

GOVERNANCE, CHILDREN'S RIGHTS AND DIGITAL HEALTH

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Introduction

Worldwide, one in three users of the internet is a child, and this number is growing daily; in particular in low- and middle-income countries.^[1] This rapid uptake represents an unprecedented opportunity to support the rights of children everywhere and to ensure their healthful transition to adulthood. And yet, the global community is still to fully conceptualise, let alone actualise, the strengths and limitations of digital technology for supporting and sustaining children's rights, now and into the future.^[2]

Childhood – and adolescence in particular – is critical to individuals' development of lifelong, healthy behaviours and practices.^[3] In turn, children's health is foundational to sustainable and prosperous societies.^[4,5] Digital health products, platforms and services – those technologies used in the provision of healthcare, health promotion, and connected health and self-care practices^[6,7] – have enormous potential to facilitate children's right to a healthy life: from improved access to quality health information, telehealth platforms, self-care tools and resources to enhance monitoring of chronic health conditions via biometric devices.

At the same time, digital health technologies can infringe children's rights, albeit it differently for diverse children. Evidence suggests these challenges span from the potential to compound inequities in healthcare service delivery to exposing children to the promotion of unhealthy products by commercial entities. Most recently, in some contexts, the COVID-19 pandemic has accelerated the development and implementation of digital health services, highlighting how the digital can promote children's access to healthcare under conditions that militate against the provision of face-to-face health services.^[8,9,10,11] Simultaneously, though, there is a concern that the pace of the digital health response to the pandemic has necessitated top-down decision-making, compromising the capacity to ensure digital health technologies are appropriately inclusive. Further, the pandemic has highlighted that, for the millions of children around the world without regular and reliable access to the internet, digital health is not a solution. Indeed, even for those with access, it is evident that digital health can supplement but not substitute for quality, face-to-face health services.^[12]

To date, governments and the digital health industry have given minimal consideration to how children's needs, rights and aspirations are impacted by digital health technologies. The 'fail-forwards' philosophy of digital innovation dominates in practice and regularly fails to address children's rights, even though children are perhaps the subjects par excellence of future-oriented innovation.^[14] At best, children's rights are overlooked and, at worst, compromised by the design, development, use and implementation of digital technologies. The challenge of harnessing the benefits of digital health technologies, while mitigating the potential risks of harm, foregrounds the need for strong and effective digital health governance.

A rapidly expanding body of scholarship and practice-based guidance has begun to explore the opportunities and challenges digital health presents for children’s rights. While this research is embryonic, alongside learnings from other domains of digital transformation, it is clear that a whole-of-community approach – which engages States, NGOs, private enterprise, educators, and others with key responsibility to children, as well as children themselves – will be critical if the global community is to harness technology to support children’s physical and mental health.

The United Nations Convention on the Rights of the Child (UNCRC)^[13] is the most widely ratified treaty in the history of human rights, and was endorsed the same year of the release of the code that became the internet.^[14] Conceived before the digital emerged as a major force in social, political and economic life internationally, the UNCRC could not have anticipated the scale, pace and impact of digital transformation in the domain of (digital) health. Even so, “human rights exist online as they do offline and have to be respected in full.”^[15] We argue here that the UNCRC, along with accompanying Optional Protocols and General Comments, provides a robust, ready-made framework to support ethical and effective digital health decision-making that supports the rights of children everywhere.^[15] However, realising the aspirations of the UNCRC in the domain of digital health will require States, business and NGOs to commit to children’s rights and to routinely account for children’s needs, desires and aspirations. This means, in particular, that digital health governance must create space and opportunity for ongoing, meaningful engagement of children themselves.

Drawing on an extensive review of the literature,ⁱ this paper firstly outlines how children’s rights might be conceptualised in relation to digital health. It then assesses the efficacy of existing digital health governance mechanisms in relation to protecting, respecting and remedying children’s rights, and identifies a range of issues where further deliberation and action are required.

Conceptualising children’s rights for promoting health in the digital age

The 54 articles of the UNCRC stipulate the rights of all children under the age of eighteen,ⁱⁱ and the obligations of State Parties and other duty bearers in respecting, protecting and remedying them. The preamble to the UNCRC asserts that, due to their “physical and mental immaturity”, children require “special safeguards and care, including appropriate legal protection, before as well as after birth.”^[13] Four guiding principles – the right to non-discrimination (Art. 2); the best interests of the child (Art. 3); the right to survival and development (Art. 6); and the right to participation (Art. 12) – drive interpretation and

ⁱ We undertook a scoping review of the literature on: children’s and young people’s experiences of their rights in relation to digital health; the design and evaluation of digital health technologies; children’s and young people’s health data collection; the instruments to promote and safeguard children’s rights in the digital age; and on digitally-enhanced health ecosystems. Literature was compiled through targeted searches of electronic databases using a combination of keywords. We prioritised recent literature (< 3 years old). Specific examples of relevant literature was further compiled through interviews with various experts in the field. The authors acknowledge the generous contributions of Kath Albury, Gabrielle Berman, Sangeet Bhullar, Emanuele Capobianco, Victoria Goodyear, Sabrina Ionata de Oliveira Granheim, Deborah Lupton, Keith Porcaro, Melissa Kang, Daniel Kardefelt-Winther, Bernadette J. Madrid, Richard Mawutor Dziku, Rafael Perez-Escamilla, Kate Steinbeck, Milka Waruguru.

