

Health of our digital child

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Our digital child who is born in New South Wales today is likely to be born to a mother aged between 30 and 34. There is a one in three chance that it will be born to a mother who was not born in Australia. We have a very high likelihood, more than 90 per cent, of having a normal birth, so the child will stay in hospital for two to three days prior to going home. Relative to the rest of the world, this child also will be very fortunate to be born in Australia, a developed country with one of the world's best health systems. It will have a life expectancy of 85 years if a girl and 81 years if a boy. However, if Indigenous, this child's life expectancy will be around eight years less than a non-Indigenous child born today.

New South Wales Health, like other organisations in our health system, is committed to ensuring that a child born today is on the way to a long and healthy life. But for our children to thrive, we need to support their development and learning from conception onwards. This will improve their health and wellbeing in the present, but also into the future; giving them longer and healthier lives. This is the essence of NSW Health's First 2000 Days strategy. The first 2000 days of life, from conception to the age of five, are critical to physical, cognitive, social and emotional health over a lifetime.

Early life experiences during this time will determine whether a child is more likely or less likely to experience good health and wellbeing into adulthood. A child's development score at just 22 months can serve as an accurate predictor for educational outcomes at 26 years of age. The first 2000 days are crucial, and our strategy recognises the power of technology as a key enabler. Digital technology already underpins the delivery of services, and it provides us with the data to understand if we are delivering the services to families and children who need to have the best start in life.

In recent times, we have seen an increased uptake of virtual care and telehealth, making a tangible difference. For instance, virtual allied healthcare complements face-to-face care and is vital in exceptional situations where there are access issues for families because of the long distances they have to travel. It's part of a blended model of care, with selected appointments held face-to-face, virtual appointments to reduce stress and various existing regular appointments. In some parts of the state, this is already a reality.

Outcomes that will predict a visiting child's health journey started before they were born; which is why a digital health record commences during pregnancy. New South Wales Health has led the National

Digital Child Health co-laboratory that harmonises all the traditional paper-based pregnancy and child health records into one single digital health record. The ability for health information systems to share data lies in common terminology, clinical information modelling and standardised technical language.

We now can enable real time interactive sharing of data centred on children and their families. The digital health record is a starting point for a lifelong digital health system, which will follow and serve this person throughout their lifetime. By 2030, when our digital child is at school, it will have a comprehensive digital health record that both the child and parents will be able to use on their smart phones. This record is likely to include health and genomic data, combined with relevant information from education and social science, making it possible to predict, diagnose and treat various health or developmental problems more precisely and personally than ever before.

The child and their family will be accessing many routine health care services virtually from the comfort of their home, and their interactions with the health system might be primarily through digital channels. AI-driven care navigators will assist the family with their health care choices and suggest the best place for them to meet their needs. And if this includes, for example, a visit to a hospital emergency department, their arrival will be anticipated, and they will be visited by clinical staff who are already familiar with the child's circumstances and the relevant healthcare issues.

Digital channels of communication between health care providers and the family will continue after their hospital episode, with information following the patient and

proactive advice and support services being provided. Wearable devices used by family members will be able to transmit biometric data, which will be analysed in real-time by autonomous, machine-learning algorithms and provide predictive and proactive advice for families and a designated health care team. The child and family will connect with new kinds of healthcare workers and professionals who will be equipped with advanced digital tools such as AI-driven decision support systems and real-time analytics. Training and development of healthcare professionals is likely to evolve towards more cross-disciplinary approaches — with deep inclusion of technology and data analytics subjects in the training curriculum. This might be combined with a stronger infusion of customer service and customer experience skills, as well as human-centred design and agile problem-solving methodology.

As a legacy of the pandemic era of the early 2020s, the health system is likely to be supported by strong population health and disease surveillance capabilities, as well as hopefully the sovereign vaccine manufacturing and distribution capacity. While many of these advances will improve health outcomes and safety and quality of care, there will be an ongoing debate about the ethics of using and sharing personal health information, especially genomic data and device-generated data. The meaning of patients' consent and how to give it effect might be of great interest. Significant concerns are likely to be raised about the "digital divide," which might result in greater health inequalities if left unaddressed. Quite simply, one's health outcomes may depend on a person's ability to access digital services and interact with them.

