# A Young Adults' Charter for Digital Health

## 10 Principles for Digital Health Innovation



**South Yorkshire** Digital Health Hub

**University of Sheffield**

**Sheffield Hallam University**

Hopkins Van Mil

ayph

CHILYPEP
CHILDREN AND YOUNG PEOPLE'S EMPOWERMENT PROJECT

UKRI — Engineering and Physical Sciences Research Council

UKRI — UK Research and Innovation

## Why our charter matters

We feel that young adulthood is a distinct stage where we experience lots of transition. Our identities are emerging and changing. In today's society, our experience as young adults is unique too, for various reasons. We are the first generation to grow up with social media, we became adults during a pandemic and cost of living crisis, and we experience a constant influx of online content, advice, and information, some helpful, some not.

We understand Digital Health in a holistic way – beyond our physical and mental health - because technology is part of our lives. We hope to be treated as people not patients, with knowledge and the desire to learn about how Digital Health can enable us to reach the futures we want. How Digital Health is shaped in the future has the potential to build trust and understanding between generations. But it also risks exacerbating mistrust on things we feel already divide us from other generations, whether that's how we use technology or how we manage our health.

We think this is an important opportunity for Digital Health technology to consider the distinct and diverse needs of young adults, and to learn from some of us who are emerging as adults into today's context. We feel that our generation is passionate about leading change, and we want to ensure our unique needs and perspectives, as well as the needs we share with others, are taken into consideration. We would like to hear from policymakers and researchers in Digital Health about how our voices and our thoughts in this Charter will help to shape the future of Digital Health.

*"If you're on a journey of getting your health under control and managing it with the various health technologies available to you, it means you are going to be so much more able to actually participate in your daily life and thrive in your career."*

## Summary of principles

**1.** Recognise us as a distinct group with unique and changing Digital Health needs

**2.** Support us as digital learners, not 'digital natives'

**3.** Ensure Digital Health tracking supports us as we develop as young adults

**4.** Enable Digital Health support to move with us

**5.** Ensure affordability of Digital Health for young adults

**6.** Integrate Digital Health consistently and appropriately with in-person services

**7.** Support and train healthcare professionals to use Digital Health tools with us

**8.** Help us to navigate trustworthy Digital Health sources

**9.** Improve transparency and trust in who is involved in Digital Health companies

**10.** Explain what's happening with our Digital Health data in ways that we'll actually engage with

# Statement from SYDHH and Background to the Charter

The South Yorkshire Digital Health Hub is a collaborative initiative involving the University 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. A core aspect of the Hub's work is involving patients, members of the public and communities in its activities.

To drive this involvement, the Hub has commissioned three rounds of deliberative engagement to take place across the region over the current period of funding, September 2023 – September 2026. The Hub is working with Hopkins Van Mil (HVM) to deliver all three engagements. 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.

This Charter is the output of the second engagement, focusing on young adults (18-25) with long term health conditions. The Hub worked with the Association for Young People's Health who have provided input into facilitation, design and analysis of this second engagement. The Hub also worked with Chilypep, who provided input into engagement design and recruitment support, as well as hosting venue for the in-person workshop session.

## Workshops included small group discussion, specialist input, and Q&As

Workshop 1 - Grounding in the topic, how young adults used Digital Health over their lifetimes

Workshop 2 - Hopes, concerns, and using Digital Health in everyday life

Workshop 3 - Responsibilities within Digital Health, getting the best out of life

Workshop 4 – Towards a Charter

Some young adults review the draft Charter

## Who is this Charter for?

The UK Government's new 10 Year Health Plan for England places Digital Health at the centre of transformational change within the National Health Service (NHS). This involves patients, carers, members of the public, government bodies making legislation and policy, digital designers and developers creating digital health applications, and healthcare organisations implementing solutions. Broadening the inclusion of who is meaningfully involved in defining, designing, and implementing digital innovations from the start is critical to the success of this mission.