ⁱⁱ Accordingly, in this paper, we follow the definition of children as all those under the age of eighteen.

application of the UNCRC. Additionally, acknowledging children’s “evolving capacities”^[13] (Art. 5.), the UNCRC asserts that protection of and guidance to the child must progressively transform as she develops and grows.^[16]

There are three dimensions to children’s rights as laid out in the UNCRC: provision, protection and participation.ⁱⁱⁱ On the latter, the UNCRC stands apart from previous declarations on the rights of children in its granting of civic and political rights to children.^[17,18] Such rights are among the most challenging to realise in practice, not least because governance structures are rarely set up to communicate effectively with children and to facilitate their contributions.^[2] As we describe later in this paper, fostering children’s participation will be critical to ensuring digital health supports and does not undermine children’s rights.

Article 24 of the UNCRC stipulates children’s right to “the enjoyment of the highest attainable standard of health”^[13], including access to facilities for the prevention and treatment of illness and the rehabilitation of health. The UNCRC General Comment 15 clarifies that children are entitled to:

Timely and appropriate prevention, health promotion, curative, rehabilitative and palliative services, but also to a right to grow and develop to their full potential and live in conditions that enable them to attain the highest standard of health through the implementation of programmes that address the underlying determinants of health.^[19]

Here, children’s right to health is conceived holistically, and integrally connected with the range of children’s other rights, highlighting why it is critical that digital health governance adopt a child rights approach.

There is much at stake for children’s rights in the governance of digital health. Digital health is interconnected with and potentially impacts a wide range of children’s rights, both positively and negatively, including their rights to: information (Art. 17); education (Arts. 28 & 29); privacy (Art. 16); identity (Art. 7); rest, leisure and play (Art. 31); freedom of expression (Art. 13); freedom of thought, conscience and religion (Art. 14); right to culture, religion and language (Art. 30); an adequate standard of living (Art. 27); protection from the illicit use of drugs (Art. 33); protection from forms of physical and mental abuse and exploitation (Arts. 34-38). Digital health is also imbricated with the specific rights of: children living with disability (Art. 23); adoptees (Art. 21); refugees (Art. 22); and those in institutional care (Art. 25) or situations of vulnerability (Art. 39).^[13] Indeed, digital health interventions may infringe or support the rights of different children uniquely, in accordance with factors such as their age, gender, geography, ability, culture, socio-economic standing, or level of exposure to the digital. There is enormous scope for research, policy and programming to better address the differential needs of, and inequities experienced by, diverse children.^[20,21]

ⁱⁱⁱ In this paper, we use the categories of provision, protection and participation as shorthand for the broad categories of children’s rights. For a more extended discussion of the categories of children’s rights, see: Quennerstedt A. Children, But Not Really Humans? Critical Reflections on the Hampering Effect of the “3 p’s”. *The International Journal of Children’s Rights*. 2010 Jan 1;18(4): p. 619-35.

The breadth of potential impacts of digital health on children’s rights – whether by design or unintentional; whether positive or negative – means that effective digital health governance is both a significant challenge and a necessity. As the global community responds, efforts must acknowledge the indivisibility of children’s diverse rights. It is not enough to consider children’s right to health in isolation. There is no hierarchy of children’s rights; they must be progressively realised in combination. Further, as the pandemic has illustrated, a balance must be struck between safeguarding individual rights and promoting collective benefit.^[22]

The UNCRC spells out states’ and other parties’ obligations in realising children’s rights, it also provides a framework for concretely navigating the tensions between children’s various rights, and the needs of diverse children, ensuring that digital health governance can appropriately balance children’s provision, protection and participation.

Research discusses children’s rights in relation to technology in three interconnected ways.^[23]

- Children’s access to technology: Children do not currently have an explicit right to digital devices or connectivity.^{iv} However, their unequal access can exacerbate existing inequities.^[14] Regular and reliable access is a precondition of children’s capacity to maximise the opportunities of technology affords for their rights.^[14] Research of this kind centres the problematic of access, identifying the key barriers and opportunities to enhance it.
- Children’s rights in digital environments: Research here focuses on digital, networked and online spaces, identifying how children’s rights are enhanced or infringed therein.
- Children’s rights in the digital age: This research recognises that the digital increasingly shapes many facets of the everyday lives of children, and that technology has potential to support the realisation of children’s rights across online and offline spaces.^[14,24,25]

Digital health governance must respond to these diverse dimensions of children’s experience with technology. A range of supporting documents, ratified by the Committee for the Rights of the Child, are available to support these efforts. General Comments, for example, provide principled and evidence-based guidance to inform the interpretation of the Convention in relation to specific issues. There are at least four recent General Comments that are of significance for digital health governance:^[15]

- CRC General Comment 25 on children’s rights in relation to the digital environment (2020)^[26]
- CRC General Comment 15 on the right of the child to the enjoyment of the highest attainable standard of health (2013)^[19]

^{iv} Acknowledging the increasingly important role of digital technology in the lives of children and adults everywhere, however, there is a rising call for universal coverage.^[22]