By 2050, our digital child will be entering the fourth decade of its life. Hopefully, it will live in a world where climate change has been to some extent controlled and where global geopolitical fault lines are not as deep as the ones that we are witnessing now. If this optimistic scenario becomes a reality, it is likely that this person will benefit from the many biomedical and technological advances made in the previous three decades. While this person is likely to be in good health themselves, they are likely to have access, if needed, to gene therapy, robotics technology, nanotechnology, bionics and bio-artificial organs. Digital technology, which was strongly used in previous decades, will be considered mature or even obsolete. Artificial intelligence is likely to be a mainstay of healthcare, with many routine tasks and activities delegated to autonomous agents.

Ethical questions, related to human machine interfaces, end-of-life issues and global health inequalities, might become very significant. Impacts on the health workforce are difficult to predict in this scenario. It is likely that AI and robotics will replace, or reduce demand for, some types of health care workers. But other health care workers might gain prominence, requiring creativity, as well as humanistic, compassionate care and ethical decision-making. And, of course, there will be immediate technical knowledge required to design and oversee the healthcare technology, which might be widely deployed to support the provision of care to an increasingly ageing population. Machines will become an integral part of patient care.

While it is hard to predict what the health of this child might be influenced by in 2050, we do know what will determine many of

their health outcomes right now and that is the child's first 2000 days. For our children to thrive, we need to make sure that they have access to all the services they need at the time they need them, which is as early as possible. We need to support them to build not only digital literacy, but digital health literacy so that they can be active participants in their health care.

The NSW Government's Bright Beginnings initiative aims to give them the best start in life. The good news is that we can make a massive difference to the future health of our digital child by taking the right policy decisions and making the right investments, today.

Louisa Jorm

I'm speaking today from the land of the Gadigal people of the Eora nation. The health of the child born today is going to be influenced by some very major environmental forces, and I think it's timely today, with COP26 going on in Glasgow, to remember that the child born today will live in a world with rapid environmental degradation unless some big decisions and changes are made now. The child potentially will be living in an environment of poor air quality, increasing storms, major weather events, disasters and, as we've seen over the last couple of years, pandemic events. Wearing a mask is probably going to be a day-to-day occurrence for our digital child.

There is a growing body of evidence around the degree of digitalisation, in particular the use of personal mobile devices impacting on child health. We've got an increasing prevalence of child obesity and evidence that short-sightedness and other vision problems are more common among children and teenagers. Also, very unfortu-

nately, there is some evidence that overuse or over-reliance on digital devices is changing the social-emotional development of children and their wellbeing; potentially resulting in a whole range of mental health problems.

So there are some real challenges that we know are already facing our children today that they will also experience possibly even more intensely than our current generation of children. However, on the upside, technologies are offering many new ways to improve and maintain health. Some interesting examples include smart nappies that are now going into production, keeping our digital child comfortable and notifying the parent's smartphone when there's something that needs to be changed. We've got smart bottles that can monitor a child's nutritional intake, and we even have smart dummies which can remotely monitor a child's temperature, to be read on a parent's phone. There's a whole plethora of these child-related digital technologies, health-related technologies that are now coming onto the market. Many are from start-ups which are making big claims but have not always got to real-world implementation and production. Yet many of these innovations will arrive over the next 20 to 30 years.

I also think that the digital child born today will over the next 10 to 20 years be accompanied by a personal health avatar. There is a debate among health professionals about whether you call this a personal health avatar or a digital twin. There seems to be consensus that what we can do with existing health data will not really provide the sort of detail that would make this a true digital twin. So, a personal health avatar is what we're calling it, at the moment. It is a something, like an app, that will accom-

pany the child and will bring together its records from a whole range of different sources, and basically simulate it as a human being and simulate its responses to health-related interventions. We already have the beginning of this, in our electronic, closely controlled, My Health Record. But over the next 10 to 20 years, the amount of data that are held in those records from a whole range of sources will become much richer. Zoran mentioned genomics information. We'll also be bringing in sensor information, social media information, information from wearables and sensors, and information from all components of the health system that currently are quite difficult to integrate across sectors.

Having such a digital avatar will enable personalised treatments to be developed for the child, but it will also allow treatments to be tested or simulated on the child before they're actually put into practice, potentially resulting in much better targeting of expensive or potentially harmful therapies and avoidance of safety issues with therapies. I'm quite confident that we will have something resembling that by 2030. However, again, others have talked about some of the potential dark sides. Zoran mentioned the digital divide.

