Priorities and principles for digital health innovation in South Yorkshire

Findings from a Citizens' Jury in Sheffield

Hopkins Van Mil & South Yorkshire Digital Health Hub
January 2024

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1. Introduction

Background to the Citizens' Jury

The [South Yorkshire Digital Health Hub](#) is a collaborative initiative involving the Universities of Sheffield, Sheffield Hallam University, industrial and health partners in the region. It is one of five Digital Health Hubs in England funded by the Engineering and Physical Sciences Research Council (EPSRC) and UK Research and Innovation (UKRI) whose purpose is to promote knowledge and skills sharing across healthcare, academia and business, to drive innovation in digital health.

The South Yorkshire Digital Health Hub's primary focus is tackling healthcare inequalities and transforming how patients are treated in South Yorkshire. Specifically, it focuses on driving the development of innovative digital health technologies to improve the way diseases are treated and diagnosed by using cutting-edge research using smartphones, wearables, new sensors, combining this with NHS data and using artificial intelligence to develop new clinical tools.[1] Its specific objective is:

> ## Objective of the South Yorkshire Digital Health Hub
> To bring together a digital health community of practice, including healthcare providers, engineers, scientists, clinicians, patient/public groups and industrial partners to develop digital health solutions that address unmet clinical needs.

The Hub's activities include (but are not limited to):

- training researchers in the many areas of expertise across digital innovation, including in understanding patients' and health professionals' needs, engineering and digital technologies, design, manufacturing, legal and ethical regulation;
- supporting collaboration with the NHS and researchers on projects;
- producing over 60 hours of training in digital health for researchers, clinicians, patients and the public; and
- holding regular 'Calls for Ideas' where funding and training is available to support digital innovators from a range of backgrounds work on specific projects.

A core aspect of the Hub's work is involving patients, members of the public and communities in the region in its activities. To drive this involvement, the Hub has commissioned three rounds of Citizens' Juries to take place across the region over the current period of funding, September 2023 – September 2026.

> ## What are Citizens' Juries?
> A Citizens' Jury is a group of ~12-24 people from all walks of life, brought together to have an honest conversation & find common ground on an issue that matters.[2]

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[1] https://www.sheffield.ac.uk/sydhh/about-us
[2] https://involve.org.uk/resource/citizens-Jury

Project Objectives

This report focuses on the activities of the first Citizens' Jury, which took place in Sheffield in November 2023, and its findings. The focus for this jury was to develop a list of citizen priorities for digital health technology innovations. The process brought together 14 individuals from across Sheffield. Jurors listened to evidence on health and digital technology from a range of specialists and perspectives, exploring their own views and those of others throughout the process. The priorities which emerged from this will inform the Hub's activities and projects, including framing the first Call for Ideas, and the selection of incubator and pilot projects.

Project Partners

This Hub is led by the [University of Sheffield's Insigneo Institute](#) which focuses on innovative research at the interface of healthcare, engineering and science to transform the future of healthcare technology, and [Sheffield Hallam University's Advanced Wellbeing Research Centre](#) which is dedicated to improving health and wellbeing through innovations that help people move.

The Hub's patient, public and community involvement and engagement is led by Professor George Peat and Dr Lidis Garbovan, both from Sheffield Hallam University, with Mrs Lynn Laidlaw advising and providing oversight on the Jury's initial set-up.

The Hub is working with [Hopkins Van Mil (HVM)](#) to deliver all three Juries. HVM is an independent social research agency specialising in deliberative engagement. HVM creates safe, impartial and productive spaces to gain an understanding of people's views on what matters to society. HVM's work brings people from across society together to hold a lens up to issues which are contentious, emotionally engaging and on which a broad range of viewpoints need to be heard.

Section 2

Methods

- Design
- Recruitment
- Workshop process
- Speakers
- Stimulus
- Data collection and reporting

2. Methods

Design

The design process began with a workshop attended by the project team. The purpose of this design workshop was to identify key questions, stimulus, potential speakers for the first Jury, and better understand how its process could influence the wider activities of the Hub. This initial workshop was followed by regular project team meetings in which the chosen methodology continued to be developed and refined.

Recruitment

14 participants were recruited from the Sheffield Local Authority District to take place in this Jury. [3] The recruitment was carried out by specialist recruiters iThoughts based on a specification designed by the project team. The aim was to recruit a Jury which broadly reflected the population of Sheffield in terms of age, gender, life-stage, socio-economic background and ethnicity. It was also decided that the Jury would include participants both with and without long term health conditions, and with and without experience of wearable technologies. A summary of the target and actual demographic characteristics of those who took part in the Jury is included at Appendix 1.

A physical and digital participant handbook was sent to all participants in advance of the Jury's first session. In addition to guidance and support, it contained practical details for taking part, including how to use the video conferencing tool Zoom and information on what to expect during each workshop, such as session aims, a programme of activities and information about the facilitation team. The facilitation team ran a tech support session in advance of the Jury's first online meeting to support jurors who may otherwise have found it difficult to take part online.

All participants received a payment in recognition of their time commitment.

Workshop process

The first three sessions in the Jury process took place online through Zoom, followed by a a full day face-to-face workshop at a venue in Sheffield (for an overview see Figure 1). The process began with a webinar which introduced jurors to the topic of digital health, the work of the Hub, their roles and responsibilities as jurors and the route to influence.

The first workshop focused on public health and priorities for healthcare, as well as current uses and opportunities for digital health. The second workshop explored innovation in digital health in more detail, including the role of industry, alongside broader social and ethical considerations, and future scenarios. Both online workshops involved a combination of facilitated small group discussion, specialist input via presentations and Q&As and plenary activities.

The Jury process concluded with an in-person workshop in which all 14 jurors came together for a full day of deliberations on priorities and key principles for digital

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[3] Participants from the wider South Yorkshire region will be recruited during rounds two and three.

health, joined by members of the Hub who observed and reflected on jurors' discussions and their potential significance for the Hub. This session concluded with the Jury making a series of recommendations to inform the Hub's first call for ideas.

The sessions were held over an 11-day period to ensure they were neither overwhelming nor so spread out as to disrupt levels of engagement. This schedule also gave jurors time to consider the issues outside of scheduled workshops, as well as discuss it with friends, family and acquaintances. Workshops were designed using Plain English materials and included frequent summaries of what had been shared to enable the discussions to develop based on what had previously been discussed, as well as remind jurors of the scope of their influence.