Young adults have been underrepresented in Digital Health research and have reported challenges and poor experiences of healthcare in the UK, particularly in the transition from child to adult services. This Charter aims to amplify the voices of young adults and understand their hopes and concerns for Digital Health to avoid perpetuating and widening these inequalities during the future digital transformation of national and local healthcare. All actors in Digital Health will have individual and interconnected roles in developing and understanding the principles and actions proposed in the Charter.

# 1 | Recognise us as a distinct group with unique and changing Digital Health needs

**We want young adults to be recognised as a distinct group experiencing rapid life changes, and for Digital Health to be designed with us in mind.**

Young adults, particularly nowadays, have lots of different roles to play and hats to wear. That means we're a diverse group of people with different needs from one another.
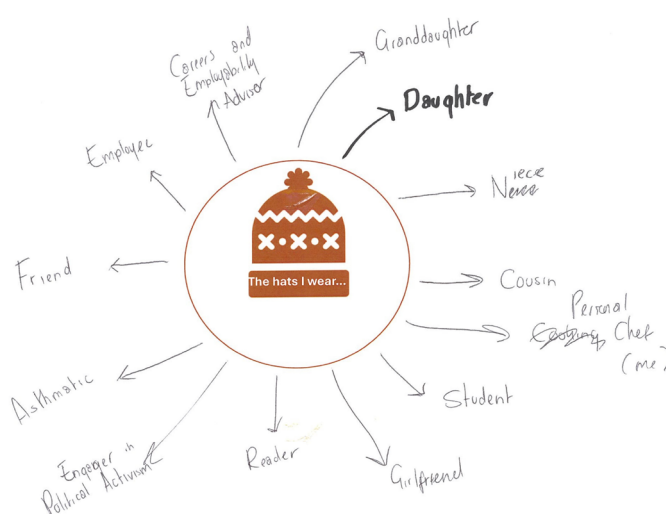


*"You're thrust into this world of being an adult and you have to wear this hat, and I don't know about anyone else but it's just, it's really overwhelming sometimes"*

We're united by the fact that who we are becoming, and our identities are rapidly changing. Young adults are often going through periods of change, whether that's moving between university and home, or starting new jobs, or getting health diagnoses.

All of this means that what we need will change rapidly too, and when we're wearing different hats, we might want different things out of Digital Health.

**We want representation and involvement of young adults in all aspects of Digital Health (e.g. commissioning bodies, policy, design, research).**

We don't always feel listened to in current affairs (e.g. Brexit, Covid). That often results in us or our peers feeling disconnected and some of us disengage. But part of our generational culture is leading positive change and establishing a sense of community, so we want the opportunity to feel heard and understood.

*"I don't think young adults are part of a demographic that they [the Government] consider when they make decisions like that [abolishing NHS England]… I think young adults as a whole slip under the radar quite a lot and I guess people who make large decisions like that, they've not even given a second thought as to how it will affect such a big population of young adults. And a lot of young adults now are a lot more comfortable talking about health and their difficulties with health"*

# 2 | Support us as digital learners, not 'digital natives'

**We want clear, accessible education and training on how to use Digital Health tools, without the assumption of digital literacy.**

We carry the expectation of being the tech-savvy generation, but we don't always feel tech-savvy. If we do it's often because we had no other choice, due to things like Covid. We don't necessarily have the digital literacy that you expect us to, whether that's how to choose and use Digital Health tools, different devices or digital services, or data security and privacy.

Yet we often hold the responsibility of teaching older people how to use technology, even though we've largely taught ourselves. This means we end up with informal care responsibilities on top of care responsibilities we already have; a burden which could be reduced for us if everyone has access to clear training and support for Digital Health.

