commissioners creates a typification framework which fits the purpose they feel they have as a CCG commissioner.

Each participant was able to describe and validate the sense they had attributed to a particular experience. Several described how non-work-related interactions had enabled them to structure work-related experiences and make them meaningful to them. Obviously, this describes the very act of typification and is not extraordinary in any way but, the individualised ways in which experiences are classified and then applied to work-based decision-making processes could be said to lack transparency:

> "if it's the College (RCGP), if it's coming from somebody in the CCG and another College mentions it, it gains more momentum" Chris.

> "there are things that come through that , that almost by serendipity, you take a dip into NHS Networks" Chris.

> "I live in the area, I work and I have family – who don't use the services but they have friends in their 70's and 80's so they tell me all sorts about older people's services" Felicity.

4.4.4 Indexicality: the relationship assigned between events and circumstances/contexts

The exploration of the attribution or assignment of relationships in the context of participation is a key element of this research endeavour. All participants understood the context of participation in terms of it involving the asking for and

giving of views on a question or proposal. The explicit reference to influence as a feature of the relationship dynamic was more difficult for both sets of participants to evaluate. In creating their individual influence maps the participants used very different strategies in order to determine what relationships were salient.

During the process of assigning relationships each participant was able to account for the nature of the perceived relationship under consideration. Each participant considered the proffered selection of potential influencers and discarded those for whom they had no frame of reference. Frequently the discarded pile contained the formal bodies and organisations that exist in order to "represent" the patient and or public in general. The larger or more remote the entity the less they were perceived to influence local activity:

> "I don't think the Department of Health should be there because it's not worth worrying about!" Tom.

Rather, the agent's potential for influence was often construed in terms of whether they (the participant) had had any personal experience of that agent (in any sphere) rather than in the abstract/general terms relating to the potential influencers role or purpose. Where the person with ACD had direct experience of the agent, estimation of power to influence was tied to that named individual and was directly related to knowledge about that specific professional's benefit to them personally:

> "I like them (Physiotherapists), they were good" Pam.

Pam placed the card with the Physiotherapist on it high up on her influence map, the higher the position on the map the greater the perceived degree of power to influence.

Consultants and General Practitioners were most frequently placed highest on the maps.

The rationales given for the decisions made about ranking the cards which represented groups other than NHS professionals were more varied suggesting that, outside of the main NHS professional groups, the participants had less strong associations to draw upon. In particular, the card representing Healthwatch was excluded from many of the participants' influence maps often on the grounds that that participant had never heard of it or did not know what it

did. Even the Stroke Association failed to achieve a consistent level of representation on the maps which suggests that, for this particular group of people, the formalised routes for achieving influence are not seen as being effective. This finding is cause for concern for if the views of stroke survivors with ACD are not being heard via these agencies then opportunities to collectively influence are being missed.

The CCG participants generated complex and intricate influence map models which again incorporated aspects of both their work and non-work personas. In determining the relative salience of each influencing element they demonstrated a significant degree of rationalisation with regard to how each of their models worked:

> ".. within each locality, each, there is a PPI representative umm, so we tap in to those. But this is also where the 3rd sector like sits at the top there as well on terms of Public and Patient Engagement in representative. So they are in there towards the very beginning. Because any design of a service has to involve those particular reps. So, it's not in a locality, say, for example, if it's about a key area- I don't know, stroke or whatever, you would then approach the Stroke Association or somebody to bring in local individuals who are representative of that group. Does that make sense?" Lorna.

Lorna would have preferred to have been able to create a three-dimensional influence map as her appreciation of how her particular commissioning environment worked was too complicated to describe two-dimensionally. The relationships she represented made sense to her but she was clearly aware that they might not be so easy to follow for those who were less intimately familiar with the process.

The degree to which the CCG participants reflected on the purpose of influence and its relationship with their commissioning role revealed how they were conscious of the responsibility to make the "right" decisions. There were degrees of uncertainty about how the participatory process should work:

"I think I am open to influence but I think the influence has to be effective enough. You don't want to be blown around in the wind but you want to be able to hear." Chris.

"You have to come back and say how representative are some people or we have got a population vs an individual the tensions between that and even, you know, the people who get involved in national groups; how representative are they of the majority of our population and the people who have the greatest needs may be the most silent and who talks the loudest isn't actually – it's getting that balance." Felicity

"See, there is a difference between "should be" and "actual" isn't there. There is rhetoric and reality." Fran.

The maps indicated that each participant had certainty about who had influence on them but the comments above demonstrated to me that there was less certainty about what that should mean for both Dorset CCG and the public of Dorset.

4.4.5 Accounting: the participants demonstration of sense-making according to their taken-for-granted assumptions and commonsense knowledge

Demonstrating the achievement of congruence between experiences and knowledge and assumptions can be challenging. My analysis of the transcripts has shown me that my method of data collection failed to routinely expose how the participants did this. However, the process of discussion and decision-making about who has influence in healthcare decision-making contexts did demonstrate that both sets of participants were able to construct views which were both informed by and accorded with their personal experiences of participatory activity.

For the participants with ACD, the particular question of their influence over healthcare planning decisions represents an, admittedly somewhat esoteric, dimension of their everyday lives as people with communication disability and for many there are bigger priorities in their lives. Their responses showed that they

are people whose view of the world is filtered through the prism of an acquired communication disability. This determined what resources were necessary for them to achieve a successful outcome but they gave no sign that they considered that it defined them as people.

Tom gave three key factors which impacted upon his ability to engage:

1. "The lack of ability to communicate, some days it is, some days it isn't."
2. "The lack of being able to speak on the phone (and) I can't use the computer."
3. "I can't go to meet somebody without A" (partner).

"Just general things make me, not cross, but make me - I don't know the word- umm, frustrated"

This information was imparted in a matter of fact way as being part of his life after stroke experience. He gave no indication that he expected any more inclusive an environment.

The national and local drive to achieve more meaningful public participation does not appear to have led any of the participants with ACD to believe that they personally have the power to influence healthcare decision-making in Dorset. The range of attitudes revealed by this set of participants covered a spectrum from a complete indifference to the concept of NHS participatory activity, to a state of virtual incandescence created by the bitter experience of participatory impotence. Neither of the holders of these views will be likely to participate in the future. Len who has never been asked for his views about healthcare sees no point in offering them as his life is fine as it is. Whereas Ray, who has participated in CCG events motivated by a desire to change things for the better for people with ACD, had an experience which led him to the conclusion that he has no influence and therefore it is not worth the bother and frustration. Both Len and Roy rated their potential to influence as nil.

Ray was forthright in his opinion of the value of the CCG decision-makers:

"shoot the bastards and then start again."

This is not to suggest that these accounts of the experience of participation are different from those which might be found in any other group of eight people.

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What I believe this group of people's sense-making procedures tell us is that there are as many routes to what might appear similar conclusions as there are people. Understanding how people account for their decisions to contribute or to stay silent requires the understanding of them as individuals.

Each of the participants produced highly individualised influence maps which may demonstrate how sensitive they were to their particular roles and remits when accounting for their influencing factors. In accounting for their selections they focussed more specifically on how they used influential people or groups to assist them in the achievement of their commissioning tasks. They provided evidence that they individually used their knowledge and assumptions about the various individuals and groups whom they had identified as influential to enable satisfactory outcomes. The values placed on the influencing groups might vary according to what outcome was needed. All the CCG participants referred to patients and the public as collectives rather than individuals.

The only non-professional representatives who were identified as individuals were the lay representatives who were members of the formal internal CCG Public Engagement Groups and therefore viewed as insiders.

The outward-facing, views-seeking activities mentioned by CCG participants ranged from locality or treatment-specific participation events to County-wide consultations that formed part of the Clinical Services Review. Naomi identified that for the locality or treatment specific events she selected participants purposively. She also recognised that the profiles of influence of the various participants would change according to the topics under consideration.

> "I think I tend to work with people that I know and that can deliver what we are looking to deliver." Naomi.

To a certain extent all the CCG participants demonstrated a foraging approach to assembling their sense-making. The participants with ACD appeared more fixed in their conclusions. It was clear that the wide-ranging and self-selected opportunities that the CCG participants used for bringing information together to make "sense" had potential to create a multiplicity of accounts, any or all of which

may then contribute to decision-making and which may not necessarily be open to challenge:

> "you are influenced by the media. It's a bit of a curate's egg isn't it ......and I am not sure how much you should be *influenced.* You end up being. Hopefully they are informing you but I think that's the story, the stories, the news stories don't always feel right." Chris.

The fact that two of the five CCG participants also highlighted that, for them, the form of the influencing environment was not hierarchical, as presented for the influence mapping exercise, but was three dimensional and matrix-like showed that, in addition to sense-making relationships, logistical issues also played a part:

> **"**OK- because some of it is hierarchical and some of it has to be in place for me to even exist and some of it is environmental because if I wasn't me then I wouldn't be able to do my role either and if I didn't have a team I wouldn't be able to do my role either." Fran.

> "So, it is almost as if we need a three-dimensional map?" Deb.

> **"**Yes, it needs to be almost 3D yes absolutely." Fran.

The accounts of the CCG participants illuminate how the participatory environment and the sense which is made of it is largely controlled by the CCG.

4.4.6   Reflexivity: how events experienced reinforce the assumptions and knowledge

The practice of decision-making in healthcare planning is obviously a complex process which operates in a dynamic and fluid context. The responses of the participants illustrate that there are moment-by-moment evaluations which both groups make in order to produce a set of individual perspectives which serve to perpetuate an "understanding" of how things are accomplished.

The contributions from the participants with ACD showed the extent to which their experiences had been assimilated according to both personal experience and assumed knowledge. What has become clear is that any change to the way they think about participation and their potential to influence decisions will not be

achieved through leaflets or rhetoric. What is needed is hard evidence that they have been listened to:

> "It makes you feel, what's the use of coming" "Lots of talk, talk, talk. Everybody is saying the same thing but nothing is done about it" Brenda

> "feedback is not individual enough- and if you don't feel that your point has been addressed you don't feel that you have been listened to... When you choose to (participate) it's not just doing it it's the feeling that you have made a difference" Fiona

At face value it seems very little to ask that participatory effort should be recognised

For the commissioners, the context of influence over healthcare planning decisions in which they see themselves as operating belongs in a work environment where certain outcomes have to be delivered. It is a context which they can move away from at the end of the day:

> "And like so many different things, when something works it just works and you move on, you forget about it don't you. So, I think some of the Stroke Reviews have worked really well, but you only ever continue to concentrate on the problems don't you." Chris.

The necessity of meeting deadlines and targets creates the framework within which participatory activity occurs. It is not possible for commissioners to dwell on past performance - they are not judged by the public's perspective of success. Unpopular decisions will be made and work-life will move on. None of the CCG participants made comment during their interviews about whether they had changed their approach to gathering public views as a result of experience to date. Felicity spoke of the need to be aware of the potential for decision bias as a consequence of demographics:

> "it's getting that balance. We have to consult but are they always representative of the whole population and how do you ensure that you don't distort things by middle class people in Dorset because we are full of middle class people who live in Dorset." Felicity.

Fran, as the CCG Patient Engagement officer, was also conscious of the need to be inclusive of a range of views but recognised that the complexity of the processes to which public views contributed were likely to deter all but the most

dedicated. This then risked that the "usual suspects" would become familiar participants whose opinions could be relied upon and that the outcomes which they contributed to would become predictable.

4.5 Summary

My analysis has revealed that the activity described as participation in the context of strategic healthcare decision-making was one which was recognised and understood by both groups of participants. Significantly, the two groups did not share a common understanding of its functionality from the point of view of accommodating public influence. The use of the ethnomethodological ethnographic framework of Harper et al. (2007) served to highlight how both sets of participants might be organising their thinking in order to accomplish the tasks I had asked them to complete. Collectively, the key aspects identified by Harper et al. (2007) were able to show how my participants' processed the purpose of participation based on their knowledge and/or experience and made sense of it. In my analysis I have identified that my participant's responses show their use of established, well used sense-making mechanisms.

The concept of influence was one which both sets of participants accepted as being relevant to the act of participation. The participants with ACD demonstrated that they did not define themselves as being without the ability to influence but they identified the challenges that communication impairment brought to achieving practical expression of that influence. They clearly indicated that experiences both pre- and post-stroke informed their views on the way of the world in the NHS. They had well-formed views about the degree of influence it was possible to have through participation in healthcare decision-making activities and considered that it was not possible to have any impact in the current NHS culture.

The strategies they brought to making sense of who else may be influential in the decision-making process showed how significant personal practical experience of an organisation or a professional group was to them in enabling an assessment of potential for influence to be made.

The CCG participants demonstrated that they saw the organisational structures of the CCG as defining their ability to be open to influence and in some instances this conflicted with their personal inclinations. They generated a very broad range of influencing agents, which included the mainstream as well as the more idiosyncratic. However, many of the influencing agents the CCG participants independently generated were also represented in the agents pictured on the cards which the participants with ACD had worked with. The strategies that were used to differentiate the degrees of influence held by the agents they had identified showed that the CCG participants thought that they were more likely to take notice of organisationally derived influencing agents.

The themes that I have identified through becoming familiar with the information my participants provided will be discussed in the next chapter. I wish to pursue the concepts of Sense-making, Belonging, Enabling, Agency, Choice and Power and how these aspects might illuminate what we can learn about performing the social activities known as participation or engagement better. I will end by evaluating how effective my elected research methods have been in achieving the ethnomethodologically inspired understanding of the topic that I was striving for and also what I have learned about being a researcher.

Chapter 5 Discussion

"What seest thou else" Shakespeare (The Tempest. Act 1, Scene 2.)

5.1 Introduction

In this chapter I draw together the information provided by the findings and discuss how these might offer new perspectives which may contribute to the understanding of the role of civic participation in NHS healthcare planning. I will explore how my initial assumptions regarding key themes have been challenged and changed by the analysis of findings and how the choice of an ethnomethodological approach could inform future investigation into the experience of participation. The conclusions achieved through the process of discussion will go on to inform my practice development in chapter six.

5.2 Initial assumptions

The specific focus on the participatory experience of people with ACD offers an insight into the relationship between this group of people and the commissioning function in Dorset CCG which has not previously been available for scrutiny. Society, according to Plato, is made up of good citizens and the themes I have pursued throughout this thesis concern one expression of citizenship in civic society. The product of Doctoral study should be the illumination of previously unexplored or under-explored areas of knowledge (Fulton et al. 2012). In my case I was keen to investigate how people viewed their ability to exercise a particular feature of social behaviour - influence which I saw as being of importance to the purpose and function of civic participatory activity. More specifically, I wanted to explore how people with ACD understood the role of influence, both their own and that of others, in the making of the strategic healthcare decisions controlled by the commissioners working in Dorset CCG. This is an aspect of people's civic relationship with the NHS which has not previously been investigated.

At the beginning of this thesis I built my corpus of knowledge according to my need to understand the underpinning theories which I saw as being important to

the development of my study. I embraced the notion that research should be a focussed activity, directed by what had gone before. I laboured to create a structure from the overwhelming chaos created by new information that I had discovered. As my understanding of the different academic contexts developed, I became able to relate the information back to the practice-based experiences which had been the catalyst for my research. This was a dynamic but deductive process which resulted in the creation of the themed framework for my literature review (chapter two) and also informed and influenced my methodological approach (chapter three). The impact of this trajectory has been such that I believe it is important at the outset of this discussion chapter to revisit the original themes, their relationship with the more inductive emergent themes arising from the analysis of findings being significant to the product of this thesis and my development as a researcher. The original themes were, Participation and Policy; Communication Disability and Inclusion, and Power and Influence.

5.2.1 Participation and policy

In the literature review I explored what UK politicians anticipated would be necessary to create a good society. In the United Kingdom access to timely, appropriate and free at the point of delivery healthcare is held to be a signifier of a good society (Klein 2012). Political will has determined that people, whether in the role of citizen or patient, should have a greater influence over how healthcare is provided. The organisational interpretation of these views, expressed through the implementation of governmental policy, has impacted upon the way that healthcare services are organised and delivered. In the process of transforming the culture of the NHS in England from one of paternalism to one of consumerism there has been, in my opinion, a lack of transparency about how we, as citizens, embrace our new role as choice-makers in the strategic sphere.

As a healthcare professional I work in an environment where the opportunity for choice over how services are commissioned is regulated by what it is possible for the NHS to provide. This is a personal assessment which has been verified by independent research by (Wistow and Davey 2011). Although Dorset CCG acknowledged the findings of Wistow and Davey (2011) as a true reflection of the participatory environment in Dorset in 2011, in 2017 it seems that no significant

change in approach has been made to improve the participatory environment. Very recent activity relating to a new stroke care pathway for Dorset (NHS England 2016) has been modified so that people are not being asked to participate in the design of services as originally intended but rather are being consulted to confirm that they are happy with what has already been determined by what can be afforded.

The research aims identified at the beginning of my D. Prof required me to answer some simple questions regarding the function of influence in healthcare decision-making. My research findings have indicated that both groups of participants could relate to the concept of influence and could evaluate the potential for influence to exist in the context of NHS service planning activity. What the participants in my research have also shown me is that each of them made their choices in the context of both generally held *and* personally specific frames of reference.

5.2.2   Communication disability and inclusion

My motivation to undertake this study was driven by a belief that people with ACD were missing out on opportunities to inform and influence strategic healthcare decisions because the mechanisms of involvement did not account for people with communication support needs. The conclusions I have drawn from my findings present a much more textured picture. I now realise that what the words participation, power, inclusion, good, citizen and society mean is dependent upon who you ask for the definition. How individuals are placed and how they place themselves in any given context is governed by what the context appears to be, according to our individual perspective. This discussion will draw out the new perspectives identified and explain why I believe these perspectives contribute to the body of knowledge regarding how people bring their knowledge and experience to bear when evaluating their potential to influence in an NHS participatory context.

5.2.3 Power and Influence

The context in which this study took place, namely the English National Health Service (NHS), has become well renowned over the last sixty years for being both hierarchical and patriarchal in its organisational structures and culture (Hughes and Lewis 2005). The research aims identified the focus of investigation; the understanding of the role of influence in civic participatory activity. As discussed in the literature review, the recent political motivation to open NHS decision-making processes up to patient and public involvement has created new sets of rules for all participants, NHS staff and public alike (NHS England 2013). This has led to both scrutiny and debate of the engagement processes and the outcomes which these processes have achieved. There remains scepticism about the sincerity of the opportunities for citizen influence which are offered (Stewart 2013; Boswell et al. 2015). The ability to evaluate what is relevant in a meaningful way, to align one's thinking according to one's personally held principles, is often a taken-for-granted process which is not usually explicitly interrogated. The findings and analysis demonstrated to me that this taken-for-granted process is central to achieving an effective participatory experience.

The learning to be gained from understanding how people construe their power to influence decisions must be derived not only through examination of the organisational structures and frameworks but also through the softer, more elusive systems of individual actors in the system. Consideration of the findings required me to recalibrate my own thinking with regard to my appreciation of the participatory experiences of others.

