Digital Health Equity

How to design and implement digital healthcare technologies for marginalised communities



Introduction & Acknowledgments	3
Executive Summary	5
Project Background	8
Key Findings	11
Conclusion & Recommendations	25
Appendix 1: Digital Health Procurement Checklist	28

Introduction & Acknowledgements

This report shares key findings, resources, and recommendations from Joe Kallarackal's 2024 - 2025 Churchill Fellowship exploring how digital health technologies can be designed and implemented to reduce and not widen health inequalities for marginalised communities.

Joe is a consultant working at the intersection of digital transformation in health and community development. Between 2020-2025 he supported the North East London NHS Integrated Care Board to increase the adoption of digital health technologies, whilst also supporting a range of community based organisations focused on reducing health inequalities for marginalised communities. The communities are typically marginalised due to economic deprivation, immigration status, racialisation or a combination of all three.

These experiences highlighted the lack of discussion, best practice and practical guidance to ensure that the benefits of digital healthcare could be experienced by all patients and avoid exacerbating existing health inequalities.

I would like to thank the Churchill Fellowship for funding this learning exchange and all of the different experts who generously shared their time with me, listed below. I hope their experiences are accurately captured in this report and can help increase digital health equity for patients in the UK and beyond.

- Dr Mathias Lalika, FAITH! Program
- Ashton Krogman, FAITH! Program
- Janne Vermeulen, Pharos
- Eline Heemskerk, Pharos
- Dicky Gingnagel, Pharos
- Fabienne Cotte, ADA Health
- Beth Wolff, Lundbeck
- Peter Christensen, Sunhend.dk
- Pernille Have, Sundhend.dk

- Dr. Cristina Vaz de Almeida, Sociedade Portuguesa de Literacia em Saúde
- Amy Heymans, Chris McCarthy and the Design for Dignity Community
- Ivelyse Andino, Radical Health
- Perfecto Sanchez, Equity Quotient
- Wendy Johannson, MiSalud Health
- Dr. Urmimala Sarkar, UCSF S.O.L.V.E Health
- Dr. Adrian Aguilera, UCSF S.O.L.V.E Health,

- Therese Kjellerup Thosrtholm, Digst.dk
- Raquel Vargas, SNS24
- João Abreu, SNS24
- Penha de Franco Medical Centre Team
- Helder Toucas, Lisbon City Council

Digital Health Equity & Access Lab

- Reymon LaChaux. SF City Council
- Andrew Broderick, SF Tech Council
- Winnie Yu, Self Help for the Elderly
- Erin Siestra, HopeLab



Executive Summary

Over the last 5 years the way healthcare is delivered to patients has been transformed through the introduction of digital health technologies. Booking an appointment, contacting a doctor, viewing test results and ordering prescriptions are now accessible for most patients in the UK on their preferred device. As outlined in the NHS 10 year plan, this trend of digitalisation is one of the key shifts that we can expect to shape healthcare over the years to come. However, not all patients are adopting digital healthcare in the same way and many of these patients are those who are most likely to face health inequalities. Having worked on digital adoption in the NHS since 2020, I undertook my Churchill Fellowship to try and gather learnings on how digital healthcare technologies can be designed and implemented to work better for marginalised communities, with a specific focus on ethnic minority communities.

My overall reflection from my fellowship is that many countries share similar challenges to the UK in increasing adoption of digital health care tools. Addressing these requires a long term commitment to, and investment, into designing inclusively and working with communities to build trust, motivation and skills. Without this focus, we risk the health system not realising the benefits of investing in innovative digital health. The findings outlined may not seem novel to many familiar with the sector. I hope that by bringing them together with real life examples acts as inspiration and a motivation for change.

- 1. The unintended consequences of increased digitalisation must be explored fully to help shape the support needed so as many patients as possible can benefit
- 2. Diverse users particularly those who face barriers to engaging with digital health tools must be engaged intentionally at the start of designing new solutions. These users may face barriers such as their digital proficiency, cognitive ability, language, access to the internet/ devices, a lack of trust in digital technology, a lack of motivation to engage with digital health that doesn't feel culturally relevant or physical disabilities.
- 3. A deep understanding of user motivations is needed to design solutions that will actually be adopted by diverse communities

- **4.** New structures are needed to bridge the gap between technology developers and diverse communities
- **5.** We need to balance the potential capabilities of digital health with what users want and what they have the capabilities for.
- **6.** We cannot avoid the need for multi-language capability to ensure adoption by diverse communities.
- **7.** Introducing one single sign in for various public services can help users overcome the challenge of logging in
- **8.** Partnering with trusted community partners over the long term and being transparent about patient data privacy can increase patient trust in digital health.
- **9.** Immersive learning tools, gamification and utilising trusted messengers are effective methods of increasing patients' digital capabilities
- **10.** Achieving equity in digital healthcare requires measurement and analysis of who is and who isn't using it.

