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Decider, overruler, or trusted companion? An exploration of the advent of the virtual human twin and its impact on decision-making in healthcare

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1 Introduction

In recent years, the healthcare sector has seen growing interest in the utility and acceptability of virtual human twins. Data-intensive, computational model-based tools are crucial for decision support and risk prevention in healthcare, with the potential to autonomously analyse scenarios and generate predictive insights to inform decision-making. The concept of the virtual human twin, also referred to as a human digital twin or simply a digital twin, holds the potential to offer this capability, paving the way for personalised, data-driven healthcare.

In the literature, digital twins are predominantly discussed within the context of engineering, where they are defined as a dynamic representation of a physical asset or system that continuously evolves in response to real-time data acquisition, enabling the prediction of its material counterpart's future states (Liu et al. 2018). A key function of digital twins is their ability to support decision-making by providing recommendations, simulating potential outcomes, and coordinating resources among stakeholders—they enhance efficiency, optimise processes, and enable value co-creation through agency, autonomy, and real-time insights at all decision levels (West et al. 2021). However, the digital twins described by Liu and West refer to objects rather than unique living organisms. Unlike object-based twins, where continuous real-time data collection can be all but guaranteed, human data from wearables and medical check-ups may be inconsistently updated or subject to behavioural changes, making longitudinal monitoring complex and often unfeasible.

The ontology and terminology associated with digital twins and virtual human twins, poses a challenge for research. As noted by Popa et al. (2021), the concept of the digital twin is evolving, with individuals interpreting and applying the term in various ways due to the emergent nature of the technology. The expert interviews described in this study confirm this view, that while the term digital twin remains valid, it should not be assumed to imply a complete correspondence between the original entity and its digital counterpart; instead, the term enables broad interpretations and is often used as an overarching label for various initiatives aimed at digitising the human body. This indicates that the term may need to be revisited in the future.

Recently, both AI as a medical device (AIaMD) and digital twins have been considered under the regulatory framework for software as a medical device (SaMD), depending on their clinical applications, such as diagnosis or treatment planning. The influence of the digital twin on decision-making remains an area yet to be thoroughly investigated. Gelernter (1991, cited in Townsend 2013) argues that while he trusts the software developers who create these systems, a key concern is the complete dependency they may foster. This can potentially diminish the decision-making capabilities of both clinicians and patients.

However, the digital twin could be instrumental in empowering individuals to assert their autonomy in specific contexts. The in-silico operation of a digital twin has the potential to provide valuable diagnostic insights and therapeutic options, and it could also serve as a means to deliver healthcare to those who are otherwise deprived of access to medical facilities (Braun 2021).

Using technology to support decision-making is not a new concept. For example, computer-aided diagnosis (CAD) utilises machine learning to analyse patient data and assist clinicians, with recent advances in deep learning accelerating

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research into its performance for complex clinical tasks (Chan et al. 2020). Furthermore, CAD systems are designed to assist clinicians in various tasks such as risk prediction, disease detection, differential diagnosis, and treatment decisions. Their evaluation and assessment stand as an instructive model for how virtual human twins may be evaluated in future. At different stages of their development, researchers may evaluate various aspects of CAD performance, including its standalone capability, relative performance against other CAD systems, its impact on clinicians' performance in controlled studies, and ultimately, its contribution to improving clinical practice (Petrick et al. 2013).

While CAD enhances diagnostic accuracy for specific medical images or data, virtual human twins could offer a more complex and detailed virtual model that can predict outcomes and support personalised treatment decisions over the patient's health journey.

In this new era, where crucial decisions shift between human and machine, there is a growing need to understand the applications of digital twins. The potential for the use of digital twins in clinical decision-making necessitates an understanding of their limitations, patient and clinician acceptability and the implications of their use.

This paper uses semi-structured interviews with experts to explore decision-making and technology adoption within a clinical context, alongside a pilot and main workshop with non-experts. The findings highlight a significant challenge regarding the 'black box' of decision-making in healthcare. The study suggests that the digital twin has the potential to address this issue by providing more transparent, data-driven insights that could transform clinical decision-making processes.

2 Background

Understanding the technological foundations, potential implications, and benefits of the digital twin is crucial in setting the stage for comprehending the rationale behind the interviews and workshops conducted for this paper. This background knowledge not only provides context but also frames the exploration of how and why these discussions took place, highlighting the significance of the digital twin in the broader landscape of technology adoption and decision-making.

2.1 Technological challenges

2.1.1 Computational models and the need for good modelling

Good modelling goes beyond good data, collaboration across stakeholders is essential. Developing a model involves more than just collecting data and applying technical expertise, effective modelling requires both users and commissioners to have a comprehensive understanding of the entire process, including the various purposes a model can serve and the different technical foundations it may rely on (Calder et al. 2018). Every model begins with a series of questions that must be addressed to tackle specific challenges, key considerations include where, why and how the model is used. Each model needs to be built to ensure data interoperability, be tailored to the specific needs of healthcare, and address ethical considerations.

