

# 'Digital Downsides': a discussion document

October 2024

# **Document control**

**Document Title** 

**Prepared by** 

**Checked by** 

Date

Contact

'Digital Downsides': a discussion document

Fraser Battye

Fraser Battye, Steven Wyatt, Peter Spilsbury

3<sup>rd</sup> October 2024

Fraser.Battye@NHS.net

# **Contents**

Foreword			1	
Su	Summary2			
1.	Introduction		4	
	1.1	Aims, premises and potential value	4	
	1.2	Approach and limitations	5	
	1.3	Structure of this discussion document	5	
2.	. Relational		7	
	2.1	Tending towards the transactional	7	
	2.2	Exacerbating and creating inequalities	9	
	2.3	Changing the nature of work	10	
3.	. Organisational		12	
	3.1	Emphasising (narrow) efficiencies	12	
	3.2	Designing for the 'average user' and the data divide	13	
	3.3	Reducing staff autonomy	14	
4.	Environmental		15	
	4.1	Challenging Evidence-Based Medicine	15	
	4.2	Narrowing policy imagination	16	
	4.3	Increasing (and shifting) cost pressures	16	
5.	Concl	uding thoughts	18	
An	Annex A: Interviewees / interview process			
Annex B: Suggestions for further research			23	

### **Foreword**

Debates on digital technology often seem polarised. One side points to the <u>Doomsday Clock</u>, where AI has joined nuclear war and environmental collapse on the list of existential threats facing humanity. The other side points to the democratisation of information, increased connectedness, and the promise of post-scarcity. Both sides contain truth; neither gives much ground.

When it comes to digital technology's role in health and care services, the debates are less fraught. They are also less divided. In policy, in strategy, in programmes, in organisations and systems - the emphasis is almost exclusively on the upsides and benefits that digital has to offer.

It is easy to see why. The combination of previous gains (arguments for a wholesale return to paper would be eccentric), commercial dynamics, and a hunger for solutions within resource-starved services creates ideal conditions for digital enthusiasm.

And yet this enthusiasm is also fundamentally peculiar. It is obvious that digital technologies bring both gain and loss. We are reminded of this every day. We might feel the joy of easy access to endless entertainment, while simultaneously regretting the smartphone's effects on our attention.

The aim of this discussion document is therefore to bring a little more balance to the conversation about using digital technology in health and care services. While not seeking to dispute any of digital technology's upsides, it examines some downsides. It does so through the lens of personcentred care: a concept that the Health Foundation (funders of this work) has done much to develop.

The experts we spoke to were incredibly impressive. They were also varied. Their perspectives took in policy, practice, philosophy, history, frontline clinical work, tech start-ups, government, social care, consultancy and more (frequently in the same person!). Their views were subtle and nuanced. We're very grateful for their participation, confident that readers will benefit from their insights.

Our paper suggests a foundational trade-off: digital technologies might provide gains in efficiency for some, while eroding the relational elements of care that many people need and value. If true, then strategies based on increased digitalisation may exacerbate inequalities.

This needs further examination. We do not attempt to settle debate on this topic: our aim is to stimulate and carefully contribute to it.

And care is needed. Melvin Kranzberg's 'first law of technology' states that: *Technology is neither good nor bad; nor is it neutral.* A useful maxim for services aiming to take the upsides of digital technology, while minimising its downsides.

#### **Peter Spilsbury**

#### **Director of the Strategy Unit**

# **Summary**

This 'discussion document' was produced by the <u>Strategy Unit</u>, from work funded by the <u>Health Foundation</u>. Without attempting to deny any of the benefits associated with digital technologies (broadly defined) in health and care services, the document seeks to map out selected downsides.

It does so using the concerns of person-centred care. It asks: what, if anything, is lost from the more 'human elements' of care when digital technologies are used? There is no attempt to prove points or settle debates. The aim is to stimulate discussion, inform decision making, and guide further research.

The document draws on interviews with 15 experts, chosen for their deep expertise and breadth of perspectives on this far-reaching topic. These perspectives included: policy and practice; health and social care; philosophical and operational concerns; industry and government (and more). Individual experts (listed in Annex A) frequently spanned multiple perspectives.

None of those interviewed saw digital technology as 'good' or 'bad'. Without exception, their views were expressed in varying shades of grey: a palette that, many noted, is routinely not employed by decision makers considering the use of digital technologies. And none attributed downsides 'solely' to digital technologies; they frequently described digital as a tool within wider trends.

Nine main downsides were raised; many appear far-reaching and profound if true. These nine downsides were mapped out at three different 'levels': the relational, the organisational, and the wider environmental context for care:

**ENVIRONMENTAL:** Wider context set by policy / politics, regulation, funding, etc.

Challenging Evidence-Based Medicine Narrowing policy imagination

Increasing (and shifting) cost pressures

**ORGANISATIONAL:** Where care is designed and managed in institutions / systems

Emphasising (narrow) efficiencies

Designing for the 'average user' and the data divide

Reducing staff autonomy

**RELATIONAL:** Where care takes place between a person and professional(s)

Tending towards the transactional

Exacerbating and creating inequalities

Changing the nature of work

Especially if bolstered by additional research (suggestions for which are in Annex B), this map of downsides could help decision makers see and navigate the broad trade-offs associated with digital technologies. It is usual (and typically required) to consider risks *to* successful delivery; this map would help identify and track risks *from* successful delivery.