Based on these findings, I have 5 recommendations for the UK Health System to embed equity and fairness into its digital transformation:

- Build a community of practice and centre of excellence to make the case for inclusively designed and implemented digital health
- Make reporting functionality that allows demographic analysis of sign up, usage and user experience a requirement for all digital health care, including NHS owned applications
- Make multi-language capability a requirement for all digital health care, including NHS owned applications

- Build inclusive user centred design into procurement processes to shift norms of what is expected of digital healthcare (example procurement guidelines included in <u>Appendix 1</u>), complimenting the existing <u>NHS Digital Technology Assessment Criteria (DTAC)</u> and <u>NHS Service Design Manual</u>
- Set up new structures that can allow trusted community partners, technology developers, and health system decision makers to collaborate and amplify the voices of those who struggle to access digital health tech.

Project Background

Me: "Amma (Mum), did you know you can order your prescriptions through the NHS app?

My Mum: "Hmm ok, I look at it but it's very confusing, I will just go to the pharmacy when I have time."

Me: "It's actually not that difficult, let me show you."

After 5 minutes of demonstrating what to do on her mobile...

My Mum: "Enough moneh (son) - that isn't meant for me. There are so many clicks - let me do it the way I'm used to"

This is a version of the conversation I have had a few times with my mother, and something I'm sure many people who have tried to help older parents use digital technology can relate to. What made this encounter more frustrating for me was that for the last 5 years I have been working to increase adoption of different digital healthcare tools across North East London, and yet I still couldn't make this seem relevant and accessible to members of my own family.

Over the same period, I was working with various community based charities looking to address health inequalities for marginalised communities, such as the excellent Parent Action, Parent Skills 2 Go and Grapevine (Coventry & Warks), I saw and heard about the various challenges communities they worked with face in accessing the health and wellbeing support. If my mother - fluent in English and economically comfortable - struggled with digital healthcare, they would face even greater challenges. Conversations with various healthcare teams I was working with raised concerns that the benefits of digital health were not being equally realised by all patients, especially those who already face health inequalities. It is difficult to quantify this in the UK given the lack of readily available data at national or regional levels on digital healthcare adoption segmented by different demographic factors. However smaller scale studies from both the UK1 and the US2 support these concerns.

^{1 &}lt;u>Unlocking Digital Health: Inequalities in the adoption of a Patient Portal, RD Barker, R Gökmen, P Mistry, D Naylor, JT Teo</u>

² Inequities in Health Care Services Caused by the Adoption of Digital Health Technologies, Rui Yao

The NHS 10 year Health plan for England sets out the ambition to make a radical shift from analogue to digital. It sets out a vision where "The NHS of the future will be a service that offers instant access to help and appointments. One that predicts and prevents ill health rather than simply diagnosing and treating it. A patient-controlled system...." with a new Neighbourhood Health service providing care as "Digital by default". It also sets out bold ambitions to narrow health inequalities.

If we are seeing digital health already being adopted unequally, whilst it is relatively limited in scope, this lack of equity will likely increase as our healthcare services become more digitalised. In order to both achieve the benefits of digital health and reduce inequalities, we need to build evidence, best practice and influence policy to ensure health technologies can work for marginalised groups.

This inspired me to apply for a Churchill Fellowship, focused on learning how we can make digital healthcare tools work better for marginalised communities and be used as a tool to reduce rather than widen health inequalities. Key questions I wanted to explore were:

- How have other countries with public health systems designed their digital tools to work for marginalised communities?
 - In privatised health care systems, where providers can customise their offerings to specific customer segments/ patient populations, how have they done this? What have been the most effective interventions?
- Are there examples where digital health is being developed specifically to target poor health outcomes that disproportionately impact some more communities? What approach has been taken to design and implement them?
 - How can we implement digital healthcare tools so that they can be best adopted by communities that are likely to experience both digital exclusion and health inequalities?
- What are effective models and approaches that build the right skills, confidence, trust and motivation?

Whilst critical components to building digital inclusion, I did not focus my fellowship on exploring innovations/best practice in affordable access to the internet or devices. I believe the

_

[,] Wenli Zhang, Richard Evans, Guang Cao, Tiangi Rui, Lining Shen, JMED - 2022

UK has lots of existing good practice and innovation in this area, for example the National Data Bank and National Device Bank offered by the <u>Good Things Foundation</u>.

My fellowship involved travelling across Europe and the United States. In Europe, I visited Utrecht, Berlin, Copenhagen, Tallinn and Lisbon to meet experts in digital inclusion, health literacy, Ministries of Health/Digitalisation and innovators using AI in health in novel ways. In the United States, I attended the <u>Dignified Futures</u> conference in Atlanta, and then travelled to New York and San Francisco to meet with academics, civil society leaders and healthtech entrepreneurs.

I hoped to bring back insights that would support health tech innovators to design better and more inclusive products, health commissioners to better know how to procure inclusive digital healthcare tools and for local health systems to better understand how they can promote and build trust in these tools. My initial definition of marginalised communities was focused on Black and Minority Ethnic communities, however I believe the majority of my findings are relevant for other groups that face health inequalities.