5.3 Emergent Themes

The social context which I believe my research illuminates shows that the way in which people engage with the NHS is simultaneously both complex and simplistic and, in addition, that the relationships which exist in Dorset between the NHS as an organisation and the citizens with ACD are simultaneously both robust and fragile. In attempting to navigate these intricately interwoven strands of thought I mapped out where I had started my thinking at the outset of my Doctoral journey

(researcher-determined themes) and where I see my thinking as being now (participant-determined themes) (see Figure 5.1).
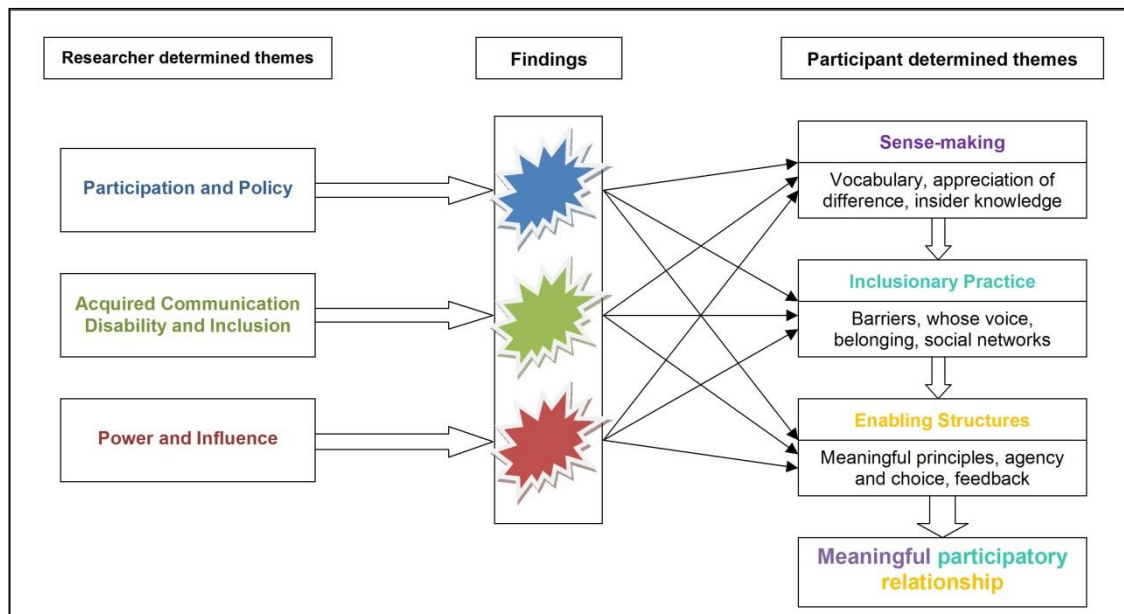
Figure 5.1:   **Discussion Theme process**

What Figure 5.1 highlights is that my initial marshalling of information and subsequent creation of themes in my literature review provided a necessary foundation for my analysis of findings. Through the process of analysing my findings I have been able to see that the original themes I identified belong in all of the emergent participant-determined themes. Without the initial simplification provided by the literature review I would have become lost in the complexity of the information provided by the participants. The relationship I have developed with the information has enabled me to see how multi-dimensional every aspect of participatory behaviour is. This following section will present what I believe is important about the themes that have emerged from the contributions made by the participants in this study. These key emergent themes I have called sense-making; inclusionary practice and enabling structures.

5.3.1 Sense-making

 Sense-making is a process of social construction which enables interpretation of events (Berger and Luckmann 1991) Furthermore, sense-making is a critical

process in the establishment of a collective, coherent understanding which in turn enables meaningful relationships to be established (Weick 1993). It is through the achievement of a sense of meaning that humans understand the world around us and our role within it. The accounts that people give of their social worlds have been constructed and maintained according to their particular sense-making procedures and as such are situated accomplishments (Rouncefield et al.2001). The importance of assumption in this process cannot be overlooked however assumption represents unrevealed knowledge and is therefore ripe for misunderstanding by others.

In using the framework provided by Harper et al. (2007) to analyse how each of my participants used their knowledge and experience to contextualise and make sense of the tasks they were asked to complete, I was attempting to uncover my participant's hitherto hidden assumptive behaviours. I was able to see that all the ethnomethodologically informed aspects contained within the Harper et al. (2007) framework contributed to each participant's achievement of the research activities.

It was clear that although not all of the participants with ACD had actively participated in a CCG views-seeking event they could all form opinions about how the NHS/CCG decision-making systems worked. In his paper "The Well-Informed Citizen" Schutz (1946) suggested that people derive knowledge through practical experience of the world. This knowledge can be gained through direct experience but also through being part of a group who share their knowledge and experience. Collecting mutually recognisable information is a way of creating shared identity. Vocabulary is an important way to signal that.

Vocabulary

The commentary approach taken by participants whilst they were undertaking the research tasks led to realisations about assumptions regarding the common understanding of vocabularies used or communication short-cuts taken which, without explanation, would have created barriers to the success of our joint endeavour. The importance of the choice of vocabulary in enabling a mutually comprehensible situation to be created is significant. The words used to communicate thoughts and ideas, together with body language, are the ways we

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signal the summary of a far more complex set of internal cognitive processes. A mutual shared vocabulary signifies common ground with or belongingness with a particular group and enables shared understanding. Recognition of this was illustrated by Fran when she apologised for using some work-related acronyms which I might not be familiar with and which, without clarification, would certainly have prevented me from following her explanations.

By and large, the way the participants used their knowledge and experience to inform their approach to the research tasks was understandable to me. However, each individual participant also used additional resources, making reference to less generic communities, relevant to their particular interests and roles which brought in much less predictable contributions. When this occurred during the session I was able to make their mechanisms of deliberation transparent through questioning but there were also instances where the participants proactively recognised that they needed to account for their reasoning. The one-to-one nature of our conversations enabled the changes in the tempo of the interaction to be picked up on and any potential or actual breakdowns repaired. In the normal course of group participation events, this opportunity for explanation and clarification may not be possible and therefore the opportunity for the creation of shared sense-making missed. It was clear from the contributions of the participants that a mismatch of understanding between the people with ACD and the CCG with regard to the potential for public influence created a sense of alienation.

It has been shown that talk between people supports the sharing of both meaning and purpose. Recent projects that have used a deliberative approach to achieving collective decisions have shown that the process of deliberation can enable participants to better understand the point of view of others, encourage the sharing of knowledge and facilitate change (Hughes and Pollard 2014). Projects such as NHS Citizen offered an opportunity to explore the potential for better dialogue on a national scale but nothing similar has been attempted locally. The power of NHS Citizen lay in its core intention to include and involve people throughout the deliberative process, the ethos being one of mutual responsibility in the creation of a participatory environment in which anyone could belong. The challenge as I see it will be to create a different way of conducting participation locally which fosters a similar sense of collective membership or

belonging. The creation of a participatory environment which recognises the existence of difference but which is capable of adapting in response would afford the chance to understand better what others might bring to the discussion.

Appreciation of difference

To be able to appreciate things differently individuals have to be able to differentiate the viewpoints. The importance of noticing difference is not a new concept. In 1895 Mary T Lathrap, published her poem, "Judge Softly", which speaks about having empathy and understanding for others and uses the phrase "walk a mile in his moccasins" before judging another man. This concept, of understanding another by putting yourself in their place, has come to the fore again recently through the "Whose shoes?" toolkit work of Gill Phillips which has been adopted by the National Voices Making it Real initiative. The Whose Shoes approach encourages health and social care workers to see the service they provide from the point of view of the receivers of the service and not to interpret situations only from their own viewpoint. The recognition that assumption should not drive healthcare culture and that personalisation and the acknowledgement of lived experience is as valid a currency as professional knowledge has become a stronger feature in the planning and delivery of care to people as individuals (NHS England 2015; DoH 2011). It is now accepted that people should be able to make their own healthcare decisions according to what they value about themselves and their lives.

This culture shift can apply to strategic decision-making too but it requires the development of an equivalent relationship between the NHS as an organisation and the citizen as there is between NHS staff and individual service users, although there is a lack of clarity over how this can be achieved in genuine and meaningful ways (Ocloo and Matthews 2016). A key conclusion I have drawn from my findings as a result of using an ethnomethodological perspective is that the reasons why people make the decisions they make are many and various. By paying attention to the range of resources individual people bring to bear in order to make their decisions, it might be possible to create organisational participatory processes which foster a more meaningful and humanised context where people can be understood and understand others as individuals. This in turn may create

a better, more reciprocal relationship between the users and commissioners of healthcare services and lead to better decisions. To achieve this, the talk people have with each other needs to leave space for exploration and negotiation of meaning. In other words, space for deliberation.

Insider knowledge

The suggestion that there might be groups of participants who were "inside" the CCG systems and who may not be truly representative of the wider public view has been recorded by other researchers (Russell 2008). The feeling of being included within or left outside a group or community can be lasting. In my personal narrative I described a meeting with the co-organisers and creators of NHS Citizen where I felt an outsider because I was unable to use the same reference framework as them. The instinct following such an experience was to turn away rather than strive to become included. Subsequently, my reading and my research has served to substantiate and validate my instinct. Rawles and Davis (2006) in particular showed how impactful the knowing of the rules is on an individual's experience of belonging to a group. In particular, Rawles and Davis explored how the absence of knowing how things were done could identify an individual as an outsider or as having "otherness".

Otherness defines an individual as not "us" (Rawles and Davis 2006, p.470). Being an outsider excludes that individual from access to the shared beliefs and knowledge held by the insiders and without these things the individual cannot belong. As social animals, humans are hard wired to respond to signals of acceptance or rejection and any discrepancies between the self-assessed category of belonging and the socially assigned category of belonging are keenly felt (Goffman 1959). The occurrence of an acquired disability can often be the cause of a change in the experience of belonging and the participants with ACD expressed feelings of exclusion from activities such as participation in CCG engagement forums, not for reasons of stigma (Goffman 1963) but because of other barriers such as those that could be described as environmental or organisational (Earle 2003), the outcome being that, for those who had attempted to participate, the experience of doing so had not made them feel included so they had chosen to withdraw from the arena.

In making sense of what it is to participate and influence, all participants drew upon their life experiences. The mechanisms of sense-making which were revealed through the analysis demonstrated how each person maintained their views through the use of assumptions and how these assumptions encouraged or discouraged participation. There was no discernible difference in how both groups of participants went about making their sense. The experience of stroke and the presence of a communication disability clearly informed the sense-making of that group of participants as did the work roles of the CCG participants. Where the problem lies, in my opinion, is in the fact that there was no evidence that sharing of understanding between the two groups ever took place. If opportunities for the adjustment and development of a shared sense of purpose between the CCG commissioners and people with ACD were to be created, it could encourage a culture of participation which benefitted all.

In the next section I examine how the information gathered contributes to better understanding of the impact of acquired communication disability on participation.

5.3.2 Inclusionary practice

In the discussion introduction I referred to the fact that my research findings had enabled me to develop a more textured appreciation of what the experiences of people with ACD might be in relation to NHS participation. At the start of my thesis I had made the assumption that they would identify their communication disability as being a significant inhibiting factor. However, this has been proved to be an over-simplistic generalisation and, in fact, the way in which each participant with ACD viewed their communication disability was particular to their personality and life circumstance. A one-size-fits-all approach to inclusion would therefore also miss the point. The lesson to be learned is that one should not make assumptions about the values of others.

Communication disability as a barrier to participation and influence

In my literature review I defined Influence as being the "action of a person or thing on or upon another, perceptible only in its effects" (OED 2016). The significance of this definition lies in the emphasis on the fact that the presence of influence cannot be determined unless the application of it has caused a change. It is clear from the information the participants have supplied that all contributors understood that participation in CCG planning processes could result in changes of view or belief on either side, but for the participants with ACD the lack of feedback following their participation indicated to them that their contributions had had no effect and no change had taken place.

The exercise of influence has been shown to have impact on subjective wellbeing (Sommer and Bourgeois 2010) with strong links made to the five basic drivers of social influence (Bourgeois et al. 2009) namely belongingness, control, self-worth, accuracy and meaning. These themes have relevance to the conclusions drawn from findings which relate to how each individual constructed their responses according to how they sense-make, how they perceive relationships and how they make choices.

The responses received from the influence mapping exercise showed that assessment of potential for influence was not driven solely by the ability to communicate. Ron and Dan in particular were the most significantly disabled verbal communicators of the group but both expressed strong opinions about the impact of their attempts to contribute. They both indicated that they thought they would have little or no influence over CCG decisions but they did not attribute this assumption to their communication disability exclusively.

This is not to say that having a communication disability does not bring difficulties. Many of the participants, and their partners when present, identified that their communication disability had robbed them of their opportunities to feel effective in social situations, their desire to engage with life conflicting with their experiences of having tried. This has resulted in them classifying themselves as non-participants. The interesting adjunct to this observation of an apparent lack of agency is that most of the participants with ACD scored themselves as being moderately influential. Some clarified that this rating applied to situations in general but not in the context of CCG participation activities. This may indicate

that the CCG processes in particular are disempowering for this group of people. Nevertheless, the difficulties inherent in group participation events identified by the people with ACD are, I would suggest, more universal experiences equally applicable to those with no acquired communication disability. Many people have anxiety about speaking in public or difficulty in reading PowerPoint slides quickly and assimilating the information. The consequence of participatory activities not being enabling is as shown by my participants' contributions. If people choose not to get involved it does not necessarily mean that they have nothing to say.

While most of the participants made reference to the impact of their stroke, including their communication disability, on their lives, their comments showed how they had re-calibrated their expectations according to their personal capabilities, although importantly this did not seem to diminish their desire to engage and participate if that is what their pre-stroke inclination would have been. Throughout their interviews, they expressed views about the services they had received and how being able to share their experiences might help to improve the experiences of future stroke survivors. There is ample evidence (Stroke Association 2013) to show that Dorset has a high number of stroke survivors and statistics identify that at least thirty percent of these people will have a lasting communication disability. Therefore, it seems sensible to consider how the experiences of those who are living with ACD might be instrumental in developing better health-care services in the future, particularly when there is evidence to suggest that there may be wider public benefit to be gained by adopting some of the adaptations designed to help those with ACD (Slate 2010). The evidence from this study indicates that this voice is being lost. The CCG recognises people with communication disability as being amongst the "hard to reach" or "seldom heard" but evidence from my study indicates that the people themselves beg to differ.

Seldom heard

Fundamentally, if people with ACD do not see their communication status as a barrier to participation then why should anyone else? In light of the findings I considered the fact that recognition of absence of a communal voice for particular groups of people in civic life has created the labels "seldom heard" or "hard to

reach" (DoH 2007). These terms have been coined to capture the absence created by the drive to achieve locally representative, person-centred services (DoH 2006) and are used organisationally to badge efforts to achieve inclusive representation. People with communication disabilities are considered to be amongst the seldom heard. The irony highlighted by the findings is that the participants with ACD had plenty to communicate and their views and opinions were thoughtfully expressed and situated in meaningful contexts but only I was there to hear them. Most individuals interviewed as part of this research had learned to accept barriers to participation as one of the consequences of their stroke but this did not mean that these barriers were not a source of frustration.

In a King's Fund presentation, Ryan (2014) raised the point that "who" who is seldom heard can vary depending on what is being said and in what context. The ability to make oneself heard can relate to social status or vocabulary but it can also relate to the palatability of the information being communicated to the listener. Research carried out in Sheffield (Todd et al. 2009) indicated that hard-to-reach groups were rendered so through lack of physical and environmental resources as much as through their confidence to join in. The views of my participants with ACD support this conclusion. Those who had chosen to become involved initially were not subsequently disinclined to participate because of an intrinsic lack of confidence to do so; they had become stranded by organisational processes which had failed to keep them engaged and attached. In Curry and Fisher's terms (2013) they had become absented rather than absenting themselves from the outset. Once lost to the system my findings indicate that there seem to be no mechanisms for reconnecting any stranded potential participants. It therefore suggests to me that without conscious investment in the rebuilding of bridges with the expressed purpose of enabling people to reconnect, some groups of citizens will remain seldom heard. This observation merits further investigation in order to establish whether it carries any substance in terms of people's actual experience. If the health community in Dorset is to benefit from what this group of people have to say, then ways of listening must be developed. Being thought of as seldom heard says more about the listener than it does about the owner of the voice.

Whose voice?

It was certainly the case that of some of the participants with ACD faced significant communication challenges. Their communication disability prevented them from being able to use the knowledge and experience they possessed to best effect and they demonstrated that restricted access to their own vocabularies could create frustration and a reliance on others to "interpret". For the most significantly disabled communicators, their partners provided much of the contextual narrative within which the contributions of the person with ACD could be understood. A less familiar interpreter with no knowledge of the person and their views might well attribute different meanings to what is being communicated by the person with ACD which would then introduce another individual's layer of sense-making "methods" into the process. Conversely, where an individual had chosen a representative, such as in the case of Joan, there was complete confidence that that person would express opinions which Joan herself would agree with.

The impact of the use of others as intermediary was not a focus of this research but deserves further investigation. The potential complication of the validity of any mediated views was addressed as an ethical consideration for my research but it is not clear that similar mechanisms have yet been embedded in the participatory culture created by the CCG. For people with ACD who want to give feedback or comment but need support to do so, my findings call to question whose views might be being recorded. In addition to the direct public-facing forums there are of course other mechanisms within the CCG for introducing public views to the CCG planning process. One of these is through a patient representative and this is a role which is included in the membership of a variety of different organisational groups within the CCG. However, it is not clear to me how the person holding a patient representative role gathers and processes the views of other patients. It would have been valuable, had I been aware of their existence, to have included the formal CCG patient representatives in my sample of CCG participants because their formal function as the mouthpiece of the users of healthcare services ought to have been central. It would also have been interesting to understand how visible the CCG thought these formal representatives were to the "public", certainly none of my participants with ACD referred to them or included the representative role in their mapping. Clearly

Patient Representatives are a group of people who very much belong to the strategic healthcare planning process but they appear not to belong to the public they represent.

Belonging

Belonging is a very fundamental human behavioural requirement which has impact upon well-being (Curry and Fisher 2013; Easterbrook and Vignoles 2013; Chapell and Funk 2010; Pritelltensky and Pritelltensky 2006). Belonging contributes to a sense of shared sense-making and common meaning which in turn enables members of a group to reinforce their connectedness. A sense of belonging is an essential element which can lead to participation (Haggarty and Williams 1999). Belonging and participating becomes a virtuous circle and Putnam (2000) emphasised the importance of participatory capital which Wellman et al. (2001) suggested led to the creation of community commitment. Community commitment, they proposed, serves to reinforce the motivation to contribute to a community through participation.

The generally held views of the participants were expressed in terms of their relevance to group membership of a "community", which could be generically defined by health condition/disability/work role/status. The concept of community from the point of view of human society is one which has academic heritage through sociological, philosophical and psychological theorising but it is not a unitary concept with a single definition (Hutchison 2008). For my purposes, I see the term community as a way of describing what defines a group of people as belonging in a group and its characteristics help non-members to decide whether they too belong or not. Bourdieusian concepts of habitus, capital and field (Bourdieu 1990, Warde 2004) provide a mechanism which explains how social behaviour is regulated according to how individuals believe they relate to each other and make sense of their relationships.

What makes a community work as an identifiable unit is contested (Gower 2014) but identification of similarity between members of that community is a well understood expression of belonging. Possession of social capital which can be established and reinforced though belonging to a community is known to be a powerful contributor to an individual's social wellbeing (WHO 2012). Research

has shown the impact of isolation and the benefit of belonging on many arenas of human behaviour (South 2015; Toepoel 2013 and Foot and Hopkins 2010).

Social networks

For people who are disadvantaged in terms of being able to communicate using all the usual channels, maintaining connectedness in modern society is more difficult (Parr 2004; Pound 2014). However, this does not mean that those individuals wish to assume a silent or passive role in life. Whilst it may be easy to assume that a communication disability robs a person of their whole portfolio of personal skills, abilities and knowledge, this has been shown to be very far from the case (Simmons-Mackie and Damico 1995). Most of those who have experienced a change in their communication status as an adult have not lost their pre-stroke personal or social skill set or their interest in being part of the world. The networks we create, within which the expression of social capital through social exchange is established and collective meaning is reinforced, are essential to the maintenance of culture and society (Bourdieu 1990; Putnam 1990). Garfinkel (1963, 1967) emphasised the importance of trust and reciprocity in the accomplishment of shared social practice and expressions of relationship. Connection with others whom we perceive as being similar to ourselves creates a sense of belonging where trust and reciprocity can be reinforced. My research method assigned participants to one of two communities for the purpose of differentiation but reassuringly each set of participants demonstrated their understanding of their assigned participatory "community" through their responses to the research tasks in hand. The participants drew on knowledge derived from their membership of their research-assigned communities but also from knowledge and experience of being members of society in the broad. In the findings I suggested that there would have been value in enabling participants to reveal more about the communities they saw themselves as belonging to, as it was evident that in both groups there were participants who derived their views from a diverse range of sources.

A notable finding from the influence mapping activity carried out by the participants with ACD was the significance of knowing the individual occupying

the role in question. People whom the participants' knew personally and had had a relationship with during their rehabilitative period, were thought to be more influential than those they did not know. That person was trusted to act in the best interests of the participant and power to influence was invested in them and not in their role. There was significant rationalisation of their decision-making according to whom they trusted as "good people" who would have their personal interests at heart. This finding substantiates the importance of trust in social relationships and demonstrates that trust is a valued commodity bestowed only upon those who have provided concrete evidence that they deserve it. The same was true of collectives or groups. The selection of potential influencers that were offered to the participants with ACD for use in influence map creation included formal community groups, organisations and public bodies as well as informal friends and family groups. Some of the formal groups, for example Dorset Partnership for Older People Programme (POPP) and Healthwatch, were not known about at all and therefore immediately discarded from consideration. Given that Dorset had been held as a leader by example in the setting up of older people's forums and of POPP forums in particular (Wistow and Davey 2011), this finding could be seen as a surprise. Others such as Age Concern, the Stroke Association and local Councils were recognised by all participants but felt to have varying, mainly low, levels of influence. This finding is of interest because of the degree of advocacy these organisations are perceived to have generally; in fact, the CCG participants did not rate their capacity to influence them highly either.