As well as mapping specific downsides, the document also considers whether there are any deeper, underlying trade-offs. One way to see this, is to consider the following elements of care:

- *Transactional*. The efficient design and management of processes e.g. scheduling appointments or ordering repeat prescriptions. Good care requires smooth transactions.
- **Technical**. The use of technical equipment and/or specialised knowledge on the likely effectiveness of specific treatments, for example. Good care here is about accessing and deploying reliable, technical inputs.
- **Contextual**. The circumstances of the person needing care: their goals, barriers, resources and capabilities. Good care means knowing what might help, given this broader understanding.
- **Relational**. The relationship between the person accessing care and the people providing it: the extent to which there is mutual trust, or a felt sense of being cared for, for example.

Looking at the nine downsides using this framework, it seemed that digital technologies boost the transactional and technical elements of care - at the expense of the contextual and relational.

If true, this would have distributional consequences. Digital technologies would tend to benefit people with single problems but who are generally otherwise well - but not people with complex needs who require ongoing and relational modes of care. This would exacerbate inequalities.



Health and care services require technical knowledge, technological breakthroughs and smooth transactions. They also require caring relationships, and the ability to apply technologies in pursuit of ends (saving lives and reducing suffering) that are fundamentally human.

Both perspectives are needed; both need to be in sight when making choices about the direction of policy and services. The aim of this discussion document is to widen the lens and illuminate some of these trade-offs. Knowing this, they can be navigated wisely.

# 1. Introduction

This 'discussion document' examines the risks and downsides of digital technology in health and care services. More specifically, it looks at downsides through the lens of person-centred care. It asks: what, if anything, is lost from the more 'human elements' of care when digital technologies are used?

The document was produced by the <u>Strategy Unit</u>, from work funded by the <u>Health</u> <u>Foundation</u> (which has done much to promote person-centred care and to investigate the use of digital technologies) as part of the partnership between the two organisations.

#### 1.1 Aims, premises and potential value

When described in policy documents and strategies, digital technology is typically described exclusively in terms of its promises and benefits. It is promoted as a route to productivity and greater efficiency, improved safety, increased personalisation, better use of staff time, more responsive services (etc).

It may be all of these things. Time and evaluation will tell. But there will surely be associated downsides. And so, without seeking to dispute any of the advantages of digital technology, the aim of this document is to map out threats, losses, risks and problems.

The discussion therefore begins from two premises:

- 1. That all change involves gain and loss. Good decision making is about understanding and navigating trade-offs. This requires that gains and losses are, as far as possible, described, weighed up and balanced out; and,
- 2. That the potential losses involved in the use of digital technology need more attention in policy making and service design decisions.

The intended value of this work is therefore:

- To stimulate thought and discussion. There is no attempt to provide a
  comprehensive survey of the field. Instead, the aim is for a short, readable summary of
  drawbacks and downsides. Anyone with an interest in using digital technology in
  health and care services should find this useful.
- 2. **To influence decision making**. Good judgement requires a rounded view of costs and benefits, advantages and drawbacks, upsides and downsides. Rounded views can be hard to come by when it comes to digital technology. People making policy and service decisions should therefore find this useful.
- 3. **To trigger further research**. Mapping downsides can be used to guide future analytical and research efforts again giving decision makers a more refined and

accurate sense of the trade-offs in play when using digital technologies. The Health Foundation and other research bodies should find this paper (and Annex B in particular) helpful.

#### 1.2 Approach and limitations

The document draws on interviews with 15 experts, listed at Annex A. Readers will recognise – and benefit from - the high grade and wide span of expertise represented. And the Strategy Unit is grateful for their participation.

Interviewees were chosen to provide a broad range of perspectives on this complex and far-reaching topic. Perspectives ranged over: policy and practice; health and social care; philosophical and operational concerns; clinical and non-clinical roles; technology start-ups; primary and secondary care; government and public service (and more). Individual experts frequently spanned multiple perspectives.

The interview process is described in Annex A, but in summary:

- Interviewees were asked to consider digital technology in the round, rather than
  thinking in terms of single / specific technologies. This broad definition therefore
  included things such as: digital decision aids, virtual care, Al, remote monitoring,
  wearables, tools for data capture and exchange, big data analytics.
- Drawing on previous Health Foundation work, they were asked to think about <u>person-centred care</u> as 'personalised, coordinated care that affords people dignity, compassion and respect, and supports them to live an independent and fulfilling life'.
- There was no requirement for experts to provide solutions to the problems they raised. Instead, they were asked where they thought more research / analytical attention was needed to inform possible solutions (see Annex B).

Findings are presented as a 'discussion document' rather than a research report. We have used the interviews to gather points and arguments, not to faithfully distil everything that was said. We have also not reached outside of the interview material (looking at wider literature for example). The intention is to spur conversation and further research, not to prove particular points.