Since applying for my Churchill fellowship in September 2023, various initiatives have emerged in the UK which support increased focus on digital inclusion and digital equity, such as the Digital Equity Charter and the NHS framework for action on Digital Inclusion. I hope this learning can support the growing movement within the UK focused on Digital Equity in health.

Key findings

1. The unintended consequences of increased digitalisation must be explored fully to help shape the support needed so as many patients as possible can benefit

Health systems across the world are coming under strain given the increasing health needs of their populations. The potential efficiencies of digital health care technologies are exciting and offer ways to truly transform the way healthcare is delivered. However many patients face challenges accessing digitalised services. Often there may be an assumption that over time challenges may lessen as populations become more "digitally native". However increasing digitalisation will continue to pose challenges for new generations - for example but not limited to, those with learning disabilities, those from different backgrounds and those who don't speak english as a first language.

The Danish Agency for Digital Government describes digital inclusion as "an imperative which must be continuously focused on when digitalising, and a key priority across the public sector." They have developed six Digital Inclusion principles³ which are shared across Regional and Local Governments. The first of these I found particularly important at the start of scoping and planning how a service will be digitalised: developing a qualified understanding of the consequences of increased digitalisation.

When setting out the vision for digital transformation, it can be easy to overly focus on the benefits without giving equal weight to the potential consequences. If there is explicit agreement and commitment that digital health should offer similar benefits to as wide a population group as possible, consideration is needed on how to make this happen. Specifically, how will communities be involved in testing digital healthcare, is there commitment to making adjustments based on this feedback and allocating resources to the different support measures required to increase adoption. As whole services become digital by default, consideration also needs to be given to what alternative processes need to be developed to not overly burden those people who will always struggle to use digital health tools. To understand

Principles for Digital Inclusion 1st edition The Danish Agency for Digital Government, Local Government Denmark and Danish Regions, 2024

the consequences, frontline health teams and diverse groups of patients need to be engaged with at the start.

For example, in Denmark they acknowledged that certain patients would always struggle with using digital public services, which are often mandatory. Rather than having to make their case to various different statutory bodies, there is a new law and supporting processes enabling a citizen to opt out of all mandatory self service solutions in one go.

When Portugal introduced their public health platform, SNS24, they appreciated that many individuals would require additional support to use it effectively for medication requests, telehealth and viewing their health record. Linking in with wider initiatives around digital inclusion, they developed the SNS24 counter network. SNS24 counters are physical spaces located in community hubs, city councils, nursing homes, prisons and mobile units. First established in 2020, they provide facilitated support for users who may struggle to otherwise use digital health services. The counters provide users a safe, free and private space to directly use digital health services - ideal for those who may have the confidence to use these services but not the access to devices or internet at home. Additionally the counters provide brokered access, where a trained digital mediator provides direct support to the user by performing key functions on behalf of the user. Given sensitivities, only a limited set of functions can be completed via brokered access, such as booking an appointment and helping a patient get set up for a teleconsultation. Organisations essentially volunteer to act as an SNS 24 counter and following an assessment that they have the right infrastructure, receive online training to allow them to then start providing services. There are currently 403 SNS 24 counters, located across the country in both urban and rural areas, with plans to expand these over the coming years.

2. Diverse users - particularly those who face barriers to engaging with digital health tools - must be engaged intentionally at the start of designing new solutions.

Digital health technologies can be better designed if they are focused on designing for those patients who may face greater challenges in accessing services digitally than others. There are various examples of the "curb cut effect" where features designed to help people with specific challenges or disabilities can create a more inclusive and accessible world for everyone.

-

⁴ The Curb Cut Effect, Angela Glover Blackwell, Stanford Social Innovation Review, Winter 2017

Examples include curb cuts (originally for wheelchairs) used by people with strollers, luggage, or bikes; closed captions (for the deaf) also used by people in noisy environments or those learning a language; and ramps (for wheelchairs) also used by people with mobility aids or moving equipment.

Taking the additional steps to engage and include patients who face challenges using digital healthcare at the start of the design process can ensure the product is inclusive and avoid costs in the long run, of having to readapt and redesign later on. When I reference patients who face challenges, this can apply to a wide variety of groups, including those who don't speak English as a first language, who have a lower reading age, who do not have digital skills, or who belong to communities where digital health technologies may not seem culturally relevant. Often when digital health tools are referred to as user centred this means a group of patients that represent the "average" user have given feedback on the user interface of a designed solution.

Case Study: Mom Connect and ADA Health

MomConnect is a flagship programme of the South African National Department of Health,(NDOH) which aims to support maternal and child health using mobile technology. Through MomConnect, pregnant women and new mothers receive free maternal health messaging via SMS or WhatsApp and can access a text-based helpdesk for ratings or queries. Since its launch in 2014, almost 5 million mothers utilising public antenatal services have registered on the MomConnect platform in over 95% of public health facilities. Mothers receive health and pregnancy-related information until their baby is two.

