

HOW HEALTH TECHNOLOGY
IN CLINICAL RESEARCH
**CAN REVOLUTIONISE,
AND JEOPARDISE,
COMMUNITY HEALTH**



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GLOSSARY

We use different terms to refer to various communities in this report. Below are some definitions to define exactly who we are talking about when we use each term.



Minoritized ethnic communities: Any ethnic community who has been minoritized by social processes of power, rather than being a statistical minority within a given population.



Minoritized communities: Any community who has been minoritized by social processes of power, including the LGBTQ+ community, people with disabilities, and more.



Underserved communities: Any community who needs better service from the clinical research community.

INTEGRATING HEALTH TECHNOLOGIES INTO THE HEALTHCARE PARADIGM

Technology gives us endless possibilities — particularly when we think about its application in the healthcare space. Technology has the potential to fix bottlenecks in service delivery by supplementing work carried out by healthcare professionals, by streamlining diagnosis for patients.¹

We've seen evidence of how quickly technology can change healthcare when in-person appointments were swiftly replaced with online interactions throughout the COVID-19 pandemic.² Technology is now being widely integrated into healthcare through digital health interventions (DHIs), defined as:

'Technologies which may help people change their behaviour, which in turn, can help improve their health. They may also help people to self-manage, self-monitor, or improve these behaviours and improve their mental, social, and emotional wellbeing'.³





DHIs have been used to **enhance access to health information and self-assessment**, driving behavioural changes that uplift health outcomes, such as quitting smoking and exercising more.⁴ **Not only do DHIs help patients take control of their own health, they also help healthcare workers to more accurately diagnose diseases**, such as glaucoma, and liver and brain diseases.^{5,6}

In 2023, DHIs have made their way into clinical research, with the Food and Drug Administration recently releasing guidance for using them effectively in clinical trials.⁷

Now, call us overly-critical, but we had to wonder — **is it possible there's a downside to integrating technology into healthcare?** If technology in healthcare holds so much power, who's making sure this power is being used to benefit everyone fairly?

Although those who develop DHIs have society's best interests in mind, DHIs can produce intervention-generated inequalities (IGIs) — where they benefit the more privileged. They're more prone to producing these inequalities when they are more accessible, adaptable, adhered to, or more effective in resource-rich communities.⁸

But when we talk about resource-rich communities — what do we mean? **There are several factors listed opposite that can impact communities' access to, and benefit gained from, DHIs.**

This report explores how these factors can widen health inequities within health technology and what the clinical research industry as a whole can do to help minimise these factors.

+ Access to the internet

People with less access to the internet are unable to use the full capabilities of any DHI that requires the internet to operate.

+ Confidence in DHIs and the healthcare system

People with lower trust in healthcare professionals and the wider industry are less likely to use DHIs.

+ Digital and health literacy

People with lower digital and health literacy are less likely to be able to use DHIs effectively, and are less likely to adhere to their use in the long-term.