Figure 1 – An overview of the Jury process
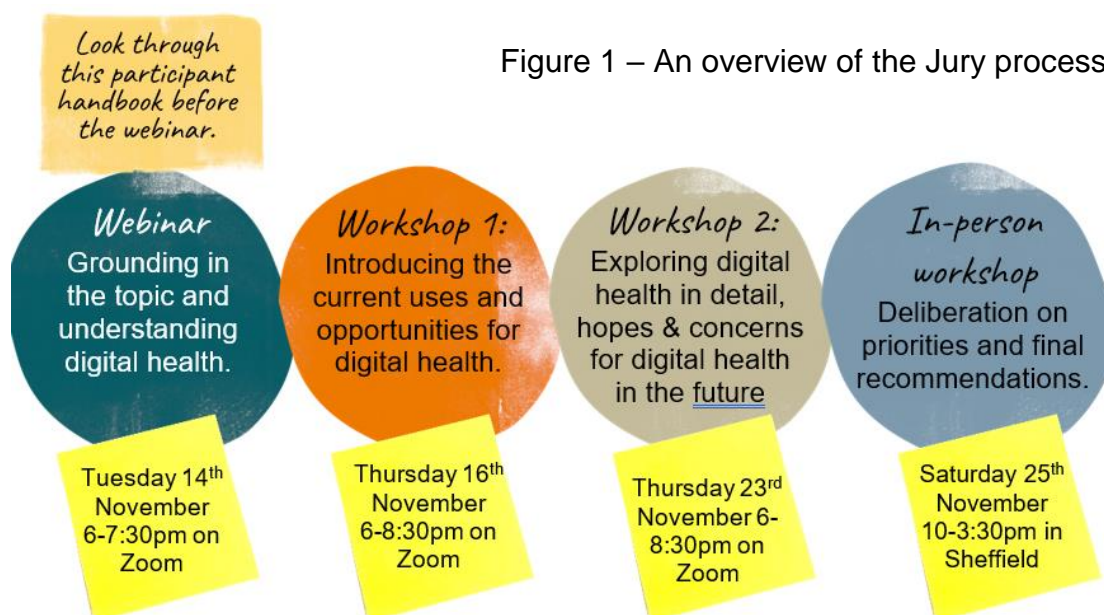
Speakers

During the workshops, jurors received presentations on a variety of topics delivered by specialist speakers, outlined in the table below.

Speaker name	Role/Organisation	Topic of presentation
Webinar		
Tim Chico	Professor of Cardiovascular Medicine, University of Sheffield	Introduction to digital health
George Peat	Director of the Centre for Applied Health & Social Care Research (CARe), Sheffield Hallam University	Who is involved in developing digital health technologies?
Workshop 1		
Greg Fell	Director of Public Health, Sheffield City Council	Public health perspective: Priorities for health and healthcare in Sheffield

Alex Rawlings, Nicki Doherty	GP, Primary Care Sheffield	Primary care perspective: Challenges in primary healthcare and potential for digital solutions
Workshop 2		
Kate Weiner	Senior Lecturer in Sociology, University of Sheffield	Social and ethical perspectives on health tracking, including through digital technology
Susan Thomas	Clinical Director, Google Health UK	Industry perspective: Why is digital technology important in health?

Stimulus

Jurors were shown a variety of stimulus materials that informed their knowledge of the topic and prompted discussion on key themes. Stimulus included a number of case studies, which were identified via desk research and in discussion with the project team and wider Hub colleagues. In workshop 1, Jury members engaged with case studies on smart watches (selected as an example of a population focused digital health technology) and continuous glucose monitors (selected as an example of a condition-focused digital health technology). Workshop 2 introduced participants to the virtual wards case study, selected as an example of digital innovation in health service infrastructure. Discussions on each case study are reported on in the next section. The case studies as presented to the Jury can be seen in full in appendix 2.[4]

Data collection and reporting

All three workshops and the introductory webinar were audio recorded by the HVM team. Data was also collected from the workshops in the form of flipcharts and jamboards, which facilitators used to keep a live record of what was said in the in-person and online workshops respectively, as well as via the anonymous interactive tool Menti.[5] Each of these tools enabled participants to review how their responses were being captured in real time and ensure their views were being recorded accurately. The subsequent writing of this report has drawn on the workshop audio recordings, transcriptions of the flipcharts and jamboards, as well as the Menti data.

The reporting team was drawn from the HVM and Hub observers attending the workshops. The team based their reporting solely on the data drawn from workshops so as to ensure findings are rooted in what jurors said across the four sessions. Meetings were held regularly during the drafting of the report so as to provide frequent opportunities for sense-checking among the team and for feedback on early drafts.

The findings are presented from the following chapter onwards.

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[4] A fourth case study – on digital modelling of the heart – was initially planned into the process design but was not introduced in discussions based on faciltators' judgement.
[5] www.Menti.com

Section 3

Findings

- Early impressions and understanding of digital health
- Hopes for the future role of digital health
- Concerns about the future role of digital health
- Priorities for (digital) health in Sheffield
- Principles for digital health in Sheffield
- Final recommendations

3. Early impressions and understanding of digital health

Initial discussions, interest in and experiences of digital health

The Jury members expressed their early understanding of 'health' and 'digital health' by using one or several key words. Participants' responses to each term are summarised in the figures below

What comes to mind when I say the word 'health'
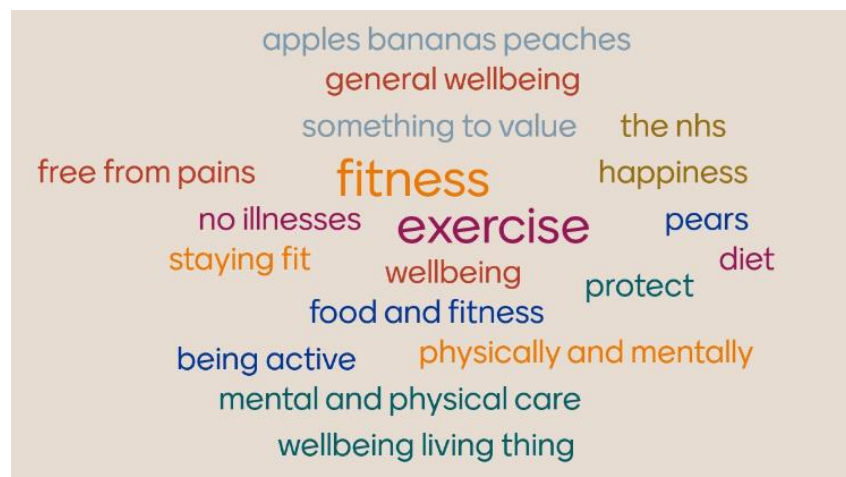
What comes to mind when I say the words 'digital health'

Following the presentations of different speakers, including healthcare professionals and academics, about the work of the Digital Health Hub and the status of the health system, the Jury participants had the chance to share early impressions and to engage with the information presented. For instance, they were surprised to learn from data about healthy life expectancy in South Yorkshire that showed people tend to become ill earlier in life, before retirement age – and about the difference in life expectancy in different areas of Sheffield as well as the years lived in poor health being below the national average in Sheffield.