Despite its automated chatbot managing most messages, demand for personalized advice remains high, with over 250,000 user queries annually handled by a small NDOH helpdesk team. To enhance MomConnect, the NDOH integrated a Clinical AI (cAI) designed for symptom assessment developed by Ada Health, providing continuous access to personalized healthcare information. The cAI allows users to input symptoms, answer guided questions, and receive detailed reports with possible conditions, health information, and actionable guidance, including when to seek medical care. Previously Ada Health's cAI had primarily been used by health systems within the global North, and adaptation was required for new users within South Africa.

A recent evaluation of the MomConnect cAIs found that it increases appropriate health-seeking behaviour, shifting users from self-care to professional care. Notably, 70% of those who sought care received treatment, including new medication, surgery, or hospital admission, strongly indicating the necessity of these visits. Half of these participants initially did not plan to seek care, suggesting their symptoms might have worsened without cAI intervention, reducing treatment options and outcomes, especially for vulnerable populations

The adaptation of ADA Health's cAI for MomConnect clearly highlights the value of early engagement of users. Through early user based research, the ADA Health team identified that many mothers from lower income backgrounds could only afford limited data packages downloading new apps would be a challenge for many. Similarly, initial user research asked the question of what sources of information mothers would trust to influence their health seeking behaviour. The majority of respondents highlighted they had higher levels of trust for messages from the government. This influenced the solution design for this project: rather than deploying their existing symptom checker app, ADA integrated the same cAI functionality into a NDOH branded Whatsapp. This reduced the psychological and technological barriers for adoption. ADA also tailored messages based on local literacy levels.

3. A deep understanding of user motivations is needed to design solutions that will actually be adopted by diverse communities

Technologies are designed to offer a streamlined and intuitive process once a user opens a patient portal or opens an app, but we need to take a step to understand why would a patient even be motivated to open an app

A fantastic example of how understanding user needs and motivations can lead to a novel design of digital health tech is the FAITH! App. The Fostering African American Improvement in Total Health programme was created by cardiologist Dr LaPrincess Brewer to address poorer cardiovascular health outcomes for African American communities. Dr. Brewer and her team undertook a community based participatory research approach to translate a previous in person intervention into a mobile health intervention. They collaborated with 16

-

⁵ADA Health South Africa Safe Mom Study

predominately African American churches in Minnesota to co-design FAITH!. The appincludes:

- Personalized messaging based on user's goals
- Physical activity tracking (Fitbit synched to app to track user's daily step count)
- Daily fruit and vegetable intake tracking
- Heart-Health Recipes based on traditional African-American cuisine 15
- Fitness instruction videos
- Video testimonials from previous program participants
- Interactive sharing board for social connection and support
- 10-week curriculum featuring videos from Mayo Clinic experts discussing elements of heart health

Users log in daily to track their food intake and monitor their steps, and each week over a 10 - week period complete an educational session. By taking the time to really understand their users' needs and motivations, the team understood that including tailored messaging reflecting on their shared faith would be a feature that would encourage users to log in and use the tool. The research team worked with FAITH! Partners - nominated representatives from participating churches - to culturally tailor the program design and implementation to meet the needs of their respective congregations, including co-developing and refining all promotional, educational, and survey materials.

A recent large clinical study of the Faith! App demonstrated that it helped participants to improve the 7 most important predictors of heart health (Life's Simple 7 - American Heart Association).

The Faith! App is a promising example of how digital health can be a tool to support addressing the health inequalities many marginalised communities face. Essential to this approach is taking the time to understand target community motivations, work with members of the community to ensure it is designed in a culturally relevant way, and to work with leaders in the community to support its implementation.

4. New structures are needed to bridge the gap between technology developers and diverse communities

Engaging users early on in the process and ensuring continuous feedback may seem obvious and something which everyone would aspire to, but it is challenging to put into practice. Private sector technology development companies lack the access to diverse population

groups to co-design their solutions and continuously test and iterate them with. Along my travels I found different structures which facilitated the connection between technology designers/ developers and diverse patient groups that may prove useful for the UK. Whilst not perfect, establishing some of these structures may facilitate the collection of user views, allowing them to have a voice in shaping new health technologies. In many of the places I visited, organisations highlighted a need to move beyond transactional communication, finding ways in which health system leaders and technology developers start to understand and empathise with the challenges marginalised communities face. In the Netherlands, Pharos have developed an "escape game" which helps bring to life these challenges and in Atlanta I saw how system designers were using creative mediums like art and poetry to convey, in way more meaningful that statistics and figures, the testimonies of those facing medical bankruptcy or unequal access to healthcare.

User Panels

Sundhed. Dk is the Danish National Health platform. Established over ten years ago, it describes itself as "a user centered health universe creating value and coherence for both health professionals and citizens and supporting the empowerment of the citizens". Logging in to Sundhed. Dk and the accompanying MyHealth App allows citizens to view their personal health record, understand more about different health conditions and access various health services.

Sundhed.DK have established a user panel with about 2,600 citizens who have signed up voluntarily, following national recruitment campaigns, and an open registration process available on their website. The Sundhed.dk Panel is a community of users who help make the platform even more user-friendly. Members provide feedback and test new features so that sundhed.dk can meet users' needs in the future, either through answering online questionnaires or participating in interviews, user tests or online workshops. The Sunhed.DK team collects demographic information on panel members to support increasing the diversity of views collected. Sundhed.DK have also established a user panel with 135 clinicians, which aligns with their vision of providing value and coherence to both patients and health professionals.

