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Authors	Cunneen, Mártín;Anand-Finn, Ruhi;Friel, Raymond;Tennent, Paul;Brandt, Sami
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# From bones to bytes: anticipating and addressing the governance challenges of human digital remains and posthumous digital human twins

Máirtín Cunneen<sup>1</sup> · Ruhi AnandFinn<sup>1</sup> · Raymond Friel<sup>1</sup> · Paul Tennent<sup>2</sup> · Sami Brandt<sup>3</sup>

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## Abstract

During the nineteenth century, advances in medical research led to grave robbing and an illicit market in human biological remains (HBR). The historical episode of grave robbing illustrates how science can upend social norms. A similar scenario could soon emerge, but this time it will not be with people's biological remains, but with people's digital remains. Artificial intelligence and extended reality now create digital representations from avatars to human digital twins. In addition to the sophisticated digital appearance, the representations are drawing on personal and biometric data to create complex behavioural and biological replications of people. These digital artefacts form part of a person's *digital estate*, which persists after death as Human Digital Remains (HDR). HDR presents an urgent socio-technological risk because like the 19th-century trade in HBR, HDR presents existing legal and ethical gaps. The research responds by adopting what is to our knowledge, the first of its kind cross-disciplinary study that combines conceptual analysis, anticipatory and precautionary governance frameworks, and doctrinal review to analyse and anticipate legal and ethical gaps and grey areas. Our analysis shows that neither General Data Protection Regulation (GDPR) nor the AI Act (2025) currently extends rights to the deceased. In response, we outline a HDR governance framework, supported by six targeted policy-facing recommendations: (1) build HDR-specific anticipatory governance capacity, (2) innovate and safeguard posthumous privacy and data protections, (3) protect citizen autonomy with advance data directives and data trustees, (4) leverage existing tools by developing a data-donor card and support the right to gift or trade HDR, (5) enhance the right to be forgotten post-mortem, and (6) update digital identity and legacy rights, including the right to continuation or erasure of Digital Human Twins.

**Keywords** Human digital remains · Digital human twin · Digital ethics · Posthumous data rights · Anticipatory governance · Digital commodification · Privacy · Digital identity

## 1 Introduction

This paper argues that human digital remains (HDR), encompassing the data, online profiles, behavioural traces, biometric profiles and emerging digital human twins (DHT) that persist after death, are poised to become the twenty-first-century analogue of the historical "resurrection trade", unless anticipatory governance mechanisms intervene to address the current legal and ethical vacuum. Section 1 defines HDR, Sect. 2 applies anticipatory-governance analysis, and Sect. 3 advances policy recommendations.

During the eighteenth and nineteenth centuries, growing demand from medical researchers led to the emergence of an illicit market in human remains (cadavers) known as the resurrection trade. It involved exhuming and selling human biological remains to medical researchers (Frank 1976).

✉ Máirtín Cunneen  
martin.cunneen@ul.ie

Ruhi AnandFinn  
ruhi.anandfinn@ul.ie

Raymond Friel  
Raymond.friel@ul.ie

Paul Tennent  
paul.tennent@nottingham.ac.uk

Sami Brandt  
sambr@itu.dk

<sup>1</sup> University of Limerick, Limerick, Ireland

<sup>2</sup> University of Nottingham, Nottingham, UK

<sup>3</sup> IT University of Copenhagen, Copenhagen, Denmark

Spencer points out that the public outcry eventually led to new laws to “*provide criminal sanctions for body snatching*” (Spencer 1985). Frank notes how typically wealthy medical students and professors justified the practice. An interesting aspect of the resurrection trade is how it was fuelled by an awareness of legal gaps that meant the grave robbers were largely outside the reach of the law (Spencer 1985). Frank appeals to an example of a medical Professor in Dublin who advised his students on how the legal gap relates to the body and not the property of the deceased person:

“...remember that if you take only the body, there is no law whereby you can be touched, but if you so much as take a rag or a stocking with it, it is a hanging matter” (Frank 1976)

Magee (2001) notes that eventually, public attitudes gradually shifted, resulting in voluntary donations of human biological remains to medical research. Both Frank (1976) and Magee (2001) point to the Anatomical Act of 1832 as a pivotal reform to addressing the difficulties. The scenario highlights a general concern regarding the lack of legal protections and conceptual tools relating to posthumous remains and how gaps could again bring about new forms of commodification of human remains in the form of HDR. In a similar way that human biological remains pose unique legal challenges, existing data and AI frameworks continue a tradition of overwhelmingly focusing on the rights of the living, neglecting posthumous interests. This continued neglect is becoming more critical today as HDR presents new commercial opportunities relating to data mining, extraction and monetisation. Datafication has created HDR and a persistent digital record of personhood, identity and remains that extends personhood beyond death in multiple ways. The rise of high-fidelity avatars and digital human twins (DHT) reflects the expanding complexity and persistence of digital life and personhood. As with the historical trade in human biological remains, HDR is now being shaped by rising interest, data value and demand, along with legal ambiguity, and a lack of posthumous data protections. All of these factors could promote a scenario where commercial exploitation of HDR emerges, and with it, potentially complex social impacts, ethical concerns and legal gaps.

There is an awareness of the problem space of posthumous data as highlighted by Reeves et al. (2024), who set out some key questions and call for more research consideration of the need to protect posthumous user data. A part of their approach is to draw attention to (a) the lack of platform support or engagement to deal with posthumous data and the need for more qualitative research to determine peoples own preferences (Reeves et al. 2024). The research by Brubaker et al (2014) was forward-thinking at the time in identifying the question of post-mortem data

management and the possible supportive role of stewardship in taking responsibility for peoples social media accounts (Brubaker et al. 2014). The work of Bahri et al. (2015) identifies the challenge of posthumous data management of social media when people are no longer able or are deceased. They maintain more data planning, and the adoption of automated tools could provide some support. Despite these early interventions, a decade later, the governance landscape remains fragmented and uncertain, with few meaningful solutions developed. Likewise, the more recent work by Reeves et al (2024) confirms that the challenges persist and that there is now a pressing need for more research and engagement.

The current wave of innovation has introduced many new technology governance challenges, ranging from the use of publicly available data to train increasingly sophisticated AI models to the creation of new forms of immersive realities. The pacing problem highlights that technological innovation and commercialisation will not wait for governance and regulation. This is what thinkers such as Gary (Marchant, 2020) have highlighted as the pacing problem and the wicked scenario of governance gaps (Marchant 2011; Marchant and Allenby 2017; Marchant et al. 2011). With innovation and commercialisation, there are governance requirements that parallel innovation but take time to develop and implement. Anticipatory governance is a framework that offers a means of looking ahead to address complex innovation challenges before they occur (Fuerth 2011, 2009, 2013; Fuerth and Bezold 2009; Fuerth and Faber 2012; Guston 2014).

Accordingly, the paper addresses the complex gaps that HDR introduces as a new high-value source of data by anticipating the potential benefits and risks of HDR to inform forward-looking governance frameworks and policy recommendations. The paper presents six targeted recommendations informed by anticipatory governance of HDR, including complex artefacts such as DHT. These recommendations constitute a foundational framework for posthumous data rights and governance that safeguards citizen autonomy while mitigating some of the risks relating to the potential illicit commodification of HDR. These include (1) investing in a robust anticipatory governance approaches to HDR, (2) safeguard posthumous privacy and data protections, (3) sustain citizen autonomy and decision making (advanced directive, and data trustee) (4) develop a Data Donor card and support citizen right to gift and trade HDR, (5) strengthen the right to be forgotten, and (6) develop an updated Digital identity, legacy and right to continuation of DHT.

## 2 Methodology

The research methodology is interdisciplinary and focuses on creating a new conceptual lens and framework to better understand and address the risks of illicit trade in HDR. The methodology is primarily an adaptation of (i) Anticipatory Governance with (ii) Conceptual Analysis and (iii) Legal Doctrinal Research. There is a logical phase of analysis that builds on Conceptual Analysis, clarifying and defining HDR boundaries to support the adaptation of Anticipatory Governance methods to better anticipate ethical/legal gaps. Both combine to inform the Doctrinal Analysis, which critically assesses regulatory contexts, particularly EU law, guiding governance proposals.

