Ensuring Digital Inclusion

Professor Vanessa Heaslip – Professor of Nursing, Salford University. Visiitng Professor of Public Health, University of Stavanger

Professor Debbie Holley – Professor of Learning Innovation, Bournemouth University

Learning outcomes

- Recognise the links between determinates of health and digitalisation across the life course
- Have a critical awareness of the range of barriers to digital technology experienced by different groups
- Consider aspects of inclusive digital practice that can be taken forward into clinical roles

Introduction

This chapter starts by providing an overview of the principles of inclusion as well as covering key terminology such as differences between equality and equity. It will note global policies driving digital healthcare recognising the potential benefits in terms of health access and quality of care, however it will also recognise that unless effectively managed it also has the potential to widen the health divide for some groups who currently have worse health outcomes. Three case studies will be presented as exemplars of those who can be digitally excluded; those experiencing homelessness, Gypsy, Roma, Travellers, and older people. Lastly, it will introduce the notion that nurses and midwives have a key role in ensuring that no-one is left behind and provides an example of a case study where digital inclusivity was considered. Learning exercises are embedded throughout, to enables nurses and midwives to see how they in their advocacy role can champion digital inclusion for all.

Genomics, artificial intelligence, digital medicine and robotics are all predicted to ensure safer, more productive and effective personal care for patients. The advent of telemedicine has been accelerated by the pandemic (Juniper Research 2021); and technology and digitalisation is significantly improving the experience of, and access to, health professionals. Yet assumptions of universal access underpin many initiatives. We argue it is important that we consider these initiatives critically from an equity lens in order to ensure that these advancements do not widen the health divide. The terms (in)equality and (in)equity are used interchangeably yet Heaslip et al. (2022a) argues that we need to appreciate and understand their nuanced differences in order to appreciate the challenges people can face in access and experience of healthcare (see table 1). Digital inclusion is defined by the United Nations (UN) as *"Equitable, meaningful, and safe access to use, lead, and design of digital technologies, services, and associated opportunities for everyone, everywhere"* (UN Round Table, live document).

Table 1	Key Terms	(Wilson	et al.,	2018)
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Health	Differences that exist between groups in health service access, health		
inequalities	status and outcomes— sometimes inequalities are acceptable, for example		
	breast screening programmes for men and women are not equal		
Health equity	Achieving equity requires the provision of different attention to groups		
	adversely affected so equality in access, status and outcomes can be		
	achieved		
Health	Underpinned by social justice, health inequities refer to the unjust or unfair		
inequities	differences in health access, status and outcomes that exist between		
	groups of people		
Health	Absolute and relative differences in health status and outcomes between		
disparities	groups and is used to provide evidence of health inequities. For instance,		
	differences in access to determinants of health and health services and		
	quality of health care		

Global policies on digitalisation and health for all

A number of global initiatives underpin the desire for access to equitable health provision. Most notably are the UN Sustainable Development Goals (SDGs) set out in the 2030 Agenda for Sustainable Development as a series of aspirations, to be embodied within Governmental policy agendas (UN 2015). Whilst we recognise that all the SDGs are related holistically in terms of the lived experiences of people across the globe, we wish to focus on the following SDGs;

- SDG 1: No Poverty: ending poverty in all its forms everywhere
- SDG 3: Good health and well-being: Ensure healthy lives and promote well-being for all at all ages
- SDG 4: Ensure inclusive and equitable quality education and promote lifelong learning opportunities for all.
- SDG 10: Reduced inequality within and among countries

Undoubtedly, the global Covid-19 pandemic placed a severe strain on the progress of the SDG (UN 2022), however it also really illuminated their importance through highlighting the global health inequities both within and across countries.

Taking the values underpinning the SDGs, the World Health Organisation (WHO) Global Strategy on Digital Health (WHO 2021) recognises that information and communication technologies present new opportunities and challenges for the achievement of the SDGs. The opportunities are to promote health for all through the strategic and innovative use of digital technologies, however the WHO (2021) also assert that both gender equality and health equity have to be considered when planning and prioritising digital interventions to ensure that digital health technological advances do not perpetuate inequity. This commitment towards health equity and gender equality was transferred into the WHO European Regional Action Plan (WHO European Region 2022) who recognised that digital technologies have to be seen as a key determinate of health (more on this later) which is a main driver towards health equity and that member countries have to develop inclusive digital societies.