Mini Assemblies

The Sociedade Portuguesa de Literacia em Saúde (Portuguese Health Literacy Society - SPLS) is a non-profit organization dedicated to promoting and improving health literacy in Portugal.

It was established to strengthen the impact of health literacy on individuals and communities, focusing on access, understanding, and use of health information. Since 2022 it has been organising mini health assemblies bringing together diverse patient groups together with municipal governments, so that local decision makers can address what is meaningful and valued by people within their communities. Previously these mini health assemblies have included a focus on digital health. This type of model can provide a rich source of information and insight for technology developers at the very earliest stages of solution design.

Public Sector/ Community Sector Collaborative Networks

The Danish Agency for Digital Government has focused on Digital Inclusion for over 10 years. A key initiative that they have developed is a Digital Inclusion Network, which brings together public sector digital teams with a range of different non profit and community based organisations. Members count around 95 different organisations and authorities, both local and central. The main objective of the network is to support and enhance the possibilities of people challenged by digitalisation to participate in the digital society. The structure provides a ready-made channel through which public sector service design/ digital teams can understand more about the challenges faced by citizens, as well as providing a clear mechanism to enable user involvement in design and testing of new solutions. The non profit organisations at both a local and national level are able to gather feedback from their members/ communities and share this back directly with those developing new digital services.

Lived experience user testing service

In the Netherlands I met with the Digital Inclusion team Pharos, the Dutch Centre of Expertise on Health Disparities. Pharos publish various resources to support and influence digital health systems to become more accessible and reduce health inequalities. During this meeting I was introduced to Dicky Gingnagel, who works at Pharos and other charities as an expert by experience, or language ambassador, as someone who personally struggles with low literacy. Dicky has received training in how to test and provide feedback on new technologies, and technology developers now pay for this service to check the accessibility of their websites, apps, patient portals and supporting materials. Dicky mentioned that he enjoys being involved at an early stage in testing different technologies, ensuring that they work in the intended way

for all patients. Having an established service that provides this support is something that many community based organisations in the UK could offer, as this can be time consuming, difficult and inefficient for tech firms or commissioners to establish each time it is needed.

5. We need to balance the potential capabilities of digital health with what users want and what they have the capabilities for.

Digital health is often viewed as the magic bullet to many of the issues healthcare systems face. As the pace of innovation increases and with the advent of AI, the list of different use cases grows exponentially. It's easy to fall into the trap of developing ever more advanced apps, with shiny, innovative features which are not what users want and most importantly are not what they will use. Being led by the technology rather than users ultimately wastes resources, both in terms of developing these functionalities and the energy used to encourage/ force patients to use them as intended.

In San Francisco, I met with Wendy Johannson, Co Founder and COO at MiSalud Health. MiSalud (My Health) has developed an innovative model where clinicians from across Latin America act as health coaches, providing basic daily healthcare, preventive care, nutrition coaching, chronic condition management and mental health support via job-site events and same-day video call, phone call or SMS chat, in both Spanish and English. Their initial target audience was largely Spanish speaking agricultural workers who face many barriers to accessing healthcare - cost, remoteness, language and a reluctance to seek treatment for mental health issues / physical issues that may not seem serious enough unless they are impacting the ability to work.

MiSalud developed its offer following detailed ethnographic user research. Through this research they understood that there was a real opportunity to increase access to healthcare for rural agricultural workers using telehealth, but they needed to design their service to maximise cultural relevance, trust and usability. Some examples of how they have shaped their service are listed below:

1. Users respond and engage more with health services when they receive culturally relevant support. MiSalud works to match someone using their service with a trained clinician from their own country. They found that rather than just hiring clinicians who can speak Spanish, hiring clinicians who understand the slang, idioms and customs of a

particular place can enable greater levels of trust and engagement with users from there (e.g. matching a Guatemalan user with a Guatemalan Health coach). To help build the trusted relationship required, health coaches will meet the users for the first time in person at a health event, helping build the foundations for continued engagement through telehealth.

- 2. Although miSalud did develop an app to support delivery of their services, they have offered different alternatives to users, such being able to access nearly identical support via SMS. Only 40% of users regularly use the app, but this isn't a concern for MiSalud, as they focus more on providing support to their users in the form and channel that they wish to receive it.
- 3. Users working in a farming environment did not organise their lives through calendars and calendar reminders, as many urban based users would. MiSalud provides appointment and medication reminders largely over SMS to reflect their users preferred way of receiving these messages.
- 4. Given lower literacy levels, MiSalud uses AI to review and update patient notes to ensure readability and understandability for lower literacy levels, which is reviewed and finalised by their health coach. Users are able to listen to their communications as an audio note, created using AI. 19
- 5. Their users had sore and cramped hands after hours of manual labour. The app has been designed to suit the needs of users with lower dexterity
- 6. MiSalud has a commitment for continually developing their platform and regularly reviews data on usage to understand at what points do users show intention and curiosity but disengage at some point in the process. Health coaches complete health visits for users and use their insights on the users living environment and context to suggest changes to the way support is delivered, via SMS or through the app.