Bonding and bridging

Although the people with ACD who participated in my study ranged in age from the mid-thirties to seventies and were therefore not all old, there are correlations which can be drawn between the effects of aging on connectedness and the effects of disability on connectedness (Pound 2014). Terrion and Zergace (2008) suggest that older adults might experience a change in their perceptions of their own social capital as a result of their aging process and this in turn affects their use of social networks. Physical and logistical barriers can also not be overlooked. In the Wistow and Davey (2011) study of Dorset's older people, the impact of rural transport on access to participatory activities was identified as well

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as the significance of changes to hearing, vision and stamina. The contributions of my participants with ACD support this hypothesis as they redefined their individual networks through both choice and necessity following their stroke.

The research by Curry and Fisher (2013) has shown that older people are more inclined to join in with community-based activities and the reasons for this are various; Wistow and Davey. (2011) and Vegeris et al. (2008) suggest that camaraderie and a sense of purpose are common motivating factors. Participants of such groups use both bonding and bridging capital (Putnam 1995, 2000), and the higher the social capital held by an individual the more likely they are to participate in civic activities (Li et al.2015). However, the act of engaging in civic participatory behaviour also require Putnam's third form of capital, linking capital, as this describes connections which are capable of bridging social power differentials. Putnam suggests linking capital is the most socially vulnerable of the three types but seen to be the most critical to sustaining connectivity with health and well-being resources (Woolcock 2001). It was the expression of linking capital which was not evident in my findings from the people with ACD.

In contrast, the CCG participants in the study all identified strongly with being members of several different groups, professional, friendship, family, etc., all of which impacted on their roles as commissioners of services. Their responses suggest a capacity to move between groups and use networks which further suggest a facility for both bridging and linking capital (Putnam 2000). Similar mobility was not as clearly evident from the responses of the participants with ACD who, in the context of civic participation, rarely brought other networks to bear unless as evidence that they did participate in other things, just not in CCG-related activities.

The maps produced by the participants from the CCG all included the public and/or patients as a group. There was little sense that these collectives contained further differentiation into recognisable individuals. Where individuals were referenced, and this was only by participant Fran, it was to identify them as representatives of a collective. Several of the CCG participants maps were complex and their creators identified that, for them, the influences were more matrix-like than two dimensional. Connections were made between many

different groups at levels which were meaningful only to the map-maker. Groups "belonged" together to enable achievement of goals. In my view, it is possible that the networking approach used by my CCG participants may contribute to a sense of opacity and a lack of inclusion in terms of who influences any decision-making activity

My findings showed that common bonds of trust and understanding with others, bonding and bridging capital, were described by the participants within both groups but these did not extend to any common bonds between the two groups of participants. There was clearly no trust relationship with the CCG commissioners on the part of the participants with ACD. For the commissioners, their relationship was expressed as being with the public or with patients and not with individuals, a position which served to distance them from any shared or meaningful bond with people who were users of the services they commissioned on an individual basis.

A question which has not been raised by this study is whether people who do not have ACD would agree or disagree with the views of the people with ACD about their chances to influence decision-makers. I have criticised the CCG for appearing to define people by diagnosis but perhaps I have committed the same sin. Future research into what other sections of the Dorset public think could prove interesting. In the next section I will discuss how the structures of participation affect the experience of participation and examine how my findings might illuminate opportunities for change.

5.3.3   Enabling structures

It was clear that the experiences of participation which the people with ACD had encountered had served to alienate them from the process rather than encourage them to become more involved. Several commented that they thought decisions had already been made regardless of what the public might want. This does not sit well with the policy rhetoric which speaks of inclusion, respect and responsiveness to views shared. The sense-making "methods" which this group

of participants had developed as a result of their experiences of participation are illustrated by comments such as this from Fiona,

"There are a variety of reasons why I personally don't choose (to be involved). Firstly, I don't think it is all that valued and secondly, I'm really busy. I've got other things. You know, it's just an e-mail to get involved and it's not that... When you choose it's not just doing it it's the feeling that you have made a difference."

As a working single mother, she has valuable experience of returning to her life following a stroke at the age of 21. She is motivated to contribute to social and civic life but not at any price. Her participation in future planning for stroke services in Dorset has been lost because she felt that nobody cared to listen or acknowledge the effort she had put in order to participate. Fiona was not alone amongst the participants with ACD in coming to the conclusion that the lack of recognition had resulted in there being no sense to participation from their perspective. The psychological concept of appraisal support (House et al. 1985) includes the requirement for affirmation and feedback to maintain the communication loop. Feedback demonstrates that there is a conversation happening and provides a platform for accountability (INVOLVE 2005). The comments made by Fiona and others substantiate the importance of a receptive and responsive space to the encouragement of continued participation. Feeling effective is motivating. Unfortunately, actual evidence of the effect of participation in care planning has been hard to find. A review undertaken by Doel et al. (2007) which explored service user participation in the design and delivery of social care services led the authors to comment that at that time there was little evidence to show what changes had been influenced by user participation. Similarly, Minogue and Hardy (2007) could find no empirical evidence of the effect of service user participation on clinical outcomes. Certainly, my findings in this study indicate that evidence of impact is still hard for people to find. It is difficult to promote opportunities to participate when people think there is no point in doing so.

It was clearly important to the participants with ACD to know that any effort made was worthwhile. For people to be able to develop a sense of community commitment, the cost to them of participating should be balanced by the reward to them of participating. This not only establishes the worth of the activity for each

participant but also for the group. Whilst each of us will assign the value of the cost and the reward according to our individual inclinations it is also the case that mutual benefit is created, so it is important that each of us recognises and respects the judgements and values of others. This is a conclusion which is supported by other research undertaken in primary care by Chisholm et al. (2006).

The contributions of the CCG participants showed that they considered the public and patients to be central to informing what they did in their roles and they provided evidence of where this had occurred but these examples did not relate to stroke services. However, the CCG participants also recognised that the processes relating to participation and engagement could be confusing. As a general comment Fran acknowledged that the Engagement Cycle process made it difficult for "lay people" to understand how what they said made a difference. This despite the fact that, throughout the current Clinical Services Review (CSR) process, the CCG has attempted to provide information designed to help potential participants understand the engagement process. None of the participants with ACD made any reference to having benefitted from this. It is entirely possible that with the benefit of additional knowledge about the rules of the participation process they may have felt more encouraged to take part.

Engagement principles

I have suggested that the structure of the participation process is driven by the culture and perspective of the CCG. In fact Dorset CCG has produced and published a set of Engagement Principles which show how the organisation intends to behave in respect of working with the public. These principles embrace the spirit and philosophy of the empowered public and indicate that the CCG will work in partnership with the public in achieving good health-care decision outcomes for the county.

The public in general have access to information about the CCG Engagement Principles on the Dorset CCG website. They set out the ambition if not the detail of the engagement process and appear in Table 5.1 below. These Engagement Principles show that there is obviously an intention on the part of Dorset CCG to effect meaningful and productive dialogue with the public. However, it is clear

from my research that these locally applicable principles are not always being achieved and have not framed the experience of the participants with ACD. In the view of people with ACD the implementation of these engagement principles would remove a barrier to participation which some thought was practically unsurmountable.

1. Engagement is a two way and proactive process and we will ensure that this is reflected in our approach to all engagement activity.

2. Engagement activities will have clear and agreed purpose, and we will use appropriate methods and standards to achieve these purposes, ensuring they are relevant to the audience and easily accessible for everyone.

3. Improving community engagement will be a continuous learning experience ensuring that there is a commitment to learning both from experience and national guidance.

4. There is an acceptance that some communities find it difficult to engage due to capacity or competency, and skills will be developed to ensure that communities are able to respond effectively to the Dorset CCG.

5. Skills will be built in the CCG to ensure the effective implementation of equalities principles, to share ownership of the wider agenda, and to enable all viewpoints to be identified, collected and reflected.

6. We will be clear with all our communities the scope of change and the influence that they can have on this change so there is a shared understanding. We will be clear about our reasons for this change and why there may be limitations on public influence for change.

7. Accurate, timely information is crucial for effective engagement and wherever possible enough time will be allowed for early information-gathering, engagement and if necessary consultation on specific issues.

8. Feedback is essential to develop a trusted and honest relationship. Feedback will be provided for all engagement activities and there will be clarity about what difference the engagement has made. If no changes have been made, this will also be explained.

Table 5.1:   Dorset CCG Engagement Principles

In their Engagement Principles statement Dorset CCG go on to summarise principles shown in Table 5.1 so as to draw attention to the importance they place on the following points of note for their commissioners:

- the diversity of people and communities

- the need to ensure that engagement has a clear sense of purpose

- the requirement to be open and transparent in what the scope of change can be

- effective methods for achieving change need to be used

- the skills and knowledge of all those involved need to be used and developed

- that continuous improvement is essential

In their responses to the influence rating and mapping tasks the CCG participants recognised that their ability to meet the ambition of the engagement principles was limited. They identified that the organisation was working towards meeting the standards it had set itself but that pressures of time and money restricted progress. In coming to this conclusion their views concurred with those of the participants with ACD. It could have been reassuring to both groups to know that a shared, if disappointing, conclusion had been reached.

Hearing every voice

The fifth CCG engagement principle states that all viewpoints will be identified, collected and reflected upon.

In addition to the participants with ACD who contributed to the research findings I also had one participant who was unable to contribute not because of communicative or physical disabilities but because of his environmental circumstances. Ted lives in a nursing home but is able to get out and about.

To make contact with him to arrange a visit it was necessary to call him on the phone. The protocol required a call to be made to the nursing home reception desk and then the call was transferred to his floor nursing station and then the

walk-about phone would be taken to him in his room. Ted and I never got to make our arrangements as the connecting links in the chain always fell through. Ted has become a seldom heard statistic as a result of the systems around him.

I want to bring Ted into my discussion because he represents a different lost opportunity. I have lost his voice from the study but his voice would as easily be lost to the CCG. He was motivated to participate but his will was foiled by his domestic setting. I believe that there will be many people like Ted who must rely on a chain of others to enable their civic participatory lives. The impact of living in a supported environment where the structures do not enable social inclusion in the wider community has been recognised as being detrimental to the residents' well-being (Anderson and Dabelko-Schoney 2010). My viewpoint is that there is also an impact upon the community when such contributions are missed. This reflection relates to my previous discussion point about the spoken-for but, in this case, Ted has neither spoken for himself nor been spoken for. The group of voices of which I believe Ted is a member should be sought out and listened to. Who knows what they might choose to say?

Agency choice and power

In circumstances where civic participation relates to decision-making it implies choice. To make and exercise choices each individual must bring to bear not only all the knowledge, experience and expertise they have in order to make sense of the choice options available to them but must also have available to them the infrastructure to make their choices effective.

Choice-making is a mechanism through which each of us exerts our own personal power or agency and with which we can exert influence. Belief in one's own capacity to choose brings a sense of empowerment and control but when, following their participation, the participants with ACD were given no evidence to show that their views had been heard, they concluded that it was others and not them who could belong to these groups. Their influence maps illustrated that, from their point of view, those who belonged were largely those who held professional or organisational roles either in the NHS or in public life. The culture of doctor-knows-best is slow to change as demonstrated in a speech by Jeremy

Hunt, Secretary of State for Health in 2015 (DoH 2015). His speech was entitled "Patient power: threat or opportunity?" and contained the following sentence, "Patients will never be powerful if we do not give their doctors enough time to listen to them." Unsurprisingly therefore, people conclude that their only way to power is via a Doctor.

It was apparent that the participants with ACD were exercising their agency by choosing not to engage with the CCG participatory processes. Of course, it is not a mandatory requirement to participate and not all of us are equally motivated to engage in civic activity. However, for those participants who had wanted to become involved and were motivated by the chance to contribute to improving the services offered to people who had strokes, the active withdrawal of their voices represents a failure of the process. The participants with ACD indicated that they saw no obvious mechanism through which they could be supported to participate more directly.

My conversation with the BU Ethics Committee demonstrated to me that the perception of the meaning and scope of "choice" is very much dependent upon who is offering the chance to choose. The perspective of the committee was that the choice to participate or withdraw from participation should be limited by the need to preserve the integrity of the research, something which is important to the credibility of both BU as an institution and the D. Prof as a qualification. My perspective was that to be true to the context of my research, participant choice, particularly to withdraw from the project, should remain an option throughout.

Research has shown that people value the opportunity to make choices concerning their individual care (Harding et al. 2014; Dixon et al. 2010). There is less research to indicate what people think about opportunities to contribute to NHS choice-making on a strategic level. The expressed purpose of the NHS strategic participation agenda is to seek the views of the healthcare-using public (DoH, 2007). This premise anticipates that, by involving people in aspects of public healthcare decision-making, it will be possible to arrive at collective, democratic conclusions that all participants will be prepared to accept. Current affairs in both the UK and in the world in general in 2017 have shown that the resources the public might use to inform their individual decisions are many and

various and frequently different from those used by people in the positions of power or authority.

Coulter et al.(1999) identified that people are inclined to choose differently about health-related matters dependent upon whether they are deciding for their own needs or on behalf of the community in general, which indicates that people are capable of changing their decision-making processes according to the purpose of the task in hand if they know what that purpose is. In a collective participatory process it is likely that the contributions of individuals become homogenised and so personal uniqueness is lost. Therefore, to focus on singular aspects of personhood as a short-cut to understanding them and their views is to miss the complexity of social space and our places within it.

As individuals, the CCG participants also demonstrated their capacity for agency and choice which translated into power. As evidenced by their responses to both my tasks, the organisation afforded each of them a degree of freedom to choose how to engage with the stakeholders they saw as being relevant to their decision-making. For this particular group of people, the term "agency" could be used not only in sociological terms where it relates to self-efficacy and empowerment but also in economic terms. Paul Healy of the NHS Confederation defines economic agency as:

"a relationship in which health professionals act as agents for patients and mostly decide on their behalf what health services they need. A perfect agent is assumed to make choices that a principal – the patient – would make if they had the same information and professional knowledge" (Healy 2016).

In terms of their expressions of agency the CCG participants clearly showed that they were operating according to both definitions. They exercised their personal agency through making informed choices using the resources available around them. I used each participant's influence map as illustrative of this as each was very different, and this degree of latitude was interesting because it evidenced how the participants created a sense of direction and meaning for themselves from a wide range of facts and opinions. The degrees of salience which they attributed to the influence of these resources showed how they rationalised conflicts of interest and how information was sourced from both knowing and unknowing contributors, from Mums to the media. Informal conversations with a

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wide range of people were included in the maps as well as information supplied by stakeholders during formal views-seeking activities.

Instances of economic interpretation of agency were apparent where the need to be effective in their job and to meet deadlines precluded the opportunity for more inclusive general participation. Whilst no one who contributed to my study suggested that public participation was unnecessary or unwelcome, they did acknowledge that it was a fact of working life that sometimes decisions had to be made on behalf of the general public rather than in collaboration with them. In these circumstances validation was gained internally using the inherent knowledge and expertise within the CCG. There was a degree of pragmatism and functionality revealed where both social and economic agency were in play. Naomi for example, differentiated positions of influence according to how "useful" that particular stakeholder was likely to be for the specific task in hand and there was recognition that certain influencers were called upon as "the usual suspects" who could be relied upon to concur with decisions made. In addition to the comprehensive public consultations such as the CSR, more routinely, the CCG processes are designed to incorporate formal public and patient feedback through the patient representative roles and several contributors included these in their influence map.

The system therefore creates its own "insider" expert public who can be relied upon to perform their responsibilities appropriately thereby achieving Bourdieu's (1986, p.180) recognised requirement that agents should be able to enact their role according to the "space of the game" without "arousing surprise or disappointment". Although this makes perfect sense organisationally it is not transparent to the wider general public who are not exposed to the workings of the organisation. If access to the decision-making arena is controlled by those who create the space then to be rendered "seldom heard" (DoH 2007) institutionalises an absence of opportunity to exercise agency and therefore power. The complex social processes which describe how individuals identify communities where they feel they can belong have been shown to be important to the maintenance of civic participation. In my earlier discussion of insiderness, which used Rawles and Davis' (2006) contrasting concept of "otherness" to demonstrate the impact of not belonging, I explored the role of power in the control of social space. Theories on power behaviour suggest that power can be

established and then maintained by controlling the social arena. The powerful can exert influence over others by explicitly determining the activities that can take place or more implicitly through the manipulation of instinctual social behaviours (Cialdini 2001; Khaneman 2011). The ways in which these rules of behaviour operate Bourdieu defined as Doxa (1991, p.66). Harrits (2006) suggests that, dependent upon one's social resources expressed through the notion of Capital and the rules of the game as expressed through Doxa, consequences are perceived differently. It was clear from the influence maps created by the participants with ACD that they thought the power to influence the CCG decision-makers lay with NHS professionals and others of a similar status. The fact that only two participants additionally included patients and the public to their map of influencers indicates to me that it was not a routine belief amongst the group that they should belong there. The responses of the CCG participants, whilst identifying the public and patients as central, all also described the benefit of working with those who already knew the way things were done.

One way of becoming an "insider" is to have the relevant rules explained and to be supported to practice them so that you become able to belong to the group (Lave and Wenger 1991). The concepts Communities of Practice and of Legitimated Peripheral Participation describe how individuals can be supported to acquire the necessary knowledge and skills to achieve effective membership of a group. This approach requires the learner to be situated in the learning experience – to belong to the community whilst acquiring the knowledge and skills of the community. In everyday life these community apprenticeships form naturally through the presence of common interest or shared values but equally the same process applies where mutual bonds have to be consciously created and relationships of trust developed. The consequence of this is that the process of becoming a member of a group is socially nurtured rather than intellectually imposed. Hanks in his introduction to Lave and Wenger's book put it this way

 'Rather than asking what kind of cognitive processes and conceptual structures are involved, they ask what kinds of social engagements provide the proper context for learning to take place' (1991, p.14).

To achieve a socially motivated forum for the development of participatory skills the purpose and processes of the activities need to be clear. The commentary provided by Fran during her influence map creation clearly illustrated for me the

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complexity and opaqueness of the PPI processes within the CCG. It emphasised for me the potential for "otherness" to exist. Fran outlined a number of different planning stages which might require the public view. From December 2016 to February 2017 the CCG's CSR proposals were open for public consultation. Consultation in this instance means that the public are being asked to comment on a proposed plan of action, the origin of which was based on information from a period of engagement activity instigated two years ago. During our meeting Fran explained that, generally, the views which are collected from the local public participatory activities are considered alongside information which is gleaned more widely from a range of sources such as national guidance, web-based feedback platforms such as NHS Choices or Healthwatch, and governmental directives with final conclusions ultimately being drawn together at some later date. This whole process is described in the Engagement Cycle (DoH 2009) which can be up to four or five years in the turning and Fran acknowledged that it was difficult for the public to understand how it worked or to feel any sense of how their contributions connected with the final outcomes.

In a recent presentation on the role of Healthwatch, Martin and Carter (2016) also identified a discrepancy in interpretation of "consultation" between the CCG and the public which led to disappointment from those who wanted more meaningful participation. Informal verbal feedback to me has indicated that the apparent lack of options in the Dorset CCG CSR consultation document has led many people to presume that the decision has already been made regardless of what the community think or might want to contribute during the consultation period.

I originally embarked upon my research topic because I felt passionately that valuable knowledge and experience was being lost to the NHS as people with ACD were not supported to contribute. In this regard I was not proved wrong as all who participated confirmed my view that the existing CCG engagement structures did not support the participation of people with ACD. I had also presumed that the participants with ACD would hold as particularly significant to themselves the fact that they had a communication disability. A salutary finding has been that I was not correct in this assumption. Although the challenges which the communication disability undoubtedly presented were not dismissed or underplayed, no one identified their disability per se as a reason not to engage. I realise that I had adopted a professional viewpoint when making this assumption

and regarded that the aspect of a person's disability which was most salient to me as a Speech and Language Therapist would be mirrored by my participants. I had made sense of their situation from my perspective, not theirs, and had demonstrated my paternalistic roots.