2.1.2 In silico methodology and the need for good simulation

'In Silico Methodology' refers to computer modelling and simulation (CM&S) as a regulatory tool for new medical products, improving clarity in regulatory discussions (Viceconti and Emili 2024). Digital twins and in silico methods are closely related, both using computational models to simulate real-world systems for analysis, prediction, and optimisation. In silico methods simulate biological processes, drug interactions, and disease progression, aiding precision medicine, safety assessments, and reducing the need for costly clinical trials.

In cardiology, various experiments are being conducted to explore new approaches aimed at improving the diagnosis, treatment, and prevention of cardiovascular diseases, as well as drug administration. Aguado-Sierra et al. (2024) suggest that computational concentration-response modelling of a virtual population, using high-resolution, three-dimensional cardiac models, can provide insights comparable to clinical data. This modelling approach has the potential to enhance both pre-clinical and clinical safety assessments by offering access to a wide range of exposure scenarios. Consequently, it can aid in trial design and deepen the understanding of how pre-clinical findings translate to clinical settings.

In silico trials involve testing devices on virtual patient cohorts using computer models, which may be based on individual data (subject-specific) or sampled from parameter distributions (population-specific). In silico trials offer several potential advantages, including the ability to be repeated as often as necessary without the need for new animal trials or additional patient recruitment for clinical studies. Virtual cohorts can be much larger than real patient populations, and rare cases that are difficult to include in traditional clinical trials can be more easily represented. Additionally, in silico simulations can improve the design of clinical trials by providing insights into the optimal number and selection of patients to effectively address research questions, thereby reducing the need for animal testing and traditional clinical trials (Verstraeten et al. 2024).

Enhanced predictive accuracy: good simulations provide accurate predictions, enabling researchers and clinicians to explore 'what if' scenarios safely. In silico models of disease can enhance the understanding of disease pathophysiology, propose new treatment strategies, and inform the design of experimental and clinical trials aimed at investigating new treatment approaches (Barh et al. 2014).

Improved safety and efficiency: simulations can reduce the need for invasive procedures or extensive clinical trials by accurately modelling outcomes in a virtual environment. This can improve patient safety and save time and resources in product development and testing.

Regulatory compliance and validation: for biomedical products, simulation is increasingly used to meet regulatory standards. Proper simulation practices ensure computational models are rigorous, reproducible, and transparent, making them suitable for regulatory evaluations (Viceconti and Emili 2024).

Cost reduction and accelerated innovation: simulation enables cost-effective testing, accelerating innovation to meet healthcare needs. In silico modelling avoids ethical issues, eliminates animal testing, and provides results within hours, saving time and reducing costs compared to in vitro studies (Barh et al. 2014).

The benefits of in silico trial are many but there is still need for regulation. Some of the key advantages include: allowing for more evidence to be gathered before bench or animal studies are conducted; expanding the trial cohort to include rare, extreme, or difficult-to-recruit patient phenotypes; enabling direct comparisons of alternative treatments within the same virtual population, thereby reducing effect variance; assessing devices under challenging physiological conditions that represent extreme but plausible scenarios (such as off-label use); and reducing the number of animals and humans required for trials, while also refining long-term studies to minimise suffering (Sarrami-Foroushani et al. 2021).

2.1.3 Data collection

Another challenge in the development of digital twins lies in data collection. Anonymisation and aggregation are key to handling sensitive information. Anonymised data is processed to prevent identification of individuals, protecting privacy while enabling use. Aggregated data, derived from original datasets, presents trends and summaries without revealing individual identities. Both are crucial for ethical research and analysis, ensuring data use while preserving privacy. These practices are especially important for digital twins, where large datasets demand responsible management.

2.1.4 Content, ownership, quality and security of data

FAIR data adheres to the principles of findability, accessibility, interoperability, and reusability, ensuring that collected data is both accessible and meaningful. The principles of data protection, cybersecurity, legality in data processing, and personal control over data are all designed to ensure that citizens can trust the system, forming the foundation of the European Health Data Space [14].

But questions around data ownership, server control, and the methods for collecting, storing, sharing, and securing data remain persistent, with ongoing efforts to address them. The NHS is advancing data integration through the Federated Data Platform (FDP), which centralises patient data to improve decision-making and personalised care. However, concerns over data privacy, security, and private sector involvement have raised ethical and governance challenges. Data quality is crucial to the success of the digital twin initiative. The accuracy of the model is determined by the data collection and input processes, which require high-quality experimental data to ensure reliable predictions (Viceconti et al. 2023).

2.1.5 AI and digital twins

Digital twins and AI are closely linked, with AI enhancing digital twins by processing data, identifying patterns, and providing predictive insights. This integration allows digital twins to evolve and support decision-making and has the ability to transform healthcare. However, the growing complexity of AI requires greater transparency and interpretability in decision-making (Metta et al. 2024).