6. We cannot avoid the need for multi-language capability.

Many patients who experience health inequalities don't speak English as their preferred language, however the majority of digital health tools in the UK are only provided in English. In many of the countries I visited, publicly owned health tools were offered in a variety of

languages to make them more accessible for a wider proportion of patients. For example in Estonia, all digital public services are offered in Estonian, Russian and English.

Technology offers the potential to more easily translate information into languages that reflect target populations. Tools such as DeepL or Google translate can often be easily integrated into existing technologies. Whilst in many scenarios these translations will require review and validation by a human, this may still save time compared to translations unassisted by technology. Similarly these types of technology can also be used to ensure that health information is being provided in an accessible way by assessing the readability and reading level associated with key messaging.

There are already examples of technology assisted translation in digital healthcare, for example the UK's own <u>Cardmedic</u> app. As the previous MiSalud case study shows, providing digital healthcare in a user's preferred language and making communications culturally relevant can have a significant impact on engagement.

7. Introducing one single sign in for various public services can help users overcome the challenge of logging in

My travels confirmed that many patients who face challenges with digital healthcare can fail at the first hurdle - logging in to their health app or patient portal. This is something which I heard many times from my work with digital inclusion teams within North East London. Challenges can be exacerbated when there are various different systems which require their own separate logins, with different password requirements.

In Denmark some of these issues have been reduced through the introduction of MitID. MitID is the Danish digital ID that can be used for various purposes, including transferring money in online banking or logging into public self-service solutions (e.g registering a business, paying tax, housing and benefits, health). MitID is primarily an app that allows users to complete actions with a simple swipe, but can also be used via a code display/reader or chip. MitID has been developed through a collaboration between the Agency for Digitisation and financial institutions. In Estonia I saw how simple it was for citizens to access health records through using their e-ID - a state issued digital identification, used to vote, access banking, access health records and services and shop securely. Many Estonian laptops come equipped with a custom ID card reader, although it is also available via an app.

I appreciate that given the challenges that many health systems face with inter-operability, the above may not seem like a feasible solution in the short term, however they are an aspirational example of what can be possible with the right leadership, vision and focus on collaboration.

8. Being transparent about patient data privacy can increase patient trust in digital health.

Many of my conversations during my travels referenced trust, and the need to build patient trust in digital health. Whilst in many of the continental European countries I visited there were high levels of trust in government digital services, in others marginalised communities can be concerned about receiving health care digitally, especially regarding who has access to their health records and data and how they are using it. For example, MiSalud shared a key barrier they have to overcome is ensuring their users understand any of their health information will not be shared with their employer.

In Portugal, Estonia and Denmark, state owned digital health platforms all provided patient level visibility over how their data was being used and who it was being shared with. Patients could see audit logs of who had accessed their health record and could report where there were issues, for example if they did not recognise a specific clinician or user. In Estonia, each user had full control over who could access their data, and could change their preferences by simply logging in to their app and toggling this on and off for different audiences. All of the teams I met believed that providing this visibility to users had increased their feeling that they owned their data and that it was being used in an appropriate way, even if this functionality was not used frequently.

9. Immersive learning tools and utilising trusted messengers are effective methods of increasing patients' digital capabilities

Alongside building trust and motivation to use digital healthcare, increasing users confidence and skills is a critical component to increasing adoption. During my fellowship I met with various organisations working on building digital skills through workshops, online training courses, training videos and leaflets. In San Francisco I learnt about an exciting model utilising

immersive learning tools and centring support within trusted community centres, approaches that have been shown to be particularly effective.

Case Study - Patient Portal Training Pilot

The San Francisco Tech Council is a multi-stakeholder initiative that advances digital inclusion for older adults and people with disabilities in San Francisco, who make up nearly one third of the population. They developed, piloted and evaluated a web based training platform - YourChart to support their constituents to better use the San Francisco Health Network Patient portal. The San Francisco Health Network offers low cost health care to San Francisco residents with no insurance or green card needed.

Unlike traditional videos, or screenshot based training guides, YourChart is an immersive simulation which allows users to practice key functions like navigation, access (logins) and tasks. The SF Tech Council piloted the tool by working with diverse community based organisations, who helped co-design supporting training materials and evaluation surveys. Individuals within these community organisations were trained to use YourChart to deliver training to participants in the pilot. Participants were diverse, (28.4% Asian,. 25.9% Black, 17.3% Latino, 17.3% White) and many preferred speaking Spanish or Chinese (32.1%).

By the end of the pilot, participants using the portal increased from 33% to 76%. Frequency of usage also increased, with occasional users (once a month) increasing from 4% to 25% and weekly users increasing from 18% to 41%.