Digital exclusion

Data from the Office for National Statistics (ONS) (2019) identified that whilst the numbers of internet non-users has been declining in the UK, in 2018 there were still 5.3 million adults, 10% of the total population who did not use the internet. Of those that did use the internet, 6.4 million adults or 12% only had limited ability in using the internet. Saifuddin and Mette Jun Lykkegaard (2016) in exploring digital exclusion in higher education identified three main contributors to digital exclusion that we argue transcends beyond higher education into general society:

- social exclusion low income, avoidance of technology, lack of motivation and commitment, or physical or mental disability
- digital exclusion lack of hardware devices and internet services
- accessibility division in Wi-Fi connectivity between rural and urban areas, and differences in digital and information literacy

However, other factors are also relevant, including age, as older people are more likely to be digitally excluded (Helsper and Reisdorf 2017), gender as the digital divide negatively affects

women (Yang and Du 2021) and educational attainment, as lower education is strongly associated with non-internet use (Helsper and Reisdorf 2017). Both Greer et al., (2019) and Helsper and Reisdorf (2017) assert that economic disadvantage is one of the strongest determinates of digital disengagement. A recent Lancet and Financial Times Commission (Kickbusch et al., 2021) argued that digital transformations have to be considered as a new determinate of health (Figure 1) due to the significant impact that digital technology has across the life course.

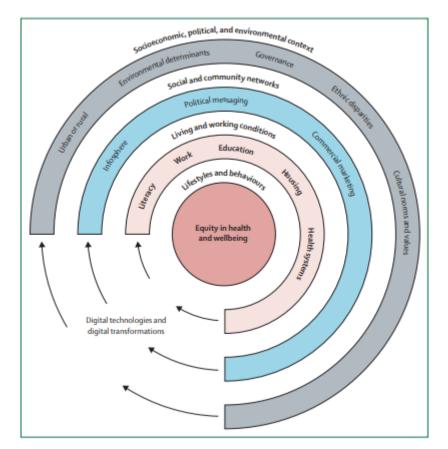


Figure 1 Digital Transformation as a new determinate of health (Kickbusch et al., 2021)

Using education as an example, home schooling during the Covid -19 pandemic has had a negative impact on education of young people living in poverty due to lack of digital infrastructure in homes (UK Parliament 2021). This can have long term health consequences as there is multiple evidence linking school attendance and attainment with better physical and mental health (Department of Health and Social Care 2021). Nurse education is also affected by digital exclusion, despite calls for every nurse being a 'e-nurse' (Royal College of Nursing (RCN) 2018) and the Topal Review (2019) both of which assert the key digital skills

required by nurses and midwives and the need to incorporate these into preparatory training programmes. Nursing and midwifery programmes have seen an increased use of hybrid and online learning, simulation skills-based packages and remote working using digital technology. However, Padagas (2021) research recognises that many nursing students' education is negatively affected due to poor internet connectivity. We also argue that as nurse and midwifery education is committed to widening participation encouraging applications from young people from disadvantaged backgrounds then we cannot assume all students have access to personal laptops. Indeed, the Office for Students (OfS) Digital Poverty report (2020) identified the intersectionality of disadvantage for those from the global majority, low income and disability. Of particular concern was 4% of students who reported no internet access was possible; this equates to 104,000 students across English Higher Education institutions.

Because of this impact that digitalisation has across all aspects of people's lives then Helsper (2021) argues that we need to consider socio-digital inequalities due to the links between digital inequity and social/societal disadvantage. Her Corresponding Fields model calls for a societal level exploration of the drivers of digital inequalities. These concepts have been amplified in calls for all people to become digitally literate through collaborations of public and private partnerships, thus moving towards a digitally connected society (Alvarez, 2021). These principles are reflected in the recently revised EU digital competence framework (Vuorikari et al 2022). Ultimately, we need to be cautious not to lay the blame on individuals and communities for their lack of digital skills, capabilities and digital linkages as digital transformation has to be embedded within wider social, political, society and economic processes (Kickbusch et al. 2021).

In order to further explore the experiences of people who could find themselves digitally excluded we wish to present the following case studies: people experiencing homeless, Gypsy, Roma, Travellers and older people.

People experiencing homelessness

Homelessness is on the increase (European Social Policy Network 2019) and the mean age at death for men is 45.5 years and for women 43.2 years (ONS 2022a), as such they are a group

with significant health inequity. A systematic review by Heaslip et al., (2021) identified that technology has the potential to support health and well-being of people who are living on the street, however there are challenges in terms of connectivity. The review identified that mobile phone ownership ranged from 53% to 100% (including both mobile and smart phones) yet access to the internet on these devices could be poor due to limited access to wi-fi and poor digital literacy skills, with older people experiencing more difficulties. Access to free Wi-fi is essential for those living on the street, as they tend to rely on pre-paid mobile plans which are more expensive (Humphry 2021). Therefore, they tend to gain access to the internet through public resources such as libraries, internet cafés, and night shelters (Heaslip et al., 2022b) and these are problematic in terms of 1) access and 2) confidentiality when dealing with health issues. Many people experiencing homelessness also have concerns using digital technologies due to worries regarding who has access to their personal data (Heaslip et al., 2021) and this inhibits their use.