As machine learning models play a key role in healthcare, their integration with digital twins could enable natural language communication between patients and doctors. Dziopa et al. (2025) suggest that combining digital twins with AI can accelerate precision medicine, improve early detection of cardiovascular disease, and enhance health research. Furthermore, Thangaraj et al. (2024) suggest that digital twins in cardiovascular medicine can enhance the granularity of phenotypes, predict outcomes through dynamic adaptation, and facilitate the development of novel in silico clinical trials.

2.2 Implications

2.2.1 Training of staff and introduction into workflow

Standardising data, processes, and workflows is essential for effective implementation. Challenges arise when physicians must adjust their practices or undergo retraining, a situation further compounded by the lack of trained staff. The digital twin could serve as a clinical support tool integrated

into routine care via decision support systems (CDSS), enhancing decision-making with data-driven insights.

2.2.2 Equal treatment or further divide

Digital twins could help ensure equal patient treatment, regardless of race, gender, or other factors, and address biases in clinical trials, such as the over-representation of white, healthy male participants. It may also reduce animal suffering through in silico applications, minimise pain and delays via less invasive consultations, and allow citizens to contribute to scientific progress by sharing or selling their data. They offer the opportunity to design and analyse trials in a manner that maintains statistical accuracy, while also reducing the required sample sizes, lowering the time and costs associated with recruiting and treating additional subjects (Walsh et al. 2021). A key concern is the growing divide between the Global South and North in access to technology and healthcare. The introduction of digital twin technology may widen this gap, with wealthier nations, like those in Europe and the USA, gaining greater healthcare advantages, exacerbating existing inequalities, leaving poorer nations further behind.

2.2.3 Individual autonomy and freedom

There is a concern that the digital twin could potentially limit the freedom and autonomy of the physical twin. Braun (2021) suggests that allowing a simulation to act as a representation of a person—especially one with predictive capabilities—requires us to consider not only the interaction between a person and their simulated twin, but also the control mechanisms necessary to ensure the interaction remains adaptive to personal freedoms. A digital twin is "not an in-silico companion to entertain or manage your tasks" Raden (2020); rather, it is an engineering concept in which physical devices are paired with digital models that represent the state of those devices. While this is a broad statement, it underscores the critical need to engage all stakeholders in conversations when developing new technologies. Access to personal data for both healthcare professionals and patients can democratise understanding, fostering shared responsibility and collaborative decision-making in a more transparent, participatory system.

3 Method

The paper used a two-part methodology: remote semi-structured online interviews with digital twin specialists to gather expert insights, followed by an in-person pilot and main workshops with non-experts to explore their understanding of digital twins and decision-making through activities like answering questions and voting on statements. An ethics checklist and measures ensured participants were fully informed and not exposed to undue stress.

3.1 Ethical considerations

The study followed a clear and ethically informed research process. Recruitment procedures ensured that no underage individuals or vulnerable adults participated. All participants received detailed information sheets and consent forms outlining their rights, the process of anonymisation, and their ability to withdraw at any stage. Data collection involved semi-structured interviews conducted online, providing flexibility while maintaining consistency. A pilot workshop with two participants was conducted and recorded to test the framework, followed by a main workshop involving four participants using the same structure. For data analysis and reporting, all recordings were transcribed verbatim and analysed thematically. Anonymisation was maintained throughout, and interviews and workshop data were initially analysed separately. The findings were then integrated in the Discussion chapter to examine the implications of healthcare digitalisation for decision-making.

3.2 Data collection for research

3.2.1 Interviews with world leading digital twin specialists

Four specialists were interviewed, providing key insights into digital twins' role in decision-making. Interviews (45-70 mins) followed a structured yet flexible format, allowing participants to offer additional insights. Three specialists focus on the digitalisation of cardiology—a biomedical researcher, a cardiovascular surgeon, and an AI cardiovascular imaging specialist—while the fourth is a general practitioner involved in healthcare digitalisation through both private companies and the NHS.

3.2.2 Pilot and main workshop with non-specialists

Pilot and main workshop structure. Inspired by the "Creative Visualization—Opportunities Workshops" framework (Kerzner et al. 2018), the workshops explored participants' perceptions of healthcare data access and the role of digitalisation in decision-making. Titled Future of Healthcare: Patient Data Access and Decision-Making, 90-minute sessions encouraged reflection on personalisation, patient empowerment, and technological advancements. The workshops began with a 15-minute introduction outlining objectives and structure. Participants were shown slides on current uses of technologies like AI, digital twins, and personalised medicine, using clear and accessible language. The goal was to deepen understanding of future healthcare

possibilities and empower participants in shaping their data access.

The session comprised three key activities. Firstly, during the Wishful Thinking: Ideal Data Access segment, participants explored and articulated their preferred models of access to, and control over, healthcare data. This was followed by a Reflection Phase, in which individuals expressed their hopes and concerns regarding the digitalisation of healthcare, including the use of artificial intelligence (AI) and the development of digital twins. Finally, an Interactive Voting activity was conducted, whereby participants used coloured dot stickers to indicate their levels of agreement with a series of statements relating to data access and emerging technologies.