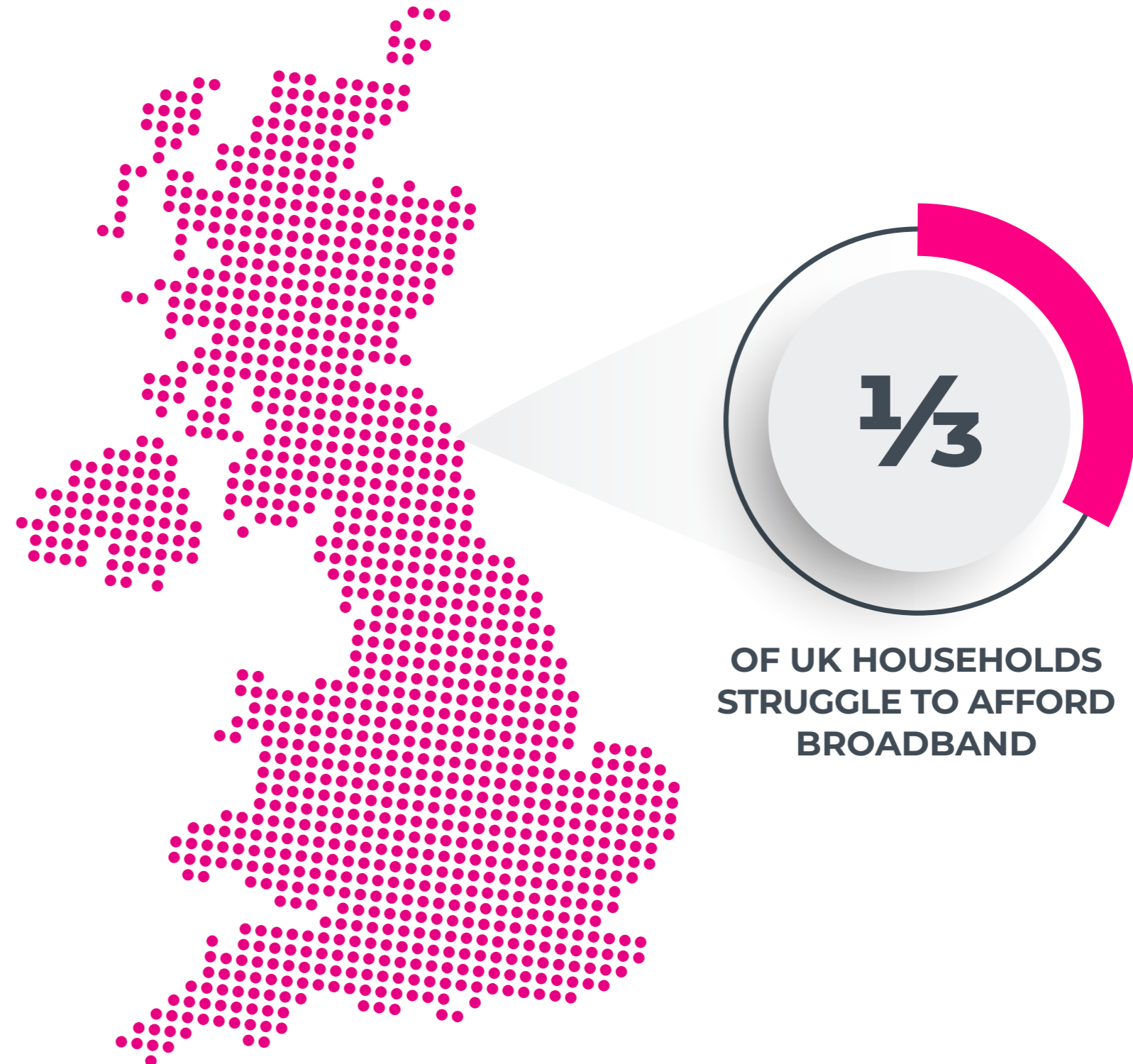
+ Using data provided or analysed by artificial intelligence (AI)

People in minoritized ethnic groups are less likely to be represented in data science teams, and are more likely to be impacted by implicit bias in data and AI.

ACCESS TO THE INTERNET

For DHIs to be effective, they must be accessible to those who need it — meaning the target demographic who will use them must have the resources and skills to use the technology, as well as adequate motivation to put it into use.