*"I don't think a lot of us have had much choice when it comes to being a digital native. I think it was thrust upon us quite intensely from being young, and the pandemic. I don't think we've had much choice, it's just been one of those things where you have to go along with it and accept it, otherwise you'll miss out on things unfortunately."*

*"You also end up being the designated teacher of how to teach people how to use it [tech]… which I think is quite a big part of being a young adult. Being that teacher and being able to advocate for digital tech."*

**We want all of us to be able to use Digital Health tools.**

We feel we are the generation who are taking the responsibility to openly and knowledgeably lead the way towards accommodating different learning styles.

We all learn differently and therefore we all learn to manage our health differently. Being able to personalise our technology e.g. altering language settings or being able to set reminders within apps for medication, will help us adapt to our health needs.

*"I've got ADHD, I forget to do important things and it's a constant battle of remembering to do anything. So these apps will help me organise my thoughts, help me organise my tasks for the week so that I'm not tiring myself out… You get exhausted so quickly or overwhelmed so quickly so it [Digital Health] makes me prioritise everything I've got to do and makes it more manageable."*

# 3 | Ensure Digital Health tracking supports us as we develop as young adults

**We want Digital Health tools to support (e.g. through education) young adults to use tracking in healthy ways without becoming obsessive.**

There is lots of disordered eating/exercise in young adults, particularly young women, which we feel is related to growing up with apps like MyFitnessPal. It became the norm for us to track and sometimes control our calories and steps digitally. We didn't receive much guidance on how to track in positive ways.

*"Ensuring technology that's rolled out has adequate training alongside it to actually be able to use that tech safely and effectively. Because young adults can't just be assumed that they'll know how to use what's given to them or what's on offer."*

**We want a better understanding of what can be tracked.**

We struggle to know what we could or should be tracking, and our preferences are varied. Understanding what we are able to track will support us to handle our health more holistically.

*"I think a lot of people don't realise the extent of what is tracked data-wise and how data is held."*

**We want to choose what we track and what we share with others.**

Some of us rely on tracking to manage and incentivise exercise, healthy eating, finances and this is effective for us, whereas others find some aspects of tracking intrusive.

For some of us, the social element of tracking e.g. sharing through Strava or MyFitnessPal can lead us to negative self-image. This can be made worse because of social media so we regularly find ourselves being compared to other people.

*"Making the app not a social thing, so you can't see other people's development because I think there's a way that tracking can easily get obsessive if you're seeing how others are doing."*

**We want Digital Health apps to be designed simply and effectively, where we can set healthy digital limits.**

Young adults are navigating what feels like a complicated and often challenging world, whether that's because of the frozen job market, university stress, or the cost of living.

If Digital Health can make the basics of life easier (things like managing our health and finances), this will give us the time and energy to help us reach other goals.

*"Make sure that it's simple but effective, so that it doesn't overcomplicate things and you don't feel the need to constantly input information into it. Maybe something where you can just access it once or twice a day and that could be satisfactory for it to gain enough information from you and you to gain enough information from it, making sure it's not overcomplicated or consuming in that way."*

# 4 | Enable Digital Health support to move with us

**We want Digital Health to be equally accessible across different regions.**

We are in a transient period of life and we face lots of changes, including moving between home, university, work, and so on. The quality of healthcare and access to Digital Health systems is different in different places.

This makes it a unique challenge for us because managing our health whilst moving about can be time consuming, bureaucratic, and fractured – and we don't know the quality of the care we'll receive.

*"It needs to be national not regional. Some places have more, let's say, Digital Health tech, some places have more of that available than others – like you say, it's a postcode lottery and it shouldn't be. You should be able to get equitable, fair, and fairly similar treatment throughout the country."*

**We want a more efficient way for our health data to be transferred between regional providers and within local networks.**

Those of us who live in more rural areas and between different healthcare providers, or those of us who move around a lot e.g. university to home, would find it helpful for our healthcare data to be safely shared between providers. This means we wouldn't regularly have to re-explain our health to different people.