3.3 Data analysis for the interviews with specialists, pilot and main workshops

To analyse all data, a thematic analysis approach following the Six Phases outlined by Braun and Clarke (Roseveare 2023) was employed. This was complemented by a systematic model for thematic analysis that identifies codes as keywords and clusters them together (Naeem et al. 2023), as well as incorporating the rainbow sheets method to highlight key points by each participant. Seven themes emerged from the interviews, with an additional six from the workshops, explaining the concept of digital twins, their challenges, and impact on decision-making. These themes were derived from the participants' responses rather than the questions posed to them.

4 Results

4.1 Results for the interviews with specialists

4.1.1 Theme 1—Patient data access and personalisation

Greater access to patient data has the potential to significantly enhance healthcare by enabling more personalised approaches, supporting informed decision-making, and promoting proactive health management. This represents a major shift from traditional one-size-fits-all treatment models towards more individualised care based on a patient's specific profile and likely response to interventions. Participants viewed this as a means of improving clinical outcomes by aligning treatments more closely with individual needs. It was noted that certain populations remain underrepresented in existing datasets, which may limit the effectiveness and equity of personalised medicine. However, the use of technologies such as in silico clinical trials and causal inference methods is seen as a possible way to address current limitations in clinical decision-making.

These tools could reduce reliance on trial-and-error prescribing, for instance in conditions like hypertension, by identifying more effective drug options earlier in the treatment process. As a result, patients may experience fewer side effects and require fewer medications overall. But P2 warns that individuals cannot be defined solely by their data:

"The disease doesn't define a person, that's what we have to be careful about. Because we think people want to be monitored, but they don't. They want to be normal and not be confronted with their illness all the time."

4.1.2 Theme 2—Technologies in healthcare

The evolution of technology in healthcare is transforming patient care and medical research, and also enabling broader knowledge sharing, with geography no longer constituting a barrier, particularly through tools such as virtual reality, where individuals are not merely sharing a screen but occupying a shared virtual environment.

For P1 the digital twin is a tool, comparable to other medical devices, functioning as Software as a Medical Device (SaMD) to support clinicians' decision-making processes. While uncertainties persist, P1 anticipates these will lessen with ongoing technological advancements, thereby reducing the likelihood of error. Over at least the next decade, digital twins are expected to provide supplementary information, similar to that offered by CT or MRI scans, albeit with an inherent degree of uncertainty. Simulations, likewise, are expected to improve in accuracy, contributing to more informed clinical judgements. Technology has demonstrated its capacity to overcome certain barriers, exemplified by the use of VR to assist clinicians in visualising stent sizes and placement during complex cardiac procedures.

These simulations are developed in response to clinical demands, such as selecting appropriate medical devices, yet they remain unable to capture all relevant variables. P1 identifies a gap in understanding their influence on clinical decision-making, emphasising the limitations of their predictive power; current simulations cannot reliably estimate outcomes such as patient survival.

A fully realised VHT, encompassing all bodily functions and with a high level of predictive capability, is not currently achievable, but P4 argues that virtual human twins exist in their infancy today. Although simulation cannot yet predict overall outcomes, easily collected, patient specific data (e.g. heart rhythm, step count, blood pressure) is valuable for guiding treatment and preventative strategies. A challenge exists in bridging the gap between these simple data points and the complexity and uncertainty of modelling an entire individual. P1 explains that progress can be made toward

this goal by validating the results of simulations through comparison with empirical observation and the reality of patient outcomes.

P1 describes in-silico or synthetic populations as a promising and feasible application for the digital twin concept. Prediction of detailed outcomes for a single patient is more challenging than predicting typical outcomes across a population of patients, an approach which already provides useful insight for clinicians and that improves the more reliable data is collected. P2 believes the digitalisation of patient data and the digital twin will bring a fundamental shift in healthcare systems:

"The main change is a democratisation of data and knowledge to individuals. We have to realise that nowadays the patient is not the centre of healthcare. It's the system that's the centre."

4.1.3 Theme 3—Ethical and social considerations

The integration of advanced technologies in healthcare raises important ethical and social issues. Patient consent is key, requiring informed and voluntary agreements, ensuring individuals understand how their data will be used within a technological framework. Healthcare legislation must evolve to address data ownership, security, and trust. Unequal access to technology risks deepening disparities and fostering paternalism. While innovations like predictive modelling and in silico trials provide alternatives, they may introduce bias. Transparency and accountability in AI are essential for equitable benefits.

For P2, it is essential for patients and clinicians that patients comprehend the significance of their data. This includes understanding whether they retain agency in medical decisions and whether they possess sufficient knowledge to provide informed consent, issues that P2 frames as inherently political. There is a broader societal responsibility to establish robust legal and ethical frameworks to govern the use of patient data and simulations. All experts concurred on the importance of ensuring patient access to their data, while also recognising the potential ethical and practical implications that such access may entail, especially given that, while a small number of patients may seek detailed engagement with their data, many do not. P3 affirms that access is essential, but a key concern is the potential for increased patient anxiety when individuals access data without adequate explanation or contextualisation. Given the broader societal sensitivity around health, poorly managed data interactions may unintentionally heighten anxiety. P2 asserts that human interpretation by experts is crucial, expressing concern that data can be taken out of context and induce anxiety in patients seeking quick answers.