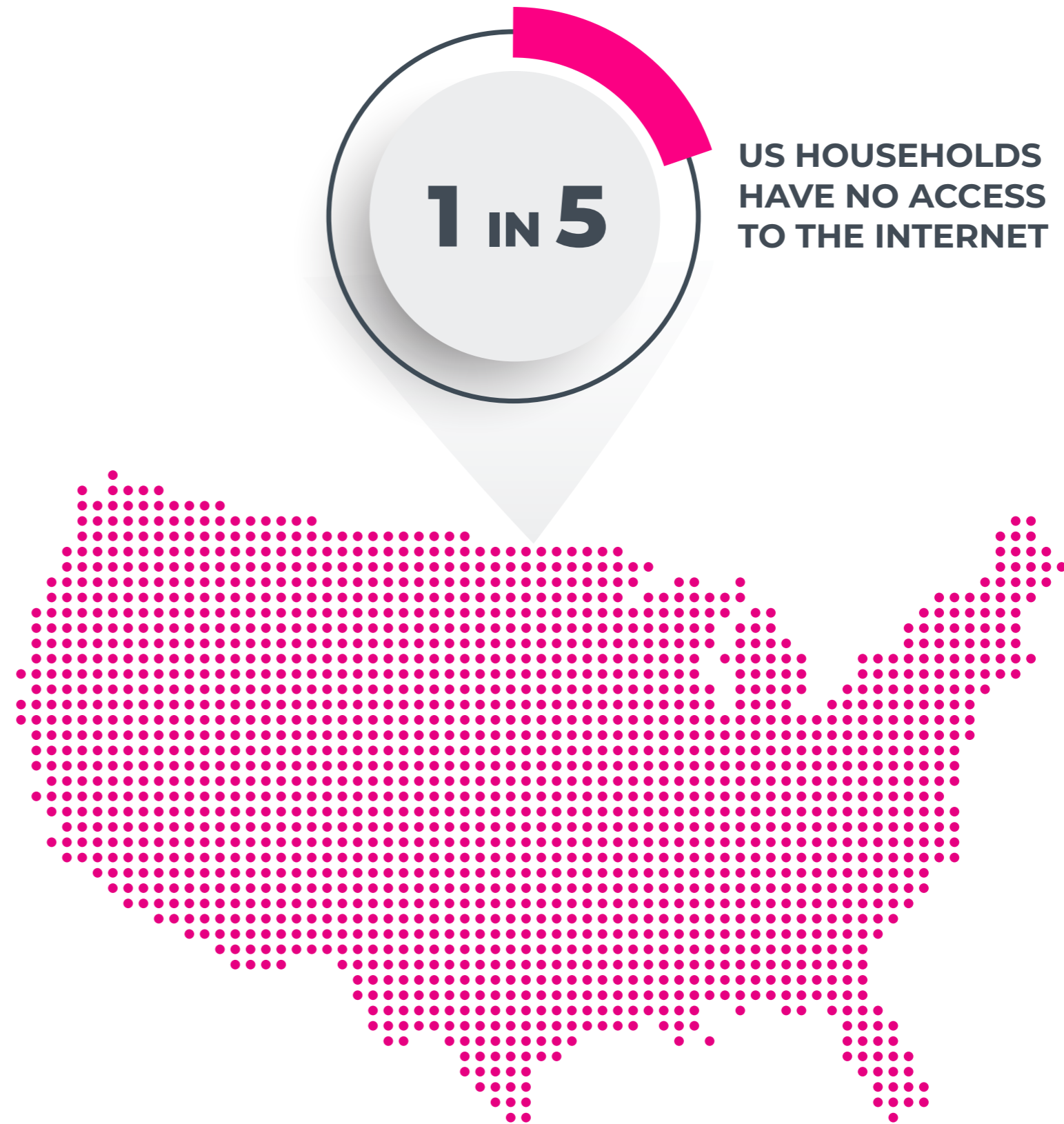
What does this mean? First and foremost, the accessibility of DHIs are determined by an individual's access to the internet. Despite nearly 100% of people in the UK reporting that they use the internet in some form, **less educated groups and users with lower incomes are more likely to be 'digitally excluded'**.⁹ Ofcom has also called for more support to be made available, as they report **8 million households, around a third of the UK, struggle to afford communications services, including broadband.**¹⁰



This situation is also reflected in the US, with **one in five households not having access to the internet.**¹¹

US households that deem internet connection as **'too expensive'** are more likely to have young children, or to be from minoritized ethnic communities.¹²

Limited internet access in the UK also extends to those living in rural areas or economically-disadvantaged metropolitan areas. People in rural areas usually pay more for internet access, and can be made to wait longer for access to the latest speeds and technologies.¹¹ Conversely, those in economically-disadvantaged metropolitan areas have less access to the internet for different reasons, including digital poverty and financial poverty.¹¹





WHAT IS DIGITAL POVERTY?

Lower access to the internet isn't just about affording internet bills, it's also about affording the devices needed to connect to the internet.¹¹ In this context, digital poverty refers to the **inability to interact with the online world**, which can also include people who have limited time to engage with it.¹³ Whereas financial poverty refers to **lower income which in turn impacts internet affordability**.