#### 1.3 Structure of this discussion document

When considering how person-centred care relates to the use of digital technology, the points raised by interviewees could be summarised as covering the following elements of care:

- *Transactional*: the efficient design and management of processes e.g. scheduling appointments, or ordering repeat prescriptions.
- **Technical**: the use of specialised equipment and/or knowledge e.g. on the likely effectiveness of specific treatments.
- **Contextual**: understanding the circumstances of the person needing it: their goals, barriers, resources and capabilities.
- **Relational**: the relationship between the person accessing it and the people providing it: the extent to which there is a felt sense of being cared for.

These elements were raised at multiple levels. Using person-centred care as a lens meant that many of the downsides suggested by interviewees occur immediately within the relationship between a person and the professional(s) supporting them - in a GP consultation, for example. But a wider set of factors were also noted: some within the organisational context (e.g. how care is arranged and overseen); others acting at a wider environmental level (e.g. how technologies are regulated).

This wider context was especially important when interviewees were describing digital technologies as tools inseparable from wider trends.

ENVIRONMENTAL: Wider context set by policy / politics, regulation, funding, etc.

ORGANISATIONAL: Where care is designed and managed in institutions / systems

RELATIONAL: Where care takes place between a person and professional(s)

The remainder of the document follows this structure:

- Section 2 focuses on the downsides of digital technologies at the relational level.
- Section 3 examines downsides at the organisational level.
- Section 4 takes a still broader perspective, considering environmental factors such as policy and regulation.
- Section 5 provides a summary and concluding thoughts. It returns to the question of trade-offs, offering a broad and cross-cutting way for thinking about how digital technology might interact with the aims of person-centred care.

# 2. Relational

This section considers the downsides of digital technologies within the relationship between the person and the professional(s) supporting them. It begins by describing effects on the nature of this relationship. It then moves on to consider the question of inequalities, before ending with downsides relating to the changing nature of work.

#### 2.1 Tending towards the transactional

The most frequently cited downside was a shift in the nature of the relationship between person and professional(s). This was characterised in different ways, but one common way interviewees described it was between the 'relational' and 'transactional' elements of care. The broad view was that digital technologies tended towards the transactional.

This view was expressed in three main ways: firstly, through negative effects on attention and human connection; secondly, through changing the shape of diagnostic conversations; and, thirdly, by eroding privacy and trust.

#### 2.1.1 Degrading attention and connection

Interviewees emphasised the fundamentally relational nature of health and care services. They noted that digital technology can degrade human connection and relation - and yet this is often what patients and service users really value.

This point was articulated in many ways – but at heart was a sense that someone was listening to, and would care for, someone else. One interviewee suggested that: 'the generous sharing of warm and open attention is the best of our humanity'.

In addition to being valued for itself, this sense of connection was cited as having instrumental benefits, such as:

- Making behaviour change and/or sticking to a course of treatment more likely (advice coming within the context of a trusting relationship);
- Having immediate therapeutic benefits in the sense of 'feeling better having been listened to' or the process of consultation helping the person to make sense of what was happening to them;
- Minimising the chances of a medical intervention being offered when social / emotional / practical support was needed (improving decision quality); and,
- Offering a more positive experience of the care process.

Digital technologies were seen as degrading this in several ways. Most immediately, and most obviously perhaps, was that using a computer splits attention: 'The clinician is more

focused on having to use a device, a tool, a product of some variety - more so than focusing on their patient'. Similar points were made by most interviewees.

A small number of interviewees also then considered the way in which clinical decision aids in particular might also affect the relationship between person and clinician. For example: 'Care is caring. It's a two-way relationship between a person and another person. If you're adding in a third party - an algorithm or a clinical decision aid, for example - you're immediately mediating their relationship'.

#### 2.1.2 Changing the shape of diagnostic conversations

The above point about decision aids also touched a related theme about the effect of digital tools – for triage or diagnosis especially – on 'the shape' of conversations.

Interviewees making this point noted that these tools are structured and powered by algorithms, with the aim of reaching a single diagnosis. The most immediate effect was therefore on the nature of the diagnostic conversation: 'With triage through an algorithm you're only allowed to have one [problem]...It forces consultations to be very transactional'.

One interviewee linked this issue to their research on remote consultations. Their point was the same: that a digitally-led form of interaction tended towards the focused diagnosis and treatment of a single need. Noting that this would be entirely desirable where problems can be diagnosed and solutions prescribed, interviewees also suggested that more complex cases – where medical and social needs might be inseparable for example – might not be well-served by digital tools: 'People live complex lives, in complex circumstances with complex conditions. They may not be able to translate all this in the way that a [triage] form is requesting them to do'. Social care was cited as an example where cases would be 'complex by default'.

Finally, two interviewees with clinical backgrounds noted that it was also common for 'the real problems' to emerge at the end of a face-to-face consultation - as a patient prepared to leave the room – and that digitally-mediated interactions reduced the opportunity for this to happen.