- CRC General Comment 16 on State obligations regarding the impact of the business sector on children’s rights (2013)^[27]
- CRC General Comment 20 on the implementation of the rights of the child during adolescence (2016)^[28]

Existing digital health governance mechanisms

Digital health finds its roots in telemedicine and is often used interchangeably with e-health and health informatics to describe a constellation of technological innovations and emergent practices in healthcare, including mobile health (mHealth), electronic health records (EHRs), and telehealth.^[29] It spans the uses of technology for health information delivery for health professionals and consumers to the improvement of health services through, for example, the training of health workers and the use of health information systems to “capture, store, manage or transmit information on patient health or health facility activities.”^[29] It also encompasses trends in practices of self-care and self-monitoring using digital technologies, such as wearable devices.^[6] It is said to facilitate greater interactivity between health professionals; between patients (e.g., online health communities); and between health professionals and their patients.^[30, 31] Digital health is touted for its potential to enhance efficiency and personalisation of healthcare,^[7] including potential low costs of implementation, wide distribution of health messaging, and reduced barriers to access.^[32, 33]

More than the legislative or regulatory powers of governments, governance is the interdependence and continuing interactions between government and non-government actors in policy networks to negotiate structures, processes and relations of decision making, accountability, control and behaviour.^[34] Digital health governance is evolving against the backdrop of a call to strengthen digital governance more broadly,^[22] in order to respond to the increasing complexity of digital environments that are ever more networked, multi-scalar, and potentially uneven in their effects. It must address the impacts on children of an expanding array of services, products, professional practices, technological capabilities – such as automated decision-making – as well as evolving practices of data capture, monitoring, storage, flows and use. Promises about digital health’s capacity to improve child health and wellbeing outcomes must thus be cautiously and continuously weighed, accounting for social, cultural and political contexts, and the attendant and transforming possibilities, risks and invisibilities, that shape digital health practices.^[6] It is critical that governance is guided by the best possible evidence. However, to date, key gaps in the evidence-base on digital health’s uses by and impacts on children, particularly in the global South, hamper the progress of governance efforts.^[35]

Spearheaded by the World Health Organization (WHO) in 2005,^[36]^v digital health governance has since gained momentum amidst the priorities of relevant global and regional policy

^v In 2005, the WHO adopted a resolution on e-health urging member states to develop long-term strategic plans for developing and implementing eHealth.

agencies, commissions,^{vi} some national governments,^{vii} and organisations and businesses internationally.

However, key governance strategies frequently overlook the needs, rights and aspirations of children. Further, they rarely situate digital health and its governance within a human rights framework, let alone a child rights framework. For example, developed as a comprehensive and practical guide for nations in conceiving and implementing digital health initiatives for the “measurable benefit of their citizens,”^[37] the World Health Organization and International Telecommunication Union National eHealth Strategy Toolkit contains no mention of children, nor human or child rights. The World Health Organisation Resolution WHA71.7 called for a global strategy on digital health, focusing narrowly on member states’ development of necessary legislation and data protection policies; again, without reference to children or child rights.^[38] So too, the World Health Organization’s Global Strategy on Digital Health 2020-24 references human rights only in generic terms, and centres the adult as the normative subject of digital health intervention.^[39] Furthermore, the Broadband Commission on Sustainable Development’s call for government leadership and cooperation on digital health focuses primarily on the human right to privacy and contains but three tangential references to child and maternal health.^[30]

Many strategies privilege top-down approaches and construct digital health primarily as a biomedical encounter, eliding the social, cultural, political and economic contexts of application. Child rights, where they feature, tend to be framed in terms of infant mortality or immunisation, or they appear via proxy in discussions of maternal health.^[38, 40] Calls for “global solutions” sometimes sit uncomfortably in digital health strategies against the assertion that digital health solutions must address the needs of “vastly different country contexts.”^[41]

The UNICEF Approach to Digital Health^[42] exemplifies how a child rights framework can inform industry, government and civil society practices in the field of digital health. It underscores the importance of evidence-based, digital health interventions targeting mothers’, children’s and adolescents’ right to health, with a focus on reaching the most disadvantaged. It argues for digital health interventions to be supported by professional training and integrated across all levels of health systems. In addition to strengthening information and service delivery, the UNICEF Approach to Digital Health conceptualises technology as critical to advocacy and policy influence. However, in its sole focus on the right to health, particularly that of very young children, UNICEF’s strategy falls short of comprehensively addressing the effects of digital health on children’s and adolescents’ broader rights.^[15] Further, prioritising provision and protection issues, the UNICEF Approach to Digital Health elides discussion of children’s participation in the development, implementation, evaluation and governance of digital health products, services and policies.

^{vi} For example, the Broadband Commission for Sustainable Development; the Lancet/Financial Times Commission on Governing Health Futures.