They were also surprised by evidence they heard on lack of data sharing between NHS trusts, even between different departments in the same hospital. Early on, jurors raised certain ideas as interesting or important, such as the theme of privacy around data. Some jurors felt this led to having 'less fear and being reassured by the rules in place', supporting in premise the need for information to be shared between stakeholders.

Jurors raised several questions and concerns about people and motives, data security and safeguards, and digital literacy and the ability to benefit from it. For instance, they were concerned about who is producing different health tools and where profits would go, also about who will fund future innovation in digital health. Other concerns expressed were related to data leaks 'to the wrong people', such as health data on a smart watch that could be hacked, hence asking how to keep it safe, also the transfer of medical information and the question of how many people have access to it. They also expressed concerns about digital literacy: everyone having the skills to use devices should not be assumed. They suggested comparing the use of different digital devices based on their benefits, and asked which conditions would best be helped by the technology.

When asked about their experiences with digital health, Jury members reported having used devices to monitor their heart, as well as to monitor sleep apnoea. Some jurors mentioned that they use a Fitbit to track steps or their menstrual cycle, whilst others use an Apple Watch for monitoring their heart rate and health, as well as daily steps or exercise. Some Jury members mentioned that they use a digital blood pressure machine, regularly taking readings at home and emailing the data to their doctor. Other jurors had used digital tools to measure their blood oxygen levels or blood sugar levels, whilst others related experiences of using a virtual reality headset for hand control and tracking movements while playing a game, including measuring how many calories they are burning.

Reflecting on their main impressions about health priorities in Sheffield, Jury members had mixed experiences and feelings. On the positive side, some reported that services they used regularly were excellent, 'staff are very nice, calm, in control'. The healthcare in Sheffield 'is really good' and some were proud of it. Jurors also reflected on more negative experiences of healthcare. These included encountering overworked staff, challenges with accessing urgent appointments, over-use of telephone consultations, and being let down by services where decisions were not based sufficiently on listening to patients and carers. Overall, it was clear the success or satisfaction jurors experienced when trying to access healthcare varied depending on the service they were trying to reach, as well as between different GP surgeries or areas within Sheffield.

Jury members noted that using digital services such as apps for identifying symptoms 'cannot always explain what is wrong' and may lead to misdiagnoses. The increasing aging population means that it is important to invest now in automated systems, because 'soon everyone will be digital, for instance using a live chat system to book a dentist's appointment.' Some jurors have already started using digital services, for instance they sent a photo of their ill child to the GP and ordered medicines and book appointments digitally to see the surgeon within 10 days. They felt this was a good way to have fewer appointments. Some male jurors also suggested that men in particular may benefit from having a chat option as a support system to obtain feedback without face-to-face interaction, as this was considered an easier form of communication for some people.

Discussions on case studies: smart watches, continuous glucose monitors and virtual wards

Smart watches: A case study on population-focused digital health tools

Smart watch devices are worn on the wrist and can measure vital signs such as heart rate, blood oxygen levels and body temperature, as well as provide information on activities such as sleep or exercise. In workshop 1, jurors were presented with a case study on smart watches, outlining their purpose and function, as well as a fictional narrative based on first-hand experience of their use.[6]

Jury members shared their first impressions about this case study, some expressing positive thoughts, for instance, about family members and friends wearing smart watches 'in competition' to compare the steps, calories burned and 'keeping on top of health.' Some jurors shared how using a smart watch helps with routine, and supports people to focus on their health, think about their diet, exercise, and keeps them active. For some members of the Jury, this case study raised questions for instance about the implications of tracking and sending data automatically to a data centre versus monitoring it themselves. And other jurors expressed the view that an oximeter is a cheaper option which also allows for the monitoring of blood oxygen levels at home.

The Jury members expressed different hopes and opportunities regarding the use of a smart watch. Some mentioned personal views, such as the fact that the case study made them consider having a smart watch for themselves. For other jurors who are already using one, they considered the smartwatch had value because it helped them keep track of their heartbeat. It was also reported that the smartwatch is 'good for younger generation to get into fitness, into gym.' Some Jury members expressed hopes about the smart watch being useful as part of the health system, for instance, as using such tools to monitor people's health could help assessing waiting lists or for early warnings for health concerns. The potential for more efficient use of health services was raised: for example, some jurors wondered whether data from a smart watch could be shared with the GP and therefore reduce the need for a full appointment.

The smart watch case study stimulated concerns and questions about the possibility of inaccuracy, false alarms and other unintended negative consequences of digital health technologies. Jurors gave examples of generating step counts when driving, of being woken at night by a fast heart rate alert, of sending data unintentionally from a smart watch being carried in a bag, and the idea that false alarms could add to waiting list pressures. They wondered whether a smart watch perhaps 'does too much'.

Continuous glucose monitors: A case study on patient-focused digital health tools

Continuous glucose monitors (CGMs) are based on a sensor which can be attached to the skin and provide real time insights on blood sugar levels to people with diabetes. They can also help a person to understand whether their blood sugar level is going up or down, and how quickly. Jurors considered a case study on CGMs alongside the one on smart watches, contrasting interventions which are typically aimed towards a specific group of patients with those which are aimed at the public more broadly.

Jury members first impressions about this case study included being surprised by the cost, 'it feels cheap compared to costs of fingerpick test', or being surprised by seeing

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[6] The case studies described here are included in appendix #.

so many CGMs are already in use and feeling personally 'encouraged to try it'. Some jurors noticed that the CGM provides an 'easy management and monitoring for a scary condition', when used for the betterment of the patient who would be exempted from 'living in fear' about their diabetes. It was considered a 'benefit to life' and worth paying for if needed. Broadly, the participants felt that the cost benefit of CGMs is significant, so 'it should be funded to monitor for the future.'

The hopes and opportunities that the Jury members associated with the CGM included viewing it as an 'excellent piece of kit which takes away the finger prick test, especially helpful if you are afraid of needles.' Some jurors noted that the insulin pump could provide a 'day off', however it can be an expensive package. While others reflected on how it could work in their families, with close family members using 5 or 6 fingerpick tests a day, for the last 45/50 years, in which case 'life builds up around tests, diet and timings.'

The concerns and questions around this case study emphasized how the 'habit and inability to actually trust in technology could be a stumbling block 'or the concern if 'something went wrong with the app', which leads to the need for providing technical support.

Comparing CGMs and smart watches

When asked for reflections and comparisons across the two cases studies, many jurors favoured the innovation seen in CGMs over the smart watch because of the impact it could have for people experiencing a serious condition such as diabetes.

A few jurors were impressed by the breadth of information the smart watch could offer but generally considered they 'aren't as important as a small device that can warn you of a life-threatening situation', in this case referring to the CGM. More often than not, jurors were drawn to the case study on CGMs because 'the health benefits appeared more tangible' and was likely to offer information which could prevent or lessen the likelihood of an emergency situation.