Although risks accompany the collection, availability, and interpretation of patient data, P3 argues that healthcare cannot remain unchanged, as it fails to meet global patient needs, making the adoption of technology an ethical imperative. Greater digitalisation and new technologies could reduce inequalities in access, but this entails, to some extent, a technology-led rather than human-led model of care, demanding a shift in mindset; otherwise, many will continue to receive no care at all.

Conversely, greater reliance on digital technology may exacerbate healthcare inequalities. P2 highlights the underrepresentation of groups excluded from digital uptake, which is more common among highly educated, higher-income populations. As a result, models risk reflecting only this subset. Careful design of data collection and modelling is therefore needed to ensure healthcare accounts for the widest possible demographic.

4.1.4 Theme 4—Challenges and limitations

Many challenges remain in using technology to predict specific outcomes, a limitation common to all technological tools. P3 notes that the digital twin should be considered not as a panacea but as a tool like any other, with limitations that should be mitigated and advantages that should be leveraged to help to improve people's lives.

Another challenge is determining whether clinicians are using the data from CM&S to inform their decision-making, as P1 commented that it is difficult to know to what extent modelling and simulation is having an impact on decision-making. For instance, while 3D organ models enable new forms of visualisation, their contribution to improved decision making remains uncertain and warrants further research. Simulations are only one way of interpreting patient data, and as digital tools proliferate, understanding how these differences affect decision-making is a key challenge.

Wearables present a promising means of collecting patient data directly, offering opportunities for patient-specific, real-time insights. However, the financial cost of devices, concerns over data collection by private companies, and questions about the reliability and consistency of the products themselves create challenges. Ensuring that the data generated is accurate, appropriately collected, unbiased, and accessible to stakeholders is critical. There is a growing recognition of the need for more direct, patient-level data, which wearables could help provide.

4.1.5 Theme 5—Multidisciplinary collaboration

The importance of collaboration within teams is underscored by P1, who emphasised that a multidisciplinary approach is essential to realising innovation. However, while such

collaboration is necessary, it also presents significant challenges, with stakeholders frequently bringing differing agendas and objectives that can complicate efforts to achieve alignment. For P1, the success of digital healthcare innovation depends on maintaining a healthy 'ecosystem' of clinicians, technicians, researchers, patients, and policymakers in developing new tools.

For P4 the development of effective models is not feasible without high-quality data. The reliability of model outputs depends directly on the quality of the input data, making the process of data collection a critical component of the modelling workflow. This stage requires a rigorous, multidisciplinary approach in which engineers collaborate closely with clinicians or domain experts to determine which information is relevant, appropriate, and fit for purpose. Such collaboration ensures that the data is properly assessed for quality and can be accurately translated into a format suitable for computational modelling.

4.1.6 Theme 6—Future vision and speculative concepts

While the idea of a virtual human twin carries a strong visionary and symbolic appeal, serving as a powerful means of communicating complex ideas, there remains a degree of scepticism about its full integration. For P1, although the concept captures the potential of representing patients digitally, the complete unification of all its components is still questionable, in some cases, potentially unnecessary for achieving meaningful clinical impact.

P2 argues that digital twins could profoundly reshape the relationship between patients and clinicians. Hospitals often hold an 'ivory tower' status, where patients seek specialist expertise, but digital technologies may disrupt this dynamic. By giving patients access to and understanding of data once limited to professionals, digital twins combined with LLMs (large language models) for plain-language interpretation and predictive modelling could transform the doctor—patient conversations and expand patient choice in care. P2 advocates for a better understanding of the need to share data and its value in research and discovering new treatments, envisioning a future where all stakeholders are willing to share data and recognise the importance of proper representation:

"I hope people will donate their data. What I'd like to see—just like what we have now – [is] a few million people who are willing to donate money to charity, I hope people are also willing to donate their data for research and be part of the research community. But that's still a vision."

4.1.7 Theme 7—Economics of implementing digitalisation

The economics of healthcare innovation present challenges, particularly around costs and implementation time. While digital tools can offer long-term savings, solutions like cloud infrastructure and federated data require ongoing investment. Increasing personalisation, as seen with digital twins, also adds cost and complexity to clinical workflows, raising questions about scalability and sustainability in everyday practice. As the healthcare landscape evolves, understanding the relationship between economic factors and technological progress will be key to ensuring innovations benefit all patients and support sustainable industry growth. This balance of needs, wants, and costs must be continually reassessed, particularly as society faces longer lifespans and slowing population growth.