### 2.1 Conceptual analysis and anticipatory governance

The research takes the initiative to conceptualise HDR as a new digital and data governance category, enabling a systematic understanding of the full spectrum of digital data, artefacts, and emerging technologies linked to the deceased. It also offers a novel framework for understanding HDR as both a governance category and normative construct. The new categorisation of HDR is beneficial. For example, it enables better anticipatory governance of emerging technologies such as sophisticated representations of human beings in the form of DHT, best described as high-fidelity digital representations of individuals. The categorisation of HDR is also helpful in addressing what we consider as a central research gap concerning the lack of specific governance addressing the unauthorised scraping, trade, and use of the increasing volume and value of HDR. Which, as it stands, could occur without informed consent or regulatory oversight. It is important to note that the approach involves tracing the socio-technical relationality to the ethical and legal contexts. These are complex social phenomena that require clarity in terms of how data and AI commercialisation use peoples data, digital lives and remains. To support the effort to accurately capture and inform potential future data and AI governance scenarios, the research adopts legal doctrinal research to create a state-of-the-art baseline of relevant present and emerging regulations to inform the possible futures. The methodological approach supports a more informed cross-disciplinary analysis by first undertaking an important preliminary phase of combined conceptual analysis.

### 2.2 Doctrinal analysis

The anticipatory governance analysis establishes a baseline of the current state of the art in legal and regulatory approaches relating to posthumous data and the categorisation of HDR primarily in the EU context. The findings then support a more focused and forward-looking legal and regulatory analysis that speaks to a clearer and more informed prescriptive anticipatory governance approach. The doctrinal research analyses multiple relevant aspects of the pillars of EU law, including those relating to digitisation, privacy, social values, human rights, data markets and commercial development. It draws from EU case law, regulatory instruments, policy documents, EU technology facing reports and strategies, and relevant national policy documents from jurisdictions ranging from Ireland to France. The analysis also utilises two important data governance thematic case studies concerning the right to be forgotten and the right to private life to be extended to the deceased and their digital remains.<sup>1</sup> The research confirms that current governance and legal recognition of personal rights are limited, and this raises complex normative, ethical and regulatory questions relating to HDR and DHT. Traditional jurisprudence has drawn on will theory (which treats posthumous rights as extensions of prior intentions) and interest theory (which presumes ongoing interests of the deceased). An important finding of the research is the potential need for an extension of certain fundamental rights to better support citizen autonomy and informed consent in managing their HDR.

<sup>1</sup> Case Study 1: Posthumous Defamation—Legal systems often lack defamation protections for the deceased. However, doctrines of dignity (such as the general personality rights (Allgemeines Persönlichkeitsrecht, Germany) and privacy (GDPR Art. 8, ECHR Art. 8)) raise questions about extending reputational protections posthumously, especially where harm affects families or where HDR/DHT are used misleadingly. As will be discussed in the law section, different countries have adopted different approaches but generally, there remains a legal vacuum in relation to such protections for the dead. The case study is linked to the law section and to recommendations two, four and six.

Case Study 2: Posthumous Data Altruism—EU's Data Governance Act introduces data altruism, yet lacks posthumous applicability. GDPR Recital 27 excludes deceased persons' data unless national law intervenes. This case explores the normative need for data donor cards and clear consent frameworks to ethically enable posthumous data use in science and public interest. As data becomes a valuable resource, the idea of donating one's data, much like organ donation is gaining traction. In a posthumous context, data donation requires clarity about consent and governance. This case study is linked to the law section and to recommendations three.

### 3 Evolving digital life and human digital remains

The historic controversy of "Grave Robbing" and the illicit trade of Human biological remains and HDR share several contextual and conceptual similarities. Both relate to legal gaps that promote commodification and monetisation of human remains and present activities that go against social norms and ethics. Both concern the interaction of (1) human life, death, and remains, and (2) the lack of context-specific legal frameworks and protections, along with (3) the emergence of new markets for the commodification of human remains and illicit trade. Digital remains present more complexities, such as the variation and longevity of data and digital artefacts, which are key concerns in terms of how the data and digital artefacts are used and who exactly are using them. For example, a relative creating a virtual memorial is very different to a commercial for profit company using a person's virtual avatar without permission. The core premise of the research maintains that with increasing demand and value of data and digital and virtual artefacts, HDR will become an important source of data for economic and social innovation. HDR as a categorisation speaks to increased scales of volume, variety and value and the broad opportunities offered.

#### 3.1 Posthumous data volume

For example, billions of people across the globe are connected to digital devices, networks and platforms. In addition to their normal everyday interactions and activities, people now have complex digital lives. Furthermore, digital life is expanding exponentially in numerous ways. Most people are digitally active and engaged for longer, fuelling growth in living and posthumous data. People now increasingly invest in existing digital spaces and worlds. People now generate larger volumes of data, adopt new digital platforms and devices, all of which further fuel an expanding volume and catalogue of digital artefacts.

#### 3.2 Posthumous data variety

As people have richer digital lives, and as this continues to increase, so does the number of people who will leave behind rich posthumous digital and datafied remains. As peoples biological lives end, their HDR with their digital lives, digital estate and remains will persist. The advancing digital spaces also introduce new forms of HDR that are growing in value and demand. The difficulty is that HDR is a broad categorisation that ranges from social media profiles

to representations of bodily form, ranging from avatars to complex medical DHT.

#### 3.3 Posthumous data value

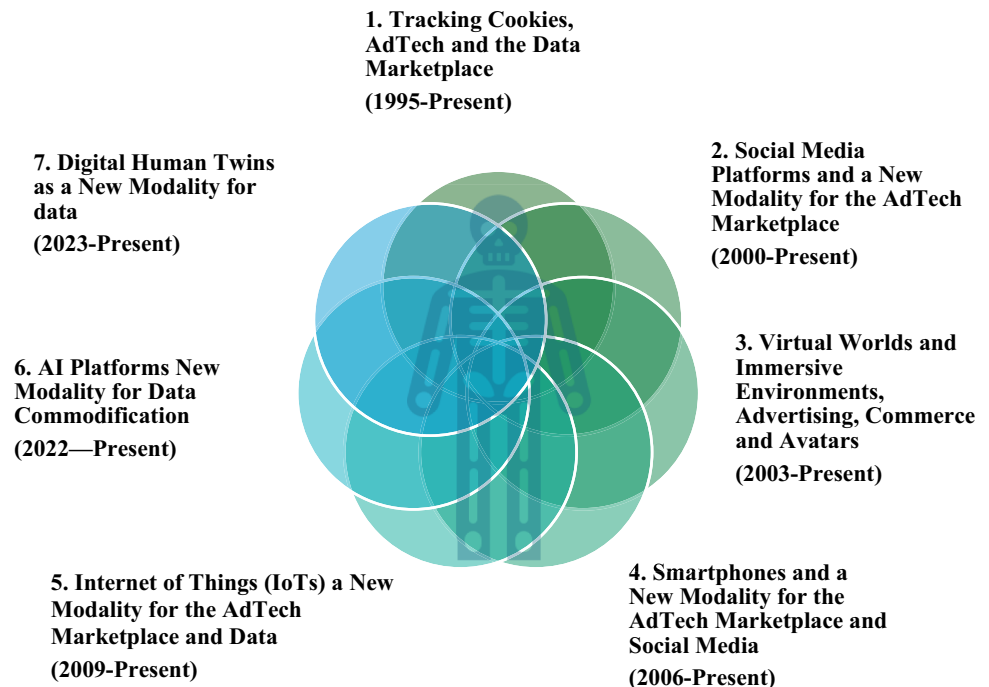
It is expected that, with the growing digital economy, increasing demand and commodification of data and specifically human-generated data, HDR will become increasingly valuable. The relatively recent and modern scenario of monetising data by scraping and transforming personal data has introduced new lucrative industries and commercial markets. This largely came about because personal data, as digital extensions of people, became valuable. The growth and significance of the new data monetisation industry introduced some risks, such as threats to privacy rights and citizen autonomy, and this required innovative responses to address the governance, legal and regulatory gaps. It was addressed to a great extent with regulatory responses such as the General Data Protection Regulation (GDPR)<sup>2</sup> in the EU, which became influential globally as the foundation for data governance for many states.