^{vii} For an analysis of the international uptake of digital health, see World Health Organisation (WHO). Global Observatory for eHealth (GOe) Atlas of eHealth country profiles: The use of eHealth in support of universal health coverage. 2015. Available from: https://www.who.int/goe/publications/atlas_2015/en/

Here, UNICEF is not alone. International mechanisms and frameworks for health governance increasingly emphasise the importance of citizen engagement in the health ecosystem.^[43] But, where they do this, they tend to conceptualise citizens as adults; or they frame children as consumers, positioning them as recipients of care rather than actors with agency. They also frequently reduce children to either the unproblematic beneficiaries of digital health or as highly vulnerable to harmful technologies and practices.^[44] The effect is to minimise the potential for realising children’s participation rights. Network governance, which engages an expanded association of actors – state governments, non-government organisations, businesses and citizens, including children– in the project of governance, can significantly foster children’s full range of rights across a complex digital health ecosystem.^[45, 46]

Scientific and industry peak bodies are contributing to societal and policy guidelines and industry standards to guide the development of technologies such as machine learning. For example, the Institute for Electrical and Electronic Engineers Global Initiative on Ethics of Autonomous and Intelligent Systems (A/IS) advocates ethical design driven by a human rights framework for A/IS creators, but does not go as far as to recommend a child rights approach.^[47]

Although national strategies have a key role to play in enabling children to claim their rights,^[48] very few specifically address children’s rights in a rapidly transforming world,^[49] let alone in relation to digital health. Many countries are not adequately resourced to develop comprehensive plans.

In sum, the current range of national and international mechanisms and instruments for guiding the ethics, compliance and administration of digital health across diverse jurisdictions, companies, communities and cultures is limited in its capacity to address child rights. There is an urgent need to develop digital health governance agendas that foreground the needs and entitlements of children in diverse settings, including their right to engage in the decision-making that impacts their lives (Art. 12).^[13]

Child rights issues for digital health governance

The task ahead for digital health governance in securing children’s rights is complex. Digital health initiatives offer enormous opportunities to support and sustain the rights of children. For example, research suggests that digital technologies, when appropriately integrated into primary healthcare, can improve children’s access to and experiences of healthcare.^[50] Digital technology can support the delivery of quality, accessible information, tailored to individual needs, which can in turn foster improved health outcomes^[50, 51] and facilitate continuity of care through, for example, enabling greater contact between health professionals and children.^[12, 52]

Children themselves believe technology significantly impacts their rights and are optimistic about the potential for digital technology to enable their right to physical and mental health.^[2, 53] They highlight how technology-based health interventions can support more traditional modes of health care delivery.^[54] They also report that they use technology primarily for communication, connection and sharing with family, friends and others, followed by information seeking;^[2, 53] all of which they conceive as vital to their health and wellbeing.

However, as we explain in more detail below, digital health initiatives can also significantly infringe children's rights. Without strong governance, the challenges of digital health to children's rights will continue to overshadow the benefits. The challenges and opportunities are deeply intertwined, meaning that intervention to support children's rights must be holistic, responsive to children's experiences and addressed in an ongoing manner, anticipating the full range of possible positive and negative consequences.

We argue that effective digital health governance that can appropriately and effectively navigate the complexities by seeking to balance children's protection, provision and participation, as well as addressing not only the behaviours of children themselves but the various broader contexts that shape their health in the digital age. Our review finds that action is urgently required across the following five areas:

- a) Digital inclusion
- b) Expanding commercial interests
- c) Rapidly evolving health data ecosystems
- d) Quality data, information and education
- e) Support for children's participation in digital health futures
- f) Robust digital health ecosystems

i. Digital Inclusion

Children's capacity to benefit from digital health initiatives requires their meaningful, regular and reliable access to technology. While the UNCRC does not go so far as to stipulate children's right to access digital technology or connectivity, as key components of health information, care and support services go digital, questions of access go to the heart of children's right to non-discrimination (Art. 2) and best interests (Art. 3).^[13]

Where children's basic access can be secured, digital technology can play a role in addressing the "socio-economic, cultural and environmental conditions"^[55] that impact children's health, thereby supporting quality health care. For example, with minimal burden on the user,^[56] Artificial Intelligence (AI) can generate effective, data-informed, personalised recommendations to enable access to safe housing, healthy food and water, and supportive social relationships.^[57]

Around the world, the majority of children go online via a mobile or smartphone.^[2, 53, 58] With the right design standards in place, there is thus particular opportunity for smartphones, social media and digital health apps to support children's personal diet and nutrition,

exercise and mental health practices, and to enhance their access to both quality, routine healthcare and time-critical care, such as helplines.^[57]

However, many children around the world, in the global South and also in the global North, face consistent barriers to their use of digital technology.^[59, 2] Indeed, just as social determinants shape children's health,^[60, 61] ^{viii} so too, social, material, geographic and economic determinants powerfully shape children's access to technology.^[59] These factors constrain the possibilities for leveraging digital health to support all children's rights.^{ix}

Children – particularly, though not exclusively, those living in the global South – report that the cost of devices and data, along with intermittent connectivity and unstable electricity supply, greatly impede their meaningful engagement with technology. Children frequently use older or second-hand devices, and many share devices with other family members or friends.^[2, 53] Further, many “rely on older technologies such as websites and search engines to find information,” and they use “newer media such as social media platforms, apps and wearable devices... less frequently... for health-related purposes.”^[20] Children also recount that social norms, gender- and age-based assumptions, parental rules, and the fear-based messaging of many online safety campaigns mediate their opportunities to engage with the digital world.^[2, 53, 62] Digital health initiatives that seek to positively impact children's rights thus need to be responsive to the very real social, cultural and economic constraints on children's use of technology in their everyday lives.