#### 2.1.3 Eroding privacy and trust

While not such a strong theme as those above, several interviewees raised the risks to privacy – and therefore trust within a relationship – presented by digital technologies. These interviewees typically made broad comments about overall privacy concerns with digital technologies, suggesting that trust in services might erode by association.

There were also specific points about the collection and sharing of data as an inherent feature of digital technologies. For example, one interviewee argued that it was not

possible for patients to fully understand what they were consenting to in sharing their data – and that it wasn't always or obviously the case that data would be used in their interest, or for wider public good. And another interviewee linked these points, while talking about the use of remote monitoring and 'wearables' for older people in social care: 'It's not just data privacy, it's also personal privacy – they [older people] don't want to be monitored 24/7'.

#### 2.2 Exacerbating and creating inequalities

The distribution of downsides across demographic groups was a core theme in the interviews. The essential point here was that digital technologies can both create new problems and exacerbate existing ones.

Interviewees noted that some of the downsides of digital might apply generally across the population: frustration at completing online triage forms, for example. But most interviewees qualified this point by suggesting that any such problems would be far more significant for people with more complex needs.

Noting that digital modes of access are increasingly becoming 'the norm' (having perhaps at first been introduced as an option), one interviewee argued that the result is that: 'Some citizens will be closed out of services in effect', while another suggested that: 'Having multiple interacting disadvantages makes it harder to keep with the pace that digital access to care is going at'.

Again, the general picture presented by interviewees was one where digital technology could create greater convenience and efficiency in the context of simpler and more transactional requirements, but that these gains may come at the expense of people with needs that are more complex and difficult to describe.

In this context, several interviewees talked about the ability of people to get the most from care provided. One suggested that the balance of risk and harms from a treatment supported by digital technology depended significantly upon a person's 'digital literacy': 'The efficacy of a technology might change depending on the skills, the confidence and the capability of the user, the design of the technology, the language that it makes available, the support that people have around them...'.

A small number of interviewees extended these points into a barrier relating to the collection and use of data. They pointed to the presence of a 'data divide', where certain demographic groups - typically those disadvantaged in other ways - are also then underrepresented in datasets used to understand population needs. This is discussed later in the report.

Finally, and while receiving nothing like the emphasis that barriers to citizens did, a small number of interviewees noted that certain staff groups may also experience barriers in terms of their ability to engage with digital technologies and progress in their work.

#### 2.3 Changing the nature of work

The downsides above mainly take the perspective of the person accessing care; interviewees also cited downsides from the perspective of those providing it.

#### 2.3.1 Increasing cognitive load

Noting that digital technology has led to an exponential growth in the amount of data available, several interviewees suggested that this brought downsides for people providing care. This was raised in terms of:

- The need to provide data e.g. updating electronic patient records during / after a consultation.
- Having instant access to an ever-expanding array of data e.g. through decision aids and having to decide what is or is not material to the specific case.
- Working with information that people bring to consultations and so having to spend time understanding what this is and how applicable it might be. (The concept of the 'infosphere' by which they meant the informational environment was mentioned by one interviewee, who cited this as a wider determinant of health).
- Feeling responsible for the performance of technology e.g. for how well video consultation software functions.

The term 'burnout' was used frequently by those raising these points, with the general sense that this would result from the increased cognitive and practical demands created by digital technology.

#### 2.3.2 De-skilling professionals

Finally, several interviewees made broad points about how digital technology has reduced space for professional intuition and expertise (and thereby autonomy – discussed in a later section). While not suggesting that digital technology was solely responsible for this, they nonetheless cited it as a tool within broader trends.

A small number of interviewees described this using the concept of 'automation bias': suggesting that because information was presented through a computer system it came with a standing and authority (that it might or might not merit).

One interviewee noted that this created a default where the clinician would be required to challenge recommendations from decision support software, while knowing that they retained liability. Another – with a clinical background – reported noticing that they assumed such recommendations were 'true and correct', yet realised that they could not explain the evidence and process underpinning the recommendations that came to them.

In each case, interviewees making this point saw a need for information to be used with a clear sense of how reliable and relevant it was – but that this was undermined by the medium of the technology: 'With humans, we always slightly doubt ourselves. It's tempting to say "computer says X, or technology says X" and not question it.'.

Another interviewee linked the idea of automation bias to more general ways of thinking and consequent effects on a sense of fulfilment at work: 'I'm not so much worried about machines becoming more like us...what I worry about is people becoming more and more like machines. And I believe they are – as though they were a machine carrying out instructions...Our work [as clinicians] has become less fulfilling as it has been taken over by mechanistic thinking'.

# 3. Organisational

This section focuses on downsides and risks at the organisational level. While presenting less immediate threats to person-centred care, the relationships that create and sustain services are mediated by organisations. The section begins by considering digital technology's emphasis on efficiency, before moving on to questions of designing services; it closes by looking at ways in which work is monitored and controlled.

#### 3.1 Emphasising (narrow) efficiencies

Many interviewees described the promise of digital technology in terms of gains in productivity and efficiency: that more care could be provided with the same or fewer resources; and (typically) that the route to this was for resources to be freed from administrative tasks and invested instead into caring tasks.