#### 3.4 Digital identity and embodiment

To further complicate the challenges of HDR, recent and emerging innovations are introducing new levels of sophistication and variation to peoples digital lives. As peoples digital lives and estates increase in volume, variety and value, the catalogue of HDR will also increase. There are at least three identifiable categories to HDR, such as (1) public, private and personal data; (2) digital constructs such as user profiles, social media accounts and influencer personas; and (3) more complex artefacts such as digital avatars as digital representations of people. It is the category of digital artefacts that presents more complex challenges, especially in the context of personal representation in digital environments. Indeed, with the increased sophistication of digital spaces and the emergence of immersive, realistic environments, people are using new forms of creative avatars, photo-realistic and AI-generated avatars. A growing spectrum of digital representations of people, their behaviour, lives and identities is emerging. They are often embedded in various digital domains and contexts that present unique assemblages of personal preferences, creativity and often anonymity. Virtual representations highlight new modalities of

<sup>2</sup> Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation) (Text with EEA relevance) OJ L 119, 4.5.2016, p. 1–88, ELI: <http://data.europa.eu/eli/reg/2016/679/oj> Accessed 12 March 2025.

**Fig. 1** The growing volume, variety and value of human digital remains



personal and behavioural data embedded in the medium of a virtual avatar (Fig. 1).

### 3.5 The evolution of data value, digital estates and human digital remains

The emergence of the World Wide Web (WWW) brought about a paradigm shift in peoples attention relating to many aspects of human life and behaviour. From the beginning of the digital wave of innovation, people want to connect, and the digital world has connected people in new and unexpected ways. The digitally connected world has transformed how many people live, especially in terms of their social engagement, search for information, communication, entertainment, and work. The rapid expansion of digital products and services also continues to increase the volume and variety of personal data rapidly.

People now have sophisticated digital identities that can link across platforms, devices and services comprising numerous online profiles, social media profiles, online personas, and digital avatars, and innovation now offers the potential of HDT, which presents a higher fidelity representation of the biological with many other attributes. All these examples demonstrate a complex catalogue of digital remains consisting of networks of digital relations, traces, and data contexts that persist posthumously. The digital remains are a persons digital estate that includes data, profiles, digital artefacts and possibly DHT, all of which speak to a wealth of personal, public and private data, information and digital representations (Cunneen 2023; Cunneen and

Mullins 2019; Cunneen et al. 2019). The point is that HDR consists of whatever defines a persons digital footprint or engagement. HDR is the container for what is left behind. The following sections outline some of the key components of HDR and identify some of the gaps to highlight the importance of the recommendations we make.

### 3.6 Social media platforms and a new modality for the Adtech marketplace (2000-present)

In 2004, Facebook was launched as a Harvard student networking site, which then evolved into a social media platform (Papacharissi and Mendelson 2011), achieving an estimated 3.07 billion monthly active users worldwide in 2024 (Statista 2024).

Zuboffs concept of Surveillance capitalism argues that social media is built on sophisticated AdTech business models (Zuboff 2015), with Facebook representing the most successful. It has achieved this by continually updating its AdTech business model to support more sophisticated behavioural analytics to maximise advertising revenue (Papacharissi and Mendelson 2011; Zuboff 2015). What followed were the many further approaches to scraping, processing, and transforming user data, modifying the data for monetisation within a digital advertising market (McGuigan 2023).

Social media use introduces challenges for HDR because it establishes (1) a profile, with large amounts of (2) behavioural data, as well as (3) publicly available data (images, avatars and behaviour) and (4) private data (messaging and behaviour). Social media use across the four points presents

a key component of HDR. Furthermore, building on the work of Brubaker et al., who identified in 2014 how there was little management of posthumous data on social media provided by the platforms and given that this difficulty still persists over a decade later, there is a need to innovate HDR governance in terms of social media (Brubaker et al. 2014). In the analysis and recommendations, we provide two governance instruments to address this challenge. First, an HDR data donation card would support a clear way to donate data to specific actors. Second, an advanced directive would support a clear mandate to instruct how social media profiles and content should be managed posthumously.

### 3.7 Virtual worlds and immersive environments, advertising, commerce and avatars (2003–present)

Since the official release of Second Life by Linden Labs in 2003, there has been a growth in the scale and sophistication of virtual online spaces as social shared spaces that, in some cases, mirror the real world. Second Life was an innovative approach and soon became a global success not only in providing a service and virtual world but also in how it became a commercial space with its first economy, currency and commercial activities on a large scale. The example of Anshe Chung Studios is a case in point where the owner became what is claimed to be the first virtual world millionaire with a lucrative property portfolio covering domestic houses to commercial properties. Anshe Chung is the most famous property developer in Second Life (Riley 2008).

In addition to the property market, Second Life also introduced a new modality for advertising where the virtual world mirrored the advertising market opportunities of the real world (Jin and Bolebruch 2009). Jin and Bolebruch (2009) describe Second Life as “Avatar-based, three-dimensional, virtual environments such as Second Life” and further emphasise the commercial advertising opportunities “the most popular and fastest growing environment, offer a promising corporate communication channel for brand marketing, advergaming, and interactive advertising” (Jin and Bolebruch 2009). Over two decades later, META has further developed the concept of virtual worlds and invested in the commercialisation of virtual and immersive Metaverses. METAs Metaverse is a commercial virtual world that will incorporate advertising (Eyada 2023; Yoo et al. 2023), property (Rodríguez 2024), intellectual property (Gupta et al. 2024), retail (Yoo et al. 2023), social spaces and commercial spaces (Cheng et al. 2022), all of which speak to the growth in the scope and value of digital artefacts that will be part of peoples digital estate and HDR. Meta system is only one, albeit perhaps the largest of an increasing number of such metaverses—platforms like VRChat (<https://hello.vrchat.com>), Spatial.io (<https://www.spatial.io/>), Gathertown (<https://www.gather.town/>) and many more allow users to create and populate new virtual spaces each part of a wider world. Similarly, many massively multiplayer online role-play games (MMORPGs) such as World of Warcraft (<https://worldofwarcraft.blizzard.com>), Fallout 76 (<https://fallout.bethesda.net>) or Elder Scrolls Online (<https://www.elderscrollsonline.com/>) allow users to build and maintain property within predefined virtual worlds.

The growth in the sophistication of Extended Reality (XR), along with three available modalities of wearable headset technologies consisting of full Virtual Reality (VR), Mixed Reality (MR) and Augmented Reality (AR), means that the virtual worlds and augmented realities introduce a new complex context to HDR, at least in part because the way we interact with these realities is more embodied, and thus more representative of our physical bodies and behaviours than what we might do via a game controller or mouse and keyboard, physical behaviour in XR is more inherently *us* than any other medium.

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### 3.8 AI platforms new modality for data commodification (2022—present)

AI will inform and further enhance the value creation of data and personal data through more sophisticated digital products and services. The development and use of AI not only creates increased demand as AI requires more data for training and development but will also continue the commercialisation of citizen data, attention and behaviour. AI assistants are a good example of AI growth as they are popular and are now embedded into many electronic devices. AI improves with use and providing access to AI serves as a means to generate data, access data and facilitate model improvements through use (Cunneen 2019). AI is a great tool offering immense utility for example AI is an extraordinary data management and analytics tool that can offer new opportunities to collate, combine, process and transform data and digital products and services.

In recent times, the popularity of platform approaches to providing AI products and services, such as generative AI (Gen-AI) in large language models (LLMs) as well as text, audio, image and video, presents a new modality of behaviour analysis and potential commodification. In short, AI will function in at least three ways to support digital growth: (1) as an enterprise tool to support existing and new AdTech and related business models in capturing and commodifying data, (2) as a support tool for citizens and (3) as an intelligence to support further refined and strategic personalisation of advertising through more accurate behaviour and sentiment analysis. The potential of real-time tracking and greater sophistication in promoting attention and engagement across platforms and devices (Tinkler 2023). As AI Governance

and regulation remain uncertain and open to political disruption, it is unclear how AI will relate to HDR and the questions of ethics and anticipatory governance and regulation; however, AI can be an inherent part of the creation of digital twins. These AI uses intensify the post-mortem data stakes.