The results of this pilot are interesting in that they show the effectiveness of using a risk-free sandbox environment to train users, a best practice in much of the commercial world but something that is still quite uncommon in healthcare systems. By delivering training via community based Digital Navigators, trained through a standardised curriculum, cohorts who typically wouldn't engage were reached, and the pilot was able to embed digital health support in community infrastructure in a methodical and replicable way e.g. with a dedicated training platform and localised protocols. Interestingly the pilot was able to granularly analyse the results by participant demographic, and could identify potential nuances that would otherwise be missed. For example, they were able to see that having access to support through their network was a greater determinant to continued usage than any other demographic factor.

Whilst this pilot is relatively small, the results achieved are impressive and encourage the use of more immersive learning technologies.. Elderly patients, especially those from marginalised groups, are often seen to have the biggest barriers to using digital healthcare, but also have the greatest need.

10. Achieving equity in digital healthcare requires measurement and analysis of who is and who isn't using it.

To quote the management expert Peter Drucker: "If you can't measure it, you can't improve it." In order to ensure there is equity in digital healthcare, there is a need to; establish a baseline of what adoption, usage and experience look like across different population groups, use this to identify interventions and then re-examine the data to see how those interventions have made a change. It's important to analyse user data through multiple lenses for example age, sex, preferred language, ethnic background, income levels to list a few. Being able to analyse and use more granular user data for improvement was something many individuals I spoke to on my travels saw as an important next step in the development of their health platforms.

One early stage project that will utilise this approach is the ACCTIVATE6 project in San Francisco. The study aims to support clinics to bridge telehealth digital divide by providing direct patient support and practice facilitation, in order to improve telehealth access and chronic disease management for patients with diabetes. Using a Quality Improvement approach, health teams will be provided with dashboards, highlighting different levels of usage for different demographics, and identifying where specific change interventions are needed. In the UK, a recent study7 conducted by Kings College Hospital NHS Foundation Trust and Guy's & St Thomas NHS Foundation Trust explored the rollout of the electronic health record (EHR) and how this differed by demographic factors. Whilst this is promising, I believe we need to move from one off studies to giving the tools for health leaders to access this information on an ongoing basis to drive improvements. The level of granularity captured during the SF Tech Council patient portal learning tool pilot can really highlight the different factors at play in preventing uptake, which highlights that complimenting the data with qualitative insights can be invaluable.

⁶ Achieving Chronic Care equiTy by leVeraging the Telehealth Ecosystem (ACCTiVATE) - Clinical Trial Overview

⁷Unlocking Digital Health: Inequalities in the adoption of a Patient Portal RD Barker, R Gökmen, P Mistry, D Naylor, JT Teo, 2025

Collecting demographic data on users, where it is not possible to link this to existing patient profile data, is not straightforward and can be culturally sensitive. If the typical ways of collecting this information, i.e. through user surveys with clear messaging about why demographic information is being requested and how it will be used, is not feasible, there are some alternatives. ADA Health compared users' postal codes to public datasets on income and education levels to better understand uptake for more marginalised groups. Where direct demographic data on users isn't available, using proxy indicators can be a useful first step, especially when complimented with more qualitative research.

Conclusion and Recommendations

My fellowship confirmed for me that if health systems work intentionally, they can ensure that the benefits of digital health care can be felt much more equally by diverse populations. Taking an inclusive user centred design approach and a community centred approach to implementing digital health can help reduce health inequalities faced by specific communities. The FAITH! App and MiSalud are great examples of this. However the pressures health systems are under mean that there is often a seductive pull towards seeing digital health tech as a lever that will deliver cost savings, efficiencies and improved patient experiences - simply by being made available. To conclude, these are five recommendations for the UK Health System to avoid this trap and embed equity and fairness into its digital transformation.

1

Build a community of practice and centre of excellence to make the case for inclusively designed and implemented digital health

There is a need to continually make the case for adopting inclusive user centred design principles. This can be supported by building rigorous knowledge. practice and research on digital health equity in the UK, similar to the work undertaken by UCSF Solve Health Tech, that can benefit both health teams and tech developers. Great work is already underway to explore this in the UK, but it can feel fragmented, highly dispersed and potentially lacking the rigour required to be credible for some audiences. Further research can also help make the economic case for why taking an inclusive user centre designed approach can save money in the long run, such as the economic evaluation of the Digital Participation in Healthcare being carried out by Digital Me_in the Netherlands. Supporting this, a community of practice is an important component to helping this shift from the bottom up, which I understand the Digital Equity Charter is looking to establish in the near future.

2

Make reporting functionality that allows demographic analysis of sign up, usage and user experience a requirement for all digital health care, including NHS owned applications

Health teams at local and national levels, committed to digital equity, need to be able to monitor how usage differs for different patient groups easily, rather than having to commission one off studies. This is something which should be requested of all new digital healthcare tools being implemented in the NHS. Alongside influencing external providers, this is something the NHS App team should seek to implement as a priority within the NHS App reporting dashboards. If there are issues with making this possible if the required data sharing permissions are not in place, a plan of action should be published highlighting how this will be rectified, and an interim solution offered in the meantime, utilising proxy datapoints.

