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Report from a Stakeholder Workshop

Digital Health in Australia: What works, and future directions

UNIVERSITY OF CANBERRA | HEALTH RESEARCH INSTITUTE | NEWS & MEDIA RESEARCH CENTRE

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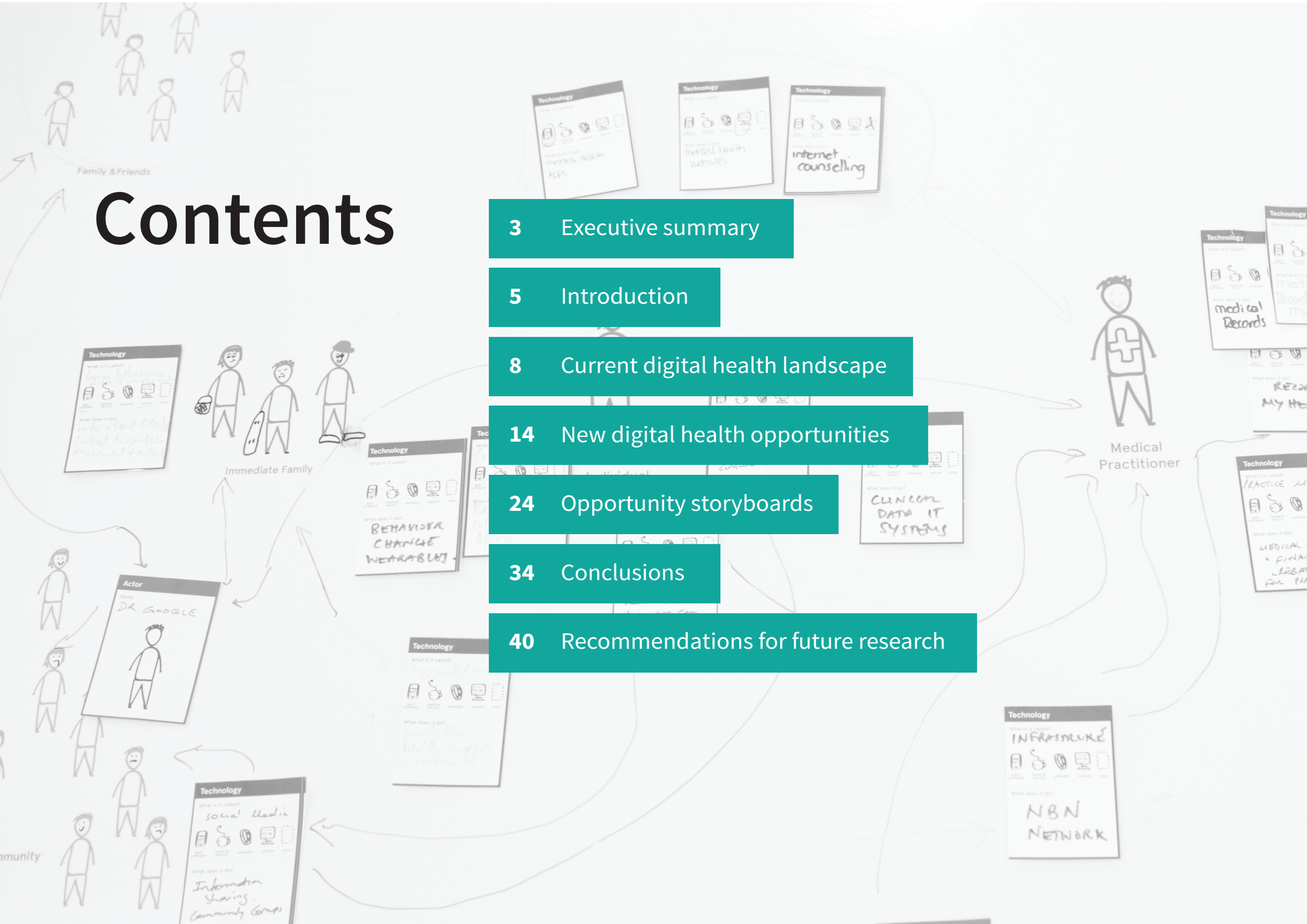
Executive summary

Digital health technologies have attracted much attention in the popular media and medical, health services and public health literature. While digital health technologies hold potential for improving health and medical care, there are many issues to be resolved in facilitating their provision and efficacy, and managing the sensitive health information generated from their use.

Eliciting the views and experiences of the diverse constituents in the digital health ecosystem is important. As a step towards this objective, a digital health stakeholder workshop was held in Canberra, Australia, in June 2017. As part of a living lab approach using social design methods, the workshop participants engaged in hands-on activities addressing two key questions:

1) What is currently working and not working in digital health? and;

2) Where should digital health go in the future?

The workshop outcomes demonstrated the complex relations between individual consumers and healthcare providers, social groups, organisations and the digital health technologies that are currently used in Australia. The activities and ensuing discussions within the group generated the following key insights:

- Digital health technologies offer valuable ways for health consumers, healthcare providers, community groups and health industries to create and share information about health, medicine and healthcare. These technologies can effectively provide information, support and social networks for health consumers and improve healthcare access and delivery.