*"I wouldn't mind if your data or your tracking was used across different services. I know some people get a little bit worried about that, but if I went to a specialist or a department in the hospital, I wouldn't mind if that data was shared and then linked somehow to the GP or mental health nurse or whatever. I think that could be a good system."*

*"A lot of the time, the doctors and departments, professionals, whoever, there's really poor communication between them, so how would you get to a point where that [tracking] data would be shared?"*

# 5 | Ensure affordability of Digital Health for young adults

**We want Digital Health to be affordable and not dependent on access to things like phones (hardware), subscriptions and updates.**

Some of us have found that if we cannot access the latest model of phone or download the newest update, this is a barrier to using Digital Health. Emerging as a young adult in a cost-of-living crisis, when many of us are students in debt, makes this a particular challenge.

*"Cost of living. I don't even say 'living', I say 'existing'. Because that's how it feels being a young person in today's society.*

**We want Digital Health to prioritise preventing poor health over commercial interests.**

We feel profit is treated as more important than our health needs. We feel we should not be treated as consumers of Digital Health but rather, that it should be an enabler for our healthcare. This is because Digital Health helps us to take ownership as individuals and have agency within our daily health needs.

*"I think Digital Health can obviously assist people with their health. So if someone had a condition, digital means could really help them with their life to improve this. I'm thinking if they need to take loads of time off work with their health, if their health goes downhill or something happens, digital means can help them either to prevent it or live with it."*

# 6 | Integrate Digital Health consistently and appropriately with in-person NHS and care services

**We want there to be consistency in how Digital Health is used by different professionals in our lives.**

Inconsistency in what we have to do digitally and what we have to do in-person can be confusing and stressful, particularly because these systems often change e.g. one day we can request a doctor's appointment by calling, but the next we have to do it through a complicated online system.

*"I think rather than taking over normal healthcare, it [Digital Health technology] needs to know its boundaries, know where it should probably be done in-person rather than online. I think it definitely needs a clear boundary where online health stops and in-person health needs to start."*

**We want in-person options at key moments, for example to explain what test results mean, and help avoid inefficiencies in Digital Health e.g. explain results that have been delivered online.**

Some of us are experiencing increased anxiety and stress around misreading results that we get digitally (e.g. blood test results). We have Google at our fingertips so we can search our symptoms. The online information instantly available to us from a number of platforms (e.g. TikTok, Instagram, Reddit) can be overwhelming and confusing. To avoid wrong self-diagnoses and unnecessary anxiety, it is important that our healthcare providers are still available to help us navigate our health in an increasingly digital world.

*"To ensure we don't 100% rely on digital, maybe incorporate a feature where if you do input any data you can get follow-up appointments with actual people or professionals or an algorithm that can identify, oh this person may need a follow-up to actually speak to a professional... so instead of relying on the consumer to contact a professional there could be an alert system of something to let someone follow it up. Maybe merging the digital and AI together with a person to follow on from this."*

**Keep Digital Health tools regularly updated and clearly inform us about what this means.**

When services are no longer provided or Digital Health tools are changed and updated, we are often left in the dark. Being kept in the loop about what's changing will help us to manage our health without being worried that we'll fall through the gaps of digital technology.

*"There have been a few times where I've gone to order my prescription and it's come up on the app that your pharmacy is no longer using this service, it's gone to a different one… So it passes hands but it doesn't let you know that until you go onto order your prescription that you're running out of."*

# 7 | Support and train healthcare professionals to use Digital Health tools with us

**We want health professionals to listen and use the Digital Health information we share.**

Healthcare professionals often trust and understand digital technology less than we do. That difference between generations can lead to a lack of trust. The way we manage our health can feel incompatible with the system we're in. Our experiences can then be dismissed and we have little place to turn for advice.

*"Making sure that professionals have the same level of trust and give the same credit to Digital Health tech as young people do. It's obviously a massive part of young people's management of their conditions, their lifestyle, everything – and sometimes there is a bit of friction with professionals and the information that's gathered. It can be a bit of a battle to get them to trust that and take it on board."*

**We want healthcare professionals to be trained in Digital Health.**

Whilst we want healthcare professionals to listen to our Digital Health information, we also want them to use this information only as a guide and to know the flaws (e.g. accuracy) of some Digital Health tools. We hope care providers can be supported to learn and engage with Digital Health tools, and to support us to use them effectively.