If my mistaken assumptions are held by others in the NHS, which life experience leads me to believe might be the case, then people's power is being taken away from them through a failure to allow them to define themselves. The consequence of this state of affairs is that opportunities to share views are being lost. How frustrating must it be to have meaningful things to say and no meaningful opportunity offered to have them heard.

A recent Public Health England research workshop about empowered and connected communities highlighted the need for more enabling systems. It was recognised by Public Health England that the greatest barrier to participation in health decision-making was not the people but the system. It was suggested that the NHS culture and systems inherently value professional knowledge and expertise over and above that of other types of knowledge and expertise. However, if all knowledge is seen as practical wisdom through the use of which all of us make sense of our own experiences, then those who are defined as "lay-people" from the perspective of professionalism become the experts in their own lives and selves. Socially-derived knowledge according to Schutz (1964) enables us to accord value to that knowledge flexibly according to the situation. In one circumstance we may be the expert, in another just the man in the street. People's confidence to engage would be enhanced if they were made to feel more connected with and valued by the decision-making processes.

5.4   Meaningful participatory relationships

Figure 5.1 identified the consequence of achieving better sense-making, inclusionary practice and enabling structures as being the creation of meaningful participatory relationships. My final conclusions are that better, more socially constructed communication of the process and purpose of engagement together with more opportunities for people to experience the principles in practice could result in people, *all people*, feeling that they belong in participatory circles.

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To feel included people need to be able build and express social networks which enable trustful relationships to be developed. My study findings suggest that, although there are people with ACD living in Dorset who would want to contribute to CCG decision-making processes, the ability of the people who are working as commissioners in Dorset CCG to be inclusive is limited. This is despite legislation requiring equality of access (e.g. Equality Act 2010, NHS England 2015). Systems and structures, both formal and informal, remain rife with challenges to the achievement and maintenance of the necessary relationships. The outcome of this is that decision-making is achieved through the use of familiar sources of information which enable deadlines to be met. Whilst I am able to recognise the unrelenting demands on time and resources which operate within the NHS in both the commissioning and providing of services but I personally cannot reconcile the acceptance of pragmatic short-cuts with the promise of open, inclusive and transparent decision-making.

In my view it is the pressure of process which renders some citizens more reachable than others. As I have already commented, the people with ACD who participated in the study were all able to understand the nature of the questions and to respond with cogent and illuminating answers. In my ethics submission I argued that my professional role as a speech and language therapist would enable me to support these participants to participate in the research. In reality, what it took to engage these people in conversation was time and the willingness to listen, neither being attributes exclusive to my profession.

Through my thesis I have developed my appreciation of the gap which exists between the political ambition to have an engaged and active citizenry who embrace their right to participate and take responsibility for decisions taken and the reality of the actual participatory culture. Here in Dorset any steps which may have been taken by the CCG to make the experience of participation more inclusive were not mentioned by my participants with ACD. The relationship between the CCG and this particular group of citizens was one which was determined by the professional perspective which seemed to me to preserve the medical diagnosis of those with ACD rather than their individuality. In no way did these participants appear to consider themselves defined by their disability. They are not any more hard to reach or vulnerable than the next person. They go to

work, pursue hobbies, enjoy time with friends and family and generally get on with their lives. They are just people

It is becoming clear that there is a synergy that I have previously overlooked between the principles of humanisation which I explored in relation to my own narrative and the significant themes I have identified as arising from my analysis of findings. In my narrative I explored how my meeting with Oliver Letwin was the catalyst to my use of the dimensions of humanisation (Todres et al. 2009). Mr Letwin's management of the conversation which took place when we met exposed me to the enormous impact which de-humanising behaviours can have. In that situation I was unable to establish any sense of shared ownership of the conversation space or the topic, even though the "topic" was ostensibly mine to control. Mr Letwin's behaviour left me with the view that any future visits to his constituency surgeries would be a waste of time. Through drawing parallels with the sentiments expressed by the participants with ACD in relation to their views about NHS participation, I can see that some had had similarly de-humanising experiences. The fundamental mistake which led, in most cases, to encounters which were less than humanising experiences, was that of assumption of shared meaning or purpose. In the normal course of participatory events, in my experience, little time is given to establishing what the attendees bring to the process while much time is spent informing participants of what they are there to do. The choice of an ethnomethodologically informed approach highlighted the importance of recognising what each individual brings to any situation and how the context and the environment can enable or disable the successful sharing of views.

What the participants with ACD showed me was that, contrary to the professional assumption that ACD is a barrier to participation, they do not define themselves as people with ACD but as **people** who happen to live with an acquired communication disability. They were therefore expecting to be able to participate and contribute. The conclusions of the participants with ACD are consistent with generally held beliefs about the power of the public to shape change. This brings me back, full circle, to my reasons for embarking on this D.Prof. What I had shown in my Dorset Stroke Network project in 2010 was that any person, appropriately enabled, can use their experiences to inform and enrich the NHS planning process. My focus on influence has revealed that evidence of the

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impact of influence is an important aspect in the creation of a meaningful participatory relationship. If people believe that the knowledge and experience they have is of equivalent value and as capable of influence as that of the professionals then a more fruitful dialogue may be possible. The motivation to embark upon this study was drawn from my observation of civic participation in practice and I have been able to confirm my initial instincts through the process of learning. In pursuing the research aims I have come to better understand the social mechanisms which power the processes of participation. I recognise that my initial assumptions represented an overly simplistic and superficial assessment of the participatory environment which reflected my professional enculturation within the NHS. My personal development has informed my approach to consideration of the contribution I might make through my practice development. I do believe that my research outcomes could be taken forward to impact on the ways in which people in general are able to meaningfully participate in healthcare planning. These beliefs will be expanded in the Practice Development chapter.

In the final section of this discussion chapter I reflect on how my choice of methodological approach has contributed to achieving my research aims and what it might offer to the development of the participatory culture in the NHS.

5.5 Ethnomethodological ethnographic analysis and its relevance to my research

Ethnomethodological ethnography is a qualitative research approach which has not been regularly used in healthcare-related research. This has presented me with both challenge and opportunity. I will use this section of my discussion to share my thoughts on the process.

As was explored in my methodology chapter, ethnomethodology has been a relatively obscure route to follow in the pursuit of understanding human social behaviour. However, in the new NHS culture of personalisation and individualisation, I have come to believe that it is an approach which offers recognition of the uniqueness of people's experience and knowledge of the world and, in this regard, Ethnomethodology's concept of "unique adequacy" is one which I believe has much to offer towards the understanding of how people use

their skills in civic participation contexts. A central precept of ethnomethodology is to discover the orderliness of ordinary activities as accomplished by social actors. This orderliness of our social interactions is created by each of us using our own unique and particular set of experiences and understandings, what Garfinkel called "member's methods", it is these methods which will colour and texture all of our day-to-day exchanges

I initially chose an ethnomethodological approach instinctively because it spoke to my fascination for rules. Through my research I wanted to draw attention to these underlying methods and explore how people might bring them to bear in tasks involving the evaluation of the participatory influence of both themselves and others. The everyday assumptions that we all make about how, when and where we engage with the social world are not usually evident to others around us but they have an impact on how we act and react. Having some insight into the methods my participants are using to inform their decisions may contribute to a better understanding of how civic participation works. If each person constructs orderliness using their own individual brand of commonsense knowledge about social order and it is a process which is unreflectively taken-for-granted, can we do participation better by explicitly sharing our assumptions? The better we understand each other the more likely we are to respect the other's viewpoint.

5.5.1 Challenge and opportunity

Discovering hidden methods without making each person conscious of the process requires purpose on the part of the researcher which is not apparent to the participants - a fact which has a certain irony to it. The tasks the participants completed supplied both tangible products and associated conversational insights into how they were approaching the decision-making that the tasks required. It is not considered to be a pure application of ethnomethodology if the data has been derived from participant reflection rather than action. This caused me some concern regarding the validity of any findings but my worries were at least partially allayed by Garrett and Anderson's assertion (2016) that ethnomethodology can be what you want it to be and do what you want it to do. My challenge was to have the confidence to try and use the approach in my

particular research design. My opportunity was that if I found the confidence to do so, I would be doing something new.

In the event, I found that I was not quite tough enough to bluff it out with "pure" ethnomethodology and, with advice from Dr Alex Dennis (personal communication 2016), modified my focus to adopt an ethnomethodological ethnographic perspective for the analysis of findings. The analysis framework which ethnomethodological ethnographic approach supplied, enabled me to take a reflective structured evaluation of both the concrete product and the conversation. It created a space where equal value could be placed on the way in which each of the participants used their resources to create meaning. I found that this retained the strength of focus I wanted in the acknowledgement of the individual and preserved the importance of uniqueness in the exploration of a collective process.

In order to remain true to my focus on uniqueness and individuality I had to overcome the temptation to summarise or re-word the narratives of the participants during the analysis. Whilst of course there was an element of processing which was in my control, the discipline which the ethnomethodological ethnographic framework imposed ensured that I took care not to overlay my own personal filter on the information I had. My purpose was to understand as best I could what each participant was offering from their own stock of knowledge about the world. As a result of using this approach I have come to acknowledge how easy it can be to mould what other people say in order that it may fit with one's own views. This inclination is particularly strong, in my opinion, where the information a person has given is held by the receiver beyond the immediate moment of it being imparted.

5.5.2   Fragility of meaning

I have become very aware that one's views are very fragile and vulnerable when detached from the direct interaction which generated them. They become hard to defend from misinterpretation. Indeed, I may well have committed this crime myself by assigning ethnomethodological purpose to the participants' contributions but I by turn have also been changed by my exposure to the views shared by the participants. I am much more sensitive to the presence of another

person's "back story", for want of a better phrase, and much more aware of the power of each individual's "methods" in determining their responses to situations. What is important to a person is not what someone else would assume is important for them. What is said is only the tip of the iceberg, the methods are the two thirds which remain below the water and can sink you.

The maps created by the participants with ACD clearly demonstrated that they saw many other people as being in possession of the power to influence, people who were not the same as them and not known to have the same complement of methods. The CCG participants' influence maps demonstrated that even where an organisational system was in place, between themselves they did not use the same approaches to evaluate the data they collected and so their interpretations of views of the public were dependent upon personal as much as organisational filters.

The ongoing CSR being undertaken by Dorset CCG is actively inviting the residents of the county to have their say on how services should be organised and to bring their own personal experience to bear. This suggests that the CCG sees value in capturing the individual public contributions and that there should be room to recognise individual difference. However, the participatory mechanisms which exist within the CCG working groups cannot physically include all members of the public who may wish to join. Currently, logistics and culture determine that one-to-one, in-depth interviews cannot be the method through which all public feedback is gathered. Despite best intentions, the civic participatory system as offered to the public by NHS strategic engagement exercises is not equipped to enable voices to be preserved individually. The systems that process the information which is collected through questionnaire or feedback form or recorded from public meetings cannot maintain the differentiation of purpose with which the contribution was made and therefore it becomes exposed to interpretation through the methods of the recipient, not the sender.

5.6   Things I could have done differently

One of the benefits of looking back to see where you have come from is the opportunity to see where things could have been done differently. My hindsight

with regard to my methodological choices provides me with the following revelations.

The value of ignorance is that it has no boundaries

I decided upon ethnomethodology because it felt right and not because I knew what it could do. This instinct has served me well but has also necessitated some clumsy wrangling with methods. Although this discovery process has taught me to look harder and see more, I have found it hard to reconcile with the pressure to produce something academically acceptable. If I was to repeat my study I would still choose to use an ethnomethodological approach but I would design my research interventions to be better suited to it. I have learned to see where boundaries might be valuable.

As a lone-practitioner I made things up as I went along

Fortuitously, I chose a methodology which has transpired to be sufficiently flexible to allow what might charitably be termed "creativity". While I remain a firm believer in the power of not having a fully worked-up plan, I can see that this approach has its drawbacks. I know why I have done what I have done and I believe that I can defend the organic nature of my approach.

If I had known then what I know now

I may not have undertaken this study at all but I am glad that I did. What I have learned has opened my eyes to an element of social behaviour that I believe is worthy of investigation.

The participatory environment as experienced by the participants, both those who work in the NHS as commissioners and those who have used the stroke care services as patients, and as viewed from the perspective of my particular investigatory angle is one which accommodates the notion of influence.

Both groups of participants indicated that a relationship which enabled influence was desirable but acknowledged that the current processes did not support the effective contribution of people with ACD. My findings suggest that more work needs to be done to establish effective relationships between people with ACD and the CCG so that opportunities to contribute can be meaningfully taken up. How this relationship might be developed to embrace a sense of shared purpose

and meaning could be informed by taking an ethnomethodological approach. Now I have a better understanding of the processes I think that a better designed and executed study would be able to illuminate more detail and provide more insights.

Chapter 6 Practice Development.

"What I hear I forget, what I see I remember, what I do I understand" (Chinese proverb)

6.1   Introduction

The map I introduced at the beginning of the discussion chapter (Figure 5.1) identified the emergent themes from the findings. The conclusion I reached through the analysis and discussion was that more work was necessary in order to develop a more meaningful participatory relationship between people with ACD and the CCG in Dorset. The next step is to explore how this new knowledge might be used to inform the development of better participatory practice.

In this chapter I establish the background to the concept of Practice Development and then examine how I have interpreted the concept in the context of my own professional practice and area of clinical interest. Finally, I will identify what steps might next be taken in pursuit of further academic investigation into civic participatory activity in the NHS.

6.2   Background to practice development

McSherry and Warr (2006) identify the origins of the concept of practice development in the NHS as being in the 1970's, stemming from a period when nursing roles and responsibilities were beginning to change. In exploring the evolution of practice development they go on to emphasise the bottom up, experientially driven processes which are necessary to the achievement of practice change. Proponents of practice development have drawn on the framework offered by Habermas (1972) whose Critical Social Theory provided a philosophical structure within which customs and practices could be interrogated and collectively accomplished change incorporated. The emergence of an appreciation of difference between research-based knowledge driven by pure academic pursuits has opened up the potential for the alignment of workplace and research activity (Carr et al. 2010) such that the ambitions of practice development can be realised.

In order to create an environment where change can happen, existing assumptions and beliefs must be recognised and become open to challenge (McCormack et al. 2002). Organisationally within the NHS, the wider context for practice development has been fostered by the NHS modernisation agenda (DoH 1998). This requires the constant application of quality improvements which draw on an evidence base which in turn has been generated through both academic and clinical enquiry. The active interface between developing knowledge and practice is complex and subject to a number of influences (Kitson et al. 1998; McCormack et al. 1999, 2002) and the barriers to change are acknowledged as considerable (NICE 2007). Consequentially the impact of practice development activity can be inconsistent. It has been acknowledged that the achievement of practice change through the process of D.Prof study is in part determined by the social and cultural environment of the organisation within which the study is situated (Weller et al. 2011). Research by Michie et al. (2005) identified twelve theoretical behaviour change domains as having relevance to the successful implementation of a practice development initiative. Their paper endorses the complexity of process which has been borne out by experience. Although I am mindful that ultimately the conclusions of my research will require the involvement of many others to achieve any change in practice, I am grateful that my first focus is on how the Doctorate of Professional Practice experience has changed me.

As one of the four core elements of the Doctor of Professional Practice degree, Practice Development serves to demonstrate the translation of academic learning into the practical real-world environment. They should be "permeated by what may be called the triple helix of practice, theory and research" (McKenna 1997 in Carr et al 2010). In my personal narrative I made use of the words of Gregory (1997) to define the purpose of the D.Prof. Gregory's emphasis on the scholarly seemed fitting as I began my learning journey. However, in her article on the Professional Doctorate, Fenge (2009, p.169) emphasised the importance of enabling practice-based professionals to find their "enterprising self". I can now identify with this description which speaks to me of the outward-looking, boundary-busting impact of developing as a researching professional (Fenge 2009). The skills of the researcher are becoming valuable when transported into the workplace. In my view therefore, an important aspect of developing practice

within my profession is that I should champion the cause of the "enterprising self" by showing how work and research can develop together. My developing identity as both a "scholarly professional" (Gregory 1997, p.19) and an "enterprising self" (Tennant 2004 cited in Fenge 2009, p.169) has materialised from a myriad of personally held ideas, ambitions and beliefs. I feel that I have possession of the "fresh lens" which Fulton et al. (2012, p.134) refer to as a product of a successful D.Prof journey. In this chapter I will identify the areas where my learning is beginning to translate into my real working-world environment and explore what this means to both me and my work.

6.3 Developing my own practice

6.3.1 Different ways of knowing

First and foremost, the practice I have developed as a result of undertaking this D. Prof is my own and I feel a strong sense of ownership of my achievement. Mezirow (1997, p.5) suggested that the process of learning should be transformative, that the learner's "frame of reference" should change. The transformative effects of learning impact upon the behavioural, cognitive and emotional self of the student (Fredricks et al. 2004; Bolton 2014; Molnar and Baergen 2016) and as a consequence of learning the learner develops different ways of knowing. Fundamental to the transformational process is the requirement to change perspective and create new meanings (Dirkx 1998) and this links directly to the work of McCormack et al. (1999; 2002) referenced earlier. I have changed my ways of knowing by becoming more aware of and open to the impact of individual sense-making procedures. The recognition of the influence of taken-for-granted knowledge on professional perception has delivered a salutary lesson. I thank my participants for enabling me to achieve these insights.

There are two academic schools of thought regarding the mechanisms of transformational learning change, Mezirow (2000) regards critical reflection as central to achieving transformational change whilst Dirkx emphasises the importance of emotion and intuition (2001). As I have explored in my personal narrative, I have used all three aspects, critical reflection, emotion and intuition as I have embraced the activity known as learning, a realisation which accords with Taylor's (2000) conclusions in his review of research related to Mezirow's work.

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The process of personal deconstruction which has taken place in order to allow new learning to take place has been destabilising and at times uncomfortable. Reassuringly, Mezirow's theory (1991) identifies these aspects as being part of a ten-stage transformative learning journey. Using his terms, I feel that I am now at step eight and about to embark upon provisionally trying out a new role.

Mazirow's Stages of Transformational Learning (2000, p.22)

- A disorienting dilemma

- A self-examination with feelings of guilt or shame

- A critical assessment of epistemic, socio-cultural, or psychic assumptions

- Recognition that one's discontent and the process of transformation are shared and that others have negotiated a similar change

- Exploration of options for new roles, relationships, and actions

- Planning a course of action

- Acquisition of knowledge and skills for implementing one's plan

- Provisional trying of new roles

- Building of competence and self-confidence in new roles and relationships

- A reintegration into one's life on the basis of conditions dictated by one's perspective.

Mezirow asserts that adult learners possess the ability to use critical reflection and apply the results of their reflections to autonomously adapt and change their habituated frames of reference. By doing so they can create new ways of knowing or new meanings and this capacity for reflexivity speaks directly to my discovery of ethnomethodology. Lynch (2000) held that, ethnomethodologically, the concept of reflexivity was an ordinary, unremarkable and unavoidable feature of action. The way in which methods inform action and action informs methods is central. The structure which ethnomethodology has given to my developing thought processes, the way in which it has framed my openness to and active engagement with challenge regarding my normal taken-for-granted assumptions

about what public participation in strategic healthcare planning is for, has undoubtedly changed my understanding about both myself and about the participatory environment created by Dorset CCG.

6.3.2 Self-centre

Through the process of investigating the conclusions arising from the achievement of my research aims I now recognise how central my own constructs have been to the focussing of my interests. From the outset I used personal observation and experience to frame the purpose of my investigations about the experiences of others. Whilst this is probably not an unusual route into academic enquiry, I can see that arguably, by taking direction from my own viewpoint, I committed the sin of perpetuating the paternalistic approach of my workplace culture. I was liberating the individual experiences of my participants as framed by my own perspectives rather than by theirs.

However, as an entry point to discovery, my personal discontent with the process of participation served as a satisfactory catalyst. The transformational outcome of this particular aspect of my learning is that now, if I were to do my research again, I would not do it in the same way. I believe it has been a key learning experience to recognise how wrong many things I did were. This reflection does not consign my current efforts to the rubbish bin, as the value of all experience is in the contribution it makes to progress; failure can breed success. The evidence of learning will be not to repeat the same mistakes again in the future.