P2 describes a potential future in which highly accurate simulations could force difficult societal trade-offs. For example, if a digital twin predicts that an aortic valve intervention for an 80-year-old will add three years of life at a cost of €150,000, society may face the ethical question of whether to fund this treatment or allocate the resources to other health priorities, such as mental health support for children. This scenario highlights how precise technology could shift responsibility from individual choice to societal decision-making.

4.2 Results for the pilot and main workshop

4.2.1 Theme 1—Need for personalised communication and support

Participants preferred personalised, empathetic communication with healthcare providers, particularly for complex diagnoses, favouring face-to-face consultations for clarity and reassurance. This underscored the importance of empathy, especially in serious health concerns. For PP1, face-to-face interactions were crucial in diagnostics, worrying that a diagnosis on a screen, seen out of context and without more information, could be particularly alarming, whilst a doctor could provide in person expertise and reassurance. Participants desired simplified, clear, jargon-free explanations of health information, supported by visual aids such as colors, symbols, or thresholds (green, red) to enhance clarity. The emphasis on straightforward language over medical terminology highlights the need for accessible communication tailored to diverse levels of health literacy.

4.2.2 Theme 2—Transparency and control over health data

Participants expressed frustration with the lack of transparency in medical data and processes, particularly the 'black box' nature of test results and treatment rationales, which limits patient understanding and control over their health. There was a strong desire for greater clarity, accuracy, and comprehensiveness of information, alongside

continuous access to personal health data and the ability to review and correct any inaccuracies. P1 affirms that data should be available whenever the patient wants to access it, but current systems limit this. They highlight that incorrect data about an individual cannot be easily corrected, meaning that incorrect information will be maintained between GPs and consultants. Patient access would mitigate this risk.

Participants openly expressed concerns about being overwhelmed by data and its potential impact on their well-being. There was a clear preference for having control over when and how to access information, with some expressing a desire for a quiet, on-demand repository rather than constant notifications. Patients emphasised the need for clearer visualisation of their healthcare journey, seeking a defined path to understand upcoming steps, as PP2 explained:

"I can imagine it better if it's following a process, and you can see the progress of it. 'You've done your test', you get a tick. 'Your results are out, you can see them here', another tick...It gives you the results, but it also guides you, shows what's next. Or 'You're all good, you don't need to do anything else'."

4.2.3 Theme 3—Concerns about data privacy and security

There was significant apprehension about sharing data with AI or digital systems, fearing misuse, privacy issues, or loss of control, particularly concerning access by non-trusted parties such as policymakers or profit-driven entities. P2 notes that personal information, could be used against individuals in critical situations, highlighting the real-world consequences of data access. This also shows how patient data can be influenced by fear or self-censorship, as concerns about privacy and access may shape what patients disclose, affecting its accuracy and usefulness:

"Every time the doctor asks me how much I drink or smoke, I'm terrified that if in the future I need a transplant, this is going to work against me. I've already seen something used against a friend in a court case, which was outrageous to me. This stuff is accessed, and it does have consequences."

4.2.4 Theme 4—Empowerment through shared decision-making

Participants wanted a collaborative approach to health management, where patients are recognised as knowledgeable and actively involved in decision-making. They emphasised the need to address power dynamics and ensure transparency and equal knowledge in care. Tools that support patient autonomy were preferred, those that offer guidance without overriding individual choices. While there was openness to data-informed care, participants emphasised that the human element must remain central to the process. The expression nihil de nobis, sine nobis—'nothing about us without us'—comes to mind, underscoring the importance of co-designing solutions and fostering active partnerships with patients to improve healthcare delivery and organisation. P1 was open to data use in decision-making, as long as the human element remained central.

4.2.5 Theme 5—Trust and scepticism in technology

Participants were apprehensive about relying on technology and AI for health information, expressing concerns over AI accuracy, misinformation, data privacy, and the impersonal nature of technology in healthcare. Distrust in wearables and AI arose from concerns over accuracy, anxiety, and profit motives, underscoring the need for rigorous validation and reliable algorithms to prevent misdiagnosis or overly generalised advice. P3 expressed concern that health recommendations overlooked intersectionality:

"I have fibromyalgia, and if I cannot climb the stairs the tech would count it as me taking the lift. It's saying you should do this and that, but it doesn't get intersectionality—it's not there yet. "

PP2 observes that technology is in constant flux, and even when users adapt to current systems, new ones inevitably introduce further learning demands. As the capacity to learn diminishes over time, the rapid introduction of new technologies becomes challenging, highlighting the need for multiple modes of interaction to accommodate diverse user capabilities. P4 expressed concern that data is often collected by untrustworthy private companies and used to maximise profit, particularly in the case of wearable devices.

4.2.6 Theme 6—Anxiety over data-driven self-monitoring

Participants were hesitant to use health-tracking technology, citing concerns about anxiety, judgment, and pressure from monitoring personal metrics, particularly when notifications conveyed unfavourable information. Participants emphasised the need for healthcare systems to consider individual variability and cultural perspectives, advocating for non-generalised treatment and culturally sensitive communication. P3 felt that continuous data feedback could provoke anxiety, even in healthy individuals, by encouraging constant self-monitoring against device-set metrics.