### 3.9 Digital twins as a new modality for data commodification (2012—present)

In addition to the innovations listed above relating to the datafication of society and the commercialisation of data, there are also other innovation waves growing in parallel that have a more industrial application but are also forking to include opportunities relating to personal data. While the idea of digital twins is relatively new, the approach to creating virtual replications and mirrors of objects and scenarios from the real world has been considered in research for many years and was likely developed in sophisticated ideation by David Gelernter in the early nineties with his conception of Mirror Worlds (Gelernter 1993). Digital twin technologies replicate real-world objects and artefacts in digital forms. The first wave of DT innovation focused on physical objects, from simple nuts and bolts to complex engineering objects such as Formula One cars and aircraft (Agrawal et al. 2023; Glaessgen and Stargel 2012; Haag and Anderl 2018; Kritzing et al. 2018; Negri et al. 2017; Schleich et al. 2017; Tao et al. 2017; Uhlemann et al. 2017).

The second wave of DT innovation saw more advanced twinning projects ranging from real-world operational twins of supermarkets and factories to utility systems (Aivaliotis et al. 2019; Angulo et al. 2019; Bao et al. 2019; Barbieri et al. 2019; Catarci et al. 2019; Damjanovic-Behrendt and Behrendt 2019; Delbrügger and Rossmann 2019; Ding et al. 2019). The third wave of DT innovation is ongoing with significant industry investment to commercialise DT applications across platforms, from Siemens strategy for pharmaceutical companies (siemens\_press 2020) to Nvidias Enterprise DT platform. In addition, the growth in DT research and application has seen a significant impact in promoting a broader research network (Gliszczynski and Ciszewska-Mlinarič, 2021; Guerra-Zubiaga et al. 2021; Hasan et al. 2021; Hosamo et al. 2022; Iqbal et al. 2022; Katsoulakis et al. 2024; Kwok et al. 2020; Laubenbacher et al. 2024; Lauer-Schmaltz et al. 2022; Pellegrino et al. 2024; Rausch et al. 2021).

Michael Grieves and Edward Hua have further highlighted the evolution of DT innovation with Immersive environments such as metaverses as a strategic development that will see AI become an enabler in creating sophisticated simulations and twins of complex systems and scenarios. They describe this as follows: “*Digital Twin-oriented metaverse... Front Running Simulation as our crystal ball into the future. AI is predicted to play a major role in making this evolution*

*possible as an assistance to humans but not a replacement.*” (Grieves and Hua 2024). Hence, leading researchers such as Grieves highlight the convergence of several innovations that will create new sophisticated and higher-fidelity digital environments. In addition to these developments, a more recent development concerns the more recent focus on digital human twins in DHT systems (Agrawal et al. 2023; Battani et al. 2024; Chung 2023; Davila-Gonzalez and Martin 2024; Fontes et al. 2024; Gaffinet et al. 2025; Hafez 2019; Lauer-Schmaltz et al. 2022, 2024; Lin et al. 2024; Naudet et al. 2021; Nikolakis et al. 2019; Song 2023; Wang et al. 2024).

### 3.10 The digital human twin (DHT) (2022—present)

The advancement of human virtual avatars also speaks to an emerging innovation building on Digital Twin technology to create DHT (Hafez 2019; Lauer-Schmaltz et al. 2024; Lin et al. 2024; Naudet et al. 2021; Shengli 2021). The ability to digitally and accurately replicate human beings is an innovation that presents many opportunities, but as Sofia Scataglini and Steven Truijen (2023) highlight, the increased attention to digital human models, virtual humans, and digital twins of humans speaks to the advancement of the technology to enable more sophisticated higher fidelity virtual representations. They also highlight that with increased attention, there is also some confusion regarding what each conceptualisation means and what the differences are (Scataglini and Truijen 2023). With this focus on the higher fidelity virtualisation of the human form, the differences are important to understand. DHT are different from other digital representations because accuracy and isomorphic feedback are key to the design and value contexts.

The goal of the DHT is to capture the required data from the physical human to replicate or twin them digitally in the most accurate way. Applications range from medicine and health to more accurate modelling of human behaviour. It is the modelling aspect that introduces significant scientific opportunities because DHT could enable innovative experimentation and forecasting. Digital remains could include DHT, and this new complexity presents an important test case for anticipatory data and AI governance. The value of such digital remains will increase with further demand from increasing data-hungry AI research, commercialisation, and data-centric innovation. There are clear social use cases relating to medical and health research that could benefit from access to digital remains. However, digital remains also introduce risks to people because posthumous use and misuse present concerns and questions regarding the lack of clear regulatory and governance guidance concerning protections and ownership. The potential risk of misuse is also complicated because of the nature of the data and the variables relating to (i)

the type of data, (ii) the digital context, (iii) the use of the data, and (iv) the ownership of the data (Andrew and Baker 2021; Godard et al. 2003; Verdegem 2024). With this in mind, HDR can be viewed as the combination of activities that form people's digital lives. It is also helpful to understand the context of the activities in terms of who facilitates, commercialises, and uses the data relating to them.

With the current phase of innovation convergence, we are starting to consider more advanced approaches to digital human twins. Understanding the relation of this to digital remains is interesting because DHT present a digital artefact that aims to replicate the biological human being. Furthermore, with the opportunity to also access and leverage behavioural data, the DHT could become something not only valuable to science in relation to medical and industry 5.0 innovation but also to more personal applications that offer people a greater understanding of their own health and well-being. The technical challenges of DHT, as well as the opportunities the technology presents, have been clarified to some extent by Shengli (Shengli 2021). There are at least three identifiable contexts for DHT and the potential growth of the applications: Medical research will hugely benefit from DHT, and the more DHT that is made available to medical research could offer immense social benefits in combating disease and illness. The potential applications could range from physical health to mental health. The DHT also present an innovative opportunity to model and forecast, and this alone is a seminal development in medical research as medicine could be tailored to individuals. Moreover, if DHT become scalable, the potential for more people to have their own DHT is not unrealistic because this also means that with the present and emerging.

From the above analysis, it is clear that data and data sharing will continue to be fundamental to future innovation and social benefits. Data has become increasingly valuable and important. This is often because data can be stored, wrangled, processed, transformed, copied, commodified, and monetised in many ways. The importance of good data, and especially personal data, is increasing as data-hungry AI models require more data to maintain the models development and performance. It is also key to achieving higher intelligence metrics. Personal and sensitive data can be immensely valuable because they have many high-value applications, ranging from behavioural and health data. The moot point here concerns the question of the social and broader benefits and opportunities presented by the potential value of posthumous data. The growing use of DHT underscores the urgent need to address governance, consent, and posthumous data ownership. Posthumous data in complex artefacts such as posthumous DHT could have significant social benefits, especially

in medical research and possibly in other areas such as AI research.

Perhaps the most familiar examples of DHT are the posthumous visual recreations of actors and celebrities images after their death for use in media. An early example was that of the actor Oliver Reed, who died partway through the filming of *Gladiator* and was reconstructed to complete the film. Several other examples such as the use of the image of Peter Cushing to reprise his *Star Wars* role in *Rogue One* similarly concerned with continuity, however other examples are used for advertisements, such as a digital recreation of Audrey Hepburn being used in a 2013 Galaxy chocolate advert, or the Painter Bob Ross being recreated to paint a *Mountain Dew* bottle in a 2021 advertisement. While similar approaches were taken in the past by editing old footage, such as the infamous *Dirt Devil* advert featuring edited footage of Fred Astaire in 1997, the more complete process of creating DHTs allows the actors to appear to be doing anything and doesn't rely on existing footage. This represents a significant reputational risk, and is perhaps why celebrity cases have been the primary source of legal and regulatory considerations around DHT thus far.

### 3.11 Risk, HDR and HDT

The increasing value of HDR could introduce social risks and tensions between the actors who place a high monetary value on data, such as the AdTech and AI sectors. The potential conflict highlights the different motivations between a data commodification industry and social actors who seek to defend data and human rights. The potential medical research and use of DHT also speaks to the interest and demand, which is a reminder of the earlier illicit trade in human biological remains. The HDR catalogue will grow in sophistication as innovation continues. HDR will encompass diverse digital artefacts, most notably DHT, as highly detailed digital replicas capable of medical and behavioural modelling. Despite significant scientific promise, DHT raise acute ethical concerns and risks, including not only unauthorised digital resurrection, mirroring historic exploitations of human remains, but also possibly behavioural and personal reanimation. The opportunities and value of sophisticated DHT also mean that there could be many scenarios where DHT and similar artefacts could lack informed protections. A concern is that in a similar way to the illicit trade of human remains in the 18th and 19th Centuries, DHT could be digitally snatched and possibly digitally resurrected in other contexts without the consent of the owners. With continued advances in DHT, data captured as part of a person's life could be embodied and developed as a DHT, as the most advanced form of digital personification of a person. Questions relate to how to manage the deletion, donation, or reanimation of DHT and digital personas.