Part of my reflection on this conclusion has been to acknowledge that the andragogological aspect of the BU Professional Doctorate which I so valued in my personal narrative has, in fact, also provided me with opportunity to escape any sustained challenge to my viewpoint. Confirmation bias or the psychological capacity of people to adapt experience to fit with existing ideas of self-worth and create a set of self-affirming beliefs in order to protect against perceptions of failure is well known (Sherman and Cohen 2002). Addressing absent, difficult or destabilising areas of knowledge requires a degree of commitment to purpose which a busy life can tempt one to avoid. Were it not for my long-suffering supervisors I fear I would have overlooked many of the ripples which my academic progress has created. By recognising how inhibiting it is to perpetuate

habits or leave assumptions unchallenged I have been able to see outside of my particular box.

My use of the Humanisation Framework (Todres and Galvin 2009) to capture how my view has changed has been an important aspect of my learning. The product of which, I hope, will continue to inform and influence my development as a practitioner of qualitative research. The culture of creative enquiry fostered by Bournemouth University encourages thinking "outside the boundaries" (Holloway and Todres 2007 p.18) and I firmly believe that my personal development throughout the course of my Professional Doctoral study has changed my professional practice by making me more aware of my own frames of reference. The peeling back of the layers of tacit knowledge so that familiar behaviours can be reviewed and justified has been, at times, an uncomfortable process. The benefit is that I am able to use my awareness of my own behaviours to help me communicate better with others.

6.3.3   Communicating better

During the course of last year I asked my fellow Group Supervision participants via e-mail if they would send me feedback on their experience of group supervision. I was interested to discover what was important to each of us about being part of a group. Some, but not all, of them responded with e-mail attachments. The same question asked during a supervision session prompted a much richer vein of information. Face-to-face sharing of views was much more satisfactory. Although there is research to suggest that modern, digitally mediated mechanisms of civic participation are becoming more highly favoured by the public (Zukin et al. 2006, Zani and Barrett 2012), recent work by Hughes and Pollard (2014) indicates that face-to-face deliberation can have a powerful influence on the outcomes of decision-making. They believe that deliberation can enable people to achieve the jump from participation to engagement and from self-interest to citizenship.

The fact that face-to-face encounters engender the creation of more meaningful relationships was also evident in my research, as personal contact with potential participants promoted a better response to my invitation to participate than did an approach by letter. Face-to-face interactions allow individuals to embody our

social actions (Goffman 1967) and mutually produce and support the context within which the exchanges take place. Each of us strives to support the other to make sense whereas more impersonal communication relies entirely on the remote recipient deducing what the intention of the sender is. There is a Korean word "nunchi" which describes "the subtle, often unnoticed art of listening and gauging another's mood" (Sanders 2015). On a personal level I realised that the easier it has become to communicate through e-mail or text message, the less I learn about the people I am communicating with and therefore the more I am likely to apply my own frames of reference to their communication with me. Depending on the depth of relationship that I have with my correspondent this may or may not allow accurate interpretation and, without some element of feedback on the appropriateness of my interpretations, my approach may remain unchanged.

6.4 Feedback

Feedback was an action defined by my participants as critical to the participatory process because it provided evidence to them that their contribution has been recognised. The importance of feedback in the production of mutually held meanings and the maintenance of interpersonal relationships is supported by behavioural and socio-emotional research (Reis et al. 2000).

Feedback, both solicited and unsolicited, is something which I often think of giving but rarely actually do. The reasons for this are various but amongst the most significant are the beliefs that no-one would be interested, or that the moment has passed, or that it will not change anything. I know that these views are not exclusive to me alone but what I now strongly believe is that feedback is how you demonstrate that something is important. If I do not care enough to give feedback why should anything change? I should not be advising others to participate if I do not exercise my capacity to do so too. Participatory behaviour is how people co-create a society in which we all have a stake. What my research revealed was the essential importance of evidence of having been heard.

Two years ago I was asked if I would be willing to have my views on the Bournemouth University Professional Doctorate recorded for the Faculty of Health and Social Care to add to their student experience resource and I was

happy to do this but unfortunately the planned recording session did not happen. Subsequently, I did not chase the faculty and it did not chase me to rearrange the session. It has been easy to merely move on and leave that moment behind as the ever-flowing current of everyday life sweeps me forward. Evidence suggests (Ipsos Mori 2010) that I am not alone in allowing myself to be carried passively, protected by the knowledge that "I could if I wanted to", but the act of floating on ignores the whole ethos of my study.

Therefore, my practice development contribution to my faculty should be to give feedback on my experience of postgraduate study as a remotely situated, part-time student. I feel that, although the D.Prof programme model has changed and now has more structure, it is important that I offer what I know in the spirit of participation in the creation of an ever-changing academic world. In giving feedback to Bournemouth University I can offer my institution the evidence that I have been engaged by the process of studentship and I care about the future of postgraduate student experience at Bournemouth University.

6.5   Practice development with others

The Department of Health aims to foster the development of a culture of innovation and improvement which will lead to enhanced patient experience and safety (DoH 2010). A vital ingredient in practice development is that it should bring about change (McSherry and Warr 2006) and furthermore that this should be change which promotes patient-centeredness (McCormack et al. 1999). The challenge which these ambitions present is the achievement of change which all involved can agree is patient/person-centred. The requirement to instigate, evaluate and implement evidence-based, patient-centred change as a continuous process of improvement places considerable pressure on both the people and the organisations involved. The findings of the study indicate that, in situations where the reasons for change are driven by mechanisms which are not sensitive to individual experience, the public become disconnected from the process of change and some of the benefit is lost.

At the beginning of this chapter I looked at how my own practice has developed as a result of undertaking this D.Prof. Some may argue that this constitutes personal or professional development rather than practice development (Mallet et

al. 1997). I cannot agree with this viewpoint as, although I understand the principles behind such a distinction, I believe that in a successful sustainable change scenario nether aspect can happen without the other. The importance of the individual practitioner as a catalyst for practice development is not to be underestimated. Through the emergence of the "enterprising self" (Tennant 2004 cited in Fenge 2009, p.169) the impetus for practice development can be seen to come from the individual who is situated in their own practice experience. Manley and McCormack (2003, p.26) go further to suggest that sustainable change is achieved through "practitioner enlightenment, empowerment and emancipation". That being said, the isolated unconnected investment of energy and emotion by a workforce of enlightened, empowered and emancipated individuals would not necessarily lead to sustainable change. It is clear that best value from practice development is gained when all involved in it understand the reasons and share the purpose (Manley et al. 2014).

However, knowledge derived from sources other than pure research, defined in Gibbons et al. (1994) as Mode 2 knowledge, acknowledges the value of socially-robust knowledge which is seen as having been generated through practice and as having relevance to everyday life. The need for the development of a knowledge base which is rooted in and retains a relationship with practice is vital. In their paper on the role of the professional doctorate in developing professional practice Fulton et al. (2012) recognise the importance of capturing the tacit knowledge held by practitioners. They also point out the inherent difficulty in breaching professional boundaries, something which must be done if the full potential of practice-based learning is to be realised. The information gathered from D.Prof research needs to be filtered through the real world in order to validate its contribution to the complex and dynamic environment which the workplace represents (Chynoweth 2012). I have therefore sought to share what I have learned and to use my sharing conversations to extend the reach of what I have done. Through presenting my findings as feedback, which in turn has generated feedback, I have been able to refine my own relationship with my study and better understand how it offers insight into the experience of civic participation.

6.5.1 Sharing with the people in Dorset who are living with ACD.

The key points of information which I took from my findings showed that there was a mismatch between the intentions expressed by the CCG commissioners regarding the openness of the organisation to accommodating changes in service design as a result of the feedback and the understandings reached by my particular group of citizens regarding their power to change things through participating. Whilst each individual participant with ACD considered themselves to have some capacity to influence in general, in the context of NHS participation they expressed views which showed that they thought participation was not worth the effort. These assumptions have not been changed by the additional views-seeking processes which are being offered as part of the County-wide Clinical Services Review being undertaken by the CCG, 2012- ongoing. However, the comments of some participants with ACD also showed that, although the personal resources for sustaining the confidence and energy they thought would be required to effectively participate were limited, this did not mean that they did not have views to contribute or were not passionate about getting their voice heard. Understanding this led me to question whether participation could be achieved a different way.

Through the process of reflecting my research conclusions back to the participants with ACD, I discovered possible reasons which may have caused the sentiments that had been expressed. One of the comments made was that it was difficult for them to join forces and use group power to get their chosen messages across. Further exploration of this suggestion brought confirmation that people felt more powerless as individuals. Existing mechanisms such as Stroke Groups have not generally afforded attendees the opportunity to become activists, and perhaps it is right that such groups should not serve that purpose. However, it is a fact that, for many, the Stroke Groups represent the only forum available to them for the collective sharing of views. Of particular note in this regard were those individuals who were not living independently, either alone or with a spouse. This group of people, who were largely reliant on paid others to mediate their access to participatory activity outside their place of residence, appeared particularly disadvantaged in terms of being able to realise their right to engage in any social or civic participation.

In an analysis of social capital in the UK it was identified that an essential ingredient for the development of social capital was the ability to connect (Seigler 2015). The report showed that in 2011/12 eleven percent of the UK population reported themselves as "feeling lonely all, most or more than half of the time" (Seigler 2015, p.2). It went on to emphasise the importance of social networks in enabling people to feel connected with society. The feedback I had been given about the desirability of becoming a group in order to have a stronger voice caused me to reflect on the potential for change within the context of the NHS participatory arena. In the conclusion to my discussion I suggested that one outcome of my research might be to contribute to change in the CCG's participation structures. However, I had overlooked the potential for a change of approach by future participants. Once again I had forgotten to maintain openness to alternative options.

Further consideration of how people could use their available resources to achieve goals led me to Asset Based Community Development (ABCD). ABCD is an approach that was originally created in the 1990's in the USA (Kretzmann and McKnight 1993) and was developed in response to an acknowledgement that the more familiar needs-driven organisational approaches to perceived social problems were not producing satisfactory or sustainable outcomes. The concepts and approaches devised in the USA were used in the UK prior to the recent focus on citizen-based solutions but their relevance has been accentuated in the last five years, partly as a result of the Marmot Review findings regarding health inequality (2010). The recognition of the importance of facilitating the use of individual resources and assets to create and sustain communities which then in turn serves to improve the general health and wellbeing of that same community was further highlighted in a recent Health Foundation Report (Hopkins and Rippon 2015). In addition, the more individuals have a sense of belonging to a community the more likely they are to participate (Wandersman and Florin 2000). The ABCD approach offers a method through which the resources of a community can be identified, recognised and connected. It embraces the concept of co-production and places a locus of control with the members of the community themselves, an outcome which sits very comfortably with the political desire to democratise healthcare decision-making.

I shared my discovery of the ABCD approach with some of those with ACD who had participated in my thesis research and they too felt that it merited further investigation. They saw it as a process which could offer an appropriate structured approach to capturing what assets they and others like them have for increasing participation in social activity. Further exploration of this model with both the Stroke Association and more widely with people with ACD confirmed its potential as a mechanism through which opportunities could be identified, and a project to "asset map" the human and environmental resources available to people with ACD in Dorset using ABCD was developed. These discussions have led to the development of a project proposal with the aim of using an ABCD approach. The ambition of the project is firstly to find out what social assets people in Dorset who are living with ACD use to keep connected to social and civic participatory activities, and secondly to explore whether their knowledge and networks can be built upon to support others to do the same. Conversations are ongoing with the Stroke Association who may be willing to support the proposal.

6.5.2 Sharing with participants from the CCG

In 2005 INVOLVE made the following statement:

"participatory practice has emerged from many disciplines and in many sectors, often quite separate from each other, and the lack of effective communication across these interests has limited the opportunities for shared learning and the effective development of theory and practice" (INVOLVE 2005, p.5)

It has been clear from the review of literature in chapter two that there is no shortage of information and advice, produced both before and since the INVOLVE report, about creating a participatory environment in the NHS. All those responsible for achieving the desired environment recognise the challenge of creating and sustaining it. It is my belief that there is still a considerable gap between the doing and the learning and sharing. The evidence I gathered from the CCG participants showed, in a small way, how the individual unshared development of practice might lead to a proliferation of different approaches. Clearly, the pressure to create a participatory culture in NHS commissioning does engender a shared sense of purpose but the participants with ACD show that there is no shared sense of meaning for them.

As with the participants with ACD I reported my findings back to the CCG participants but this time on an individual basis. Their availability for collective, post-feedback discussion has been limited because the CCG is currently in full consultation mode over the CSR proposals. However, they may feel that they have more time available for a meeting once the consultation closes in February 2017. My primary desire is to be able to engage with them in some reflective discussion about the findings in order to explore what they think the messages are. From my perspective, I believe it will be valuable to share with the CCG the fact that the participants with ACD did not consider themselves "hard to reach" but they did think that they were "seldom heard". Their personal experience of the situations where these terms may be applied informs the semantics underpinning their use. If usage is perceived to be more related to organisational targets and less to actual human experience then it is possible that unintentional barriers are created. Further investigation of this specific insight would contribute to an understanding of how public participation in CCG healthcare planning could be made more inclusive. It would be interesting to discover how much flexibility there is within the CCG participatory structure to allow for different approaches to be adopted. I would particularly like to hear their views on the potential for an ABCD approach to facilitate the participation of groups of people, such as those with ACD, who are perceived as being hard to reach

In addition, and particularly in the light of my new knowledge on the formal patient representative role within the CCG, I would also like to gain more understanding of how the representational function works from the current incumbent's perspectives. Further research on how relationships can be developed between those formal representative roles and the general public might enhance this aspect of the participatory structure. This, together with more information on how Healthwatch can support people in voicing their views, could be shared with the stroke survivor community and contribute to the creation of a better connected system. The fact addressed in the discussion chapter (chapter 5), that the POPP's groups were not widely known about yet research in 2007 identified that Dorset had established eighteen forums for the over fifty-fives and had secured funding to enable "capacity building" (Wistow and Davey 2011, p.36), suggests that there is still work to do. Ongoing dialogue might serve to

raise awareness within both the CCG and the community of what is available and what is still needed to support participation.

6.5.3 Sharing with colleagues, clinical and academic

The advancement of a "knowledge economy" (Bourner et al. 2001, p.74) within the NHS is being driven by the need to deliver an evidence-based, patient-centred transformation of the service. Being free to be "enterprising" (Tennant 2004 cited in Fenge 2009, p169) should mean that professionals can use their individual experiences in the workplace to inspire investigation, analysis and change. Speech and Language Therapists, like many clinicians, have a seemingly boundless capacity for problem-solving. This practical experience is not necessarily well-suited to standard medical-model clinical trials and in the past evidence has been found to support this (Pring 2004), however it might amply be encompassed by Fulton et al.'s suggestion that this Mode 2 knowledge is the essence of a D.Prof. In my opinion, the value of undertaking a more qualitative, real-world embedded route for postgraduate study in Speech and Language Therapy (SLT) is significant. Embracing my desire to evangelise on the benefits of a D.Prof, I have shared both my postgraduate student experiences and my research outcomes with my SLT colleagues locally through informal discussion and more widely through presentation at a Royal College of Speech and Language Therapists (RCSLT) Research Network meeting. I have also been contacted by other SLT's and asked for my views on the Professional Doctorate as a vehicle for doctoral level study.

Finally, I have used the knowledge I have gained about the practice of public participation in my involvement with the Public and Patient Engagement (PPE) work stream of the Stroke Vanguard (NHS England 2015) programme in Dorset. This work has been particularly enlightening as it has been the intention of the work stream managers to enable the public, including those with ACD, to contribute to the decision-making regarding how stroke care services should be delivered in Dorset (Dorset CCG 2017). In particular, plans were made to enable people with ACD to give their views through one-to-one meetings if they felt they could not do so at the public events. Seven people asked for one-to-one meetings but as yet none have taken place. In reality, the agenda and timescale

for the conclusion of the public engagement activity has been such that the views of those with ACD are unlikely to be included in the final decision. I have included this example in my Practice Development chapter because it illuminated for me the scale of the challenge for change. As in my study, both professionals and public were motivated to engage in the decision-making but success was undermined by the process. I believe that this is an example of how challenging making a patient-centred change can be and serves to highlight how important it is that more work is done in this area.

6.6   What, so what and now what?

I began this chapter with an overview of practice development in terms of its philosophy and origins as an academic activity. However, the whole raison d'etre of practice development is that it should, in some way, develop practice. Driscoll (2007) has suggested that three stem questions, based on those developed by Bolton (1970), namely "What?", "So What?" and "Now What?" should stimulate reflection in a learning cycle. The questions require the practitioner to make critical assessment of the inputs (what?) and outputs (so what?) of their learning. This then informs what happens next (now what?). I have used these questions as "thinking triggers" to help me clarify the practical points of contact between knowledge and practice which my research has supplied.

In the body of this chapter I have described the areas of post-research activity which I initiated as a result of the analysis of findings and discussion. Some of these activities, such as giving feedback on my research, represented simple responses which, whilst satisfying the question So What? (did I do), do not interrogate at the level of "so what?" as in "why should anyone care?" Consideration of what the answer to this second challenge might be requires a level of critical honesty which is hard to achieve.

In any research endeavour there must be belief on the part of the researcher, that the topic of their research is worthy of attention. Sometimes this belief is generated through pursuit of a common endeavour with colleagues but in my case my research question was derived as a result of personal and professional conclusions about the experience of others. In developing my thesis I have worked hard at harmonising my professional interests and my developing skill as

a researcher but what I have yet to prove is how this development has projected outwards to make contribution to the world of civic participatory behaviour. The importance of practice-based research is that it should grow from and feed back into working life. The power which academically motivated enquiry has to stimulate and sustain best practice is derived from it being on the edge rather than in the complacent middle. Building a body of knowledge from the edge inwards requires the confidence to speak out and share what you know and think.

The feedback I provided to the participants has informed them of the outcomes of the research. Their responses have demonstrated that, although they had interest in the findings, they had little expectation that anything further would happen. The everyday pressures which demand attention leave little capacity for the taking up of causes. As some of the participants with ACD remarked, sometimes it is a triumph just to have got up and dressed. For both groups of participants in this study the impetus to create change is hard to sustain and I recognise that the "so what-ness" factor must be dependent upon many, often unpredictable, variables. However, the start of any process of behaviour change begins with dialogue and, in part, this is what I have initiated with my discussions with the Stroke Association. These conversations have shown me how important it is to those with ACD to think that they can play an equal part in civic life should they choose to.

I recently presented some of my thesis work relating to the use of the Humanisation Framework as a reflective tool at a Bournemouth University Humanisation Conference (Slate 2017). Many of the contributors presented research which was addressing the challenge of effecting behaviour change in situations where the culture and practice of the organisation inhibited the adoption of new, more inclusive ways of working. In most cases the change agents, be they the researchers themselves or the people involved in the projects more broadly, identified that organisational responses were more likely to focus on the negative reasons "why not" rather than the permissive "why not!" The security provided by maintaining the accustomed "ways of being" is hard to relinquish. I identified this at a personal level when, in chapter one, I described how destabilising and uncomfortable it was for me to step out of familiar ways of behaving and to adjust to a new culture. What I discovered about myself was that

I could strive for change and development because I was not changing everything about me. There were strands of my personal narrative which remained constant and this stability supported the new learning. In the workplace, surely the skill of creating an environment where change and development can take place lies in allowing exactly the same process to take place for all the people who are involved. This leads me to the final stem question "Now what?" which I will answer in the next section.

6.7   Now what? Conclusions and Recommendations

Through exploration of my own practice development I have identified both the personal and the professional impact of my research. Throughout this chapter the discussion themes of sense-making and enabling structures have continued as dominant references within the discourse. Practice development is the process of making new knowledge real and in this case the signposts for practice development have been identified. I have shown how I have undertaken a variety of activities which have been determined as a result of my research and personal reflection. Although these actions have enabled me to simplistically connect my findings and discussion to some practical work-based outcomes, the challenge of "now what?" remains largely unanswered.

In my view, the significance of the findings presented in this thesis is that they reveal a facet of public behaviour in a way previously unexplored. The insight offered is a suggestion of what rich sources of information might be found if further research in the same vein was undertaken. The existing mechanisms through which the state and the citizen communicate are under challenge. My research has shown that by exploring the methods which the different groups of participants used to create their understanding of the situation in question, it is possible to begin a dialogue which can bridge any gaps.