Virtual Wards: A case study on emerging digital health innovation

Virtual wards support patients to access hospital-level care at home using technology that allows staff to monitor them remotely. The information jurors received included a summary case study created by the project team and a film clip from NHS England.[7]

Most Jurors were unfamiliar with virtual wards. The concept was well received and the rationale for introducing them in the NHS was clear to many. There was widespread recognition of the mental health benefits of receiving care at home, as well as of their potential to cut hospital costs and increase overall capacity. One juror pointed out that virtual wards could also protect vulnerable patients from the risk of hospital-acquired infections. Furthermore, virtual consultations are seen as an effective method for obtaining a quick diagnosis and eliminating physical barriers to care.

> *In terms of keeping people at home, you've got the crisis with the number of hospital beds available, it frees up space in the hospital. It's a really, really effective idea.*

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[7] The video produced by NHS England is 'Virtual wards enabled by technology: hospital-level care for people in their own home', available online at: https://www.youtube.com/watch?v=1dxHT_QuDxM

However, jurors expressed some concern about potential limitations and unintended consequences of the technology. There is a consensus that virtual wards should not be seen as a *one size fits all* solution. For instance, staying at home may cause significant distress for patients who might otherwise be reassured by the physical presence of staff. Jurors also point to difficulties associated with increased personal responsibility placed on patients. Particularly those suffering with complex conditions such as addiction. Furthermore, jurors are concerned about the impact that a patient being at home could have on potentially exhausted family members and carers. Emergency response times were also brought up and are seen as a source of added stress given that people in England are waiting longer than ever for ambulances. Jurors therefore agreed that there should be a careful set of criteria, taking these factors into account, that stipulate which patients would benefit from a virtual ward.

> *I think there has to be some criteria that is measured to see the state of the patient that is fit. If you have someone that can have a very unreliable diagnosis it might be more practical to keep them in the hospital. Whereas if there is someone who has had this issue for a while, and it is a case of having regular checkups, there should be some kind of standards that are met to be involved. But I agree that as many people as possible should get access to it.*

4. Hopes for the future role of digital health

In the first workshop Jury members shared their hopes about the type of health-related issues they would like to see digital technologies help address and the conditions these should focus on. They provided examples of conditions they would like to see digital health focus on, such as asthma, cancer, COPD[8] and fibromyalgia[9]. They also highlighted the importance of having ongoing online support, such as online support groups. And they noted that waiting times are a major issue and some were 'not sure how technology can address but if it can, it will be helpful'. Some suggested that patients could let their clinician know that their condition has become manageable, to reduce the number of people on the list.

Jury members expressed hope for people with serious and life-threatening conditions to have easy access to ambulances and health services, especially for those at the end of life when time can be most pressured. Reflecting on the idea 'it takes time to be seen', they considered whether digital technology could help reduce time spent on administrative tasks by processing these more efficiently. Some jurors also highlighted the importance of early detection and early warning, for instance in cases of cancer, which is one of the biggest causes of morbidity. In such cases the hope for an early warning digital tool could speed up getting first referrals and would also help save money for the health service. The same could apply to heart conditions and asthma which need early warning and diagnosis.

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[8] Chronic obstructive pulmonary disease (COPD) is the name for a group of lung conditions that cause breathing difficulties: https://www.nhs.uk/conditions/chronic-obstructive-pulmonary-disease-copd/

[9] Fibromyalgia is a long-lasting disorder that causes pain and tenderness throughout the body, as well as fatigue and trouble sleeping – reference: https://www.niams.nih.gov/health-topics/fibromyalgia.

Another key health issue that Jury members had hopes for was related to detecting and monitoring mood and behaviours to detect signs of depression which may lead to a potential risk of suicide. Linked to this, it was considered important to diagnose sleep issues, snoring and sleep apnoea which have links to depression and low mood, for instance via an app sleep tracker. Some jurors pointed to potential digital tools for tracking issues for brain aneurisms and the signs of this over time, for instance monitoring an injury from an accident. Jurors also proposed ideas about potential wearables for monitoring the weight of children in instances when this may be necessary but could be detrimental to their overall wellbeing if given too much focus.

Jury members mentioned the potential for a predictive tool using AI and focused on lifestyle, which could help to prevent heart disease by providing data to the person's GP to help them to monitor their risks. Jurors also shared hopes for a digital tool to track blood vessels to identify the early signs and causes of stroke. These examples were inspired by personal experiences that the Jury members had or health conditions they witnessed in their families, friends or community circles.

Jury members also expressed hopes about what they would not like to see digital technologies do in relation to health. These were formulated more specifically in relation to who uses it and how:

- who has access to the information being collected, hence a question of ownership of data: '*I'd like to be able to decide who I choose to share my medical history with.*'
- hopes that clinical diagnosis shouldn't rely solely on technology: '*relaying symptoms to a device should not lead directly to a certain diagnosis.*'

'It's 2030 and digital health is working well for people in South Yorkshire. What does this look like to you?'

Their answers highlighted the following themes and examples:

- **Virtual wards** in regular use**.**

Jurors can foresee a future in which there is more space in hospitals if the 'elder generation is happy to be seen at home: someone goes around to support them to use digital technology.' The people involved might not have to be medical staff visiting elderly, but 'people who are more socially involved, people who know technology, sit down and say: *this is how you use this equipmen*t.' This could save time and address bed shortages. Medical professionals could be in hospitals monitoring information that is coming in while people may find healthcare easier or more comfortable if it is taking place in their own home.

- **Artificial intelligence** playing a key role alongside health professionals.

AI would be incorporated into day-to-day services, helping with diagnosis in particular. People using digital health might have been advised by medical professionals in the first place but could also use devices independently if they are not feeling well, for instance a blood pressure machine. And they should be able to pick up or borrow this equipment from a health facility and use it.

- **Systems that work together to enable sharing of data.**

Different services would run programmes that are more compatible. They will 'need to speak to each other', for instance across different departments involving doctors and mental health professionals. For patients and public, this means 'avoiding too many apps that do similar things.'

- **Basic access to digital health by 2030**.

Digital health tools should be available to people for instance at a GPs or community health venue. People should be able to get a smart watch, monitor or book a virtual appointment, for instance, by sending a photo of a rash for diagnosis to their GP.

- **'Contact a virtual doctor** any time of day or night'.

This involves using AI to help diagnosis, particularly for common, typically non-life-threatening problems, such as a cough or a rash. This would provide a quick response time to prevent the issue from getting worse. It will also enable prescribing simple medication. The AI could also be used as a guideline to enable referring to a doctor. The option of Chat with a Virtual GP would be advancing very quickly for smaller health issues.