CONFIDENCE IN DIGITAL HEALTHCARE INTERVENTIONS

Confidence can impact the inclusivity of DHIs in two ways — **confidence in the healthcare system providing the DHI, and confidence in the DHI’s capabilities itself.**

For DHIs to be impactful, the user must feel **confident about using the device**, as well as **trust the healthcare system that recommended its use.**^{14,15} For this reason, DHIs may disproportionately impact communities who have greater levels of mistrust in healthcare professionals and the healthcare industry. Such communities include those from minoritized ethnic communities, the LGBTQ+ community, and those with disabilities, to name a few.



“We need to directly address people’s concerns by laying out our ethical approval to dealing with data and providing absolute clarity on how we intend to use health data”¹⁸

— Sarah Wilkinson, NHS Digital Chief

Communities may feel distrust towards the recommendations produced by DHIs, or they may be mistrusting of sharing their healthcare data.

Without clear communication about how a person’s data may be used, such mistrust may deepen.

And we have seen this happen recently, when NHS Digital made updates to their data collection process in 2021¹⁶— prompting a wave of privacy campaigners to speak out against the proposals on social media.¹⁷

Medical mistreatment of minoritized communities is not entirely historic; **both generational and current experiences of mistreatment and/or discrimination fuel a legacy of mistrust of the healthcare industry.** This mistrust can be both system-level, with the healthcare industry, and individual level, with healthcare professionals and providers. In some cases, the two levels interplay to generate a complex web of mistrust that is difficult to overcome.

The mistreatment and consequent mistrust experienced by minoritized ethnic communities is well-documented. **The impact of this deep-rooted mistrust was highlighted during the COVID-19 pandemic, where vaccine hesitancy was at an all-time high within minoritized ethnic communities across the UK.**¹⁹ On top of this, there was **little trust in communication from UK governments** to alleviate this hesitancy within communities²⁰ — resulting in **greater mistrust in the vaccines**. Healthcare providers who saw the impact of vaccine hesitancy first-hand worked to fill the gap. Alongside their clinical roles, they made open communication a priority, answering questions to alleviate fears and build vaccine confidence with these communities in order to increase vaccine uptake.²⁰



DIGITAL AND HEALTH LITERACY

Digital poverty can severely impact the success of deployed DHIs. Another factor that contributes to digital poverty is lower digital literacy — produced by a lack of digital skills and education. In the UK, **10 million people lack the foundational skills needed to navigate our digital world, and 6.9 million people will remain digitally excluded if nothing is done to help them.**²¹ People who are digitally excluded are **10 times more likely to be over the age of 65**, and are **8 times less likely to have been educated past the age of 18.**²²

Education around using digital devices isn't the only thing impacting the success of DHIs, low health literacy is also a contributing factor. Health literacy is a term used to describe a person's ability to find, understand, and apply medical information to better their own health by guiding well-informed decision-making.²³

This is a greater challenge than you might think — **nearly 9 out of 10 adults struggle with health literacy.**²³ It's worth remembering that even those who usually have high health literacy skills can have low health literacy in certain situations, such as when a person is stressed or sick — leading to challenges in remembering, understanding, and using health information.

DIGITAL POVERTY IN THE UK

PEOPLE WHO ARE DIGITALLY EXCLUDED ARE:

10x

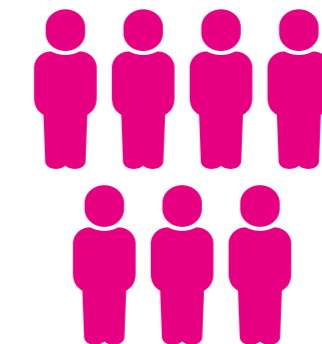
more likely to be over the age of **65**



10 MILLION people lack the foundational skills needed to navigate our digital world

8x

less likely to have been educated past the age of **18**



6.9 MILLION people will remain digitally excluded if nothing is done to help them



WHAT IS DIGITAL HEALTH LITERACY?

Digital health literacy is defined as **the ability to find, understand, and appraise health information from electronic sources, and using this information to address or solve a health problem.**²³

Low digital health literacy predominantly impacts those who are socioeconomically disadvantaged or have lower formal education.²⁴ Older adults are also at greater risk of having lower digital health literacy, as research shows that learning ability declines with age, making complex DHIs increasingly difficult to use.²⁴ In addition, information has become simultaneously more accessible and harder to critique. People are increasingly likely to find out-of-date or incorrect health information, and are unlikely to have the necessary skills or time to analyse the accuracy of information they are presented with.