An interesting feature of DHT as part of HDR concerns the social benefits and potential medical value of digital human twinning, which could offer important research information and data to support medical research in addition to human biological remains.

Therefore, the high commercial and social value of HDR and DHT means that commodification, along with legal and ethical gaps, could prompt actors to trade the HDR or DHT. Hence, without the appropriate data governance in place, governance grey areas and governance gaps will persist and further increase the risk of scraping, snatching and commodifying HDR and DHT. In response to this challenging scenario, the research promotes a hybrid anticipatory governance and legal analysis to inform governance approaches and assess the effectiveness of several positive strategies. The fundamental point is to support a range of vested parties, from people to policy writers, to better understand the opportunities for data value commodification and potential donation of posthumous digital remains, ranging from data and social media profiles to DHT. This will, in part, require data governance approaches that support a persons ability to determine the use of their digital remains and their DHT. More precisely, questions regarding posthumous data ownership, use, commodification, and potential misuse of HDR and DHT are becoming increasingly important.

#### 4 Analysing the current legal complexities of human digital remains and human digital twins

It is crucial to highlight that, as there are benefits, there are also numerous questions, potential concerns and risks relating to the use of personal data and AI to create DT and DHT. In particular, the emphasis on individualisation introduces new ethical and legal complexities, especially concerning the handling of sensitive or personal data. Key questions arise around ownership and control of the DHT, ownership of data, privacy, and the right to be forgotten during a persons lifetime. Following this, new complex questions regarding posthumous ownership, control, and lifecycle of the DHT after a persons death also arise. While there has been some research on the complex questions of posthumous data use (Ashley 2020) and control (Harbinja 2017), the right to be forgotten (Harbinja 2017) and broader questions of data rights (Allen 2024; Ashley 2020; Chu 2015; Enriquez-Sarano 2020), there has to date been no research linking such questions and concerns to DHT and posthumous control and use of DHT. Normatively, such aspects of life have been discussed through the lens of the following fields of law (Rothman 2022; Cohen 2023):

##### 4.1 Intellectual property rights: insufficient for protecting identity

IP rights and, in particular, copyright and trademarks arise during the lifetime of the decedent and are protected by legislation which provides for their survival post-mortem for a period of years in the case of copyright and potentially in perpetuity in the case of trademarks. The decedent can deal with these as assets during their lifetime, and as they exist post-mortem, they will form part of the estate either by direction of the decedents will or through the rules of intestate succession. As such, there is already a current system of governance in place for post-mortem rights in this area. However, it has been observed that non-celebrity plaintiffs do not receive the same treatment that celebrity plaintiffs do.<sup>3</sup> Similarly, Copyright protections, while providing protections to some interests of individuals, fall short as one cannot copyright their name, likeness, or persona (Cohen 2023). This inability of the law to protect non-celebrity plaintiffs from appropriations of their persona and likeness highlights the need for further legislation to protect against risks arising from the advancement in technology and data use (Cohen 2023; Rothman 2022).

##### 4.2 Privacy and the limits of posthumous protection

This doctrine protects both the consumer and, to a lesser extent, the deceased from false or deceitful representations that the decedent is the author of or has in some way approved or validated their use. This doctrine seeks not to protect the right of the decedent, but that of the general public not to be deceived as to the source of the material (Cohen 2023). It may be argued that this has nothing to do with the decedent, although well-meaning relations of the deceased may bring this deceit to the attention of the authorities or pursue a private prosecution.

##### 4.3 Gaps in consumer and contract law

By definition, the right to privacy cannot survive death in just the same way as the right to a good name. However, arguably, there have been examples of legislation which convert the right to privacy into a right to publicity, which takes a variety of forms. New York and California state regulations are classic examples (there is no similar federal right)

<sup>3</sup> See further, the Lanham Act [https://www.law.cornell.edu/wex/lanham\\_act](https://www.law.cornell.edu/wex/lanham_act) Accessed 21 March 2025. The application of the law requires proof of ‘distinctiveness’.

(Cohen 2023).<sup>4</sup> Both are focused on the commercial aspects of exploitation of the likeness, image, etc., of the decedent. NY also deals with digital holograms. It continues the right for some time after death, similar to copyright. However, not all states restrict the right to publicity to commercial exploitation, and the NY statute in particular seems like an extension of copyright and consumer protections. Other states provide for a general right.

Recently, in the US, proposals for a Digital Replica bill have been made (Rothman 2024). This new NO FAKES Act proposes the establishment of a new digital replica right that would extend 70 years after a persons death. However, again this Act focuses on the rights of performers and celebrities, which although crucial, in this context further creates pathways for disparate treatment of the general citizenry (Rothman 2024).

With the enhanced use of data and datafication of our lives, it is understandable that the first response for the legal field was to turn to IPR, consumer protection and Privacy rights. However, further advancements in technology and data use, have led to what Professor Rothman has referred to as an identity thicket of overlapping and conflicting rights (Rothman 2022). Although there is a growing consensus among scholars that the data associated with DHT should be deleted upon the individuals passing (Gaffinet et al. 2025; Lauer-Schmaltz et al. 2022, 2024, (Lauer-Schmaltz 2024) B; Pellegrino et al. 2024), the absence of a concrete, universally accepted governance framework leaves many questions unanswered. These include questions such as: Should the DHT and the related data be deleted, archived, or transferred to next of kin? Who retains control over the digital remains of a deceased individual, and what ethical or legal rights should apply? Do the Dead have a Right to Privacy? Or a Right to be Forgotten? Some of these questions are explored in this section.

Rights of the dead have traditionally been non-existent or, in some cases, transferred to the executor of the deceased persons estate. The transfer is, however, not absolute, and is limited by the wishes of the deceased individual as documented in a will or other such legal instruments. Posthumous wishes that are usually considered legally valid are limited to burial rights and organ donation requests (Smolensky 2009). Jurisprudence suggests that courts have applied a best interest test when honouring the wishes of the dead. The best interest test contemplates the impact of following a wish on the living, as, at the end of the day, the law is concerned with the actions of the living (Smolensky 2009).

There are two key theories to consider when discussing the rights of the dead: Will Theory and Interest Theory (Waldron, 1985). The Will Theory argues that the existence of the right is contingent on the capability of the right-holder to make a choice (Kramer 2013). Will theorists, therefore, argue that a deceased individual cannot be a right-holder for that reason; they may have certain protections afforded to them, but not rights (Kramer 2013). Interest Theory, on the other hand, argues that a deceased individual has rights that arise from legitimate interests they have even when they are incapable of communicating those interests (Bruhl 2002). Smolensky argues that the Interest Theory is the most effective mechanism for recognising posthumous rights as it acknowledges the underlying interests of a deceased individual (Smolensky 2009). Historically, courts have supported this theory and have considered dignity and autonomy as the impetus for a finding of posthumous legal rights (Spitko 1999). Smolensky, through her work, has explored the many limitations imposed on posthumous legal rights such as impossibility, the importance of the right itself, the passage of time, and the conflict of interest between the dead and the living (Smolensky 2009). This last limitation, that is conflicting interest is a crucial one, as a balancing test needs to be applied between a deceased individuals autonomy and a living persons interests. It is this limitation that has often hindered the development and finding of posthumous rights, or in some instances, the extension of universal rights to the dead.

As is most appropriate in respect of this paper, the right to privacy and the right to be forgotten are the key rights to be considered. In 1890, Samuel Warren and Louis Brandeis wrote about the right to privacy and the necessity of such a right for modern life. They voiced concerns over the development of the newspaper industry and the capturing of photographs and discussed how this impacted the sanctity of private life (Warren and Brandeis 1890). Over a hundred years from that, the right to privacy is still challenged by advancing technologies. In the European context, the Right to Privacy has been enshrined as a fundamental right under Articles 7 & 8 of the European Charter of Fundamental Rights<sup>5</sup> and Article 8 of the European Convention on Human Rights.<sup>6</sup> The scope of Privacy under the above-mentioned conventions encompasses an individuals physical privacy in the home and life, as well as in a digital environment which includes the privacy of the digital human in DHT systems, that use sensitive and personal data.