Jury members expressed their '**one hope for digital health**' in one or several key words, as shown in the table below, categorised per key themes:

Early detection and diagnosis	Improved, affordable and inclusive access	To enhance and help the NHS (not make profit or replace staff)	Overall improving one's health, includes privacy
'Everyone will get the chance to find any health issues early on.'		**'**To make everything easier and to lean pressure off the NHS.'	'Longer and better lives.'
'Quicker diagnosis and responsive equipment.'	'Easy, transferable and inclusive'.	'It works well and takes some strain off our current health service.'	'Respect for privacy'.
'To provide quicker diagnosis and save lives and time.'	'Accessible for everyone and not expensive or require expensive devices in order to run effectively.'	'To enhance and help the NHS - hospitals and not replace them.'	**'**That this is a project that will definitely take off as it seems a very good one that will help a lot of people if data input is correct and monitored.'
	'Improved AI accuracy'.	'All intentions are for the betterment of the patient - not commercial gain.'	
	'Improve health care, both at point of access and benefits to the individual'.		

	'Monitoring devices, such as the FitBit watch, come in different styles - Able to wear one around your waist if you were to have no arms.'		

5. Concerns about the future role of digital health

Jury members also expressed potential concerns for digital health. These were related to the issue of technology moving fast and creating a social divide. This is based on the view that digital health could 'work well for some but not others'. While being seamlessly integrated for those with access, it risks creating a 'two-tier society' felt by those who can't access it and would still prefer to use traditional routes to access their GP appointments or other services. Hence the question of a 'new digital health divide' between, for instance, the north and south of Sheffield or between different socio-economic groups emerged, or a generational divide with tools that would work well only for younger people.

In the second half of the session Jury members were asked to describe a hypothetical future situation:

'It's 2030 and digital health is not working well for people in South Yorkshire. What does this look like to you?'

Their answers highlighted the following themes and examples:

- **Lack of knowledge and skills to use digital health by marginalised groups and those with multiple complex needs.**

These groups include the elderly, people with learning difficulties, people who use English as a second language, and those physically disabled, as well as people with drug and alcohol problems. These are people who need digital health technologies but aren't being supported enough to be able to use them, hence there is a risk that the data and technology is not going to be helpful for them.

- **Questions of access to digital health.**

This includes a concern about lack of access to digital health due to age, or finances or lack of accessible training for people, and this might lead to a health divide. It has been suggested that it might not be just the elderly who find it difficult to access digital tools but also those groups mentioned in the point above.

- **Data access and lack of data sharing.**

This means a concern about information not being shared across different departments and groups, for instance across emergency services. But other questions also emerged, related to who has access to data and who has the authority to grant such access.

- **Risk of digital health being taken over by commercially interested parties**.

The concern here was about commercial parties competing for access to digital health and questions over who has the marketing and financial influence to gain it. There was also a concern about the risk of an 'oversaturated market', with different companies competing with each other and people having too many options and subsequently choosing none. Jurors considered whether private companies may be given contracts in digital health because of their connections with people in Government, rather than because of the quality and value for money of their products or services, drawing on media reports about the contracting or personal protective equipment during the Covid-19 pandemic.

- **Implementing these technologies is complex and may be too difficult to achieve.**

The risk is that the implementation is going too fast which means that some people will not be able to cope with it and might be 'lost in the transition'. There was a comparison made with the digitalization of the supermarkets and the situations when self-service tills are replacing staffed check outs - which should not be reproduced in a healthcare setting, with wards being reduced for instance.

- **Risk of being too reliant on digital systems.**

This includes scenarios in 2035 with petrol cars being banned and only electric ambulances in place, hence the risk of power cuts for instance would lead to ambulances not running at all.
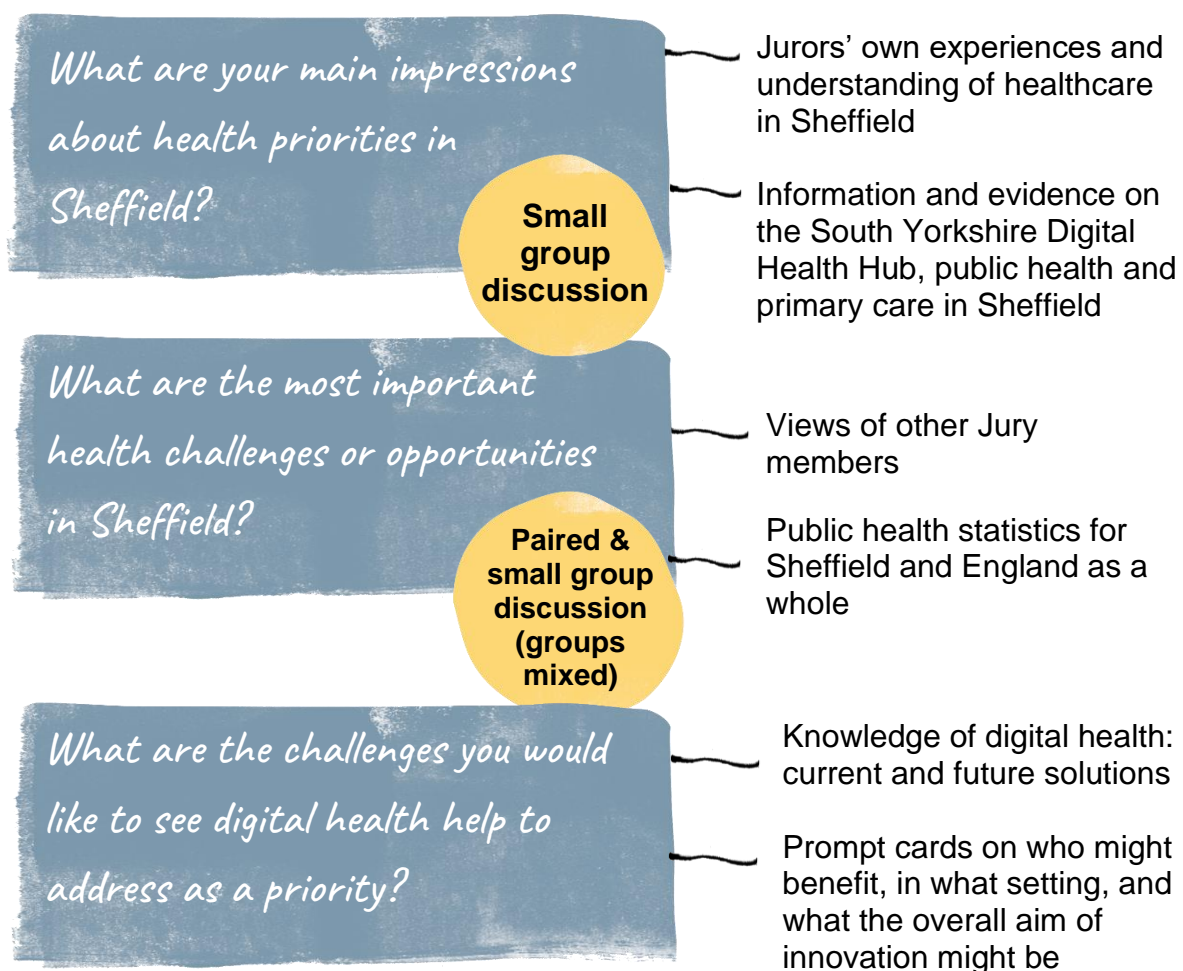
In the final part of the session Jury members expressed their '**one concern for digital health**' in one or several key words, as shown in the table below, categorised per key themes:

Security of data	Access to data and privacy	Data auditing
'Data leaks or hacked.'	'Incorrect use by users, (data) needs proper auditing set up and access requirement levels. Not every user needs to see all data.'	
'Data is hacked and used inappropriately.'	'Data will be sold to the highest bidder.'	
'That data breaches could mean your entire medical history, location and everything about you could be easily accessed by third parties.'	'Personal medical information shared with too many.'	
	'Where the data will be stored and who gets to use the data.'	