Gypsy, Roma, Travellers

Gypsy, Roma, Traveller communities experience significant health inequities linked to higher mortality, morbidity and infant mortality as well as difficulties accessing healthcare (Heaslip et al., 2019). In terms of Gypsy, Roma, Travellers digital access there is a mixed picture in terms of access and connectivity with some writers arguing poor (Garmendia and Karrera 2019) and others noting good access (Salemink 2016) depending upon location in terms of site provision and country of residence. Research in the UK by Scadding and Sweeney (2018) with Gypsies and Travellers identified that 20% had never used the internet, 52% reported low confidence in using the internet and only 38% had a household internet connection and this is much lower than people living outside of these communities.

Where Gypsy, Roma, Travellers have a smart phone they typically use this to communicate with other people in the community or family through closed social media sites such as WhatsApp or Facebook (Garmendia and Karrera 2019, Salemink 2016). Digital literacy is also lower in these communities (Salemink 2016; Garmendia and Karrera 2019), largely due to poor literacy skills in general (Scadding and Sweeney 2018) and this can inhibit wider use of digitalisation, especially for older people. Salemink (2016) argues there is also a gender aspect here as women tended to spend more time at home providing more opportunity to develop

digital skills compared to men who they argue are at greater risk of digital exclusion. Reasons for low internet use was linked to age (above 40), which is much younger than those in non-Gypsy/Traveller communities as well as challenges with connectivity due to cost of the internet (Scadding and Sweeney 2018). Many Gypsy, Roma, Travellers also live in rural communities or travel in rural areas and as such there are additional problems with connectivity due to rurality (Townsend et al., 2020).

Older people

Unlike the two previous examples, both of which experience overt discrimination and marginalisation within society, older people who are less stigmatised can also find themselves marginalised in terms of digital exclusion. The numbers of older people both in the UK and globally is increasing, especially in the older age group (>80 years) (WHO 2022). The most recent Census in 2021 identified that in the UK there are over 11 million people (18.6% of the total population) aged 65 and older and in this were 527,900 people who were ≥90 years old (ONS 2022c). It is important to recognise that older people are not a homogeneous group but consist of people from different ethnicities, social, economic and health status and these intersectionality's may have an impact upon their health, well-being and access to services.

Older people are at risk of digital exclusion because they are less likely to utilise communication technologies such as smart phones and tablets (Hill et al 2015). A large multi cohort study of 108,621 older people identified a range of digital exclusion across multiple countries from 23.8% (Denmark), 30.4% (England), 65.5% (Mexico) and 96.9% (China) (Lu et al, 2022). However, intersectionality is important here as research by Lui (2021) identified that Black and Minority Ethnic females with lower social status tend to have the lowest computer and smart phone ownership. This research also showed a decline in online information seeking amongst white males, regardless of social status and black and ethnic minority males and females with a lower social status. Digital exclusion in older people is influenced by a lack of digital literacy, research among older non digital users by GallistI (et al., 2021) identified that lack of training and support acted as a barrier to engagement. Furthermore, trust in using digital technology is lower in older people and this too is a barrier (Mubarak and Suomi 2022). There is a link between digital inclusion and health as research

identified that functional dependency was increased in those who were digitally excluded (Lu et al 2022).

Learning Exercise 1: Reflecting on excluded groups

Considering the three case studies presented previously. Take one of these groups and apply it to your service. Reflect upon

- How you communicate to clients in this group regarding access to services and wider resources available
- 2) How much of this communication utilises digital aspects?
- 3) Identify the barriers and challenges they may face in accessing your service
- 4) What alternative provision could be provided

One way to promote digital inclusivity is through the use of digital intermediaries to assist with the digital divide (Warren 2007). These are typically friends or family members who assist those digitally excluded to be able to utilise digital technology (such as completing online forms, internet shopping etc). Whilst this is beneficial, there are issues regarding confidentiality and privacy with regards to relying on personal intermediaries. As such, we argue that any further growth in digital healthcare provision must be matched by a growth in professional digital healthcare intermediaries to support those digitally excluded to navigate the digital resources provided. Furthermore, we also assert there needs to be an investment in digital champions and digital training to support those who lack digital literacy.