<sup>4</sup> See further, the Right to Publicity, New York (2021) <[https://dos.ny.gov/system/files/documents/2024/05/right\\_of\\_privacy\\_law.pdf](https://dos.ny.gov/system/files/documents/2024/05/right_of_privacy_law.pdf)> Accessed 24 April 2025.

See also, the Right to Publicity, California Civil Code 3344 <https://rightofpublicity.com/statutes/california> Accessed 24 April 2025.

<sup>5</sup> Charter of Fundamental Rights of the European Union (2000/C 364/01) (18 December 2000), art 7, 8. <https://fra.europa.eu/en/eu-charter/title/title-ii-freedoms>: Accessed 18 December 2024.

<sup>6</sup> Convention for the Protection of Human Rights and Fundamental Freedoms (European Convention on Human Rights, as amended) (ECHR) art 8. [https://www.echr.coe.int/documents/d/echr/Convention\\_ENG](https://www.echr.coe.int/documents/d/echr/Convention_ENG): Accessed 18 December 2024.

With the reliance on data and the increase in data collection, there is evidence of a need to consider a third categorisation regarding a further extension of the right to privacy of digital assets, posthumously. Digital Assets may be defined as digital accounts or services that may hold sensitive information about the creator (Banta 2016). An interesting case study to refer to here is how Meta deals with death. Most internet service providers now have policies that govern the management of accounts and user data after their death (Facebook 2025). However, there is little choice beyond memorialisation when it comes to deceased user profiles.<sup>7</sup> These policies do not discuss the privacy interests of the deceased and, in some instances, simply ignore these interests and rely on the pleas of friends and family of the deceased to govern the profiles (Chu 2015). Although insufficient in the protection offered, given the lack of legislation governing the extension of the right to privacy posthumously, we may rely on contract law and property law theories to define the justifications for an extension. The contract law theory proposes that the extent of posthumous protection of an individual's privacy will depend on the terms of service they agreed to during their lifetime. Often, users do not read the terms of service carefully and agree without understanding the implications of this acceptance, making them unlikely to be aware of how their digital assets will be handled after death. These terms are drafted by the providers in a manner that is favourable to their interests over user rights.<sup>8</sup> Without the individual alive to contest the terms of the agreement, the service provider can choose to disregard the wishes of the deceased (Chu 2015). Additionally, certain service providers prohibit the transfer of accounts or login credentials, further limiting the wishes of the deceased to share information for digital assets under contract law. The situation becomes further limiting when an individual dies intestate. Therefore, while the contract law theory offers some protection, the right to privacy of a deceased individual remains largely at the mercy of the service provider.

The property law theory, on the other hand, assesses whether an individual's digital assets may be treated with the same regard as real property (Chu 2015). There is little indication from probate law in relation to the treatment of digital assets so far. However, there are services for the management of one's digital footprint after death available in the market.<sup>9</sup> There are limitations to this, as the individual must elect this service before death. Although it may be

noted that an extension of the property law theory to include digital assets will lead to the extension of succession laws. This may result in a violation of the deceased's privacy as sensitive personal data may then become accessible to the next of kin, who, in some situations of intestate death, may not have been the intended heir.

Right to be Forgotten or Right to Erasure can be found under Article 17 of the GDPR.<sup>10</sup> Article 17 creates a right for an individual to request the removal of any personal data, and the controller of the data will have an obligation to remove the data without undue delay.<sup>11</sup> As integral as these rights are to a societal existence, they are not absolute and are limited by a balancing test between the right to private life, the right to freedom of expression and information and public interest. This right has been exercised successfully across the EU by citizens.<sup>12</sup> It may be noted that, following Recital 27 of the GDPR, protections afforded to the living are not extended to the deceased, especially in relation to personal data.<sup>13</sup> However, it provides for Member States to regulate, where necessary, the processing of personal data of deceased persons.

But so far the references to protection for the personal data of the deceased are limited. The Irish Data Protection Act (2018) provides that the Security of Processing under Article 32 of the GDPR shall apply to a deceased individual's relevant information (Part 6, Application of Data Protection Regulation, 27).<sup>14</sup> Similarly, references to the rights of the dead may be found under Article 85 of the *Loi Informatique et Libertés* (France), which holds that, "*Any person may define guidelines relating to the retention, deletion and*

<sup>10</sup> Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation) (Text with EEA relevance) OJ L 119, 4.5.2016, p. 1–88, Article 17 ELI: <http://data.europa.eu/eli/reg/2016/679/oj> Accessed 12 March 2025.

<sup>11</sup> Undue Delay is considered to be about a month. See, everything you need to know about the "Right to be Forgotten" GDPR.EU <https://gdpr.eu/right-to-be-forgotten/> Accessed 4 February 2025.

<sup>12</sup> C-136/17-GC and Others (De-referencing of sensitive data) <https://curia.europa.eu/juris/document/document.jsf?text=&docid=220863&pageIndex=0&doclang=en&mode=req&dir=&occ=first&part=1&cid=28310822> Accessed 4 February 2025.

<sup>13</sup> Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation) (Text with EEA relevance) OJ L 119, 4.5.2016, p. 1–88, Recital 27, ELI: <http://data.europa.eu/eli/reg/2016/679/oj> Accessed 12 March 2025.

<sup>14</sup> Data Protection Act 2018 (No 7), part 6. <https://www.irishstatutebook.ie/eli/2018/act/7/enacted/en/print.html> Accessed 31 January 2025.

<sup>7</sup> See, How do I Report a Deceased Person or an Account That Needs to be Memorialised? Facebook <<https://www.facebook.com/help/150486848354038>> Accessed 4 February 2025.

<sup>8</sup> See, Digital Footprint: Managing your online identity after death, Coop UK <https://www.coop.co.uk/funeralcare/advice/digital-footprint-managing-your-online-identity-after-death> Accessed 4 February 2025.

<sup>9</sup> *ibid.*



important to appreciate that the emerging scenario, while presenting new complex phenomena and questions, does not enter a governance or legal vacuum. The inadequate and often divergent national approaches towards posthumous rights and data subject protections in the face of advanced datafication due to technological advancements illustrate a fragmented global landscape. It is crucial to note that meaningful protection of posthumous digital rights cannot be effectively achieved through isolated national laws. The analysis here underscores the need for a coordinated international framework that addresses cross-border inconsistencies and provides a harmonised baseline for posthumous digital rights. Existing governance and legal mechanisms are actively at play, and this corpus of mechanisms and instruments could provide future HDR and DHT governance approaches with support and also further complexities and even difficulties. The discussion section that follows will unpack some of the aspects of this.

### 5 Discussion

The normative perspective from a legal standpoint maintains that personal rights do not continue after death and cannot be transferred to others; they are bound to the living person. This means that with death, common personal rights are terminated. Typically, this fact does not raise questions or concerns because there is no person with legal standing (*locus standi*) seeking protections or remedies. While death

terminates both property and personal rights, property interests may persist and are determined by complex succession rules. Rules to protect the personal rights of the deceased can and have been legislated for, but the consequences have not been fully thought out. Some argue that these laws suggest a limited posthumous extension of personal rights.

Bodily integrity is a personal right that, in some sense, continues after death, but the contexts are very different. For example, post-mortem examinations are a reserved process that is justifiable in cases where there is a context relating to some benefit to society or others from the examination, such as if a criminal investigation is ongoing or if an insurance or financial determination depends on the findings of the examination. Since the prohibition is societal (sacrilege and public health) and not personal to the decedent. Enforcement is by the state, not the successors of the decedent.