*"Because I get chronic pain, if a healthcare professional said to me 'how many steps do you do a day?' and they were to look at that information on the app and for example, if I was having a good day pain-wise like I did yesterday or the day before, and I did 9000, they might then question… But actually it doesn't work like that, well it doesn't work like that for me. So maybe not taking the information at face value and just using it as a guide."*

**We want to track and understand family health history and our own risks.**

Many of us don't have access to our family's health history or the tools to make sense of what this may mean for our own future. We've grown up in a health system that often feels reactive instead of preventative, and we want to change that. With the support and knowledge from health professionals, Digital Health could help us to know our health risks at an earlier stage in our lives, empowering us to make informed decisions as advocators for our own health.

# 8 | Help us to navigate trustworthy Digital Health sources

**We want help to identify Digital Health tools from credible, trustworthy, and verified sources.**

There are so many Digital Health tools. So many different aspects of our lives are online that it can be overwhelming to know what to use, and difficult to know who to trust. Digital Health should make life easier, not complicate it.

*"We're lucky enough to have the NHS websites and they're fairly accurate, they provide good education to people… but people can surpass that and sometimes go on their own little deep dives, WebMD and Wikipedia and it becomes very unregulated very quickly."*

**We want the Digital Health sector, including tech companies, to take responsibility for challenging online health misinformation.**

We have access to lots of health information through social media, particularly TikTok, which means it is quickly accessible and we can access it whenever. Whilst this can be helpful for understanding our health in ways that we are comfortable engaging with, it is difficult to know what's right or wrong. We are concerned that inaccurate health information leads to unnecessary stress for us, a burden on the healthcare system, and some people misdiagnosing themselves.

*"It's [social media] a catch 22 - you want the awareness so people with it [ADHD] can get diagnosed, but that awareness also creates people falsely self-diagnosing and taking up the space that people who need that diagnosis may need."*

# 9 | Improve transparency and trust in who is involved in Digital Health companies

**We want young adults to be involved as co-designers in Digital Health development e.g. providing regular feedback.**

In a transitional period of life, our opinions and experiences will change. Being able to provide regular feedback means that Digital Health can evolve with us.

**We want digital companies to be transparent about who they are funded by, partnered with, and whether employees are paid a living wage.**

We feel our generation are pioneers of positive change towards diversity and inclusion, and that this is an opportunity for Digital Health. Ethical practice matters more to us than ever before because we are worried by the political climate.

*"Transparency from the company standpoint – make sure they tell the patients or whoever exactly what they're doing with things… So if they say we're going to use this data to develop the product, tell us how they're going to use that data to develop the product. What does that mean?"*

**We want independent/not-for-profit organisations to be meaningfully involved in the development and review of Digital Health tech to improve trust.**

We hope that Digital Health can meaningfully involve people who know about our needs and that they can be transparent about this collaboration. This will build our trust in a system that is evidently focused on our health over commercial interests.

*"Ensuring that specialist organisations, maybe charities that work with people and know about what's best for them, maybe they have a place in the development of Digital Health tools in the future. That might also make the consumer/ user a bit more trusting of them [DH tools]... there are specialist nurses or representatives who have a lot of knowledge and guidance... thinking about how they might be implemented into the processes at any point in the Digital Health development, whether that's the tools, the app, making sure that the information is backed by that research that charities have from real life people and experiences."*

**Explain what's happening with our Digital Health data in ways that we'll actually engage with**

**We want to be educated about data security and protection so we know what we're agreeing to.**

Part of being a digital native is blind or at least required trust in sharing our data – partly because we've had little choice and little explanation about the tech we've grown up with.