3

Make multi-language capability a requirement for all digital health care, including NHS owned applications

For decades, health systems have been translating letters, leaflets and posters into languages spoken in their communities, and yet the same isn't true for digital health technologies. Prioritising multi-language capability in the NHS App over other developments, as well as seeking this capability in all other procured digital health technologies is a critical step for ensuring digital health equity.

4

Build inclusive user centred design into procurement processes to shift norms of what is expected of digital healthcare

My experience has been that change at scale can be accelerated when money flows in the same direction as the desired change.

Who commissions digital health is set to change within the UK over the next 10 years. As decisions are taken on a more devolved level, it gives more power to Neighbourhood commissioners to procure the technologies that best meet the needs of their diverse communities. Perhaps this change will help disrupt the monopolies of larger digital health companies who have limited impetus to innovate and change. I've developed additional procurement guidance (see Appendix 1) which can support commissioners to ensure they are evaluating how tech firms have adopted inclusive user centred design principles.

5

Set up new structures that can allow trusted community partners, technology developers, and health system decision makers to collaborate and amplify the voices of those who struggle to access digital health tech

As I experienced during my research, there are lots of interesting models out there which help bring communities, tech developers and health system leaders together to help shape the way digital health services are designed to take into account users' needs and motivations. These can operate at the national, regional and neighbourhood level. There are interesting examples of these types of collaborations emerging across the UK, however given the ambitions on increased digitalisation we need more of these and much faster, especially given that Health Watch, the current custodian of patient voice, is being disbanded. Greater guidance into the different ways, methods and best practices of establishing these types of collaborations, and making the case for them, could help accelerate their development at a local level. These collaborations can partly be funded by healthcare technology companies who will need to access diverse patients if the procurement guidelines referenced in Appendix 1 are implemented. Similarly there should be an expectation that nationally owned digital health tools, such as the NHS App, would also engage with these collaborations to ensure diverse community voices are helping to shape the digital NHS of the future. These collaborations will contain the same community organisations that will ultimately be best placed to build trust and skills that will support adoption of digital healthcare.

Appendix 1: Digital Health Equity Procurement Checklist

This tool is intended to act as a supplementary guide for teams procuring digital health technologies. It features questions that can be included in procurement processes to ensure digital health tools have the necessary features and have been designed in the right way to support adoption by the widest range of patients possible.

It builds on and is not intended to replace:

- Accessibility sections in the NHS Digital Technology Assessment Criteria,
- Web Content Accessibility Guidelines (WCAG) 2.1,
- NHS Service Design Manual 28
- ISO ISO/TS 82304-2:2021 Health software.

To support evaluating these criteria, Procurement Leads would benefit from engaging their EDI lead to understand how to best engage a Patient and Public Involvement and Engagement (PPIE) group or staff network.

Digital Health Equity Procurement Checklist

Criteria	Evaluation Guidance
How have diverse users/ users who face challenges using digital health been involved in product design and initial testing? Describe the types of users who were involved and what activities were completed.	High Scoring Answers here would show that the vendor has engaged users through one on one interviews, focus groups or co-design workshops during different stages of the design and testing process. High scoring answers here would share that they have tested the technology with a diverse group of users i.e. by age, gender, ethnicity, reading ability, income level.
What user preferences/ user challenges were identified during this engagement and how has the product been adjusted in response?	High scoring answers here would show that the vendor has explored challenges to users' varying capabilities, environment and wider context i.e. how the solution fits in with their wider lives. They should be able to list changes made to their solution proportionate to the challenges raised, for example offering different ways to engage with their tool based on preference such as a website alongside an app and the ability to print easy to read material.
Do users have the ability to have information presented in different languages? If so, how have translations been developed?	High scoring answers would include the availability of patients to choose their language, with translations created through engagement with actual users so that messages can be tailored and made culturally relevant.
How do you collect ongoing user feedback to identify future improvements? How do you test these improvements?	High scoring answers here would include gaining user feedback via channels that would not limit feedback from users that face challenges e.g. not solely collecting feedback via online surveys. User testing of improvements should reference specific engagement of diverse groups.

Digital Health Equity Procurement Checklist

Criteria	Evaluation Guidance
What reporting functionalities does your solution offer to analyse usage and experience by patient demographic?	High scoring answers here would include that systems can report on sign up, usage, and user feedback, segmented by various demographic filters, e.g. age, sex, ethnicity, preferred language.
What user instruction and training is available? Please list the different support available and how this has been designed for diverse audiences.	Here higher scoring answers would include more immersive training solutions that allow users to practice different functions. Higher scoring answers would provide a range of different tools to support different learning styles. This would also include testing the readability of all customer support material and emphasising more visual materials
What user support is available? Please list the different support available and how this has been designed for diverse audiences.	Higher scoring answers here would highlight different channels to receive support including non digital channels such as a phoneline rather than simply email.

Please get in touch if you'd like to discuss any of the content of this report



JOE KALLARACKAL CHURCHILL FELLOW 2024

joseph.kallarackal@nhs.net