6. Priorities for (digital) health in Sheffield

People's priorities for improving healthcare in Sheffield were explored across multiple sessions during the Jury's sessions so that these could develop gradually and iteratively (see figure 2). In the first workshop, discussions built on the healthcare topics or issues which were already in jurors' minds as they entered the process. Facilitators emphasised here that jurors could draw on any aspect of their experience or knowledge of healthcare and that their priorities did not need to demonstrate a clear link with digital technologies. This freed jurors to suggest a broad range of priorities which could then be revisited in the context of digital innovation once they were further into their deliberations.

Figure 2 – Exploring people's priorities throughout the Jury process.

What are your main impressions about health priorities in Sheffield?

Small group discussion

Jurors' own experiences and understanding of healthcare in Sheffield

Information and evidence on the South Yorkshire Digital Health Hub, public health and primary care in Sheffield

What are the most important health challenges or opportunities in Sheffield?

Paired & small group discussion (groups mixed)

Views of other Jury members

Public health statistics for Sheffield and England as a whole

What are the challenges you would like to see digital health help to address as a priority?

Knowledge of digital health: current and future solutions

Prompt cards on who might benefit, in what setting, and what the overall aim of innovation might be

Initial perceptions

As introduced earlier in this section, the priorities jurors raised at this stage often reflected either their own experiences of the healthcare system in Sheffield, or the experience of people they know. Many of the healthcare issues mentioned were articulated anecdotally.

> *I just think that when you ring the GP, it takes a million phone calls just to get through to your GP. So you'd be waiting just to get in a queue. And then you can't even get an appointment for that day half the time, in my doctor's anyway. So it's like they say keep on ringing every day but your issue is happening that day.*

Staff availability and interaction featured high among jurors' priorities in this early discussion. Several jurors described being impressed by their experiences of GP and wider health services in Sheffield. However, jurors also considered the significant pressure placed upon healthcare staff and its impact on services.

> *I do feel that a lot of the empathy of frontline staff, that the staff are just so pushed, that they are coming across, the personal side of the services gone, because the staff are just so overworked. I feel sorry for frontline staff, from, you know, the GPs to the receptionist, to everybody, the personal side of the service has deteriorated.*

Jurors also expressed frustration at needing to repeat the same information to multiple members of staff, an issue which was linked to concerns about medical records being incomplete. This was considered particularly concerning in the context of mental health, which itself was raised as a key interest for some jurors at this stage.

A final key theme was cheap and easy access to fast food and alcohol in Sheffield. Jurors drew on an early presentation on public health when raising this as an important factor in the city's health challenges.

Final deliberations

The Jury's final day of deliberations began by returning to the discussion of challenges and opportunities for healthcare in Sheffield more broadly, and not necessarily those which participants related to digital technology. The intention was to generate an extended list of priorities which could be refined throughout the day. This included contributions from all 14 jurors and was informed by the evidence presented to them. The priorities raised here continued to reflect those mentioned earlier in the process, broadly falling into three categories:

- specific conditions and health concerns
- health services and staffing, with a particular focus on GPs and community healthcare
- addressing the wider determinants of health.

Specific conditions and health concerns

Jury members saw a general need for the leading causes of ill-health to be addressed as soon as possible by digital health technologies. However, they also prioritised specific issues and conditions including Alzheimer's and dementia, diabetes, high blood pressure, stroke, epilepsy, and alcohol and drug misuse. Within Alzheimer's and dementia, early diagnosis and improved support for carers were considered to be particularly acute challenges in the context of an ageing population. High blood pressure and diabetes, both of which jurors recognised as common

conditions affecting a large number of people, were also frequently returned to in discussions.

Likewise, mental health is a considerable and urgent priority for many jurors. There is a perceived lack of understanding in relation to mental health, as well as uncertainty about how people who experience mental health issues can be supported most effectively.

Health services and staffing

Jury members would like to see better access to healthcare in general. They raised the current demand placed on GPs as a challenge in particularly urgent need of addressing, citing the impact on staff and patients. They highlighted the importance of being able to access healthcare in the community, including via GPs and specialist clinics, and would like more choice and better availability among their initial point of contact with the healthcare system. They saw a scenario in which digital health could help to alleviate hospital bed shortages, which they also perceived to be an important issue in need of addressing.

> *The opportunity to alleviate pressure from the NHS. I mean, it can reduce numbers in hospital, free up space for hospital bed with online virtual wards. It has an opportunity to help people that really require time at the hospital.*

Wider determinants of health

Many of the priorities raised by jurors at this point in their deliberations were social, economic and environmental factors, considered here under the umbrella of the wider determinants of health. Social care and social housing, diet and lifestyle, and wealth inequalities were all considered to be relevant targets for improving health in Sheffield. Drawing on public health evidence provided in an earlier workshop, jurors made points about the unequal distribution of health across Sheffield and saw a need for resources to be invested accordingly.

> *For me right now the biggest challenges in South Yorkshire is deprivation, until we actually tackle that in the county or the area or city, we're never gonna get any improvements… it means a lot to different people, to some it'll be education, education, for some it will be about money, earning power, how they spend their time socially, are they in the pub, are they smoking and drinking, are they hitting the gym or are they eating healthy?*

Establishing priorities for digital health

Jurors were then asked to suggest which of the priorities raised so far they would like to see digital technologies help to address first, bearing in mind the different kinds of digital health tools previously explored. Two main categories emerged through this prioritisation, outlined in the table below.

Priority health conditions and groups to focus on	Priority aims for digital health innovation
- Alzheimer's - Cancer - Seizures - Stroke - High blood pressure - Diabetes - Mental health - Maternal health - People who are terminally ill - People with disabilities - People without English as a first language	- Prevention and early detection (e.g. via screening and improved access to testing) - Encouraging healthy lifestyles (e.g. via education and opportunities for exercise, healthy eating) - Reducing NHS waiting times - One system for improved data sharing

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7. Principles for digital health in Sheffield

The Jury's role was not only to influence decisions about the kinds of projects pursued by the Hub – its *priorities* – but also to establish cross-cutting *principles* which can inform the Hub's overall approach to innovation in digital health. Broader values and expectations held by the jurors often emerged spontaneously during their discussions. Immediate concerns about the protection of personal data, for instance, pointed to the importance of upholding privacy for several jurors. At the same time, jurors who expressed surprise and dissatisfaction about the lack of joined up data across the NHS considered the importance of coordinating access to health data in the context of healthcare.

