Access Denied!

Transforming care pathways equitably in an increasingly digital world

Health Innovation Network South London

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Foreword

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To meet the needs of patients and residents, the NHS and social care system in England has the opportunity to digitally evolve and transform services to help patients get to the most appropriate environment for their assessment, for their treatment and for their care and to improve clinical productivity by making the right thing to do for patients always be the easiest thing to be done by our clinicians. In doing so, it is vitally important that inequalities are not exacerbated or created in the process, a concern recognised in the four reform goals in the Government's plan for digital health and social care which specifically mentioned preventing people's health and social care needs from escalating and the need to reduce health disparities.

At the same time we live in an increasingly multichannel world with many services offered via physical or digital channels and healthcare is no longer an exception. Through the pandemic, there has been a rapid proliferation of digital channels to access and interface with healthcare services (such as the NHS App, online consultation or triage tools and improvements with NHS111 Online) along with an array of tools and platforms designed to enable remote monitoring of patients and support patients in managing their conditions.

This rapid uptake of digital channels can be beneficial to many. For example, improved flexible access to services out-of-hours and accessibility for those preferring digital formats for communication if visually impaired or with poor English skills. Nevertheless, there are also increasing concerns around the use of and access to digital tools exacerbating health inequalities leading to a specific mention in the newly published Data Saves Lives report.

"...digital tools to support care should not exacerbate health and care inequalities. Digital services should be inclusive for all communities and requirements, and should always be part of a multi-channel offering with appropriate support (including face to face) available to those who need it."

There's a growing evidence base supporting this, which indicates a close correlation between digital exclusion and social disadvantages. According to NHS Digital research, people who have characteristics that are protected under the Equality Act 2010 (age, disability, race) are less likely to have access to the internet, and the skills to use it. The nature and impact of these risks have not yet been properly understood and this has led to wide variations (both warranted and unwarranted) in the impact of digital services. It is therefore of paramount importance to better understand, plan for and/or mitigate against these risks.

So whose role is it to address these risks of exacerbating health inequalities through digital? In the current landscape, it is not clearly defined, but it is likely that the burden for driving this agenda will rest jointly between the designers and developers of digital tools and the NHS organisations who select and implement them. This confusion is why this report includes eight practical tips, which can be used immediately to help those who want to help but perhaps don't know where to start:

1. Work with digital innovations that meet the highest standards for accessibility and usability.
2. Test digital products and services thoroughly with a cross section of patients, providers and commissioners.
3. Use data to optimise and improve delivery to improve outcomes and minimise exclusion over time.

4. Understand how different people may need specific channels of delivery at different times or for different services.
5. Ensure you capture data so you can measure and compare outcomes and experience by channel.
6. Don't plan care pathways for the majority – ensure it is optimised for those from minority backgrounds too.
7. Consider the support needed to move people to digital pathways.
8. Ensure equality impact assessments for transforming care pathways pay attention to digital exclusion as a potential risk of inequality.

Alongside these are two wider recommendations that we would call on designers, developers and the NHS to work together on:

1. We need to develop frameworks, similar to those seen for information governance and clinical safety, which would set out guidance for mitigating against health inequalities that could become adopted and embedded by design.
2. Ethical considerations must be built into the clinical safety case of the tool and data used to inform or train algorithms must be thoroughly examined for bias.

Digital technology innovation can undoubtedly improve health inequalities for our most vulnerable communities - as long as the humans embedding it address its weaknesses as well as its strengths.

While the role of digital is being considered by the newly formed ICBs across England, we have an opportunity to ensure it is embedded correctly. Digital technology innovation can undoubtedly improve health inequalities for our most vulnerable communities - as long as the humans embedding it address its weaknesses as well as its strengths.

Background

The Health Innovation Network (HIN) is one of 15 Academic Health Science Networks (AHSNs) across England whose mission is to drive the spread and scale of evidence-based innovations across the NHS and social care in England. Recent years have seen a rapid increase in the propagation of digital health innovations and digitally-enabled services, which has further intensified and accelerated due to the COVID-19 pandemic.

Through this work, we have seen a wide variation in how digitally enabled pathways and services mitigate against creating or increasing inequalities. Whilst acknowledging that some current practices are suboptimal, we must also bear in mind that we are at a relatively early stage on this digital transformation journey within healthcare. Therefore, it is helpful to take a learning systems approach to iteratively improve practices, as the digital maturity of the system increases along with the digital literacy of the population.

Moving forwards, we want to support the transformation of care pathways through adopting and scaling innovations equitably, ensuring that no one is excluded when trying to access services and/or suffers poorer clinical outcomes as a result.