Virtual reality, augmented reality, telehealth and medical devices offer significant possibilities for addressing the key healthcare challenges of those children with complex healthcare needs or long-term chronic conditions.^[63, 64] With the right governance structures, market mechanisms, and research and development incentives, there is scope to extend to children recent developments to enable people with complex and chronic conditions to self-manage their health using digital technologies.^[63] However, success requires that the basic accessibility needs of these children are addressed through inclusive design and adherence to accessibility standards. For example, children living with disability – who are perhaps among those who may have most to gain from digital health initiatives – report that technologies are frequently inaccessible to them.^[65]

As health services increasingly migrate online and/or are supplemented significantly by digital health tools and services, there is potential for digital health to create new or exacerbate existing structures of inequity.^[66] Digital health governance efforts must thus acknowledge and align with broader efforts to address equity of technology access – and development of the accompanying literacies – for all children, everywhere. Moreover, digital health governance ideally should address the social determinants of both children's health and their access to the digital world.

viii In accordance with UNCRC General Comment 15, digital governance must acknowledge and address “a number of determinants... including individual factors such as age, sex, educational attainment, socioeconomic status and domicile; determinants at work in the immediate environment of families, peers, teachers and service providers, notably the violence that threatens the life and survival of children as part of their immediate environment; and structural determinants, including policies, administrative structures and systems, social and cultural values and norms.”

ix Alongside socio-economic status, gender discrimination is a particular concern among the child rights community vis-à-vis both children's health outcomes and their access and use of digital technology.^[60]

ii. Expanding commercial interests

In addition to governments and not-for-profit organisations, large corporations, small- and medium-sized enterprises and start-ups driven by commercial interest design, develop and manage digital health technologies, raising the potential for children's rights to be compromised for corporate gain. Further, children often seek information and engage in other health practices using proprietary platforms – such as social media – that are not designed specifically for health,^[67] and which tend to construct children primarily as consumers.^[68] Rapid innovation within the digital marketing sector has embedded new ways of tracking, nudging and profiling children and young people across their device usage and everyday lives. In concert with the rise of adtech, kidtech,^x and sophisticated digital neuromarketing techniques,^{xi} advertising and marketing priorities increasingly drive the design and functionality of children's media experiences.^[69]

Children's engagement with digital health thus frequently unfolds in heavily commodified digital environments that 'push' technologies and products to children via internet enabled toys, games, apps or via social media, with significant implications for the ways they make sense of and use digital health technologies. For example, children's use of digital health tools to support their right to a healthy diet (Art. 24)^[13] competes with – and is potentially negated by – the international food industry's aggressive marketing of highly processed and/or unhealthy foods, with consequences for children's health.^{xii}

If digital health tools are to appropriately support children's positive health practices, governance must simultaneously create conditions to encourage children's healthy behaviours and habits and enact stronger regulation and legislation of exploitative commercial practices. Given children themselves tend to trust governments more than private companies to protect their rights,^[53] there is scope for governance mechanisms to encourage states to invest more deeply in partnerships with the NGO sector to generate ethical digital health technologies for children, thereby balancing commercialised digital health offerings to children with those that are produced by entities with a clear and enforceable mandate to respect, protect and uphold children's rights. Further, Montgomery and colleagues suggest that governance should make provision for independent review of digital operations to "determine whether they take unfair advantage of young people's developmental vulnerabilities, health, or well-being."^[69]

As we discuss further below, health systems, services, social media platforms and mobile and wearable devices also gather children's data.^[71, 72] Where private digital health entities engage in these practices, without appropriate legislative and regulatory protections in place, children are potentially exposed to economic exploitation (Art. 32).^[13] Indeed, digital health governance must urgently address the potential for private interests to override and

x Built on sophisticated targeting software systems, adtech and kidtech can track children across all their devices.^[69]

xi Neuromarketing techniques that identify and trigger an individual's attention, and generate detailed metrics based on continuous tracking of movements and communications are particularly problematic.^[69]

xii Indeed, a recent internationally comparative study of adolescents' diet and nutrition showed that digital technologies, and in particular social media, plays a powerful role in adolescents' food choices, as well as their body image, and was seen to fuel negative self-perceptions and harmful eating practices.^[70]

compromise children’s best interests (Art. 3)^[13], as well as their rights to health (Art. 24)^[13], protection (Arts. 34-38)^[13], information (Art. 17)^[13], education (Arts. 28 & 29)^[13], privacy (Art. 16)^[13] and so on. Resources, such as UNICEF’s industry toolkit,^[42] which communicate how companies should align with human rights principles are a step towards raising private entities’ awareness of policies and practices that support children’s and young people’s rights. Safety by design, which encourages technology developers to embed “user safety and rights at the centre of the design, development and release of online products and services,”^[73] is one mechanism that might be promoted by digital health governance to secure children’s broad range of rights in the face of trends in commercialisation and commodification in digital health. Further, UNCRC General Comment 16^l on state obligations regarding the impact of the business sector on children’s rights provides important guidance for digital health governance on these issues.^[27]

iii. **Rapidly evolving health data ecosystems**

Digital health data ecosystems^{xiii} are constituted in and through the data practices of children, governments, private entities and civil society, as well as those of automated systems, which mobilise children’s data to monitor, assess and act upon various aspects of children’s health and wellbeing, such as their growth, health, relationships and moods.^[75] Digital health technologies both draw upon and contribute to interconnected health data sources, generated across diverse devices and platforms. These include electronic health records, drug side-effects data, data from wearables and sensors, hospital and healthcare claims data, epidemiological data, imaging and clinical trial data, as well as social media data relating to individual preferences and health-seeking behaviours.^[74]