4.2.7 Results for voting activity

The final activity involved voting on statements to capture participants' views on data sharing and its role in decision-making, with options for agreement (green), disagreement (red), or neutrality (yellow). Despite debates, all participants favoured having a digital twin. They wanted full control over their healthcare data but expressed concerns about automated systems misinterpreting or misusing it. Regarding

the use of CM&S for medical recommendations, four out of six participants were neutral, while two disagreed, though open to it as technology advances and trust grows. Below are the eleven statements and the votes of each participant:

Results for voting activity

Statements	Agree	Neutral	Disagree
I want to have full control over my healthcare data.	6		
I would trust computer models and simulations to make medical recommendations for me.		4 – to a certain extent, with a second opinion and more in the future.	2 – not yet, but maybe in the future depending on the tech.
I want a digital twin of myself.	2 – only if it's good and with access only to myself and who I wish to share with.		4 – I want it, but I am sceptical that it wouldn't be used against me/ without my consent.
My healthcare decisions should be personalised based on my data.	6		
I am comfortable sharing my data with researchers.	3	2 – if it's anonymised and depending on what kind of research.	1 – agree and disagree – depends on the research aim.
I worry that my personal health information might not be secure or could be shared without my consent.	6		
I am concerned that the systems managing my health data are too complex for me to easily navigate.	3 – too many hurdles, not comprehensive, partial, inaccurate, not transparent, not usable.	3	
I am excited about the possibility of using technologies like Artificial Intelligence to better understand my health data.	2	2 – tech is not there yet, too hyped up.	2
I would like my health data to be presented to me in a way that is easy to understand and use, such as with visual aids or digital tools.	6 – power to data visualisation.		
I'm concerned that having access to too much of my own health data could lead to unnecessary worry or stress.	2	2	2 – no, I would use it when I needed it.
I'm worried that my health data could be misinterpreted or misused if handled by automated systems.	6 – security should be top-notch.		

The voting results showed participants are not opposed to digital healthcare or digital twins as tools for patients and clinicians. However, they stressed the need for greater involvement in their healthcare and emphasised clinician input over relying solely on computers for outcomes.

5 Discussion

As the public grows more familiar with generative AI, such as using ChatGPT or algorithms filtering CVs, the use of AI in healthcare, particularly in creating digital twins, seems less implausible. However, significant challenges remain, with stakeholders still navigating its complexities.

5.1 Specialist and non-specialist views

Both specialists and non-specialists recognise the potential of digital twins to personalise healthcare, enhancing disease understanding, prevention, and treatment. Both groups prioritise personalised care but acknowledge the need for detailed data collection and sharing, with concerns over possible negative outcomes. Views on data collection, purpose, and access vary. Governments are strengthening healthcare data security, with the FDP ensuring NHS control

over patient data (Morley and Zhang 2023), there is also an option for patients to opt out entirely using the National Data Opt-Out (NHS England / NHS Digital 2025). In the United States, GINA (Genetic Information Non-discrimination Act) (2024) protects against genetic discrimination, and the EU's Health Data Space empowers individuals to control and share health data (2024).

5.2 Challenges for the digital twin

Limited citizen participation in understanding healthcare data and its research importance is a significant issue, worsened by reluctance to donate data to biobanks like the UK Biobank, leading to bias and reduced generalisability. Concerns over data privacy, heightened by incidents like the NHS England cyberattack, are shared by patients fearing misuse and specialists concerned about broader data use. Initiatives like the FDP face challenges, including legal issues over transparency, particularly regarding Palantir's role in NHS data integration (Armstrong 2024; Osborne 2024). Wider awareness of data security initiatives among both specialists and non-specialists may improve trust and participation.

5.3 Ethical and social considerations overview

Both groups raised ethical and social concerns. Some participants expressed a desire for a data repository accessible to both themselves and their healthcare providers, while recognising that access without proper interpretation could lead to anxiety. Specialists voiced concerns about unrestricted data sharing, pointing out that it could heighten anxiety and place additional burdens on healthcare providers. Therefore, careful and thoughtful data management is essential. Ethical assessments of technology are crucial, not only for identifying and mitigating potential negative impacts on society but also for providing stakeholders from various sectors with the opportunity to reflect on and carefully consider the associated cost-benefit implications (Popa et al. 2021). Similar values were shared but expressed differently: non-specialists valued personalised communication, while specialists saw technology as a way to spend more time with patients. Patients felt accessing their data could empower them, improve decision-making, and increase transparency, but were sceptical of AI and digital twins, questioning the trustworthiness of computer models in healthcare decisions.

5.4 Research in wider perspective

Technology knows no boundaries, and its discoveries and applications will spread globally. The collection and use of data is an urgent concern, as political shifts and changing alliances, alongside individuals moving across borders, complicate how personal data is protected. How can data be kept safe without causing harm? This brings us back to the fundamental principle of medicine: 'nonmaleficence' – the need to 'do no harm.' This principle must be carefully considered to ensure safety for healthcare systems and patients.