To make a success of public and patient engagement, reaching a common ground of understanding between the consumers and providers of healthcare services will be crucial. The mechanisms which might be developed to support and sustain better connection between the public and the providers of the services the public use could benefit from a greater focus on the creation of shared meaning.

In addition, I suggest that the use of the humanisation framework as a guiding philosophy for seeking future insight into public engagement could offer a valuable structure. There is much more work to be done to examine in detail how people create their understanding of participation. I propose that the most important "now what?" will be to continue to explore the communication interface between patients, the public and the commissioning of healthcare services.

Chapter 7 Personal narrative concluding thoughts

7.1 Introduction.

The conclusion of this D.Prof marks the end of the beginning of a process of change. In the final chapter I will reprise the personal narrative framework which I adopted as my tool for reflection and offer my thoughts on where I am now as a person and a practitioner. I think, feel and believe that I have changed.

7.2 The Humanisation of me

In chapter one I opened a conversation with myself which could only take place because I was engaged in the D.Prof process. I mapped myself on to the Humanisation Framework (see Table 7.1) devised by Todres et al. (2009). I found it to be a useful way of capturing my thoughts and feelings. By returning to the same process I can document the instances of change.

Forms of Humanisation	Forms of Dehumanisation
Insiderness	Objectification
Agency	Passivity
Uniqueness	Homogenisation
Togetherness	Isolation
Sense – making	Loss of meaning
Personal journey	Loss of personal journey
Sense of Place	Dislocation
Embodiment	Reductionist body

Table 7.1:　　　**Conceptual framework of the dimensions of Humanisation.**

(Todres et al. 2009)

7.2.1 Insiderness

I have developed over the course of this D.Prof from someone who had ambition to study at postgraduate level to someone who has studied at post-graduate level. This has required me to expose and acknowledge strengths and weaknesses in myself as a person and has been a challenging process. I was initially worried about making myself *appear* academic and about *assuming* the role of a "scholarly professional" (Gregory 1997) but, as with my initial thoughts about my research topic, I was being too confined by my assumptions regarding conformity. I can identify with the sentiments expressed by Horsefall (2001, p.88) who said

"our knowings, our understandings are often multi-faceted, multi-dimensional and sometimes chaotic. And yet we are required to explain ourselves in one dimension; there is no room for the multitude of voices, thoughts, feelings that occur in the meaning-making in our bodies"

Her suggestion that the internal complexity of meaning-making is challenged by the external world's requirement for consistency and simplicity is a liberating one. It gives me a different view on insiderness and permission to interpret myself as I choose. Through acknowledging this, I feel that I know myself better and am beginning to be able to express myself as myself through my research. I recently heard someone refer to the importance of being authentic (C. Kilgore, Advanced Nurse Practitioner 19.05.2017). The philosophical complexity underlying the use of the term authentic was not addressed but the intention of the statement was to emphasise the importance of being true to one's self as a clinician and as a researcher. In seeking my own authenticity as a researching professional I have needed the reassurance of others. The process of becoming capable of sharing who I am becoming as a researcher has been long and slow and has been directly related to the development of confidence in my own credibility. The imposter syndrome which I referred to in my personal narrative is a syndrome which is insidious in its effects. It creates a lack of belief which is hard to shift when contact with other people who are in similar circumstances is limited. As I have already referred to, for me one of the consequences of part-time study has been the absence of an academic community other than my D.Prof cohort. However, the only way to realise that everyone is in the same situation is to get out there and show your stuff, warts and all. I am now more capable of accepting that who I am as a postgraduate student can only be who I am as a person.

7.2.2 Agency

In the Humanisation Framework, agency is defined as the range of choice an individual has and how that choice is realised. The relationship between actor and environment is one which I explored in relation to choice and participation in the literature review. In chapter one, section 1.2.2, I wrote about my struggle to achieve agency and of the circumstances where passivity had value. In the light of my new understanding of theories relating to structure and agency I have been able to reflect more on the way in which I have interacted with the academic environment and how this developing relationship has shaped my choices. What this has taught me is that my initial struggle with initiating a course of action was in large part due to my unfamiliarity with the academic world, its culture and its language. My lack of certainty about my competence in the new environment robbed me of the power to choose for myself. A recent supervisory discussion about the difference between capacity and ability opened a new perspective on the state I found myself in at the beginning of my studies. I argued that you could have the capacity for something but this could only be realised if the circumstances enabled you to do so. Therefore, capacity resides in the individual and ability relates to how the individual is able to use their capacity in a particular context. Using this definition, my capacity to choose has not been changed by my undertaking of this D.Prof. but my ability to make academic choices has. The benefit I have gained from understanding that I can express myself through what I do has caused me to think differently about why I choose in the way that I do. I am more confident to follow my own instincts and this changes the relationship I have with my academic self.

7.2.3 Uniqueness: what I am as an individual

In considering what I am as an individual now, I have brought to bear my new academic perspectives in addition to those I used at the beginning of this thesis. The changes which these new perspectives illuminate are not ones of substance but rather of detail. I think I knew myself well then but I know myself better now.

One on my choices, which was to use an ethnomethodological approach in my research, has contributed to my appreciation of uniqueness. The benefit of having attempted to embrace this particular methodological approach is that it has helped me to see connections between two significant influences on my thinking throughout this study. I have developed my original beliefs about how systems facilitate or inhibit the expression of individual experience through my understanding of how people make social meaning. In that ethnomethodology embraces the individual as an independent actor who may express their relationship with the social world according to their moment by moment assessment of the situation in hand, I can see that uniqueness is a flexible commodity. In section 7.2.1 of this chapter I referred to having an authentic relationship between who I am as me and who I am as a researching professional. Heidegger (1927 cited in Park 2007) proposed that authenticity was created through the constant, dynamic construction between self and social structure. In chapter one I used my Lifeworld project assemblage of thread and stone as a visual representation of my view of uniqueness. This image is still appropriate, however I would now animate that image and make it three dimensional so that the individual strands of thread could constantly move in relation to each other, to the outside world and to the stone.

7.2.4 Togetherness

To feel a sense of togetherness with others is important to all of us as social animals. In chapter three I explored some concepts of vulnerability which had been raised as part of my ethics approval submission. In this context the vulnerability arose from the participants with ACD being perceived as being apart from the mainstream on account of their communication disability. Some of the participants with ACD themselves identified the potential for isolation as a result of their stroke and one of the practice development proposals I have identified takes up their notion of creating togetherness to increase the potential for influence. My research has taught me the importance of belonging from both theoretical and practical perspectives.

On a personal level it has been interesting to realise that this D.Prof experience has simultaneously brought me together with others but has also, at the moment

of finishing, created a feeling of isolation. The process of bringing all one's thoughts together in preparation for examination is an isolating one for me. Although I am well supported by those around me, it is only I who can realise this thesis. In the practice development chapter I referred to the concept of the "enterprising self" (Tennant 2004, cited in Fenge 2009) which I think aptly captures the experience of branching out from a professional place of togetherness in order to create something new. An enterprise is defined as "an undertaking; especially a bold or difficult one" and to be enterprising is to be "ready to engage" to "show courage or imaginativeness" (OED 2017). Developing as a researching professional necessitates reaching out into the unknown and it has taken me seven years to realise how I might do this.

7.2.5 Sense-making

My thesis has emphasised the importance of sense-making and I have suggested that deliberation and sharing of meaning are important aspects of sense-making. This thesis has also emphasised the importance of recognising that each of us will make sense in our own way. How I have made sense of my research reflects me as a researcher and as Malterud (2001, pp.483-484) identified

"A researcher's background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate and the framing and communication of the conclusions"

Researching is therefore a personally integrated activity but, to be successful, research has to be capable of also making sense to others. In a D.Prof the sense has to meet both theoretical and practical thresholds. The development of a shared sense of purpose with work colleagues is critical to the success of practice development (Manley et al. 2014). The introduction of new practice-based approaches which have grown from the pursuit of a specific perspective or a particular observation may fail because others whose involvement is necessary to success do not share a vision of the changed future. Change management

theories emphasise the significance of internalisation in the successful accomplishment of change (Kotter 2008)

My next steps will be to test the sense I have made in the real world to see if it fits with the reasoning of others, for if I were to leave the process at the point of independent endeavour it would miss the point of this degree. An early attempt to do this with Speech and Language Therapy colleagues showed me that I was still too consumed by my postgraduate studentship to be able to do this well. The feedback has been limited, possibly because my colleagues perceived my study as being too removed from clinical practice to be able to relate easily to their own experiences. However, they were interested in my findings which suggested that my participants did not define their likelihood of participation on grounds of communication impairment. What this taught me is that to begin the creation of a shared sense of meaning, even amongst a group who have a professional identity in common, the new information needs to be coated in a mutually agreed context through which its novelty can be accepted.

My findings, both personal and research-wise, have supported the importance of sense-making in the accomplishment of socially motivated activities and I will use what I have learned to contribute to making a shared sense of purpose in the context of NHS public participation in Dorset.

7.2.6   Personal Journey

At the outset of my Doctoral journey I had a map of my proposed journey and an imagined view of the academic landscape I would travel through in pursuit of my destination. Now, with the route mostly travelled, the landscape I can see is different from that which I had imagined. It is clear to me that the assumptions of simplicity and clarity of purpose which I had made at the start of this process were uninformed. The actuality of the experience of pursuing doctoral study has drawn different potential paths into prominence and the decision-making over which path to tread has become more, not less complex. The recognition that my original research questions had been derived as a result of relatively superficial thinking could only be achieved as a result of the learning and development the

Doctorate has delivered. My reflection has established how integral to my research my own development has been. I have not been "doing" research; I have been "being" research. I have been as much the subject of my investigation as have my research questions, and although this was not part of my anticipated vista I accept completely that to see it has been a necessary excursion. There has been a developing dialogue between my strands of narrative and research which has drawn me to be more truly part of my research than I had at first realised, or intended. It would seem that I am both "pig and chicken".

7.2.7   Sense of place: where I flourish and feel at home

Despite the use of the word "flourish" in the definition of this dimension I did not fully recognise it. It was during the course of my reading around the concept of practice development that I came across it again in the term "human flourishing" in relation to person-centred care (Manley 2014; McCormack and McCance 2010). The concept of flourishing relates to well-being and happiness and it originated in ancient Greece. During the course of my studies I have learned about the expression of meaning and purpose and the philosophy of flourishing seems wholly appropriate to both my research and to my personal development, for we should all feel able to find the place in which we can flourish and feel at home. In the original meaning of the Greek word, Eudaimonia refers to desiring and striving with fulfilment not always being a certainty but with the focus always remaining on achieving happiness. Looking back on my experience I have "travelled hopefully" and I have "laboured" (Stephenson 1896, p.178) but here I differ from Stephenson as my success will be to have arrived at my first destination.

This image (see Figure 7.1) is where I have been at home during my D.Prof. It shows a place which has not always been functional - sometimes there has been so much piled up that I could not work here. A tree's worth of paper has ebbed and flowed, been lost and found, read and remembered (or forgotten). This place has changed with me but deserves recognition as the constant and familiar nest which I referred to in chapter one.

Figure 7.1: **My desk 2017**

7.2.8 Embodiment: how I experience the world holistically

Todres et al. (2009) use the term embodiment to describe a person's holistic experience of the world. In my personal narrative I chose to represent my experience of embodiment in two ways, firstly by using the analogy of diamonds which hold the capacity to both reflect and refract light and then by using the image of Stubbs' painting Whistlejacket, the common theme being that appreciation of the whole cannot be divorced from the acknowledgement of difference and detail.

Through my research I have come to understand how my abilities and disabilities have affected my assessment of myself. I had thought that I was unconcerned with the bother of detail but I now know that details bother me quite a lot and that I do have the equipment to deal with them. Attention to detail, or noticing, is how we all detect what social resources to use to get what we need, how we know whether we fit in or not. Attention to detail gives texture to meaning and is how you show what matters to you. My bricoleur self has collected all manner of detailed information from a wide range of sources and I have relished the notion

of curatorship as the collection has grown. I have brought together disparate parts and the biggest challenge for me has been to create a whole from the assembled parts in such a way that it means something new. I believe that I have identified a new perspective on participation. I also believe that this perspective merits further development and that there is much more to learn. I have not managed the academic equivalent of a Whistlejacket but I may have a Camelopard (see Figure 7.2). A Camelopard is the visual representation achieved by mediaeval artists from descriptions of giraffe and was the best they could manage with the information and understanding they had. It was a work-in-progress.
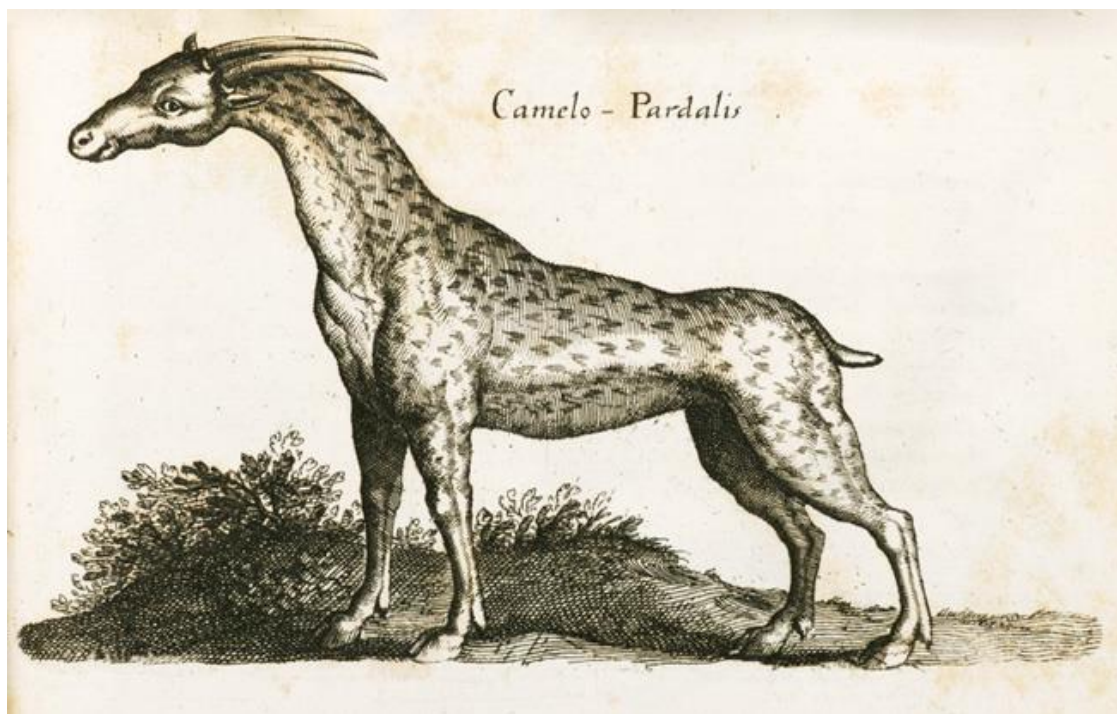
Figure 7.2:   **A Camelopard.**

This image of a Camelopard symbolises my progress towards my academic goal. For the time being I take reassurance from seeing that it has all the elements of a horse put together in a way which suggests that a horse might be possible. The fact that there are also a number of extraneous aspects does give rise to the potential for misattribution or confusion and more work may be needed to provide clarification. But, as I suggested at the beginning of this chapter, in the section on insiderness, sometimes you have to share what you have with confidence and

through sharing your work becomes better, more refined and more meaningful as a finished article.

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Appendix 1   NIHR Ethics checklist

NHS
Health Research Authority

MRC | Medical Research Council

Do I need NHS REC approval?

ℹ **To print your result with title and IRAS Project ID please enter your details below:**

Title of your research:

"Nothing about us without us" Do people who have an acquired communication disability feel able to influence the design and delivery of healthcare

IRAS Project ID (if available):

Your answers to the following questions indicate that **you do not need NHS REC approval for sites in England.** However, **you may need other approvals.**

You have answered **'YES'** to: Is your study research?

Appendix 2   Bournemouth University Ethics Approval

Research Ethics Checklist

Reference Id	4587
Status	Approved
Date Approved	15/01/2015

Researcher Details

Name	Deborah Slate
School	Health and Social Care
Status	Postgraduate Research (MRes, MPhil, PhD, DProf, DEng)
Course	Postgraduate Research - HSC
Have you received external funding to support this research project?	No

Project Details

Title	"Nothing about us without us" Do people who have an acquired communication disability feel able to influence the design and delivery of healthcare services?
Proposed Start Date of Data Collection	03/11/2014
Proposed End Date of Project	31/03/2015
Original Supervisor	Ethics Programme Team
Approver	Research Ethics Panel

Summary - no more than 500 words (including detail on background methodology, sample, outcomes, etc.)

Appendix 3   Consent forms, aphasia friendly and CCG

Consent Form, Aphasia Friendly

 "Nothing about us without us" Do people who have an acquired communication disability following a stroke think they are able to influence health care decision makers with regard to the commissioning of services for stroke patients in Dorset?

Name, position and contact details of researcher: Deborah Slate, Post Graduate Student, School of Health and Social Care Bournemouth University. Tel Mobile 0774 092 9178

Name, position and contact details of supervisor : Professor Jonathan Parker PhD, FAcSS, FHEA, FRSA, Director Centre of Social Work, Sociology & Social Policy, School of Health & Social Care, Bournemouth University, Royal London House, Christchurch Road, Bournemouth, BH1 3LT

Please Initial Here

I **confirm** that I have **read and understood** the participant **information sheet** for the above research project and have had the **opportunity to ask questions.**	
I **understand** that my **participation** is **voluntary** and that **I am free to withdraw** at any time, without giving reason and without there being any negative consequences. In addition, should I not wish to answer any particular question(s) or complete a test **I am free to decline**.	
I give permission for members of the research team to have **access** to my **anonymised responses.** I **understand** that my **responses** may be **captured on a video recording** as **well as on paper**. I **understand** that **my name** will **not be linked** with the research materials, **and I will not be identified** or identifiable **in the report or reports that result from the research.** I **understand** that **any recordings** made during my participation will be **managed and stored in accordance with the Data protection Act 1998.**	
I agree to take part in the above research project.	

_____ _____ _____

Name of Participant   Date   Signature

Consent Form, Commissioners

Full title of project: "Nothing about us without us" Do people who have an acquired communication disability following a stroke think they are able to influence health care decision makers with regard to the commissioning of services for stroke patients in Dorset?

Name, position and contact details of researcher: Deborah Slate, Post Graduate Student, School of Health and Social Care Bournemouth University. Tel Mobile 0774 092 9178

Name, position and contact details of supervisor : Professor Jonathan Parker PhD, FAcSS, FHEA, FRSA, Director Centre of Social Work, Sociology & Social Policy, School of Health & Social Care, Bournemouth University, Royal London House, Christchurch Road, Bournemouth, BH1 3LT

Please Initial Here

I confirm that I have read and understood the participant information sheet for the above research project and have had the opportunity to ask questions.	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason and without there being any negative consequences. In addition, should I not wish to answer any particular question(s) or complete a test, I am free to decline.	
I understand that my responses may be captured on an audio recording. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.	
I agree to take part in the above research project.	

_____   _____
_____

Name of Participant   Date   Signature

Appendix 4   Recruitment Letters aphasia friendly and CCG

Recruitment Letter, Aphasia Friendly

Dear

I am a Doctoral **student** at Bournemouth University and I am undertaking **research** into **participation in health service planning**. I am particularly **interested in** whether **people who have a communication disability** following a stroke **think they are able to influence the decisions** made about healthcare services.

If you think **you** may be **interested in learning more** about what might be involved in taking part in my research **I will be attending the Communication Support group at   on   to explain more about it.**

If **you** are **unable to attend** that meeting or if you would prefer me to **meet you separately** to explain my project then please **let me know by phone** 07786 251 116 or **by email** i7910099@bournemouth.ac.uk.

Thank you for taking the time to consider my request,

Yours sincerely,

Deborah Slate.

Dear

I am a postgraduate student at Bournemouth University and as part of my Professional Doctorate I am undertaking research into participation in health service planning. I am particularly interested in whether people who have a communication disability following a stroke think they are able to influence the decisions made about healthcare services and additionally whether health service commissioners think that they are open to being influenced in their decision making.