There is a current campaign in New Zealand called "leave no one behind", which is trying to address digital exclusion. I think we in Australia also need to take this sort of initiative. Not only is there a divide in whether or not people can access devices, have the money to pay for devices, or have the knowledge and skills to use them and to interact with them, but there's also the potential for algorithmic bias in AI technologies. A prime example of the potential for this is that around half of the cur-

rent published scientific papers, which apply machine learning to hospital-based electronic medical records, actually use a single dataset which comes from a hospital in Boston in the USA. A very large number of AI algorithms have been built using this one dataset, and it comes from a population that looks nothing like the Australian population. Obviously it does not include any Indigenous Australians or many other population groups that we have here. There's a really urgent need for our own Australian electronic medical record data to be made much more available for research and development of AI algorithms. If we don't produce our own health database, we potentially will inadvertently implement things that may result in increasing inequalities and potential harm to unsurveyed members of the population. Any algorithm is only as good as the data that it has been fed; it cannot predict the future for, or adapt to, individuals who were not present in the training data.

To end on a slightly positive note, there is potential for digital health technologies to help address inequalities. There is an example, called Kushi Baby, that came originally from Yale, but is now implemented in Rajasthan, India. This is basically a near-field communication tag, which is used to store compressed vaccine records in an offline and battery-free format. Children are taking their health records with them in lovely little tags around their necks.

These sorts of technologies can allow countries that have been slow to adopt digital systems, who are less wealthy, to leapfrog over the paper-based records and complex electronic medical records that we now have in Australia, to far more personally

controlled, low-cost and effective devices like these.

To sum up, there will be many challenges for our child, not least those relating to climate change and environmental degradation. There will also be a lot of very exciting developments emerging with technology and in particular, AI. But we need to ask a big question in 2030 and in 2050: Who's been left behind?

Discussion

Prof Oppermann: The first audience question is for Zoran: Is there a risk that the likely use of historical data is going to make the outcome inevitable by shaping decisions which lead to a self-fulfilling prophecy?

ZB: It's really important that the government health agencies have a human judgment and self-disciplined sense of the whole decision-making process, which is why it is important to look for changes in workforce development and health.

Prof Oppermann: If we wind forward and think about the richness of diagnostic, genetic, behavioural and epigenetic data, how do you envisage the interplay between all of these different sorts of data about us and about our health and our environment? And what about self-sovereign identity in e-health?

LJ: It's a real double-edged sword, isn't it? The idea that we should control our data and consent to all the uses of our data. But then, if we don't have representative data about whole populations that include all members of that population, you could end up with biased algorithms. So how does one balance that? As a researcher who works with data, I believe that we don't make enough use of the data we already have. I

believe there are increasing ways that we can safeguard and protect privacy. But there's always going to be a risk of a privacy breach if large-scale individual records are being used even in aggregated ways. So I guess it's a risk management framework that we have to work with. I do strongly believe that people should have a degree of control over the use of their data and that we probably need far more dynamic ways of people being able to provide consent for specific uses of their data than they currently have.

I also think we're going to be in trouble unless we make our data more openly accessible for research and development of algorithms. One interesting area is use of public sector data by the private sector and who should share in the benefits from that. An earlier speaker mentioned the potential dollar value of data. I feel very strongly that if data are being generated by services in the public sector, any commercial returns on that data need to fund returns to the public, both in terms of potential health benefits, but also financial benefits.

Prof Oppermann: Zoran, when do you think we will have sufficient control systems, processes in place so that we're not having this conversation about appropriate use of data anymore? When we will be more focused more on the use of the data, rather than concerns around protections of data.

ZB: I see some options and opportunities with blockchain technology that could help with the present digital process. I think some governance processes are maturing and becoming more and more seamless and more permissive, but in a safer way, which would be a positive way forward. What's still missing? In the Senate context, this needs more engagement with the community, and I'm all for an honest conversation about the pros and cons; what's okay and what's not. How can we, together with the community, come up with the right balance and discover the future together? I think that's the testament, and it needs more work.

Prof Oppermann: Louisa, in 2050, what is no longer an issue? What are we spending our time discussing in the world of health?

LJ: I hope that data privacy is no longer an issue and that we will have developed the safeguards needed so that people feel comfortable with how their data are being used. What are we going to be discussing? Probably, what is the role of the health professional going forward? They're going to be working in a very, very different health system, with much more done in automated ways.

Prof Oppermann: Zoran, the same questions to you: What is no longer an issue? What are we really focused on?

ZB: I hope that this whole issue around privacy and confidentiality will be overcome.