On rare occasions, relatives of deceased people have taken action to seek remedies to concerns they have identified, such as defamation of the deceaseds identity and standing (see case above with *M.L. v Slovakia*). That said, the common approach is to emphasise that personal rights cannot themselves survive death, nor should we create more rights for the dead at the expense of the living. The rights of the living should always outweigh the rights of the dead. While traditional doctrine denies posthumous rights, digital remains create novel contexts that challenge this foundation. For example, hypothetical scenarios can be considered that challenge this approach, such as when a living person threatens the standing of a dead person by publishing damaging

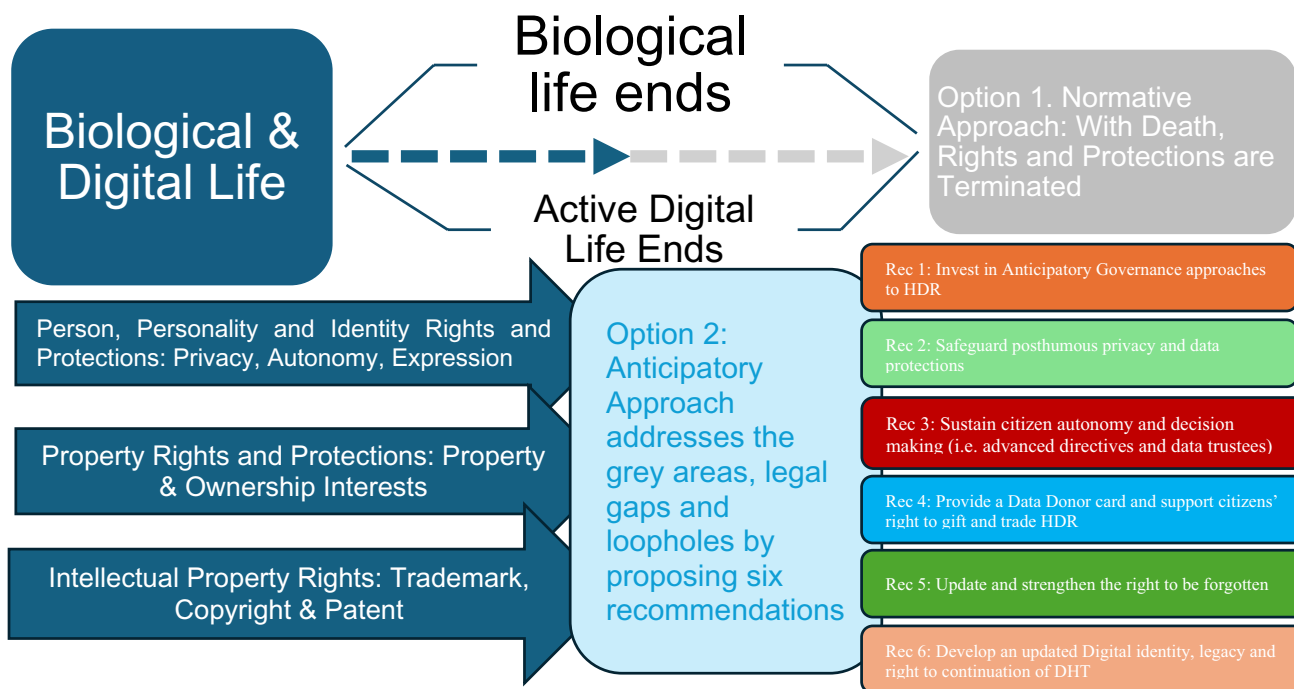


Fig. 2 Digital continuation: addressing governance grey area and anticipatory HDR governance

information that has no benefit to them or others. As shown in the case of *M.L. v Slovakia*, digital identity and reputation may persist beyond death, making HDR governance a pressing legal concern. There are potential approaches, such as interest theory, that could assist in unpacking such questions.

The standard view could be described as a simple statement that the dead have no rights. In the context of data, this also means that the dead have no rights in relation to data. However, as the analysis has highlighted, several states have already taken action to introduce some protections for the data rights of the deceased. In summary, although legal tradition denies posthumous rights, HDR introduces new ethical and legal challenges, as digital reputation and dignity persist posthumously. This necessitates reconsidering traditional legal paradigms in favour of proactive anticipatory governance. This approach only presents one core aspect of the challenge introduced by increasingly complex HDR. As digital technology and society continue to fuse, more examples will fall under the category of HDR (Fig. 2).

## 6 Recommendations: anticipatory governance and human digital remains

### 6.1 Recommendation one: invest in anticipatory governance approaches to HDR

The value anticipatory governance (AG) offers is in providing a methodological basis to support a variety of actors to construct tangible futures that act as future scenario models that enable more informed and strategic critical assessment and dialogue of governance strategies, mechanisms and instruments. AG is a framework that offers a means of looking ahead to address complex innovation challenges before they occur. In this way, AG can support transnational, national, commercial and community-focused governance research. That said, there are some constraints to AG regarding how effective it can be. The works of Fuerth and Guston emphasise the importance of confronting the pacing problem through anticipatory governance, which looks to future possibilities and assesses governance challenges (Guston 2010, 2014). The emergence of HDR and the sub-categorisations within data profiles, virtual representations, digital avatars, and DHT is an important development that can be strategically supported by informed and timely anticipatory governance.

### 6.2 Recommendation two: safeguard posthumous privacy and data protections

HDR introduce complex new ways in which our data and digital lives can be scraped, used, reused, and misused. All of which highlight a complex risk space for HDR. Anonymised

data may offer a way to leverage HDR for social good. However, personal data and sophisticated digital avatars, along with the emerging innovation of HDT, present high-value digital representations of deceased people. A persons likeness, voice, and behavioural traces can be harvested at scale, re-animated, and monetised long after death, which, as it stands, with the current legal gaps, digital representations could be used and misused in many ways such as reputational manipulation with synthetic “resurrections” that families cannot block. Misuse ranges from identity theft, manipulation, to deepfakes. Because current data-protection law generally expires with the data subject, platforms, brokers, and developers can repurpose the deceaseds archives with minimal legal friction, leaving next-of-kin with no standing to object. All of which speaks to the need to anticipate and address the complex questions of posthumous privacy rights and protections. Without clear rights that persist after death, platforms and data brokers face no legal friction in repurposing the deceaseds information, AI developers can fine-tune models on sensitive archives, and families have little standing to intervene. With this in mind, there is now a need to investigate the question of posthumous privacy rights and controls. This recommendation speaks to the development of advocates, data executors, and representatives to support protections while there are legal gaps and grey areas.

### 6.3 Recommendation three: sustain citizen autonomy and decision making (i.e. advanced directives and data trustees)

Advanced directives in healthcare have proven to be important instruments in supporting the continuation of patient voice and autonomy. Advanced directives can be legally binding instructions that carry out citizens and patients decision-making in periods where they may lack capacity or presence to make such decisions. Advanced directives for HDR could provide positive support to HDR governance. Accordingly, a key recommendation is to highlight to policy writers and to inform future governance approaches that the mechanisms to address HDR must empower citizens to make informed decisions and provide a mechanism to support those decisions, may be in the form of advanced directives. This requires providing a transparent process for users to be able to provide directives on how their HDR and parts within it should be used posthumously. Such advanced directives should particularly address the social value and potential importance of DHT. The use of advanced directives in this way is supported by the Interest Theory, which maintains that reputational harm and the erosion of dignity can continue beyond physical death, especially in the digital era (Jamison-Powell et al. 2016). Users may be afforded the option to create an advance directive for data, which may ensure the observance of the wishes of the individual,

where they can no longer decide or control the use of their data. This will prevent the reconstruction of a digital human twin without their consent and thereby prevent undue and unnecessary harm to the memory of the individual and their living relatives.

#### 6.4 Recommendation four: provide a data donor card and support citizens right to gift and trade HDR

A parallel to organ donation cards may be drawn for the introduction of data donation cards that have potential implications for posthumous data donation and data autonomy, especially in relation to digital remains, digital estates, and DHT. These cards may be used to signify a clear choice made by an individual for what may happen to their data (personal and non-personal) after death. There have been increasing calls from industry, academic research, and medical and health professionals for the health-related data to be made available after death with minimal stipulations (Snow and Barry 2024).

So far, there are no national-level institutions that speak to data donation. However, there are several online/app-based services offering the choice to become a data donor, such as DataDonor,<sup>21</sup> Tidepool,<sup>22</sup> and Data Donation Lab<sup>131</sup>(Snow and Barry 2024). As helpful as these efforts on behalf of private actors may be, a centralised national initiative is needed to prevent the misuse and unchecked posthumous data use. In terms of the practical application and maintenance of a record of data donor cards, reference may be made to organ donation registers. Organ donation registers are widely used systems to facilitate the process of organ donation. They allow individuals to legally consent to organ donation. A national register, like the organ donation register, may be maintained by countries. For example, in the US, the Organ Procurement and Transplantation Network<sup>23</sup> maintains a national database of registered organ donors. Similarly, in the UK, the NHS maintains a national Organ Donor Register.<sup>24</sup> A similar ledger or register may be maintained for data donation. Once registered, an individual's decision is legally binding, and sectors and industries looking to use the data may refer to the registries to confirm their consent for data donation.