They suggested that this promise did not hold in practice, giving three main reasons:

#### 1) Benefits are invariably overstated

One interviewee summarised this view as follows: 'Technology rarely works as well as it's claimed, and it never works that well as quickly as is claimed'.

A small number of interviewees making this point also linked it to optimism bias. Here the argument was not just that there would be an in-built human tendency towards assuming that technology would achieve its claimed benefits (a psychological explanation), or that firms selling technology would present optimistic cases (a commercial explanation), but that highly resource-constrained services were often desperate for optimistic cases to be true.

One interviewee gave the example of claims that AI could introduce significant efficiencies into adult social care services - by conducting case reviews currently done by staff – and that this led to: '...people doing business planning on a desperate and unrealistic basis'.

#### 2) Time freed does not (obviously) mean to time to care

The second – less prominent – reason was that any time saved through efficiency gains was not straightforwardly then invested into providing care: 'Technology offloading administration is good, but I don't think the time goes back into the patient from what I'm seeing. Time goes back into research'.

#### 3) Tasks may be displaced rather than removed

The question of perspective was also raised. Where technology is introduced to bring efficiency, where do the expected efficiencies fall? And to what extent are time costs displaced rather than reduced?

Several interviewees drew attention to the perspective of the people accessing care. The suggestion here was that what might be efficient from an organisation's perspective might be inefficient once implications for the service user or patient were accounted for.

One interviewee explained this using the example of an online triaging form: 'Before it was online, it was a conversation with a member of staff. Now, it's something that the individual [patient] has to do. That becomes invisible work for the individual, which requires the individual to have certain skills, certain capabilities, etc, etc. So, is that empowering for person-centred care?'

Another interviewee, summarising their work evaluating patient apps, agreed that online systems tend to displace work from organisations to patients. They saw this as a trade-off between organisational efficiency and person-centred care. They further argued that a wider 'systems lens' – rather than a single organisational perspective - was needed when it comes to assessing efficiencies, and that time costs for people accessing care should be taken into account.

#### 3.1.1 Trading efficiency and effectiveness

A small number of interviewees extended the point about efficiency into a wider suggestion that there might be trade-offs between efficiency from the perspective of the organisation, and safety / quality from the perspective of the patient.

One interviewee cited research they were involved in which suggested remote consultations were more likely to lead to missed information, which then turned out to be diagnostically important. They raised the concept of 'e-iatrogenesis': that the introduction of new technologies creates additional risk of medical harm.

Several interviewees gave the example of remote monitoring devices. The suggestion here was that this could be efficient for organisations – and effective for some patients – while creating anxiety for others.

#### 3.2 Designing for the 'average user' and the data divide

Linking to points raised in Section 2.2 about the risks of exacerbating inequalities, a small number of interviewees drew attention to the way that this follows from the design process.

The fundamental argument here was that technology-driven interfaces lack human flexibility. Interviewees raising this point were not suggesting that this was always the case in principle - but that it was typically the case in practice.

For example, one interviewee argued that – because most such tools in the NHS are 'one-size-fits-all' – inequity is 'designed in': 'If you design your technology for one assumed set of capabilities and characteristics, then you're not meeting that range of user capabilities. You're meeting a subset'. Another interviewee noted that digital products were designed against the needs of an assumed 'average patient'.

A small number of interviewees raised the related concept of the 'data divide'. Noting that digital technologies run very largely off the gathering, aggregation and analysis of data, they argued that under- and over- representation of specific demographic groups would lead to downside consequences in the planning and design of services. For example: 'We are creating the inverse data quality law: the availability of high-quality data varies inversely with the need for healthcare'.

#### 3.3 Reducing staff autonomy

Finally from the perspective of downsides at the organisational level, two interviewees noted that digital technologies reduced levels of professional autonomy and discretion. One described this in terms of the ability of organisations to structure and monitor activities in a more detailed and sustained way, changing the nature of the organisation-staff relationship.

And another, taking the perspective of clinical staff, argued that clinical decision aids eroded the development of clinical intuition – and that this moved decision making discretion away from the clinician-patient relationship and into the managerial / organisational realm. They saw negative implications for clinicians: 'There has been a reduction in a sense of job satisfaction, autonomy and respect as an expert.'

## 4. Environmental

This section takes the broadest perspective on digital risks and downsides. It considers the environment within which organisations provide care. The section begins with threats to the current model of Evidence-Based Medicine. It moves on to look at effects on policy formulation, before concluding with the challenges of increasing cost pressures. Downsides cited at this level are the most distant from the focus on person-centred care; this section is therefore relatively brief.

#### 4.1 Challenging Evidence-Based Medicine

Many interviewees noted that digital technologies present a range of challenges to the use of evidence in providing care. One interviewee began by noting the importance of *both* evidence of effectiveness *and* evidence of context in providing person-centred care: 'Evidence-based medicine is taking the best possible treatment with the best possible evidence and contextualising it to the patient'.