Datafication – the process by which often vast amounts of data are collected and repurposed – enables digital health technologies to leverage artificial intelligence in the service of users’ health goals. Existing evidence suggests that datafication can enhance research, development and innovation; create operational and cost-efficiencies and opportunities to scale effective healthcare delivery; strengthen public health promotion and prevention strategies; bolster emergency preparedness; and enable better regulation and improved planning and workflows.^[74] Some research also suggests that datafication can improve health systems’ capacity to identify and target end-users’ health needs, thereby enhancing the quality and efficiency of healthcare, enabling personalised care, and ‘nudging’ healthier lifestyles.^[56, 76]

However, in general, existing research delineates potential benefit for users’ health, rather than documented impact.^[74] Despite optimistic predictions about the power of AI-driven nudges, overall, few theoretically sound, developmentally-informed, technological interventions targeting children as beneficiaries have been developed and tested, and evaluations have yielded ambivalent results vis-à-vis positive behaviour change.^[77] For example, while some research suggests that trends in datafication and artificial intelligence are enabling children to track and better manage their health, other research finds that those

xiii We follow Marjanovic et al in defining digital health ecosystems as “the technological and social arrangements underpinning the environments in which health data is generated, analysed, shared and used.” [74]

who adopt self-tracking apps and wearables find these burdensome and rarely use them on a long-term basis.^[20]

At the level of children's own data practices, recent consultations show that children themselves are increasingly aware that their digital data is being collected, stored and used by third parties.^[53, 78] However, they frequently have very little visibility over complex data ecosystems and are demanding more information and greater transparency about how their data is being used, by whom and for what purpose.^[53, 78] Some understand that their data is used to tailor services to their needs. However, many also perceive much potential for exploitation, worrying about how their data might be used in the future,^[53] and reporting a sense of powerlessness in relation to the collection and use of their digital data.^[79] Further, research suggests that standard industry terms and conditions and traditional consent processes are impenetrable to children and do not allow for their meaningful provision of consent. ^{[42] xiv}

Here, we must remember that such data practices are not "value-free or neutral" but "politically and economically charged,"^[80] potentially serving government or proprietary objectives rather than children's best interests. In particular, ethical concerns have been raised around industry and government behavioural interventions grounded in AI-powered 'nudging', including their reproduction or exacerbation of inequities and discrimination along existing fault lines of class, race/ethnicity and gender.^{[22, 81] xv} Effective governance must find ways to respond to these concerns, including incentivising diverse and inclusive AI initiatives attuned to cultural, geographic and gender differences (Art. 2) and, importantly for children, developmental considerations (Art. 5). This would also include ensuring debates and actions are informed by appropriate representation from the global South, where the benefits of AI for citizens' health are substantial.^[22]

So too, emerging health data ecosystems raise challenges for children's privacy and security in online settings. Children themselves are concerned about whether or not current data collection, storage and use practices adequately respect the privacy of their data, and the extent to which such data practices might expose them to cybersecurity breaches, such as hacking.^[53]

In general, "existing regulatory frameworks designed to ensure children's privacy... frequently fail to require minimum standards (beyond loose prescriptions of age of consent and post hoc requirements for removal of data)" and this is "problematic, given the speed at which technologies and solutions develop."^[82] As the UN Secretary-General has asserted in relation to human rights broadly:

Effective personal data protection and the protection of the right to privacy in line with internationally agreed standards are imperative. Human rights-based domestic laws and practices for the protection of data privacy, including enforcement mechanisms such as access to

xiv Here, General Comment 25, in particular, provides useful guidance to facilitate robust digital health governance. [26]

xv Although children's freedom of thought is primarily applied in relation to their right to practice the religion of their choosing, there is perhaps scope here for governance to consider and address the impacts of 'nudging' and correlate practices on children's freedom of thought.

judicial review, or fully independent and well-re-sourced data protection authorities, are needed to address the use of data by private companies or Governments.^[22]

Given the increasing reliance of digital health ecosystems on digital identities, and that many of today's children will be shadowed for their whole lives by their digital data, protecting the privacy and security of children's digital health data is critical. As children of this and future generations grow, it is foreseeable that, without proper protections in place, their digital health records might expose them to forms of discrimination, such as being denied health insurance. Further, in light of recent cybersecurity breaches of digital health data systems during the pandemic, it will be critical to ensure safeguards – including “decentralized data storage, identification and authentication, encrypted communications and... the incorporation of ‘privacy by design’ principles”^[22] – are in place to protect critical digital infrastructure and, specifically, children's digital health identities and data. Such protections will be necessary to building public trust in and acceptability of digital health data ecosystems into the future.^[74]