Attention may be drawn to the Data Governance Act,<sup>25</sup> which introduces a framework for data sharing across the EU through mechanisms like data altruism. Data Altruism refers to the voluntary sharing of data (personal and non-personal), in keeping with the GDPR, without seeking financial compensation and for serving the public interest. However, as it stands, the DGA does not discuss postmortem data rights and is primarily focused on data management and sharing of data of the living. Therefore, a key recommendation may be proposed to legislators to consider an amendment to the Act that discusses the data-sharing rights of the deceased. Becoming a posthumous Data Donor may have an impact on the lives of the living. Data from DHT could be nearly as valuable as data from a human data subject, as it can transform/inform the lives of the living well beyond the data subjects time (Snow and Barry 2024). In 2020, the European Commission proposed the idea of making an EU Digital Identity available to all its citizens. The idea is to consolidate all the different digital profiles/identities and to support one central digital identity that is protected under the framework of a European Digital Identity Regulation.<sup>26</sup> The proposed regulation has the potential to create a framework for a secure, trusted, and interoperable European Digital Identity (EUDI), giving individuals greater autonomy and control over personal data. However, much like the DGA, it fails to address the issue of the deceased's data. This legislation is still in the drafting stage, and it is hoped that it will be amended to include reference to the rights and data of the dead before it is passed into law.

There is scope for the finding of a *Right to Gift* ones digital estate, HDR or components of it under property law, in that an individual can Will their data to an individual of their choosing, much in the same way as individuals have willed digital assets such as security keys for Cryptocurrencies or Non-Fungible Tokens to their next of kin. Therefore, there may be grounds to justify the treatment of data as a digital asset that could be gifted/willed to someone.

<sup>21</sup> See further here [https://play.google.com/store/apps/details?id=com.capgemini.com.data\\_donor\\_app&hl=en\\_US](https://play.google.com/store/apps/details?id=com.capgemini.com.data_donor_app&hl=en_US)

<sup>22</sup> See further here <https://www.tidepool.org/bigdata>

<sup>23</sup> See further <https://www.organdonor.gov/>

<sup>24</sup> See further <https://www.organdonation.nhs.uk/helping-you-to-decide/about-organ-donation/nhs-organ-donor-register/>

<sup>25</sup> Regulation (EU) 2022/868 of the European Parliament and of the Council of 30 May 2022 on European data governance and amending Regulation (EU) 2018/1724 (Data Governance Act) (Text with EEA relevance) PE/85/2021/REV/1 OJ L 152, 3.6.2022, p.44. <http://data.europa.eu/eli/reg/2022/868/oj> Accessed 20 February 2025.

<sup>26</sup> European Commission, European Digital Identity, <[https://commission.europa.eu/strategy-and-policy/priorities-2019-2024/europe-fit-digital-age/european-digital-identity\\_en](https://commission.europa.eu/strategy-and-policy/priorities-2019-2024/europe-fit-digital-age/european-digital-identity_en), > Accessed 21 February 2025. See also, Proposal for a REGULATION OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL amending Regulation (EU) No 910/2014 as regards establishing a framework for a European Digital Identity COM/2021/281 final. <<https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A52021PC0281> > Accessed 21 February 2025.

## 6.5 Recommendation five: update and strengthen the right to be forgotten relating to HDR

Although specifically in the context of the EU, the most effective solution for the management of the digital Rights of Privacy and Erasure of the deceased would be to amend existing laws like the GDPR and the DGA to extend the relevant rights to include digital remains. However, that may be a difficult and expensive affair for the EU institutions (for several reasons, the discussion of which unfortunately goes beyond the scope of this paper).

Therefore, this leaves us with three (semi-effective) options:

- 1) The Commission may direct the Member States to develop local legislation to cover these issues. However, such a manoeuvre may lead to a further fragmentation of data governance in the Union, which is not desirable.
- 2) The Commission may propose a Directive to supplement the existing Regulations. However, it is crucial to note that Directives can take several years to develop and refine, and the acceptance is contingent on institutional approval by the Parliament and the Council. After which, the Member States may take another two years to incorporate it into national law, leaving the rights of privacy and erasure of the dead unsupported for an unduly long time.
- 3) The short-term solution to this issue may be to leave it to the courts to breathe meaning into the existing legislation or for the judiciary to interpret the legislation in a manner that broadens the application of the relevant principles to HDR. In the coming years, we may see that the right to privacy and the right to be forgotten are extended to include the digital remains of the deceased through the jurisprudence of the ECJ and the ECtHR.

## 6.6 Recommendation six: develop an updated digital identity, legacy and right to continuation of DHT

As avatars and HDT increase in fidelity and sophistication, the digital representations will play more important roles in peoples digital lives. It is not too far-fetched to imagine peoples DHT and AI-based avatars becoming sources of revenue for people in a similar way to how AI agents are already becoming lucrative influencers and models. Existing privacy and probate rules stop at the grave, leaving no lawful pathway for citizens to decide whether an avatar or DHT should be deleted, memorialised, donated to research, or licensed for commercial use. Citizen Autonomy and informed consent are the obvious instruments to inform and determine how to manage and provide an advanced directive regarding the use of posthumous data, representations and the potential

use of DHT. It is likely that with clearer governmental guidance, information, and risk assessment of the opportunities and impacts of DHT is necessary to support citizens to make informed decisions regarding (a) their right to be forgotten, erasure or continuation of representations such as DHT and (b) their right to privacy for their digital remains and (c) a right to digital dignity.

## 7 Conclusion

This paper argues that the digital remains individuals leave behind after death, including profiles, data, and digital human twins, require urgent ethical, legal, and governance attention. The research has communicated how HDR are increasingly growing in size, variation and complexity and present unprecedented challenges for governance given the technical complexity and personal value. With the addition of increasingly sophisticated digital avatars and the emergence of DHT, it is clear that anticipatory governance research frameworks can support a strategic and more timely response to the challenge of HDR and DHT. The interesting example of the black-market trade in human remains and the challenge to address the phenomenon, along with the comprehensive examples of increased use and scraping of available user, citizen and personal data, makes it clear that the emerging scenario of HDR and DHT is a serious one. Moreover, with the emphasis on the pacing problem and the continued challenge of governance gaps and grey areas, the research provides a timely and valuable contribution to establishing a more coherent research and policy focus on HDR and DHT.

The analysis appeals to the evident challenges of posthumous rights and the gaps in thinking regarding the challenge of regulating posthumous data and complex digital artefacts such as DHT. The important point here is that a persons right to dignity, privacy, ownership and rights are limited to living people, and the analysis is communicated through an in-depth consideration of existing legal mechanisms and instruments that, if not addressed, will lead to significant risks and harms that will burden citizens. A part of the analysis concerns how this pattern of governance gaps fuels and feeds into continued data extraction, dark patterns and commodification of citizen data for commercial gain.

The recommendations are informed by the comprehensive analysis that addresses gaps in the research and thinking about HDR and DHT. The recommendation aims to respond to fundamental governance questions regarding citizen autonomy, informed consent and rights. Each recommendation addresses a fundamental question and provides an innovative and citizen-centric policy response that can collectively empower citizens to support the social value of HDR and DHT by innovating proven mechanisms such as advanced directives and HDR

donor cards, highlighting the importance of continuing social altruism applied as digital altruism, the right to be forgotten, and property rights extensions. Overall, the research provides an innovative and informed approach that lays the foundation for others to develop and assess further innovative approaches, such as context-specific frameworks that can be better supported as the technology becomes clearer. Without proactive governance, the unchecked commodification of HDR poses significant ethical, legal, and social risks. The recommendations provided offer a foundational step toward ethically sound, citizen-centred digital legacy governance. Substantively, the research reframes posthumous data not as a footnote to living-person privacy but as its own domain of digital personhood requiring proactive stewardship.

Future research should stress-test these proposals in sector-specific sandboxes (health, creative industries, XR platforms) and quantify their economic and social impacts. But the central message is already clear. Namely, that if regulators fail to act now, the commodification of our digital afterlives will be decided by the innovative business models that commodify HDR rather than by the values of privacy, respect and dignity we hold in life. Implementing the recommended safeguards is therefore not optional but is a part of human-centric digital innovation and another facet of the ever increasingly sophisticated data-driven society that must respect the living and the dead.

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## Declarations

**Conflict of interest** The authors declare no competing interests.

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