This interviewee then argued that digital technologies presented threats to both of these features: that evidence of context - especially where someone's needs are complex - is best understood qualitatively (whereas digital tools typically require quantitative data); and that digital technologies presented serious and novel challenges to studying effectiveness. Following this logic led them to see a wide and deep range of consequences for standards of evidence, regulation, clinical liability, post-market surveillance (and more): *'The entire governance of the system in this space is disrupted'*.

The point about the difficulties of studying effectiveness was raised by several interviewees. This was raised in two main ways:

- Firstly, at a conceptual or in-principle level to suggest that since digital tools (such as apps or decision aids) are designed to constantly iterate and update it would be difficult to specify what was being evaluated, since the object of evaluation would constantly change.
- Secondly, at a practical level. Here the main argument was about the clash between commercial incentives (to suggest that benefits are high, and costs low) with research incentives (to establish what is the case empirically). One interviewee gave the example of an evaluation of a patient-facing app they were involved in: 'When I tried to get data about how many people were using it, and at what times of day, and then how much it costs to provide, how many staff were doing what I was told I couldn't have this data because it was commercially sensitive'.

A small number of interviewees drew an explicit analogy between the digital technology and pharmaceutical sectors. They noted the presence of similar incentives, and similar

asymmetries of information between buyers and sellers - before noting that the regulations and norms around digital technologies were far less well developed. Interviewees making this point contrasted the processes and institutions governing decisions around drug safety and effectiveness, with those for digital products that would also – even if less immediately and obviously – affect treatments and treatment choices.

#### 4.2 Narrowing policy imagination

Many interviewees raised risks that digital technologies present to the process of policy formulation. The main points made here were that digital technologies encourage:

- 'Policy by announcement' and a lack of realism. One interviewee noted that this wasn't necessarily because of cynicism, but that the attraction of digital solutions was: '...because they [policy makers] want to be seen as modern and at the forefront of something'. Another interviewee, giving an example from time in government, did, however, see cynical motivations: 'The one thing they [politicians] would lean to is digital'. They argued that this stemmed from a desire to 'do something without really doing something'.
- Targeting of individuals, not their circumstances. A small number of interviewees noted that digital 'interventions' are designed to act upon individuals, and not at a more systemic or environmental level. Citing the example of a weight loss app, one interviewee argued that: 'We use digital products to say to people 'you should lose weight' or 'you have a gambling problem' and this puts systemic issues back onto the individual'.

Interviewees raising points about the effect of digital technology on policy saw the context of significant resource constraints as material: that digital technologies offered decision makers apparent routes to efficiency, thereby reducing the need to make trade-offs.

#### 4.3 Increasing (and shifting) cost pressures

Finally, a small number of interviewees extended many of the points above (and particularly those around threats to Evidence-Based Medicine) to argue that digital technologies posed some fundamental challenges to the affordability of services.

For some, this was a question of balancing the trade-offs between different possible investments, when the costs and benefits of digital technologies can be so uncertain: 'You've got finite resources. Do you spend on bytes versus bricks, for example? So, where you invest in cutting edge technology, that might be expensive, and that means you've got less to spend on physical infrastructure to deliver care in'.

For others, there were potentially novel threats associated with digital technologies. One interviewee argued that the decoupling of geography (because of remote access) allied to policies around patient choice could lead to 'unbalanced' bulges in demand, with some providers of care being overwhelmed because of becoming known for good quality digital care.

And another - pointing to the fact that technological development expands treatment possibilities, and that digital is a highly dynamic source of development – saw the risk of greatly increased cost pressures, as possibilities outstripped budgets at an ever-increasing rate: 'Digital, in a nutshell, has the potential to become completely unaffordable'. They therefore saw the need for radical improvements in the way that these technologies are studied, regulated and deployed.

# 5. Concluding thoughts

This final section draws together many of the themes outlined in previous sections. Because this work was designed to open the topic up, the report does not close with recommendations. Instead, following a short summary, it outlines a possible fundamental trade-off between person-centred care and the use of digital technologies.

This document began with the notion of trade-offs - and with two associated premises:

- 1. That any change will have upsides and downsides, gains and losses. High quality decision making depends, in part, upon understanding what these are, and how they are distributed, before seeking to maximise gains and minimise losses; and,
- 2. That decision making would be helped if the downsides associated with digital technologies in health and care were better articulated.

The paper then described downsides drawn from interviews with 15 experts. None of those interviewed saw digital technology as either 'all good' or 'all bad'. Without exception, their views were expressed in varying shades of grey: a palette that, many noted, is routinely not employed by decision makers considering the use of digital technologies.

Nine main downsides were raised. These were mapped out at three different 'levels'. Downsides were most keenly and obviously felt at the relational level; but relational effects were seen as contingent upon impacts on broader organisational and environmental levels:

**ENVIRONMENTAL:** Wider context set by policy / politics, regulation, funding, etc. Increasing (and Narrowing policy Challenging Evidenceimagination **Based Medicine** shifting) cost pressures **ORGANISATIONAL:** Where care is designed and managed in institutions / systems Designing for the 'average Reducing staff Emphasising (narrow) user' and the data divide autonomy efficiencies **RELATIONAL:** Where care takes place between a person and professional(s) Exacerbating and Changing the nature Tending towards the of work creating inequalities transactional

This document - and any subsequent research spurred by it (see Annex B) - could therefore add value by revealing trade-offs in the promotion and use of digital technologies.