In December 2021 the HIN hosted a roundtable discussion exploring health inequalities in the context of developing and implementing digital health innovations so that we could further the discussion and understanding of this critical and complex issue. The roundtable was attended by 17 participants who represented expert views from across industry, academia, the voluntary and charity sector, healthcare providers and commissioners. The HIN would like to thank all those who attended the roundtable and shared their valuable insights.

Health Inequalities Related to Digital

According to NHS Digital, exclusion in healthcare pertains to those who are unable to access or use healthcare services by digital means because they lack the digital skills to do so, cannot access the internet or are unable to use the tool due to inadequate accessibility of the solution.

Digital exclusion is one dimension of health inequalities related to digital services. However, those that are not digitally excluded may also experience different levels of access and outcomes depending on whether they use digital in place of traditional means. For example, a person using an online GP consultation tool may be unsuccessful in obtaining a same-day appointment because all the same-day appointment slots had been reserved for walk-ins, or for those who phoned the practice that morning. It is therefore important to consider and mitigate against health inequalities that may arise from both using, and not using, digital tools.

While there is fear that digital is increasing health inequalities, one should not forget that there are also digital technologies that are specifically seeking to reduce health inequalities. Examples of these include:

Health data exchange portals such as the Coronavirus Dashboard set up across sectors, primary, secondary, social and voluntary care organisations to improve integrated care for all patients, often particularly benefiting people requiring cross-sectional care (who tend to suffer inequalities).

Technology being used to tackle health inequalities by supporting women in the workplace, as well as the LGBTQ+ community.

Adding text and chatbot functions into clinical practice to reduce costs, refine workflow efficiencies and improve patient outcomes.

SMS positively increasing the uptake of antenatal care visits and skilled birth attendance in low to middle income countries to improve maternal healthcare.

Design and Development

Digital health innovators don't intend to exacerbate health inequalities when designing, developing and commercialising their products. Nevertheless, inequalities do arise or increase through the design and development of the product itself.

Limitations of Standards and Guidance: Measures to mitigate against health inequalities related to digital within product design and procurement standards are currently lacking.

Although progress has been made by NHS Digital and NHSx around accessibility and usability standards and guidance, the main risk management standard for developers (DCB0129) does not align well with agile development where software is frequently released and updated. There are benefits for both patients and the digital health industry in developing frameworks, similar to those seen for information governance and clinical safety, which would set out guidance for mitigating against health inequalities that could become adopted and embedded by design.

Driving Responsible Innovation: Most companies working with the NHS and social care services operate ethically and develop innovations in a responsible way. However, without mandated standards, some companies will invest less time and money in mitigating against any inequalities arising from their products. This may manifest as failing to adhere to the Web Content Accessibility Guidelines (known as WCAG 2.1) or through more subtle decisions, such as the number of languages the solution is made available in or whether the software is built to operate on multiple operating systems.

Throughout the development of any digital health product, hundreds of small decisions will be made by the developers which may impact positively or negatively on inequalities. To practically enact responsible innovation, some companies are beginning to develop strategies to mitigate against implicit biases which may have negative consequences for patients. These can involve simple checkpoints and escalation routes from coders to in-house experts and advisory boards, in order to save companies from making decisions that might seem technically or commercially sensible but may be deemed unacceptable by clinical communities or by broader society.

Tip 1:

Work with digital innovations that meet the highest standards for accessibility and usability.

Bias by Design:

Industry has a social and ethical responsibility to mitigate against this risk by incorporating, from the very beginning of the journey, clinical safety by design and governance with lived experience by design, which examines how a tool makes decisions and should ensure that decisions made by the technology do not negatively affect a patient in their journey based on a health inequality. Part of a responsible approach to innovation is ensuring that ethical considerations are built into the clinical safety case of the tool and that the data used to inform or train algorithms is thoroughly examined for bias.

Tip 2:

Test digital products and services thoroughly with a cross section of patients, providers and commissioners.

Good Product Design Practices: Throughout the product design stages innovators need to work with their intended users, along with the healthcare service providers and commissioners, to ensure that their product ends up meeting the needs of each group. Poor product design or poorly designed digital pathways can exacerbate the actual health issue as much as helping it, therefore it is critical that good product design practices are adhered to.

Engaging the intended users in the design is critical to mitigating against inequalities. It must be representative of the full range of intended users, ideally including those who would be considered at risk of being excluded. More alpha and beta testing of solutions should be undertaken with people who have both low digital and low health literacy to ensure the design will meet the requirements for everyone who needs to access the solution.