*"I'm cautious that there's nothing I can do about it. I need to use these apps, so they'll have my data. I also don't know the consequence, like how bad is it if someone has my data? What could happen? I don't know, nobody tells me these things."*

**We want clear, concise language to explain what's happening with our data – we're not going to read pages of T&Cs.**

Having clear and visual communication about where our data goes will improve our trust in and understanding of how Digital Health works. Accessible communication means all of us could use Digital Health tools in a fully informed way.

*"Transparency from the company standpoint – make sure they tell the patients or whoever exactly what they're doing with things [data]… So if they say we're going to use this data to develop the product, tell us how they're going to use that data to develop the product. What does that mean?"*

**We want to customise data sharing with easy to understand consent options: e.g. who sees my data and how it's used.**

Young adults are a diverse group of people with rapidly changing needs and various responsibilities in different areas of life. That means we all have different data preferences, and that our data preferences may change.

*"You can't customise terms and conditions. It's not like you can say I agree to everything but not this. You have to accept everything and everything, and sometimes you don't want to. But you have no choice."*

# Methods – design, recruitment and workshop process

The young adult Digital Health engagement process involved three online workshops and one in-person workshop with 18-25 year olds from across South Yorkshire in March 2025. 12 young adults[1] who have a range of different long-term health conditions took part. Ten participants were recruited by specialist recruiters Acumen. Two participants were recruited through Chilypep, an organisation that helps coordinate and facilitate opportunities for children and young people to engage with and influence the work of the Children and Young People's Alliance and the South Yorkshire Integrated Care Board. These two young people are also involved in the South Yorkshire Young Health Champions project, which brings together young people from across South Yorkshire and Bassetlaw to improve the lives of children, young people, and their families. A summary of the demographic characteristics of those who took part is included at Appendix 1.

Participants were supported throughout the process with a Participant Handbook and introductory calls, both of which provided information on what to expect at the workshops, information about the facilitation team, how to use Zoom for online workshops, and discussions about accessibility requirements. All participants received payment in recognition of their time.

The workshops were held over a two-week period to ensure maximum engagement without being too overwhelming. Workshop 1 focused on grounding in the topic and understanding how participants used Digital Health over their lifetimes. Workshop 2 focused on how participants use Digital Health in their day-to-day lives, and their hopes and concerns. The third workshop focused on the responsibilities within Digital Health for helping participants to get the best out of their lives. Online workshops involved a combination of facilitated small group discussion, specialist input via presentations and Q&As and plenary activities. The process concluded with a full-day in-person workshop focused on developing priorities and principles to include in the Charter. Workshops were predominantly facilitated by researchers who are also young adults.

With the consent of participants, the workshops were audio recorded. Data was also collected from workshops in the form of flipcharts, which facilitators used to keep a live record of what participants said. This Charter has drawn from qualitative analysis of the flipcharts, audio recordings, and frequent sense-checking sessions between HVM, SYDHH, and AYPH. Three participants provided their comments on a draft of the Charter to ensure that they felt their voices have been authentically represented.

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1    1 participant could only attend the first two workshops.

## Appendix 1: Summary of participant demographics

| Demographic* | Number |
|---|---|
| **Gender** | |
| Female | 5 |
| Male | 6 |
| Non-Binary | 1 |
| **Age** | |
| 19 years | 3 |
| 21 years | 2 |
| 22 years | 2 |
| 23 years | 2 |
| 24 years | 1 |
| **Ethnic background** | |
| Asian/Asian British | 1 |
| Black/Black British/Caribbean/African | 1 |
| Mixed/multiple ethnicities | 1 |
| Other | 1 |
| White | 8 |
| **Life stage / employment status** | |
| Working full time | 3 |
| Working part time | 3 |
| Not working/unemployed | 2 |
| Student | 2 |
| **Home location: Indices of Multiple Deprivation** | |
| 10-40% Most Deprived Area | 6 |
| 20-40% Least Deprived Area | 4 |

*2 participants did not provide all demographic information