Role of Nurses and Midwives

Despite the advances in technological and digital health there are concerns that nurses and midwives have not kept pace with the rapid changes in digital technology (Booth et al., 2021). We must however remember that the nursing and midwifery profession is diverse and as such they may also face challenges in accessing and utilising digital technology and therefore may find themselves digitally excluded. Indeed, research conducted by the Royal College of Nursing (2018) with 896 nurses and midwives identified that whilst 81% perceived that data information, knowledge and technology would make a positive contribution to nursing and midwifery just under 50% felt that their organisation was doing a good job in supporting them to develop their digital capabilities.

Learning Exercise 2: Map your digital skills

- 1) Please access one of these digital capability frameworks and undertake a selfassessment of the areas of competence.
- a. Health Education England
 <u>A Health and Care Digital Capabilities Framework</u> (Digital Literacy Capability <u>Framework 2018.pdf (hee.nhs.uk).</u>
- b. The Australian Digital Literacy Self-Assessment Tool (2020) <u>https://thinkspace.csu.edu.au/digitalcitizenshipguideetI523/digital-literacy-self-assessment-tool/</u>
- 2) Investigate whether your Trust has a Chief Nurse Information Officer (CNIO) and explore what your Trust is doing in terms to addressing Digital Inclusion for staff

We argue you do not need to be an expert in digital health in order to influence the digital agenda. As a nurse of a midwife, you have significant expertise about your service and the population you work with and as such you have a key role in highlighting to your organisation the impact of digitalisation in the clients you work with. This may include highlighting the digitally excluded groups you work with and advocating for these patients to ensure that they are able to access all dimensions of your service (including digital). This advocacy may include being part of task and finish groups looking at developing new digital technologies to ensure that it is user friendly, patient centred and inclusive.

Building Inclusivity

In order to support readers to consider how they can build or ensure digital inclusivity, we share an exemplar; The Greater Manchester Kidney Information Network (GMKIN). This network was set up in 2013 and aims to support people living with kidney disease (Vasilica and Ormandy 2017). The network consists of three main online sites including:

- GMKIN website (www.kinet.site), which include informational pages, a forum, blogs and commentaries
- GM Kidney Information Network Facebook page
- Twitter @GMKInet

At the development of the network, it was recognised that engagement of users was essential. This was facilitated through the network development group consisting of patients/ carers (n=10) and health practitioners (n=5) who worked together to co-design the network (Vasilica 2015). This was done in three stages; stage 1 was an initial consultation where different social media platforms were reviewed to explore what was good and the potential hub was explored. Stage 2 consisted of a presentation of the hub and discussions regarding colour, usability, and accessibility (creating accounts, writing and sharing posts and adding comments). Stage 3, platform testing and virtual meetings to refine the hub before it was released to the public. At stage three, a forum was developed on the GMKIN platform to allow patients/carers to post technical queries and support each other thus building social support (Vasilica 2015).

Inclusivity was also built into the testing stage as patients who were not regular internet users were also recruited. They were provided with an ipad and broadband was purchased to enable them to go online, they also received training by the researcher so that their feedback regarding using the site were incorporated. This training typically lasted for an hour to build confidence in using the technology and this was supplemented by step-by-step user guides (Vasilica 2015). This example demonstrates the important principals of digital inclusivity namely co-production with people as well as consideration and amelioration of some of the barriers to digital inclusivity.

Conclusion

Digitalisation is a fundamental component of contemporary society and as such we as nurses and midwives have to consider it as integral to the wider determinates of health across the life course. There is huge possibility for ensuring health for all through digitalisation however, to achieve this we must ensure that all communities we work with are able to access and utilise any digital services developed. We cannot assume universal access and have to recognise there are many individuals and communities who may find themselves digitally excluded and this may also include our professional colleagues. We have a professional responsibility to ensure that any digital health services developed consider those who experience digital exclusion. If we fail to do this then we risk widening the health divide for individuals and communities that already experience health inequity.

Key Points

- We must critically challenge perceptions of universal digital access, recognising that individuals and communities experience digital exclusion, including the impact of intersectionality which compounds exclusion
- 2) We must critically examine our current provision, exploring whether there are aspects of our services which unintentionally exclude those experiencing digital exclusion and seek ways to address this
- 3) People who are marginalised and experience discrimination may lack trust in digital healthcare technology and we as nurses and midwives need to feel confident in the digital services offered so we can build trust in their use
- 4) We must be aware of digital innovation being considered within our organisations and use our advocacy role to ensure they enable inclusion for all
- 5) We must ensure robust evaluation of new services in terms of equity and the degree to which they do or do not facilitate access for those digitally excluded

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