USING DATA GUIDED BY ARTIFICIAL INTELLIGENCE

DHIs can also be used to **enhance diagnostic efficiency**, helping to reduce workload on an already overwhelmed workforce. Using AI, diseases can be diagnosed more quickly and more accurately — enabling those with less expertise to make well-informed diagnostic decisions.⁵ This, in turn, leads to a reduction of misdiagnoses, with research showing lower rates of misdiagnosis in glaucoma, liver, and brain diseases.⁶

Overall, DHIs within the diagnostic sector appear to be very helpful tools — until you take a closer look at the data being used to inform AI diagnostic tools.



Let's take skin cancer as an example. Recently, AI has been used to distinguish between benign and malignant moles with similar accuracy to that of board-certified dermatologists, creating an incredibly useful tool in the diagnosis of skin cancer.²⁵ However, as highlighted by the success of **'Mind The Gap'** in 2020 — a book developed by Malone Mukwende at St George's University of London detailing the differences in diagnostic criteria between light and dark skin tones²⁶ — the diagnostic criteria for many skin diseases is largely based on people with White or lighter skin tones.

The AI tools being used to assist in the diagnosis process are developed using the data we currently have available to us. **This means that as long as our data is biased, our AI-based technologies will also be inherently biased.** If DHIs are not created with inclusivity in mind, using such AI-driven tools will further exacerbate disparities in health.²⁵

As long as our data is biased, our AI-based technologies will also be inherently biased

HOW TO MAKE HEALTH TECHNOLOGIES MORE INCLUSIVE

A combination of the above barriers now **threaten the future of successful implementation of DHIs from a diversity and inclusion perspective**. We've established that if DHIs are implemented without considering their potential to exclude groups of people, they may continue to widen health disparities in underserved communities — and those who have lower digital health literacy, reduced access to technology and the internet, and are underrepresented in the data used to inform AI diagnostic tools, will be the ones who are left behind by the technological advances of DHIs.

However, DHIs are not a lost cause. There are opportunities to create better, more inclusive approaches to implementing them into the healthcare industry.



BELOW ARE OUR RECOMMENDATIONS FOR FACILITATING MORE INCLUSIVE DHIs:

+ DHIs should be developed to function with low broadband internet, blended online-offline functionality, or with an ability to use older channels, such as SMS text, to make them accessible for those with limited internet access.

+ Studies investigating the impacts of implementing DHIs should focus on those who are predisposed to be at a disadvantage owing to their demographic or socioeconomic identities.

+ DHIs should be designed with the end user in mind, meaning that unmet needs are addressed and met by design.

+ DHIs should be designed to be cost-effective, to help mitigate the possibility of non-adherence by those with lower incomes.

+ DHIs should be informed by data that is unbiased, so that AI tools are not exclusionary by design.

+ DHIs should include training and tech support for new users, to help overcome digital literacy barriers.

+ Studies investigating DHIs should carry out assessments to analyse the possible risk of producing IGIs, and should have mitigation plans in place to counter these risks.

From our perspective, there's one crucial ingredient the health technology industry is missing — the patient voice. We've just discussed how DHIs have the potential to widen health disparities, especially for those who:

Belong to minoritized ethnic communities



Have lower incomes



Have lower digital health literacy



Have reduced access to the internet



Have higher levels of mistrust in the healthcare system

These are the people who should be informing the design of upcoming DHIs. Collaborating with people who will be directly impacted by the implementation of DHIs is imperative to inclusive design. By using insights from populations who are at risk of being excluded from DHIs, you will be able to accurately identify the barriers preventing these groups from engaging with them, helping you to find ways of overcoming them when you co-create your products. It's also important to remember to consider these groups when looking at implementing DHIs into the clinical research space too, as inclusion of them may present as a barrier to participation.

Want to learn more about the potential of co-creation in the health technology space? Talk to us — we're experts in navigating collaborations with underserved groups and communities. Get in touch to learn more about how we could support your upcoming health technology innovation.

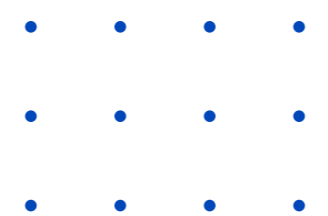
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