I have attached my Participant Information Sheet which gives details of the project. Please do not hesitate to contact me on the phone or by email (details above) if you need more information or have any questions. The same contact details can be used if you wish to register interest in taking part in the project.

 Thank you for taking the time to consider my request,

Yours sincerely,

Deborah Slate.

Appendix 5   Echo Axis parameters

Position 1. Closed to community influence.

The concept of "community influence" is not on the agenda and any consultation is likely to be of the "tick box" variety. Decisions are based on professional knowledge and no input from customers or communities.

Position 2. Respond to individuals.

React only to individual users and customers, which may be appropriate in terms of customer insight and a "customer focussed approach" and feeds customers voices back to agencies. Individuals within agencies might build personal contacts and relationships with individuals in other agencies, sectors or departments.

Position 3. Make contact with people.

More proactive in relationships with customers and make contact with people on CCG's terms and expect people to fit into existing structures and mechanisms. Community engagement is viewed as an "add-on".

Position 4. Change focus to groups and communities.

Realise the limitations of work with individuals around community engagement, distinguish when consultation needs to be about more than individual views, and recognise when it is appropriate to work with groups and communities. Actively explore ways of seeking the opinions of organised and constituted groups and offer practical opportunities for people to come together and have a genuine say. There is an appreciation that the views of individuals don't necessarily "represent" the views of others.

Position 5. Recognise the value of community influence.

Recognise and acknowledge the potential value of community influence: improved relationships, community focussed decisions, value for money and effective services. Think and plan for communities to have influence.

Position 6. Recognise the possibilities from community influence.

Recognise that CCG has a key role to play in encouraging communities to influence and be aware that own structures and processes can have a positive or negative impact on levels of community influence, as well as own potential to respond to community influence. Scope out what is likely to support and what may get in the way of developing community influence.

Position 7. Support communities to influence.

Proactively support and inform communities so that thay can engage on a more equal footing and be influential on relevant bodies and committees. This is likely to entail ensuring that people in communities have the time and resources to "represent" more that just their own voice.

Position 8. Work together.

Create positive alliances with communities and develop intelligence-led approaches which build on existing work. Recognise that this will entail developing more open and accessible structures and mechanisms.

Position 9. Change how we do things.

Willingness and flexibility to change how things are done at all levels to ensure the "community engagement" is integrated – this is about cultural change not individual working styles. Taking an empowered and empowering approach which includes thinking about ways of dealing with competing demands.

Position 10. Open to influence.

Constantly assessing and evidencing the engagement work being done together with the supporting engagement and equality strategies. Able to be confident that the relationship with communities is open, constructive and outcome focussed proving the best possible quality services for the greatest number of people.

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Appendix 6   Examples of influence maps created by participants with ACD

Dorset CCG

Family.

Friends

Community OT

Stroke association

Member of Parliament

GP

Hospital Physiotherapist

Community Physiotherapist

Hospital Consultant.

DH Department of Health

Hospital Nurse

Appendix 7   Examples of influence maps created by participants from CCG

FA

YOU

- Myself
- My Family

- DOH
- My Manager(s)
- My Close Colleagues
- My Team

- People
  Patients
  Carers
  People with Physical Disabilities
  People with Cognitive Disabilities
  People I the 9 protected Characteristic Groups

- My Friends

- Twitter
  Facebook

- Provider Trusts
- Community Services

- NHS England
- CCGCSR Assurance Group
- David Jenkins
- Gov Body

- PPEG Chair
- PPEG CSR
- SSV
- HIN

- Law Reps
- PPG Reps

- NHS Staff
- LA Staff

- Health & Wellbeing Board
- Senate
- HOSC
- Monitor

- Engagement & Comms Leads Group

- Community Groups
  CVS
  Access Dorset
  Dorset Youth Association
  DYCE
  DCA
  DREC

- Councillors

Appendix 8 Transcript Participant with ACD Interview, "Ray" 20.07.2016

Preliminary conversation not recorded.

DS. What I am thinking about is whether you think that you could make a difference to the services that people who have had a stroke get from the NHS.

RP Erm.

DS. So, not within Sue's group,

RP. Nothing.

DS. Nothing?

RP. Nothing.

DS. So, on this line number one means nothing and number ten means that you can make a big difference. So there you go you put your........ doesn't matter, cross it, circle it whatever you fancy.

Fantastic , that was very definite.

RP. What, what we can ?? is anything today. It's the- oh you, blah, blah, blah. You've done this then now, this, this oh- when- oh no. To myself so and so, oh no you're there you're finished.

DS. So you are on your own yeah?

RP. Yeah, yeah.

DS and it doesn't really matter, you felt , what you felt that you might have wanted.

RP. No.

DS. No?

RP. They don't want to know.

DS. Which is annoying I would imagine.

RP. Yep.

DS. Yeah, yeah. Do you think that if somebody asked you, you could say what you wanted?- Or make them understand what you wanted?

RP. Only as long as they can- say ???

I'm doing anything tomorrow

I don't want- nothing out.

DS Mmm.

RP. And you know that you are not the ? that's waiting to do the thing.

You say- we are here- we can't do it, we want a bit of help.

What sort of paper, oh ah, er- but here nothing.

DS. In an ideal world, what would make it easier for you to have your say. What would they do to make it easier?

DS. People who are similar to you in that they have had a stroke and it has affected their speech- it hasn't affected their ability to have opinions or have thoughts about what has worked and what hasn't worked or what's good and what's bad. But nobody offers you the chance to say that.

RP. It doesn't ?? What, whether that we have some ?? people.

PP (wife) Who are the people? Are you talking about your friends in the stroke group?

RP. Yeah.

Shoot the bastards and then start again. People don't understand that they say that they – new one they go to this and that but- wait just a minute, look right to come from our part of it the lads that you- .We are all people that are in trouble. They are dumped – and we don't want them......... duh well here, we'll do that.

They come out with new things and that doesn't work.

Look you are in your ? This year or fifteen years ago or whatever it was and we think those would do with ?? In seventy, in ninety, about that sort of time. I mean once a girl-R- she

PP Fifteen years ago she's been...

RP. And all we's can do is- she going along way by err- leaving ? with a car – scooter then all ? – she said a lot of things but her sons have said then but they are growing up, it's there it's with her ???

The wife they person is getting er. I don't it's ??? it's, it wouldn't - don't -. What we are doing is tec- we can go in we look at the teas- oh no tse

DS. You are doing really well.

RP. (sigh) I do not see that new chap thinking instead of saying ?? rest is, is this was given to new chap when they come to this. They say, hey, look- we working to make, maybe seventy five percent instead being on nine or one hundred (sigh).

DS. I think I am understanding what you are telling me and I appreciate how frustrating it all is that you can see things that are happening but you can't change the fact that that is what's happening.

RP. ??

DS. Nobody is asking- listening to what your opinions are.

RP. Don't say- they say oi don't you this- this is you, what can we do now. They say this is what we are doing. Now how you saying, you haven't comment ? anything you?

DS. Yeah. And that experience; What it is making me think of is the experience you had of the Stroke Association and with Sue's group and with changing that. Where you, eventually you did take matters into your own hands didn't you- and you said, well I don't agree with what you are saying so I am going to do this.

PP. Providing they have carers who can speak up for them they can but I don't know how people with aphasia who don't have anyone manage.

DS. But what you have just demonstrated is that you absolutely can communicate what you think and what your preferences are because you have just one that with me.

RP. Yes, that's right. Beautifully ??.

DS. But, if nobody bothers to ask you and give you the time to give your answer as it comes to you

RP. Ahh, ahhh now we come to the point because you might say I am trying my best by so and so, blah, blah, blah. Sorry we can't take time about other than that. He's out and it's his wife the same---

PP. T? (a fellow group attendee)

RP. Yes, he's good.

He can speak quite well and he's, he's absolutely a good but it's what we are talking about, just leave him-he's very good

DS. But then everybody who has a stroke is an individual and so how your stroke affects you is going to be individual. So, you can't expect something that works for person A will also work for person B. You have to doit on a one to one don't you really.

PP. The NHS have been brilliant on the medical side of things but since those early years over the years they don't listen to what he needs to carry on life- to carry on. I think that is where there's a gap. There are lots of things he would have loved to have done and at the age of sixty three having had, like many, an active life you don't want to be left to sit around and do nothing.

We can carry on and try and get what we want but people with aphasia and haven't got anyone to speak up for them – they just.....

RP. Errrgh!

DS. I can totally appreciate that that's how it makes you feel- just as it is, let alone all the other rubbish.

RP. It's so annoying.

Pause.

DS. Well, that's brilliant. That's the first bit done then.

So, the second bit – is where we- these are the cards that I brought to show you at Sue's group as well. So, this part of the exercise is for you to have a look at these different people and organisations to see who, in this pile, you think *does* influence the decisions that are made. So, the organisation that books and arranges all the healthcare that people in Dorset have is called the Clinical Commissioning Group. They are responsible for arranging and paying for all the healthcare that happens in Dorset.

RP (grimace)

DS. Now, obviously they have to make decisions about how things happen and you have told me that you don't think that you could make any difference to what they decide.

RP. Yeah.

DS. But, who do you think might?

RP. I could work it.

PP. Have a look through.

DS. This is just me putting together a group of organisations and people. But there might be people that you think ought to be in this pile that I haven't put in. So, I have put a blank one for you to put in whoever else you think might be important.

So, you have a look and see who might be able to change things.

PP. You need to read them.

DS. That picture is a group of friends to represent your friends.

PP. It's all women!

What she's asking is, do you think they would have any influence on how services are paid for/ organised?

RP. – don't know.

RP and PP (laugh)

DS. Now that one represents- I know they are not your family- but everyone in your family.

Do you think they could make any difference?

RP. Oh yeah.

DS. Yep.

RP. Home?

DS. Yes, that's the physio who would come and see you at home.

RP. Yeah.

DS. And that physio is the one who would see you when you were in hospital.

Those are the nurses who would come and see you at home and that's the nurse who would see you when you were in hospital.

That's a Member of Parliament- MP, don't know who he is but just to represent.

PP. What do you rsckon- would the MP make any difference?

DS. Have you got a he or a she?

PP. He.

DS. That's your GP.

RP. They are getting so busy now that those nurse- you can't.

PP. You can't get to see them can you.

RP. You can't under three weeks.

DS. Golly.

SLT that one.

RP. Well I think there would only be, um

DS. That's the manager at the hospital. Do you think that they would have any say over what happens?

RP. What's that one?

DS. It's the hospital Consultant.

Social Worker.

And that's the Occupational Therapist.

So have you already organised them? So the ones that are near the top, up this end are the ones that have most power?

RP. No.

DS. Ah.

RP. These are the girls from the factory.

DS. From the hospital

RP. They're important.

PP. Have you put them in order of importance to you or do you think they would have influence over how the money is spent in the NHS?

RP. No.

PP. That's what we need to.

RP Right.

DS. That's important to you- is that what you are saying?

RP. Yeah.

DS. Can I take a photograph of that and then I am going to ask you to do it again! With a different point of view.

Okey doke, now this time I am going to ask you to sort them out again depending on what you think has most influence over- good way of putting it- how the money is spent in the NHS.

Does that make sense?

RP. No.

You see these are people who are sharing in the home. They come at the time that the girls at hospital and they've had. I think it's very good you have to have for we had but umm, umm,

It's most influence number one

DS. He's the most important.

RP. Is that your "temp" intention or me do what we are doing.

DS. It's you- do you think he is the most important.

RP. No. Um, the people who are the most important are the people that will put you what you get

PP. Do you think those are the people who should be making decisions how the money is spent.

RP. Yes, yes.

DS. Do you think that really is who does?

PP. How do you think it is done now?

RP. The bloke who came

PP. The consultant- do you think he has an input in how it is spent today

RP. Umm

PP. Don't know

RP. No.

DS. That's fair enough 'cos it's not obvious who makes the decisions. You know you were saying right at the beginning you were once you had gone out of hospital you were just sort of like "cheerio".

RP. Well, they do. But it has changed very very recently and now they saying de- come and see this. But they are there are these- taking to see them. The ???

PP. Doctor.

RP. The DGM.

PP. The GP.

RP. Yeah, he will only do you very lately, oh go there, don't um, um.

DS. So do you think your GP, do you think he would be able to get you something like Speech and Language Therapy or Physiotherapy if you needed it.

RP. That could be all right. I think they are- them very good and they are all right when you go to them. But it's bet ??

(getting tired)

DS. You have worked really hard.

PP. Well done.

DS. It is a very hard question that I am asking you because, if you feel like you do- that whatever you say it doesn't make any difference – then it doesn't really matter.

RP. Because

DS. Who does make a difference because

RP.- it finish, oh- good bye, finish but this isn't what being told they will going out- you could say to him but- I don't think he's not got the face. He hasn't got the thing coming up.

PP. Not a strong influence.

RP. No. he's got a good boss behind the nice that's good, very good and I always got friends in the who's and they just see

And this ?? that is going to be essential being of you. When these girls, what I was saying, they---

RP. What's this?

DS. Social Worker- you might not have seen one of those, ok you did see one of those

PP. Yeah, G. G the Social Worker.

RP. Yeah.

DS. That's a blank one in case we came up with something I didn't have a picture for.

Can I ask another question?

Or, tell me if you want to have a bit of a rest and drink your coffee.

Pause

DS. Can we have a look at these that you put right out of the way because these have got more writing on

So there is the Department of Health- (grimace) RP. No.

Councils- RP. No.

Dorset Echo.- RP. No

Stroke Association. – RP. No

Age UK. – RP. No.

Healthwatch.- RP. No.

Partnership for Older People.- RP. No.

DS.Just wanted to check.

RP. Usless!

DS. What you are telling me is absolutely vital.

RP. You'll get me shot!

It's money. They group you don't think they will, but they will.

PP. Sue's group has been the only ongoing regular thing.

RP. WE go every day, Monday/Wednesday/ Thursday. I've getting lost the name but they are, they have we all at home and err umm

DS. So they are the ones that make the difference.

Appendix 9   Transcript Commissioner Interview "Fran" 07.2015

DS. On the Post-it notes I want you to put any one who has an influence on you in your role.

FA. Ok. So, can I just clarify because my role has changed so much, so dramatically that the way I would answer it would be different depending on what I was working on. So, for example for the first six months of last year I was working in the engagement team as a –um- engagement and communication lead for three specific CCP's- 2 specific CCP's and 1 cluster area. So, I was working on projects in North Dorset, in Weymouth and Portland. I was working on ophthalmology , dermatology and um, you know, and various things to do with maternity and family but, and so, within that I would be following up the engagement cycle um and, and I would be working with patient groups, current patients, to influence current and developing pathways and that for me is very different from, ... I was then seconded into the PMO office for the CSR (clinical service) um, as public engagement lead and that work has been very different levels of engagement than following that specific engagement cycles- obviously overlaps um and some of the processes are absolutely mirrored in terms of what do we know already. What have people been telling us, how can they inform where we are, where we are going as a start point we would do in any project importantly. Um, but then it was very much about informing as another element of engagement . But it was about informing because we had done- initial views seeking had been done over the last four, five, six years in terms of what people want, need .They want care closer to home It's what we know, what virtually every view seeking comes up with so, what do you do?- Give people a blank piece of paper and they come back with the same findings. We have evidence from the Big Ask and lots of other reports. So, that was done and then it was about informing and now we are going into the stage of public consultation. But the consultation is about testing out where we are and do people agree – um and so in terms of informing change the change- we know the change has to happen so they have kind of informed it already and this bit is about um,um, so this is the "need" to change do you agree? Looking at the evidence, this our vision based on what you have said already do you- and clinical evidence and best practice and so forth- do you agree? Um, and then these are the proposed models what do you think? And then, have we missed anything? So, and the views that we collect for that are going to be vitally important but it is not a vote, it's not a referendum it's more of a , it's a it's a touching base of where we are.

DS. A validation?

FA. Yes, and if we have missed anything dramatic that can inform decisions it would be vitally important to know but for me then the next stage would be implementation. That's when we can get back to the engagement cycle where people will have the opportunity to directly influence the "how". So, we are looking at the "what" and the "what" is based on um workforce and funds and best practice and clinicians and experience and expertise and need and any, so called, patient views and um, but it's the implementation phase from my perspective that is where people will most influence how because then it will be care pathways and specific localities and... do you see what I am saying?

DS. Yes.

FA. It's a very long journey, so will people saying, at this stage, I want mental health beds in that location- will that inform the outcome of the consultation? Probably not because that is not what we are asking them but, they will think that they are not having a view ?achieved? at this stage but down the line at the communication stage where those views will be taken into account appropriately and I have tried to get that message over but- when we have done all the public meetings to say that engagement is very much a process and that it is made up of lots of different elements and they are all vitally important and that they are all important at different times and that they are interconnected and that, you know, information giving is a very important part of engagement and that on-going dialogue is a very important part of engagement but people's views when they give them won't necessarily inform stuff *there* but it might inform stuff *there.* Do you see what I mean about them connecting- they might say, if you asked them after the consultation, do you think your views informed change because that's actually that part of, it's not where their views is appropriate in terms of informing change. Whereas it is at that stage. Um, that's a challenge for me- us- because we have got to communicate that and people don't- even if you say that to people – they'll listen but then they will say, fine, but what I want to tell you about... and therefore they will see decisions being made, um, when they are made, and they might feel – well my views didn't inform that and yet, actually, they will.

DS. Yep.

FA. So, you see what I mean, so it is really complicated because it is so big and it is so long- because it is not a project that can be done in six months where people can see the output of their – this is really helpful actually for me exploring it for myself- um, yes- it's not a six month engagement cycle where they can see within six months- you said we did, boom! Um, it's a five year engagement cycle so in five years time they might feel like they have influenced but currently they might not. So, it's really difficult, it's really difficult to manage people's

expectations because people are saying I went to a meeting (I will start this in a minute but just explaining the background!) – because, I went to a meeting last week and someone said "decisions have already been made" and I said "no decisions have already been made" and they said "well, we feel as a public that they have" They said " how do we inform change?" And I, through this whole process, have said "if you are talking about how your services are provided, how; at a grass-roots level in your locality; then that is further down the line so stay involved and have an ongoing conversation. But, he said "people will feel like it is a tokenistic exercise because what they say during the conversation wasn't necessarily acted on there and then"

DS. Hmm.

FA. Do you see what I am?

DS. Yes, and that is really helpful.

FA. Do you see what I am saying?

DS. I totally see what you are saying.

FA. And it's really, it's a real challenge because I don't want to disengage people by them feeling that they are not influencing change but for them to see – and I have been working in engagement for twenty five years – for them to see that this engagement process is made up of all these different elements and that it is starting, in fact it started pre last October, for as long as we have been asking people's views and it is going to go on into however long into the future because it is about the healthcare system. It's about making it sustainable for now and in the future, high quality, equitable, deliverable- you know- it's a massive piece of work and, and, yeah, I think it is about the challenge because if it was a six month engagement project they can see we said this, you did this- I have influenced change- yes I can. That would be my answer. Um, yeah- with this one it is different.

DS. Yeah, so in terms of you feeling you are actually able to make a product out of this first exercise I mean, in my question It's actually saying "do people who have aphasia following a stroke feel they can influence stroke service provision decisions.

FA. Yeah.

DS. From what you have just said, obviously the CSR context is just massive and stroke is only a tiny strand of that tapestry.

FA. Yes, a very important part- it's obviously a high priority being that it is a very high condition area and so, yeah, exactly.

DS. And so, from your kind of perspective does it help to just think about stroke services in general, bringing together all of the things you have just said- or is it easier for you to think about what you are currently working on? I don't think- you have got to do it in a way that makes most sense to you.

FA. If I can think about the CSR as the big picture in it. I think it is probably easier for me to think about what I am currently working on, cos it is an engagement cycle and in fact having explored that with you I can see that it is- it does mirror it it is just that the size and the time. So, what was a six month cycle is actually a six year if not more but the elements are still there.

DS. OK.

FA. So, everybody that I am touched- who will influence the work that I do – influence the work that I do.

OK. Some of it is going to be repetitive isn't it.

DS. Umhumm- what's the difference between people and public?

FA. I don't know, I'm just brainstorming.

DS. OK.

FA. Yes, you know what I mean, they are not necessarily mutually exclusive.

DS. What does PPG stand for?

FA. Patient Participation Group- uh- there is another one! (acronym) But, am I allowed to use acronyms because it is my mapping!