Decision makers should be better equipped, especially when it comes to losses and downsides in terms of person-centred care. Knowing what these might be, they can be mitigated.

If this is to be true, there is one immediate practical implication: initiatives using digital technology could be screened for likely downsides. It is usual (and typically required) to consider risks *to* successful delivery; why not risks *from* successful delivery? It could be – given the content that follows - that this should be done as part of prospective impact assessments when considering equity.

It might also be useful to step back from specific concerns and consider whether there are any deeper trade-offs underlying the views and topics set out in preceding sections. One way to see this, and drawing on interviewees' responses and previous Health Foundation work (on <u>person-centred care</u> and <u>technology and the human elements of care</u>), would be to consider the following elements of care:

- **Transactional**. Some elements of care are about the efficient design and management of processes scheduling appointments, or ordering repeat prescriptions, for example. In these terms, good care requires smooth transactions.
- **Technical**. Some elements of care are about the use of technical equipment and/or specialised knowledge on the likely effectiveness of specific treatments, for example. In these terms, good care is about accessing and deploying reliable, technical inputs.
- **Contextual**. Some elements of care are about the understanding the circumstances of the person needing it: their goals, barriers, resources and capabilities, for example. Good care here means understanding what might help given this broader context.
- **Relational**. Some elements of care are about the relationship between the person accessing it and the people providing it: the extent to which there is mutual trust and respect, or a felt sense of being cared for, for example.

In many of the downsides cited, it seemed that digital technologies boost the transactional and technical elements of care - and that they may do so at the expense of the contextual and relational elements.

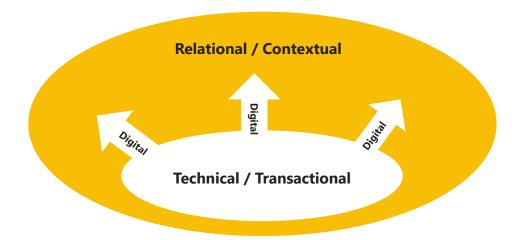
If true, this would have distributional consequences. Digital technologies would tend to benefit people with single problems but who are generally otherwise well, but not people with complex needs who require more relational modes of care. (Several interviewees noted, without making a cynical point, that decision makers would typically fall into the former group). The effect would be to widen inequalities.

This trade-off could be represented as follows, with the tendency of digital technologies being to pull the balance of care towards technical / transactional concerns:

# Technical / Transactional 'Simple' needs, emphasis on speed of access, diagnosis and treatment of soluble problems Tendency of digital technology Contextual Complex needs, emphasis on ongoing management of insoluble predicaments

And yet this representation doesn't reflect the primacy that interviewees gave to the relational and contextual elements of care. On balance, they saw this as being what service users and patients say they value most. And they saw the technical and transactional elements of care as having value *in service of* the relational: that these was an asymmetry between them that the diagram above does not capture.

From this perspective, perhaps the relationship is better represented by the figure below. If true, this would suggest that increasing use of digital technologies erodes the space for the relational and contextual elements of care.



In the final analysis, there can be no 'either/or'. Health and care services require technical knowledge and technological breakthroughs. They also require caring relationships and the ability to apply technologies in pursuit of goals (saving lives and reducing suffering) that are fundamentally human.

Both perspectives are needed; and both need to be in sight when making choices about the direction of policy and services. The aim of this discussion document was to widen the lens.

# Annex A: Interviewees / interview process

The Strategy Unit would like to extend thanks to everyone listed below, who generously gave their time and thoughts for this work:

- Albert Mulley, The Dartmouth Institute
- Alicia Ridout, Involve Me Digital Health Ltd
- Ann Blandford, University College London
- Anna Studman, Ada Lovelace Institute
- Caitjan Gainty, King's College, London
- Chris Salisbury, University of Bristol
- Chrysanthi Papoutsi, University of Oxford
- Iain McGilchrist, writer
- Jess Morley, Yale University
- Kassandra Karpathakis, Decimal.health
- Kiran Patel, University Hospitals Birmingham
- Pritesh Mistry, Kings Fund
- Rishi Das-Gupta, Health Innovation Network
- Robin Miller, University of Birmingham
- Sam Shah, Ulster University

#### Interview structure

Interviews were structured in terms of focus and definition; the exact content was then determined by the interviewee. They were given the definitions below to work within, and asked to describe what they saw as the main threats to person-centred care posed by digital technologies.

A broad definition of digital technologies. Taken largely as defined by the WHO: '..." the field of knowledge and practice associated with the development and use of digital technologies to improve health". So, this might include technologies such as: 'Internet of things, virtual care, remote monitoring, artificial intelligence, big data analytics, blockchain, smart wearables, platforms, tools enabling data exchange and storage and tools enabling remote data capture and the exchange of data and sharing of relevant information across the health ecosystem'.