In sum, children and experts alike are calling for much greater transparency in the collection, storage and use of children's data, including child-friendly communication, equitable consent processes, and fair treatment of their data and privacy.^[42, 53, 82] There is a clear role here for governance to ensure that processes are in place to support children's development of the necessary critical data literacies^[79] for navigating the data practices that shape digital health ecosystems (Arts. 28 & 29); that data practices uphold children's right to privacy (Art. 16) and protection from harm (Arts. 34-38); and that appropriate mechanisms ensure that those agents that collect children's data comply with international standards and communicate with children about how their data is collected and wielded (Art. 17).

iv. **Quality data, information and health education**

Digital health initiatives afford strong potential for children to access quality health information (Art. 24), thereby encouraging them “to think about their health, enhancing readiness to interact with providers, and identifying important risk factors to facilitate delivery of preventive services.”^[77] Children want quality health information to be accessible to them online.^[53]^{xvi} Evidence suggests that they commonly turn to the internet, social media platforms and online health services for information on a wide range of health topics,^[51,83] and have changed their behaviours as a consequence of such information.^[51, 77] Adolescents in particular share such health information with their peer networks,^[54] enabling them to mobilise social support in realising their health goals,^[51, 83] and some create their own health content for distribution. Indeed, many of those with regular and reliable access to digital technology engage in complex digital health information curation strategies, which facilitate their connection to support networks and services, and, at the same time, navigate stigmas related to health, illness and identity characteristics.^[84, 85] Effective digital health governance

^{xvi} During the pandemic, there have been some stellar examples of using digital means to respond to children's health concerns. For example, New Zealand Prime Minister, Jacinda Ardern, held an online press conference for children in which she, an epidemiologist and a young, popular science communicator responded to children's questions about COVID-19. Even so, while children have had access to some quality information about the physical health effects of the pandemic, public health responses are yet to respond to children's broader wellbeing concerns, such as the financial impacts of the pandemic on their families' livelihoods and increased levels of violence against children in the home.

would capitalise on children's existing practices by creating conditions for children to access and, where desirable, share high quality, scientifically-grounded health information.

Adolescents are particularly keen to have access to evidence-based information, particularly that which responds to their questions about sensitive or, in some contexts, taboo issues, such as mental health, sexuality and sexual and reproductive health.^[53] Some evidence suggests that adolescents are receptive to receiving such information via trusted, automated digital health services.^{[86] xvii} Above all, though, adolescents are keen that such health information be provided in ways that does not compromise their right to privacy (Art. 16) or expose them to disapproval or punishment by others (Arts. 34-38).

That said, echoing international debates around the prevalence of dangerous forms of misinformation during the COVID-19 pandemic, children have concerns about the reliability of online health information, and they worry about the possibility of mis- or disinformation.^[53] The implications of health-related mis- or disinformation for children range from incorrect self-diagnosis to the perpetuation of harmful stereotypes and forms of discrimination. This raises important challenges for digital health governance in ensuring quality information standards prevail; that the generation of high quality, child-friendly information is appropriately resourced; that trends in mis- and/or dis-information are addressed by regulatory, legislative and, where necessary, law enforcement mechanisms; and that children are equipped to filter and evaluate the health content they encounter via digital platforms.

For those children with regular and reliable access to technology, another important form of information is the kinds of data they produce, or which are produced about them by practitioners and services as part of clinical care, through interactions with the digital health ecosystem. These data range from sleep, eating and exercise data to tracking of medical conditions and medication routines and have consequences not only for their health outcomes but also their subjective health identities, imaginaries and practices. There is a tendency for contemporary governance to focus on the technological dimensions of digital health,^[30] and to conceive it primarily as a biomedical interaction. Such framings downplay the important role of social and cultural practices for children's experiences of health in technologically mediated settings.

Technologies constitute 'pedagogical devices'^[87] that create 'teachable moments'^[88] for children's learning and training about bodies, health and wellbeing. However, not all forms of digital health data generated by children themselves using technology is straightforwardly useful. Some research shows that digital health technologies generate large volumes of data, leading to data overwhelm, and that such levels of information might perpetuate negative health identities, amplify children's anxieties and exacerbate tensions within families.^[89] These data practices raise the question of whether or not we are encouraging children to think about their bodies and their health in 'healthy' ways, as well as which societal freedoms are valued.

xvii See also UN Committee on the Rights of the Child (CRC), General comment No. 16 on State obligations regarding the impact of the business sector on children's rights. 2013; CRC/C/GC/16.

To address these culturally-oriented concerns about the effects of data practices and ensure that children are developing constructive understandings and attitudes towards health – and, for that matter, illness – in the digital age, in addition to the health, medical and computer sciences, digital health governance must leverage insights from across the humanities and social sciences. Ecosystemic and interdisciplinary approaches to digital health governance can strengthen responses to the social determinants of health in the digital age.

v. Mechanisms for children’s participation in digital health futures

UNCRC Art. 12 stipulates children’s right to participate in the decision making that impacts their lives. The UNCRC General Comment 15 explicitly urges states to conduct regular participatory consultations with children and their caregivers in order that their insights and experiences may directly inform the design of effective interventions and health programs.^[27] Engaging with children to define, design, monitor and report on digital health initiatives at all levels of government, business and community, is consistent with broader international efforts to establish principles and standards for ethical design and the governance of technologies.^[47] However, while participatory design is growing more prominent in the development of health and mental health technologies,^[90] children are not yet appropriately and systematically engaged in the design, evaluation or the governance of digital health.