DS. Yes, absolutely.

FA.That's the Patient Participation and Engagement Group for the CSR.

Supporting Stronger Voices, Health Involvement Network- someone would have a heart attack to come and see this, they would be like, don't use any acronyms!!

OK, um, so I don't know what level you want me to go down to?

DS. It's yours, it's your map!

FA. We might run out of Post It notes!

DS. I've got another pack here!

FA. Some of these, well lots of these can be grouped-um- I don't know, because I work with so many people it's probably not completely inclusive – completely comprehensive. Um, ok.

DS. I don't think anything can be totally exhaustive.

What's HOSC?

FA. Um, Health Overview and Scrutiny Committee

Hummm

He's the Public and Patient rep on the Board (David)

DS. OK.

FA. Now I have paused I have lost my flow. Is that enough? I mean it looks like there is more.

DS. You may want to add more once you have started doing the mapping exercise 'cos you may think, ok there is that and this comes here or whatever.

FA. OK.

DS. So, we can have a little pause while you just review what you have done.

FA. And this is organisations and people isn't it?

DS. Mmhum.

FA. Ahh, that's an odd one

DS. Twitter

FA. Yeah, yeah- um

I'm getting like, going into policy like that but that is set by these people.

I think that is quite comprehensive

DS. Good to go?

FA. I think so.

DS. So

FA. I keep thinking I have left out someone really massive. I haven't put down condition specific groups because I think that everybody belongs to- umm ok.

DS. So, second stage is..

FA. Ooh, I've got another one.

DS. DYCD?

FA. Dorset Youth Council Disabled, Dorset Youth Association.

DS. OK, so, you in your role here- use the Post It notes to

FA. This is going to be hard isn't it!

DS. Use the Post It notes to put them in order, strongest influence closest to you, more peripheral influence further away, if that makes sense.

FA. See, there is a difference between "should be" and actual isn't there. There is rhetoric and reality.

DS. I'm wanting reality.

FA. Because the biggest influence should be the people.

DS. And is it?

FA. No, because I am told what to do and that influences how I work with the people

DS. And that is exactly what this research is all about really- it's that dissonance between

FA. Yeah, so on certain levels it is because I am constantly thinking about the person so I make myself, I make them a key influencer in my whole approach but actually- the work that I am doing

DS. (in your role) is influenced by

FA. Oh my, ok so, I guess the ultimate , ultimate influencer in my role is the DoH because without that we wouldn't have the NHS- I didn't put NHS, oh, I put NHS England. OK, so I would put them – am I allowed to

DS. Yeah, wherever you like and they can overlap

FA. OK, so DoH and NHS England-um over there-err-ooh- Monitor (new Post It)

Umm, oo, this is hard, this is hard. Who influences me in my role?

I think I need to group some of these.

DS. Yeah, I mean they can stck up on top of each other if they are all in the same

FA. Yeah, 'cos I think in terms of, ok so I've got Monitor, Health and wellbeing, Senate, HoS-they are all, not policing bodies but they are all bodies that give

DS. Scrutiny.

FA. Scrutiny,yeah. They would scrutinise what we do and therefore have a direct impact on whether we, on the direction we take. So, the direction is stipulated by them and the fact that engagement is able, in the CCG, is directly influenced by them because if they said we don't want any engagement it

DS. It wouldn't happen.

FA. We wouldn't be here. So, there would be no engagement , so CSR-wise we need to check our direction of travel with these people and if they say "no" then the direction being given by them (people) stops. So, they are quite influential in my role especially with this project they would be less influential with the smaller projects.

DS. Yeah.

FA. But for the project they are kind of

DS. And are they, that's not a hierarchy, they are just one on top of the other?

FA. Yes.

DS. And there is no order implied by the way they are stacked?

FA. No,

DS. It's just that they all belong in the same

FA. No, they all have the same- the Health and Wellbeing Board is slightly different scrutiny role

I mean that is external scrutiny but you have also got internal scrutiny so the Assurance Group, the Chair of our Patient Participation and Engagement Group, who by the way is Anya de Jong and did you see that she has got, she has just been awarded one of the top patient leader in the country. Yeah, 50 HSJ list, one of the top patient leaders, this week.

DS. Wow.

FA. She is wonderful, so Assurance Group, the CCG Assurance Group, they have an element of, an important element of, are we going in the right direction and if not, stop. So, it is an internal scrutiny. So, PPEG chair less influential probably slightly, rightly or wrongly. I'm trying to be honest.

Governing Body which David Jenkins is an important part of sits on the Assurance Group. Yeah that's the internal assurance and she feeds into that but I would say that she sits, yeah but I would say in terms of internal assurance slightly lower doesn't it because if that doesn't happen , that doesn't happen. Does that make sense?

DS. Yeah.

FA. So, it's funny isn't it, I'm sitting here thinking at the end of it I know what I am going to want to do with that. I am going to want to say let's turn it all upside down- which is exactly what your research is showing. Umm, ok, so in terms of what my , I next do, my actual actions are obviously influenced by my manager- I'll put managers- so people who tell me what to do and agree my objectives and umm, are (?) I suppose.

OK, so, Ok so, I can make a big grouping – so, local people, vitally important to my role- it's what it's all about. So, I would group, I would group the public, people because they are the same. In fact I might throw away public because otherwise it is just a complete repetition and I like the word people because we are all people and umm people would include our patients; they would include our carers; they would include – there is a slight- I think there is a slight hierarchy to this because of the way it all feeds into each other. So, people patient's carer's stakeholders- they are all stakeholders- I'll remove them like I removed the public because these are all stakeholders.

Um, so, people, patients, carers, people with physical disabilities, people with cognitive disabilities, people with the 9 protected characteristic groups.

DS. What does that mean- 9 protected characteristic groups?

FA. So, that's the equality-you know this don't you, you are just testing me! From the Equality Act 2010 these are the 9 groups of people who could be disadvantaged if they weren't included equally, Do you want me to list them? No? OK, and then they should all be treated equally in terms of having a voice from my perspective and having an opportunity and because of their protected characteristics we might need to take certain different approaches and methodologies of access to enable them to have a four um opportunity to be involved. Um, for

example when we worked together with people with stroke we made sure that there was an easy read format, we made sure that we provided the staff that were communicating with them with cognition training, language training and so forth. So, communication training.

Umm, ok so- there is my family and myself, my colleagues and my team; Healthwatch, Community Services. That's Dorset Youth association. Dorset Youth Disabled, staff, Dorset Community Action, Provider Trusts, Community Services Equality Council, community GP's, lay reps. I'm getting there.

DS. Yeah

FA. So, in terms of. I think in terms of influencing what I do, I think these are almost all on a level now- which is actually refreshing 'cos I don't think that the, that the views of the patient-patient/people are less influential in my role than all the community organisations so I am just grouping them 'cos they have a way of accessing people if that makes sense.

DS Yes, that's more formal I suppose, as an organisation.

FA. Yes, so we would work through the CVS to reach out to the appropriate people to talk to who might have a particular interest in a particular project for CSR. But they aren't and me, they aren't more important than the general public. If that makes sense.

DS. Yes, it does.

FA. Where did I put people?

DS. There.

FA. Ok, here, I was going to say where have they gone!

So, there are people and they are subdivided into different ways of accessing them if that makes sense.

DS. Mmhmm

FA. Healthwatch have an important role they have an important critical friend role so they wouldn't necessarily stop what we do but they would inform what we do because we would listen very much to their advice through their experience and skill and their links with people and so I think they would be- I mean they are slightly separate.

DS. Yes.

FA. I'll put them there. OK, now I'm just not sure where to put (?) now, so my colleagues, my team, myself and my family and my friends. That 's almost I think that's my environment in which I work because that's how I am influenced my role in my approach because that is how my emotions and my energies and so forth. My family very much influence me , my energies, my positivity, my approach. My friends very much do but slightly less.

I'd say my family come above me in terms of my, how I am because if everything is fine at home I am pretty fine and my friends would come slightly below myself because they don't influence me as much as my family do So I think that kind of , I think, I don't know where all that goes- because that is almost at the top. Because although this is how I do it , this is how I am able to almost. Isn't it. So, I think me, myself, my family, goes up there and I think my colleagues and my team similarly affect my day to day working but they don't affect the fact that I have to do it and the fact of what I do they are the part of doing it with me. So, I don't think this is necessarily –I don't know, and umm. They are an ongoing part, absolutely, of how I work 'cos we work very closely a sa team and decide our methodologies as a team so they are very important –but they are integral rather than influential. Does that make sense?

DS. It does make sense.

FA. So, I don't know where to put them 'cos it's not less important.

DS. Not hierarchical.

FA. No, it's not less important and it's vital to doing my job just as I am myself but it is not as important as me in terms of .... in terms of.... of course they are as important as me I don't mean it that way, they are as important as me but in terms of **me** doing **my** role, getting up, getting out, getting on delivering I have to harness my own skill set my own me. So, I don't know where to put them from that perspective- it's kind of access all...

DS. Part of the environment.

FA. Yes, as are those. I'm not, I'm not – I'm going into too much depth aren't I?

DS. No, no you are not. There is no such thing as too much depth.

FA. OK- because some of it is hierarchical and some of it has to be in place for me to even exist and some of it is environmental because if I wasn't me then I wouldn't be able to do my role either and if I didn't have a team I wouldn't be able to do my role either.

DS. So, it is almost as if we need a three dimensional map.

FA. Yes, it needs to be almost 3D yes absolutely.

DS. So, if it were 3D where would they be?

FA. Here, here. (above map)

DS. So, if you stick them that way (90 degrees) and this one would they be on the same level or would they be down at this level?

FA. No, they are not at that level- or, are they at that level?- I don't know 'cos...

I think that my family and myself are absolutely at the top – not my friends. Absolutely at the top, I really do. 'cos I know how affected I was when my mum was critically ill, my whole world was about that and my role was about existing. So, without that being in place the rest of it – does that make sense?

DS. Yes, it does.

FA. My friends are almost more like my colleagues. Do they influence my job? No I don't think they do. Do they influence how I am? They do, but they don't have a, they do 'cos if one of my friends is struggling then it-

But, if one of my family is struggling, like when my daughter's best friend was killed that affected my **whole** world. When my Mum was critically ill that affected my **whole** world. So they do, but not- do you understand? But they are not at the bottom, but they are part of... No, they probably are at the bottom not because they are not important but they are not as important to my work. Yep.

DS. Yep.

FA. Ahh, this is quite fun!!! Quite challenging and I haven't put the most important people on the board yet and that is the people!

I think I am almost getting to a level across here now because I think people, patients, people- just people. So, let's put people kind of in the middle cos they should be central but they are actually in a hierarchy because I wouldn't be talking to them if this wasn't all in place and I would be talking to them but I wouldn't be talking to them about the NHS.

DS. Yes.

FA. And, ok, and we have offshoots of this so that, like I say that's the kind of mechanism of reaching people. So, for the CSR the PPEG is really- it plays a massive role in informing and

influencing my role and I would say that they were probably, for this particular project, the most influential group and having proper outcomes that are being considered and listened to. So, I would put them high in terms of –um- and obviously they link with the PPEG chair which puts them in terms of assurance group. So, um, and so um.

And then Stronger Voices, kind of links with the PPEG and Involvement Network both link into the Stronger Voices and they are all people. So this is more process does that make sense?

DS. Yes.

FA. These

DS. So they are sort of interconnected?

FA. Yeah, in fact can I just (drew arrow)

DS. Yes you can.

FA. Ok. But they, yes, so they are, they have. Their input led to the production of a public facing need to change. Their input led to, or um, was taken into consideration when developing the evaluation criteria. They developed the consultation principles and that has been fed through into the Assurance Group and there has been that direct feedback so that has been really ,really good.

OK, so then we have got, ok Lay Reps, they are also – they. So, they are sitting with Stronger Voices so probably would put them there and Councillors- they are stakeholders, but I don't know why I specifically said Councillors- Councillors, Community Groups. No they are probably different from Community Groups aren't they? The Community Groups are a way of reaching people so that is a mechanism. PPEG, Stronger Voices etc that is our network of people and in addition to that we reach out to people through Community Groups, Through Dorset Race Equality Council, through DCA, through Dorset Youth Council, through Dorset Youth Association, ? Dorset and through CVS. So, and that's not exhaustive cos I haven't included every voluntary organisation that we work with just some of the key ones but I will put them here then I will have another...

DS. That's your internal-like you have got internal and external.

FA. Yeah like internal and external body for scrutiny- um and then internal management then external processes/networks. They are on an equal level and they are just another mechanism for communicating with people.

OK. Then we have obviously got our partner organisations which-

Where have I put the Governing Body-have i put them on already? They must be here- yes they are, internal assurance.

So, obviously, the work of the Governing Body is inextricably linked with the work of our providers. So the staff that I work with whether they be Local Authority, NHS Community Services, Provider Trusts, Councillors, whoever they be. Councillors is slightly separate, I don't know why I've got that one- it's an odd one because, I suppose they kind of link with Local Authorities don't they. So, they all- influence they have on my work? I mean, without Provider Trusts we wouldn't need a CCG, without providers and, the staff views are really important they are people , so I think they are probably separate.

I'm just thinking aloud now 'cos this is a bit of a.....

DS. Thinking aloud is good.

FA. Because I work specifically with the public and there are other engagement with staff but they are important because they are people. So, I think I might put staff – um- here and again they link in because they are people. Does that make sense?

DS Yep.

FA. And this is providers really and I have just got them on two stickies but – providers. Are they more influential in terms of my work? Than people. No, I don't think they are, and quite rightly.

The Engagement and Comms Leads Group was set up with the CSR and it is basically 16 partner organisations and it's the Engagement and Comms Leads from all those so it's all the provider trusts, local authorities, public account Healthwatch, Fire and Rescue, SWAST etc. So, they are important and they influence in a similar way to Healthwatch but not exactly the same so I'll just put them up there and I think, I don't know where I am going to put these. They have a role but they don't set the direction of my work the CCG does but it- I feel like they should be up here somewhere but actually they are not that influential to me in my role.

DS. And that is what you are reflecting.

FA. Yes. So, I think they link into the people but they link into the organisation bit. I think I kind of want to put them on the side and they are not at this level but they are linked to what we do and what we are doing because we are commissioning their services. So, the views of local

people should be influencing us- the views of local people, with our processes in place and working meaningfully will inform our local Governing Body and therefore our commissioning and that's who we commission for so I have put that there.

Twitter, Facebook, social media has an ongoing influence because I follow it and I learn and I gather views so I think social media is here and feeds in again to the whole views seeking.

Does that make sense?

DS. It does.

FA. And councillors are public- but I don't want to put them with them because they

DS. – because that's their role.

FA. Ys, so they probably do fit- here- There we go, how's that?

DS. Perfect, perfect, brilliant!

FA. Oh, I definitely want to know what the others did! Is there any similarity? I know you can't say because of confidentiality but is there any similarity to peoples thinking?

DS. The process of thinking has been similar and the mechanism you use to kind of, like, unpick the question. In order to understand, you know, what you needed to bring in has been the same. The profiles of the maps has had similarities but possibly as many differences as similarities.

FA. How interesting.

DS. Yeah, yeah it has, it is really interesting.

FA. Although there won't be many people that have all of these relationships will there?

DS. No, no.

FA. Um, because of my role, so they are specific to my role and they will have their own specifics to their role so....

DS. They will. But I suppose the contexts that everybody sets in order to achieve that map has been really interesting and a lot have raised that issue of "is it me as me or is it me as my role" and it has been each individual as their role but- yeah.

But, you have been the best talker througher!

FA. I bet you say that to all the girls- boys! But it's funny isn't it because I applied then the same kind of facilitation to myself as I would apply if I was asking someone to do it – you know, as a facilitator. So, you know, break it down and then put it together. So, the best talker througher!!

DS. Gold star! Fantastic.

So, having accomplished that, the next bit is looking at- you know you have mapped the people who are influential to you in your role but how open to them do you think you are able to be with regard to their influence?

And this is talking about community- so these.... (explanation)

FA. I don't see them as a collective, as we talked about. Some are directive, some are scrutinising and then some are enabling and so on but they are quite different but as a collective they are all part of my role so together how influential are they. No, together how...

DS. Open are you

FA. Able am I to influence

DS. To allow them to influence you.

FA. How open am I to allow them to influence me?

DS. I've just made that more confusing haven't I?!

FA. It's hard to explain.

DS. I think probably, because of the way you have mapped, it may be that you feel you want to have two axes – so you have an axis for your structured entity and you have an axis for the people ? of your role.

FA. Yes.

DS. I am not supposed to be putting words into your mouth but!

FA. But that is my logical conclusion because

DS. You can't conflate them into one.

FA. No, but they are one- ooh, but oh, I don't know, this is hard! It's not easy.

DS. I know.

FA. So am I supposed to be giving one answer?

DS. Not if that doesn't feel right for you.

FA. I find it very difficult to see them as a collective.

DS. Ok, that's fine.

FA. It's all because, some of it is "you must do this" we as the NHS believe you have to engage and consult in line with the duty. But the "how" is very much led by me-us- the Team. So, there is them saying that and then across the community/world you have different people responding to that in different ways and some of them will be very tokenistic and some of them will be very the opposite- meaningful. And then in between you have got a whole range and then the other influencers even if you have got the intention to be meaningful – which is my intention- you have got a number of other pressures making you tokenistic.

You know what I am saying?

DS. I do know what you are saying.

FA. So, therefore, to make that as a community seems to me to be virtually impossible I think.

And also you have got the whole process of the CSR and like we said at the beginning, you've got the whole process of consultation. It's a different element in terms of influence than implementation.

OK. Let me read these.

So basically, going from closed to open, I think basically, because it is mandated it has to be open.

I'm doing this without reading it properly but the descriptions would have to- they are confusing me slightly. Umm, ohh.

And also different elements of this apply to different parts of that. Like, for example, "proactively support different communities" I would say we are doing that with PPEG, Stronger Voices- that's very much up this end. But overall it's the CCG. Overall, is the CCG that high up because of its other restrictions and must do's etc.

DS. So where would the CCG be?

FA. See, I think my Team is here (8) and yet we are doing this as well with the community groups. See, this is where the CCG aspires to be (10) but some of that will be because they

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should aspire to that rather than at the time, do. Whereas me, as an individual working with patient leader chair and PPEG are absolutely up here. And they have been very receptive to what has been said by the PPEG with the CSR and we have got loads of other stuff going on, we have got the work within the various different communities- it is so variable that it is almost impossible. Because there is work within the communities we have got locality variation, you have got Team variation, you have got individual variation. Not only to want, but ability, knowledge, skill, expertise, background, approach- ohh!!!

DS. So, if you are talking about you, in your role.

FA.OK, going back to me – I thought we were talking about the CCG.

DS. Well, I distracted you. But your role in the CCG, you have to sit in the CCG to deliver what you are employed to deliver. How open to influence do you think you are in that role?

FA. How open to influence you are- me?

How open to influence am I, not what can I influence?

DS. Mmm.

FA. How open to influence from local people am I?

DS. That's you community that you have identified.

FA. So, in reality, how open to influence am I able to be?

DS. Yes.

FA. Ok, so that is different. I would say I am here (10) individually but the reality is different because of the structure.

How open to influence am I able to be- oh bloody hell, sorry!

Oh my God this is very hard.

It shouldn't be this hard should it? Or is the whole essence of it that it is hard?

OK, so it is definitely up here. We definitely proactively inform and support communities so that they can engage on an equal footing and be influential on relevant bodies and committees. We definitely do that. I am able to do that.

The whole essence of Stronger Voices, the whole essence of the HIN, working with CVS, our contract with the DVA is about them supporting their communities to have a stronger voice. Our

Stronger Voices work is all about supporting communities to have a stronger voice. Our work with the localities is all about developing the patient groups they have for stronger voice. So, we are definitely a 7. I am able to be definitely 7 in my role.

I think that these are where we aspire to be and I think there is willingness, for example, I have been asked to meet with David Jenkins next week to look at our PPEG Stronger Voices structure so we can make sure it is meaningful before implementation. So that is absolutely willingness. But, I think this is aspirational but I think the reality we are probably a 7.

The shift in the last year of the assurance that our work has given people like David Jenkins and Healthwatch and so on and they are working towards this because of the progress they have seen us make and the relationships we have built with them and so on.

Resources will affect capacity to maintain 7 across the board.