**'Person centred care'** as defined by the <u>Health Foundation</u> 'personalised, coordinated care that affords people dignity, compassion and respect, and supports them to live an independent and

fulfilling life'. So including factors like social and emotional intelligence, empathy, compassion, dignity, respect, co-production and shared decision making.

**Health and social care services** of the type provided in the UK.

**Current and potential future risks / downsides**. Interviewees could draw attention to current threats to the human element of care (perhaps citing specific instances / studies) and / or emerging / potential threats.

Content and emphasis was therefore determined by interviewees, with probes used to explore and clarify the nature and implications of downsides raised.

To conclude, interviewees were asked for their recommendations for future work: where did they think additional research / analysis is needed? Responses are set out in Annex B.

# **Annex B: Suggestions for further research**

As part of the interviews, having described risks and downsides, interviewees were asked where they thought more research and analysis was needed to better understand trade-offs and mitigate risks. These are listed below, clustered into broad themes.

# Detailed 'real world' analysis of the efficiency and effectiveness of digital technologies

By far the most frequently suggested type of research was to look beyond modelled, 'in principle' or pilot research and to undertake detailed, empirical analysis of how technologies are actually used in practice. Before offering specific suggestions, several interviewees made the more general point that there is a need to increase the volume of audits and evaluations of digital tools to properly inform policy and service decisions.

Suggestions within this theme included:

- Detailed examination of how online triage forms work in practice. Specifically, to examine the distribution of time costs (to staff and patients) and changes in 'the user experience'. Has this led to gains in efficiency when taking a system perspective?
- Detailed comparative research on whether digital technologies have changed the content of consultations in primary care. Specifically, to see whether these technologies drive towards more narrow and focused diagnostic consultations.
- Evaluations and audits to see how far business cases used to support the adoption of technologies then track into real world experiences. Taking a system lens, to what extent do hypothesised efficiencies (e.g. savings in staff time) and effects transpire?
- Audits to see how far the costs and benefits revealed in pilot studies of new technologies hold up as adoption spreads beyond initial pilots. (The exact suggestion was to focus this kind of research on the use of home-based remote monitoring technologies).
- Research to track what happens as efficiencies in terms of technology substituting for labour come to pass in practice: does freed up time lead to more / better patient care? (The specific example here was the use of AI to summarise patient notes).

#### Research to examine impacts on service users / patients and staff

Within the general theme of the need for more 'real world' research, several interviewees suggested zeroing in on the particular experiences of patients / service users and staff. Suggestions here focused on qualitative research into:

• The experience of using digital technology to access care – particularly for people from marginalised groups, and perhaps using peer research approaches to do so.

- The experiences of getting more information from different kinds of digital technologies. For patients and service users, what kinds of information helps them feel more in control, and what kinds of information generates anxiety / lack of control?
- Impacts on staff satisfaction; specifically which kinds of digital technologies seem to increase staff satisfaction, and which tend towards dissatisfaction? And what might this mean for recruitment and retention strategies given current workforce pressures?
- How Al can be used to support professional practice (in health and social care) without losing human connection and the relational elements of care that many patients and service users value.

#### Broader, and more conceptual, research

In addition to the suggested need for more real world analysis, several interviewees also saw a need for broader, more conceptual research. Suggestions within this theme included:

- Examining the concept of the 'Infosphere' as a social determinant of health. What might this mean, how might its effects play out differentially across population groups, and what could be done to improve the informational environment?
- Related research into digital poverty as a particular form of social inequality. What does digital poverty mean, and how might its effects unfold as digital technologies play an increasing role in the provision of health and care services?
- Fundamental research into what people actually want and need from health and care and how this is served or hindered by digital technologies.
- Public engagement research to examine views on what healthcare can (and should) do: how it has changed over time, what have been the broad sweeps of its development. What can medicine do and how does digital technology change this?
- Does use of digital technology tend away from community based / preventive services and towards medical interventions / treatments? If so, what are the mechanisms behind this?
- To what extent, and in what ways, does the current evaluation and licencing of digital technologies represent an effective regulatory system? How could it be improved to balance commercial interests / innovation with pressures on public service budgets?
- Does the use of digital technologies tend towards simplifying complex problems (especially in diagnosis)? If so, what are the benefits and drawbacks of this?

- Does the use of digital technologies tend towards targeting individuals, rather than broader, environment changes when it comes to behaviour change? If so, what are the benefits and drawbacks of this?
- Where are there actual opportunities for using digital technologies to substitute for human labour in heath and care services? Can this be used to address specific labour market / workforce pressures?

The above is a collection of suggestions, rather than a coherent research programme. Moreover, suggestions were made without searching to see whether sufficiently similar work already exists or is in train. This would be an important step in developing the above.

The above also misses one obvious suggestion, which would be to take the same broad lens adopted for this project and review associated literature: to what extent do the downsides noted by interviewees occur in broader research on this topic?



**The Strategy Unit** 

strategy.unit@nhs.net

www.strategyunitwm.nhs.uk

@strategy\_unit