5.5 Key insights for digital twin technology

Data transparency at the point of collection, while avoiding overwhelming patients and clinicians, and clearly informing them of the type of data being collected and its intended purposes. Understanding the importance of data to transforming healthcare will unlock how people share their data.

Private patient information security is crucial for building trust and enabling benefits, such as improved prevention, treatment, and understanding of diseases. Trust in the system will reassure patients that their data is secure and only accessed by the right people at the right time.

Data interoperability is crucial for digital twins to effectively receive and share data with other systems, thereby enhancing their usability and efficiency as a tool. Data sharing is crucial for system to operate seamlessly.

Multidisciplinary teams are crucial in digital twin development, involving all stakeholders at every stage—from data collection and model input to model development and the integration of various models using the same data. Healthcare professionals will collaborate with colleagues from other fields, such as data analytics specialists, developers, and patients, to ensure the best outcome for users.

Shared decision-making between patients and clinicians for healthcare delivery. Clear communication channels are essential to quickly understand treatment stages. Including patients in the decision-making process helps to promote greater transparency, the use of non-jargon language, and more effective communication between patients and clinicians.

Training for staff, clinicians, and patients is vital to ensure they understand how to access their data and know where to seek help if needed. Training will be necessary, especially as technology evolves rapidly and new ways of accessing information emerge.

Digital twin as a tool that enhances self-care and supports clinicians in healthcare delivery, without becoming a source of profit-driven information or overriding decision-making. Like other tools within the healthcare system, the digital twin will create new opportunities for clinicians and patients to work together in improving healthcare treatments.

6 Evaluation, reflections and conclusions

6.1 Reflections and limitations

Ideally, a bigger section of society would have been represented in the pilot and main workshop, as all six participants were HCID past or present students. This is great in terms of getting fully formed ideas and having creative suggestion, but it does not represent the general population who might have less of a technical grasp and visualisation skills.

An important point to note is that all the world-class specialists were European, which means the perspective is influenced by Western or Global North approaches. While terms like Global North and Global South can be problematic, grouping entire regions as homogeneous, this analysis is limited to European and U.S. policies, with no examination of other regions in this dissertation.

This paper does not address the sustainability issues associated with supercomputers. While it briefly mentions how big tech companies are investing in nuclear power plants for computational needs, a more in-depth analysis is needed on the environmental impact and the potential for widening the divide, as access to such technology and supercomputing remains limited.

6.2 Future work

For future work multiple workshops need to be held in community centres, GP surgeries, and local libraries to engage a diverse range of participants, from young parents to senior citizens, in-patients to outpatients, as well as individuals currently not using the healthcare system.

What is clear is that there is an urgent need to involve all stakeholders into the digital twin world being built. A multidisciplinary approach is not only essential in the built of it, but on its application as well. In clinical settings, collaboration between medical practitioners and technical experts is increasingly common, particularly as healthcare becomes more reliant on technology and data-driven approaches. This multidisciplinary collaboration could improve patient outcomes, foster innovation, and strengthens the overall quality of care provided in healthcare settings.

6.3 Conclusions

Patient data access and personalisation are central to modern healthcare, especially in personalised medicine. Greater access empowers patients, enhancing clinician interactions, informed consent, and transparency. The era of 'black box' decision-making in healthcare, where patients are excluded from decisions about their care, is coming to an end. Personalised medicine, particularly for those with rare diseases, offers significant benefits through tailored approaches that can improve outcomes. However, the responsibility for managing and securing health records must be shared amongst all stakeholders—patients, clinicians, policymakers, researchers, industry—to ensure data security and ethical handling of sensitive information.

Digital twin technology in healthcare could either bridge gaps or deepen inequalities, especially in poorer countries. While it offers remote diagnostics, personalised treatment, and predictive analytics, its adoption requires significant investment in data infrastructure, expertise, and technology. Limited connectivity, funding, and skills may prevent poorer nations from benefiting, widening the healthcare divide. Without global efforts like subsidised technology, training, and collaboration, digital twins could reinforce existing disparities.

For these innovations to succeed, challenges in privacy, security, and interoperability must be addressed. Digital twins offer a "technological cocktail" (Popa et al., 2021), but without clinical validation, their predictions remain uncertain, raising safety concerns. The utilisation of mathematical simulations in conjunction with medical imaging offers unprecedented insights into patient-specific responses to therapies, thereby refining drug prediction and validation processes. Yet their impact depends on addressing underlying assumptions and regulatory compliance.

Human interaction in healthcare is essential, as both clinicians and patients recognise the irreplaceable role of human expertise. While digital twins can support clinical decision-making, relying too heavily on them could overshadow the critical elements of human interaction, potentially diminishing the nuanced understanding that comes from shared decision-making, which ensures patients feel valued and heard.

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Declarations

Conflict of interest The authors declare no conflict of interest.

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