> *I'm just thinking regarding the privacy, I know you want everything in one thing, want to know about the person, you want to know about the health, about everything, about one person. So it's a bit like a big brother thing. But where does the privacy come into this?*

During the Jury's final day of deliberations principles for digital health innovation became a main topic for discussion. Using the points raised in previous discussions on future scenarios for digital health as a point of departure, jurors deliberated on the question of *what matters most for how digital health works in the future.* This began the process of translating jurors' broader values and expectations into a set of standalone principles for the Hub to take forward.

The importance of both privacy and improved access to data via the joining up of currently separate NHS systems continued to figure heavily in these discussions. Jurors spoke about taking a controlled approach to data access, which embraces data sharing for public and patient benefit in healthcare settings whilst maintaining high levels of privacy. Jurors expressed hope that digital health could enable the NHS and its patient care to benefit from more accessible health data without the same data falling into the hands of third parties in the private sector. They shared an

expectation that measures should be put in place to prevent misuse, including the use of data for commercial advantage, or unauthorised access.

> *We agreed that privacy is something that's going to be really important, we need to uphold that. Digital technology, there's a risk of that being broken and patient confidentiality being affected. So in terms of going forward with whatever implementations that involves, we would just like to know what is happening, where our documents are going, our medical information, who's getting access to it and why.*

Jurors also raised clear communication as crucial to the future success of digital health. One element of this communication is around the collection and storage of individual data, based on the view that everyone should be able to easily find out the data that is available about them and who it is available to. Another is about setting clear expectations for the public and patients about their responsibilities when it comes to using digital health tools and collecting and storing their own health data. Jurors would also like to see digital health clearly benefit healthcare services and staff. Both are seen as overstretched and unlikely to welcome or profit from innovation that duplicates effort or increases workload.

It was also important to Jurors that the digital health tools which are developed are accessible and inclusive. In their view, this might be as simple as making a tool work on a range of smartphones or similar devices. It could also mean integrating multiple innovations into one tool so that access is made easier for those who depend on them. However, jurors also highlighted the importance of putting support in place for particular groups who may otherwise face additional barriers to engaging or benefitting from digital health tools, such as those in vulnerable financial circumstances or who are otherwise excluded from digital aspects of society. With this in mind, jurors suggested the focus of digital health innovations should be on enhancing healthcare but not replacing staff and other core components of an NHS which is already highly regarded.

The final key principle to emerge in these discussions relates to mechanisms for accountability and public scrutiny. Jurors' proposals for the Hub include establishing a panel with public membership who could scrutinise the work of the Hub and its decision-making. They suggest this panel should draw on people of a range of ages and backgrounds in South Yorkshire, who can reflect and communicate diverse community interests, and respond dynamically to the pace of development among projects the Hub is supporting.

> *How does this platform, how does this technology gain the trust of the people? One of those methods is by the overarching implementation of it, [so they] are actually accountable to a board, a commission, some sort of scrutiny panel, and who will actually hold the implementers, the funders, the technology providers to account and that will get the trust of the people and hopefully embed it further.*

8. Final recommendations

The entire Jury voted to sort their recommendations in order of importance, once each for principles and priorities.[10] The recommendations shared here have been further grouped by the research team to distinguish priorities which relate to specific health conditions or groups of people from broader aims. Within each section, recommendations are listed in order of importance as ranked by Jury members, with particularly low-scoring recommendations excluded from this summary.

Priority health conditions and groups to focus on

- **Mental health** and people living with mental health conditions.
- People living with **long term health conditions**, particularly high blood pressure, diabetes, dementia and Alzheimer's disease.
- Individuals identified at **higher risk** of particular conditions, such as through family history.
- People who are **terminally ill**.
- People living with **disabilities**.

Priority aims for innovation in digital health

- Improve and **enhance the physical and mental health, and wellbeing** of the people of Sheffield **through early detection**.
- **Smooth out health inequalities** across Sheffield.
- **Free education** and **training** to promote healthy living **tailored to each person**. Information should be provided in multiple languages, available in person and online, and support people to take decisions which benefit their health rather than telling them what to do.
- Improve the **accuracy** and **reliability** of **current devices** over coming up with new 'gadgets'. This means promoting projects which focus on fixing existing issues first, for example ECG machines that give faulty readings, over those which try to create devices that might do something 'new' but don't solve problems with current technology.

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[10] Where both small groups generated recommendations with a shared theme, each recommendation was included in the ranking exercise but these have been combined for reporting purposes. For instance, the top recommendation on privacy combines 'Safeguarding data privacy and security' with 'Privacy must be respected and maintained within digital health.'

Principles for innovation in digital health

- **Privacy** must be respected and maintained within digital health, with safeguards in place to ensure **data security**.
- Digital health tools should be **accessible** and **affordable**. They should be easy for all to use, whether for patients or healthcare staff.
- Digital health should promote **controlled access to data**, starting with the person who the data relates to: *I should be able to look at my data and control who has access to it*.
- Digital technology should **enhance existing NHS services** and **not replace people** in healthcare – *we don't all want self-scanning checkouts!*
- **Inclusive support** must be put in place **for vulnerable groups** to use digital health tools.
- Decision-making must be open to **public scrutiny and governance**.

Section 4
Conclusions

- Researchers' reflections
- Acknowledgements

9. Researcher reflections

In designing this first Citizens' Jury for the South Yorkshire Digital Health Hub (SYDHH), there were a couple of important overarching concerns.

Can we give a strong voice to diverse public concerns and priorities early on in the life and work of the Hub?

Can we ensure that the Jury is not an isolated 'performance' of public involvement but the beginning of a meaningful process?

On first of these concerns, we feel reassured. The composition of the Jury, and the clear recommendations they have delivered within three months of the Hub's launch, provide a strong point of reference for the subsequent work of the Hub that is already being heard within the Hub and beyond.

On the second matter, the jury is still out, and rightly so. The Citizens' Jury in Sheffield in November 2023 constitutes the first major step in the process of engaging people, public and patients to guide the work of the SYDHH

Further steps in enacting the recommendations of the Citizens' Jury involve collaborating with diverse groups of people, public and patients and the Jury members themselves to help with:

- identifying and creating training materials aimed at patients and members of the public as well as digital health innovators;
- engaging with digital innovators to help them develop and test new digital health technologies;
- deciding which ideas and products the SYDHH and its partners should encourage and invest in.