Finally, collaboration with commissioners is important throughout the design of a digital health product so that there is a clear value proposition that is inclusive. Cost may be a factor driving digital transformation, however, reducing inequalities through the design of the product can add to the value proposition. For example, a digital product that enables the completion and management of Mental Health Act forms can save money, but the commissioner is really purchasing the outcome, which reduces the time that a patient spends in crisis before being placed in an appropriate care environment.

Iterative improvement: The health system is still learning about all the potential impacts of digital transformation on inequalities, so it is unlikely that all risks of exclusion will be identified and mitigated in advance of development. Iterative development and continuous improvements to the product based on analysing use-data and user interface design to improve usability, ideally with an outcomes-based feedback loop, is preferable.

Tip 3:

Use data to optimise and improve delivery to improve outcomes and minimise exclusion over time.

Establishing trust: Patient feedback shows there are two key areas where trust must be established to maximise positive engagement and reduce hesitancy to engage with digital. These are, assuring people that their data is being handled responsibly and securely and trust that the clinical effectiveness of the digital health product is comparable with traditional routes. A lack of trust can be a disproportionately big issue in certain sections of the population and may lead to people avoiding digital tools, which leads to inequalities. There are many theories around how to establish and build trust and two elements that are believed to be critical are being transparent about privacy and use of data and clearly explaining how the technology fits into the broader delivery of people's care. NHS England has written a detailed report on how data can improve individual care, speed up diagnosis, plan local services and research new treatments.

Implementation and Adoption

A digital health product can be perfectly designed and developed for inclusive care, but still lead to health inequalities because of the way it is implemented and adopted into services or care pathways.

Selecting the right channel to solve the right problem: When thinking about improving health services, it is important to be clear whether digital is indeed the right solution to a problem. We need to focus on what the impact of particular pathways is on different groups, taking into consideration the relevant population's social and physical characteristics and paying particular attention to the needs of those who are already likely to be disadvantaged because of a protected characteristic or who already suffer from poorer health outcomes. The transformed pathway should take into account and mitigate for those who might struggle to access services, The optimal inclusive pathways could be formed through an amalgamation of pathways, blending traditional and digital routes, allowing choice for the individual. In order to sustain an equitable service when multi-channel pathways are being used, it is important to collect the data to evidence individual outcomes and experiences of different channels, to enable us to ensure equitable outcomes and design better services in future.

Tip 4:

Understand how different people may need specific channels of delivery at different times or for different services.

This multi-channel and blended/hybrid approach also takes into account the difference between designing pathways for people who are digitally mature, compared to those who suffer from a health inequality translating into a digital exclusion. For example, a person of working age with an early long-term condition will mostly likely be able to use digital solutions to empower them to take better control of their condition and avoid unnecessary trips to the hospital. This is different to implementing a pathway for people who cannot (due to an underlying health inequality) or will not, engage digitally due to lack of motivation or trust, poor digital literacy, and/or accessibility issues. In this scenario, exploring the root-cause of the problem to plan the pathway for the minority, whilst optimising for the majority will require a multichannel approach.

Tip 5:

Ensure you capture data so you can measure and compare outcomes and experience by channel.

For example, when the AHSN learning network supported the implementation of COVID-19 Oximetry @home and COVID-19 Virtual Wards to support patients through the pandemic, they adapted the pathways based on local needs. In some areas, people were given access to technology that gave information about their readings directly to the healthcare team who were monitoring people as well as to the pulse oximeters. Whereas in other areas, people had to record their oxygen reading in a diary and provide updates on the telephone. It remains to be seen which solution led to best outcomes at a population and individual level.

Accessibility: A key aspect of inclusive service design is meeting the user's accessibility needs to ensure equitable access is provided. Frameworks to ensure digital services can be accessed by all, such as the Digital Technology Assessment Criteria (DTAC), have become national baseline criteria for digital health technologies to adhere to when entering the NHS and social care. DTAC gives staff, patients and citizens confidence that the digital health tools they use meet our clinical safety, data protection, technical security, interoperability and usability and accessibility standards. The NHS service standard 5 also provides detail on why and how to build an inclusive service so that everyone is able to access the care they need. It includes GOV.UK resources and NHS Digital guidance on accessibility support and requirements for public sector organisations.

Other ways to support digital accessibility include trusts, local organisations, councils or digital companies themselves offering digital support packages to reach those who feel excluded because they don't have the skills or tools necessary to engage. Some digital companies are known to have set up Digital Support Hubs across the UK with a team of volunteers offering free training and support in local libraries or community venues where people can learn how to use technology and digital devices through informal learning and guidance.