Involving children in governance processes supports more effective digital health policy, service, product and practice design^[91] and reduces the risks that digital health initiatives will undermine their rights, health and wellbeing. In particular, children’s participation can support culturally-appropriate digital health technologies that are responsive to children’s developmental needs and evolving capacities (Art. 5). Digital health technologies compete with the other demands –technological and otherwise – on children’s time and attention within their everyday lives. Working with children to understand and respond to these constraints can help children meaningfully integrate health technologies in their everyday lives and maximise their benefits.^[56] Further, children’s participation can shed light on how social determinants might be addressed to foster greater inclusion and accessibility and better health outcomes.

Children want and have capacity to contribute to digital health research, design, monitoring and evaluation processes.^[2, 53, 72, 92] Yet, they report that their opportunities to participate in decision making processes are deeply uneven.^{[93] xviii} Where children are consulted, frequently they are involved in one-off, extractive engagement activities that seek their views on adult-defined questions and priorities, with the result that children have limited agency in decision-making.^[53] There is a clear role for digital health governance to assert ethical and ongoing processes for engaging with children to ensure digital health addresses their needs and rights.^[53, 20] This requires that digital health governance assert the importance of and develop the necessary tools, methods and structures of accountability for child participation in agenda setting, research, design, implementation, evaluation, legislation, regulation and

xviii For example, differential laws regarding young children and young people’s autonomy within a jurisdiction can further complicate their rights to inform, control or evaluate how digital health technologies and data are governed.

other activities shaping the digital health ecosystem. Enabling children to contribute effectively to governance processes that support them to enact their rights requires that children are educated about their own rights, and the rights of others (Art. 29). So too, key decision-makers and the digital health workforce need to be educated – via formal education curricular and professional development – about children’s rights, including their rights to participation. These efforts must be accompanied by commitment to and resourcing of partnerships to support children’s participation in all aspects of digital health governance.

Finally, for the greatest success, it is not enough to listen to and respond to children’s insights and concerns. Rather, digital health governance must “embed a radical openness to children’s participation and a commitment to ongoing intergenerational dialogue at the heart of the organisations and institutions that work with and for children.”^[53]

Conclusion

While the need for systemic change across the healthcare sector is clear, the full possibilities for digital health to support children’s rights are yet to be imagined and realised, underscoring the need for strong governance in this domain. Children themselves recognise the important role of different actors and processes of governance for protecting their rights and helping them derive the physical and mental health benefits the digital can offer.^[53] However, children feel that, collectively, diverse stakeholders are currently failing to prioritise their rights in processes of digital transformation.^[53] They acknowledge governance efforts to address child protection and education issues, though they also note that when such efforts are grounded in adults’ perceptions of the issues, they fail to address children’s most pressing concerns. Further, too often, digital initiatives reproduce problematic assumptions about children and their needs, framing them in deficit terms as either disproportionately ‘at risk’ or as a source of risk to others and themselves.^[44]

Asserting the importance of children’s rights in digital health governance, including their right to shape the decision-making that impacts their everyday lives, will require a concerted and coordinated effort on behalf of decision-makers and the various players who sustain digital health ecosystems. Digital health governance will need to align with efforts to strengthen digital governance more broadly. A child rights-focused ethical framework – and accompanying internationally-agreed standards and periodic child rights impact assessments – to specifically guide the design, implementation and evaluation of digital health initiatives that impact children would constitute a significant advance in the quest to protect, respect and remedy children’s rights within the digital health ecosystem. However, such a framework will need to be systematically activated across the field of practice internationally. In particular, there is a need to strengthen regulation, legislation and processes of remedy for children; to build child-facing health workforce capabilities in child rights and digital health; to address issues relating to the quality, capture, storage and usage of children’s digital health data; and to build children’s trust in digital health systems. And, of course, there is a need to meaningfully engage children in these processes.

Efforts to build a robust, child-rights responsive digital health ecosystem will necessarily unfold against a rapidly shifting digital landscape, characterised by multiple and competing interests. Many questions remain; not least of which is the question of how to effectively balance individual children's rights with those of the collective. However, in the UNCRC and its accompanying General Comments and Optional Protocols we have at our fingertips vital child rights instruments for navigating the complexities that lie ahead. As we proceed, however, we must resist the impulse towards thinking children's rights in the abstract, relegating them to the debates of technical experts. While the UNCRC secures important legal protections for children, children's rights are activated, refined and reinvented at the level of children's lived experiences. The UNCRC "is valuable for its imaginative and aspirational vision and its capacity to frame and mobilize action"^[14] to realise a better world for children. To enact good digital health governance, which progressively realises the full suite of children's rights, and balances children's provision, protection and participation rights, the global community must activate the UNCRC for and with children everywhere. The time to act is now; "before systems, processes and industry practices [further] sediment."^[59] Indeed, digital health governance that embeds children's rights will likely ensure that the rights of all human beings can be realised.^[14]

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