The deliberations and guiding principles of the Citizens' Jury will support the SYDHH to achieving the objective it set up for itself: *to bring together a digital health community of practice, including healthcare providers, engineers, scientists, clinicians, patient/public groups and industrial partners to develop digital health solutions that address unmet clinical needs.*

Acknowledgements

Appendix

Appendix 1 – Summary of Jury Demographics

Demographic	Sheffield LAD	Target	Actual
Gender			
Female	51%	7	7
Male	49%	7	7
Age group			
18-24 years	9%	~2	3
25-34 years	14%	~2	2
35-49 years	18%	~2-3	4
50-64 years	18%	~2-3	3
65+ years	17%	~2-3	2
Ethnic background			
Asian/Asian British	10%		1
Black/Black British/Caribbean/African	5%	~4	1
Mixed/multiple ethnicities	4%		2
Other	3%		0
White	80%	~10	10
Lifestage / employment status			
Working F/T	53%	~6	3
Working P/T			4
Not working/unemployed	17%	~3	3
Retired	20%	~2-3	2
Student	10%	~1-2	2
Socioeconomic status			
A Senior professional	22%	~3	4
B Lower professional			
C1 Skilled	33%	~4-5	4
C2 Semi-skilled	19%	~2-3	3
D Low skilled	27%	~3-4	3
E Unemployed			
Marital status			
Cohabiting			4
Married / Civil Partnership	40%		5
Single			5
Living with disability / long-term health condition	21%	~4	4
Ever worn wearable device			
Yes – most days or everyday	-	An even spread	7
Yes – occasionally/to try it out	-		2
No	-		5
Unsure	-		0
Experience of smartphone or similar device (e.g. tablet)			
Does not own	-		0
Owns, but not confident using it	-	An even spread	4
Owns, confident using it to make phone calls or sending messages but not much else	-		5
Owns, confident using it for most things/everything	-		5
Frequency of health self-monitoring			
Very often	-		4
Often	-	An even spread	5
Occasionally	-		4
Rarely	-		1
Very rarely	-		0
20-24y Disabled under the Equality Act: Day-to-day activities limited a lot/a little			

Case Study 1: Smart Watches

1. What is a smart watch?

A device worn on your wrist that can link to your phone. They can measure heart rate, body temp, sleep duration and blood oxygen level. Examples include the Apple Watch, Garmin Forerunner and Fitbit Charge. Prices range from £100-£400 on average.

2. Why are they useful?

They can be used to track health and fitness progress and, in some instances, have helped people to identify otherwise unknown health conditions or raise the alarm in an emergency.

Important!

In 2020, A group of heart specialists concluded that "wearables may be very valuable in the future but at the moment they do not have a defined place in risk assessment". They highlighted the number of false alarms in individuals without symptoms.

3. Patricia's Story

Patricia had recently retired and decided to get fit, so she went out and bought a Fitbit to track her steps. A few weeks later she began to feel unwell and thought she might have pneumonia. However, all her tests came back negative. She began experiencing shortness of breath and tiredness. Looking at her Fitbit she noticed that her resting heart rate, which was normally 65bpm, was rising each day. When her resting heart rate reached 140bpm she phoned the emergency services and was taken into hospital. Doctors found two large blood clots in her lungs which were quickly treated.

"If I didn't have a Fitbit on my wrist, I would never have known that my heart rate was getting dangerously high, and I might not be here to tell my story" - Patricia

4. Things to think about

- How affordable and accessible are they?
- Data security and ownership.
- Monitoring your health in daily life.
- Concerns about their accuracy, or unintended consequences.
- How could they be improved in the future?

Hopkins Van Mil

1. What is a Continuous Glucose Monitor (CGM)?

A sensor attached to the skin that provides real time insights on blood sugar level to people with diabetes without the need for finger prick tests. CGMs also help to predict whether blood sugar levels are going up or down, and how quickly.

2. Why are they useful?

- CGMs can help people to stay on top of their blood sugar level more easily.
- They also allow people to see how exercise, food and medications affect their blood sugar level.
- Some sensors have alarms that alert people when their blood sugar level is too high or too low. Others can be linked to pumps which provide insulin to the patient when needed.

Important!

Currently CGMs are provided by the NHS for free to those with type 1 diabetes. Some people with type 2 diabetes receive them if they are on insulin and at risk of low blood sugar levels. They are also available to buy - a year's supply is around £1200.

Some people report feeling more anxious from seeing their blood sugar levels all the time.

3. Natalie's story

When Natalie, 20, was diagnosed with Type 1 diabetes, she was told that she would have to administer injections and carry out finger-prick tests for the rest of her life. The fear of low blood sugar was a big source of stress and kept her up at night. CGM's have gone a long way to alleviate this fear. Whilst the reading is not as up to date as from a finger-prick test, the ability to look at the data on her phone allows for longer intervals between the more invasive and inconvenient finger-prick tests. She says that wearing the monitor has allowed her to live more confidently as she feels more in control of her illness.

"You don't get a day off [from type 1 diabetes]…so having something that just allowed my mind to have a bit of a break and take that exhaustion away" - Natalie

4. Things to think about

- What they offer people living with diabetes
- The cost and accessibility of these devices
- Impact of regularly monitoring blood sugar levels
- Other conditions which could benefit from similar technology?

Hopkins Van Mil

1. What is a Virtual Ward?

These allow patients to access hospital-level care at home, helping speed up their recovery while freeing up hospital beds. Whilst at home patients are cared for by a team providing a range of tests and treatments. Patients are reviewed daily and the 'ward round' may be a home visit or take place via video. Virtual wards use technology like apps and wearables which enable staff to easily check in and monitor a patient's recovery.

Important!

Several thousand virtual ward 'beds' are available across the country. The long-term ambition is to double the current number, which would allow for more than 50,000 'admissions' a month. This is approximately 1/3 of the total number of hospital beds in the UK.

2. Martin's Story

Virtual wards have enabled Martin to live at home despite his disability that would have otherwise kept him in hospital. Being able to be at home, in a familiar and comfortable environment, has benefited Martin's mental health and reduced the impact on his local hospital. Martin has several wearables at home with him which he wears every day to measure his heart rate, oxygen level, skin temperature and respiration. This data is then sent to the hospital every 15 minutes and is monitored by staff. This has given Martin flexibility to go about his daily life without the disruption of in-person hospital visits. It has also given him a feeling of greater control over his recovery and rehabilitation.

"Without this technology I wouldn't be at home, and it would be worse for me because you'd be very anxious and nervous. Whereas if they let you go home with this technology, you would be safer and you would be a lot happier" - Martin

3. Things to think about

- What does the virtual ward offer patients, and healthcare staff?
- What's important about patients and staff staying in contact on a virtual ward?
- Accessibility – for those with limited mobility; for those less comfortable with digital technology
- Potential impact: on healthcare system, on family members at home.

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