Tip 6:

Plan care pathways for minorities as well as optimising for the majority.

Tip 7:

Consider the support needed to move people to digital pathways.

Digitally mature GP Practices are getting more and more inventive with the way they support their patients to access the care they need. Digital patient champions are being trained to support those who are less digitally savvy and practices are developing their own inclusive tools and guidance for colleagues and patients, based on local population needs. For example, providing information packs in a variety of languages. NHS England is also developing a programme of work to support all practices and PCNs to move towards providing Digital First services. All of this work can help focus support on the areas where health inequalities are more prevalent.

Human bias: Human unconscious bias can also inappropriately impact patient outcomes. Professionals may not allow or avoid signposting someone in their care to access or engage with a digital service because the professional's own biases categorise them to be unsuitable or unable to engage with digital, perhaps due to being elderly, disabled or from a deprived background. This can unfairly disadvantage someone who would benefit from using digital. A professional's own views and experiences of digital channels in general and around the efficacy and utility of specific digital tools may also disadvantage patients. Moving forwards, commissioners and service providers will need to address this through training to mitigate against these causal factors maintaining the digital divide.

Tip 8:

Ensure equality impact assessment for transforming care pathways pay attention to digital exclusion as a potential risk of inequality.

Optimisation: Digital transformation can happen gradually as well as a large-scale change. This means there may be tools already in use in pathways, as well as new pathways where a review of the impact on equalities

could be beneficial for patients. Integrated Care Systems (ICSs) and commissioners of new solutions should

seek to undertake an Equality Impact Assessment (EIA) and mitigate against the risks of inequalities. However, there are often gaps in information systems preventing the collection of outcome data that will tell whether a digital pathway is working better than a traditional route, especially when the user is going through a multi-channel pathway. Collection and assessment of this data will help highlight and reduce system, as well as individual, inequalities.

"Professionals may not allow or avoid signposting someone in their care to access or engage with a digital service because the professional's own biases categorise them to be unsuitable or unable to engage with digital, perhaps due to being elderly, disabled or from a deprived background."

Conclusion

Health inequalities are a pervasive and enduring challenge to the delivery of a world-class health system seeking to improve outcomes. The recent massive shift to digital to complement face-to-face services has scope to both increase and decrease health inequalities. Digital exclusion, in particular, has scope to challenge the pace and scale of digital transformation, as it may result in increased health inequalities for those excluded. These inequalities need to be better understood so risks can be assessed and mitigated against, and the opportunities for digital transformation to improve outcomes can be fully realised.

"Health inequalities are a pervasive and enduring challenge to the delivery of a world-class health system seeking to improve outcomes."

The NHS is used to managing inequalities. However, the types of inequalities generated by digital transformation are different from those seen with the implementation of face-to-face services, so the risks and mitigations may be different. Inequalities of access and clinical outcomes can stem from poor product and/or service design or sub-optimal implementation of digital, and neither are well understood. The rapid shift to digital seen in recent years has had different effects on different sections of the population, both positive and negative. Therefore, when designing digital health products and the services they will sit within, it is imperative to understand the needs and desired outcomes for the population group being targeted and ensure that the channel is tailored appropriately, whether this is digital or traditional pathways, or blended pathways combining the two.

Success isn't just about getting people signed up to a digital service, it is about the effectiveness and outcomes of pathways at an individual level, but also at a system level. It is necessary to evaluate the current outcome data on the pathways that are already in place to understand if they are resolving or amplifying health inequalities, ensuring the known as well as the unknown excluded population are not left behind. Any digital intervention should be needs-driven and co-designed from the start with a large and diverse sample of people. They must focus on embedding a quality improvement culture underpinning user-centred design and seek to drive responsible and ethical innovation with industry partners. This is important as it ensures that the service design builds in equity of access and equality of outcome, creating trust in the effectiveness of the service, as well as trust in the privacy and security of the channel.

"Success isn't just about getting people signed up to a digital service, it is about the effectiveness and outcomes of pathways at an individual level, but also at a system level."

If we can take all of this on board, we should be well-positioned to transform care pathways equitably in our increasingly digital world.

"When designing digital health products and the services they will sit within, it is imperative to understand the needs and desired outcomes for the population group being targeted and ensure that the channel is tailored appropriately, whether this is digital or traditional pathways, or blended pathways combining the two."

Tackling digital health inequalities will undoubtedly be a long-term challenge for the health and care sector. At the Health Innovation Network we are determined to play a leading role in equitable health innovation and transformation of services. We welcome comments, suggestions for further discussion, or opportunities for collaboration in this space.

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