- Ethical and social issues need to be considered, including whether some individuals or social groups might be stigmatised by a focus on self-management of health.

- Some consumer groups and providers are currently excluded from full participation in the digital health ecosystem, due to lack of necessary infrastructure, social disadvantage or economic factors, their health status, lack of skills or interest, or because their needs are not adequately recognised.

- Health data are potentially valuable to all stakeholders, albeit in different ways.

- Establishing a system for the effective collection, protection and sharing of health data is highly complex. While Australia is leading the way in some respects in terms of developing the legislation, digital infrastructure and systems required, there is much that still to be accomplished.

- Mechanisms for facilitating further consultation between the various stakeholders involved in

Executive summary

digital health, including consumers and carers, need to be established, so that their needs and interests can be incorporated into future policy development and planning.

- The rights and responsibilities of the different stakeholders involved in connected digital health need to be better identified and highlighted.

- It is important to find an effective and ethical way to connect health data with all involved stakeholders. Siloed data needs to be better shared across sectors and parties.

- At the same time, personal data privacy and security need protection. Health consumers need to be able to invest their trust in government and other stakeholders to protect their personal data.

Introduction

In June 2017, 25 people took part in a half-day stakeholder workshop on digital health.

The workshop was convened by Professor Deborah Lupton and run in conjunction with consultants from the design research company Paper Giant. It was organised as the inaugural event of the newly established Smart Technology Living Lab, based in the Faculty of Arts & Design at the University of Canberra (designsociology.wordpress.com). The workshop was also supported by the University's Health Research Institute.

The Smart Technology Living Lab

The Smart Technology Living Lab uses problem-solving and ideas generation activities related to end-users' experiences of smart technologies. We employ social and design research methods to facilitate participants from community groups, not-for-profit organisations, government and industry to work on a specific topic. Our approach is interested in the here-and-now but also the future. Our projects work to map the current landscape of smart technology use, identify problems, find solutions and imagine new ways of doing things. We are interested in discovering what smart technologies are working well for people, how they use them, and what the future might hold for further developments. We conduct participatory research on a range of smart technologies, including digital health, social media, and self-tracking devices such as apps, smartwatches and wearable technologies.

Digital Health Stakeholder Workshop Participants

The workshop participants included researchers at the University of Canberra interested in digital health and professionals who work in healthcare provision or health-related government and professional associations or community or consumer organisations. They included the following:

- Researchers from the News and Media Research Centre and the Centre for Creative and Cultural Research in the Faculty of Arts & Design and the UC Health Research Institute
- Australian Digital Health Agency
- Australian Institute of Sport
- ACT Health
- Urban Synergies planning and design consultancy
- Australian Healthcare and Hospitals Association
- Health Care Consumers Association
- Accenture business consultancy
- Centre for Culture, Ethnicity and Health
- Australian College of Midwives
- Headspace
- Australian Pharmacy Guild
- Women's Centre for Health Matters
- Ochre Health general practice service

Workshop Questions and Activities

The workshop was directed at answering two key questions:

- **What is currently working and not working in digital health?**
- **Where should digital health go in the future?**

Three hands-on activities were used to stimulate discussion and ideas relating to these key questions.
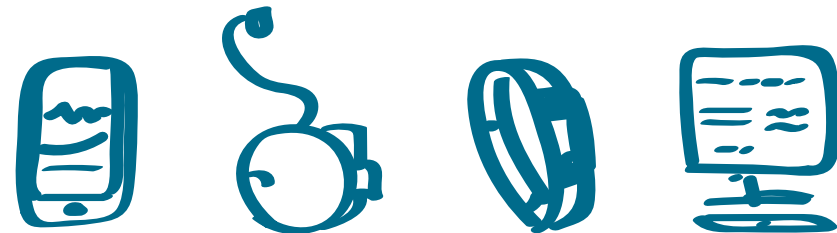
Current digital health landscape

In this activity, participants worked in groups of 5-6 people to collaboratively map the technologies and social relationships contributing to the current digital health landscape. The point of this activity was to identify shared understandings in the group of what technologies are currently available and how they are embedded in social interactions and social groups.
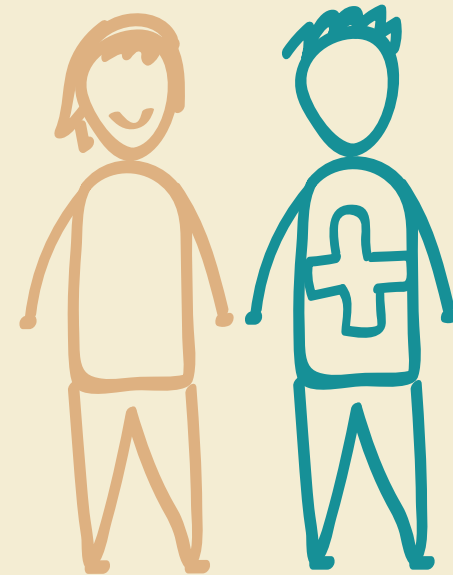
Current digital health landscape

Each group was provided with a large-scale map template showing various actors in the digital health ecosystem. These include a patient and a medical practitioner at the centre of the map, with other potentially involved groups at either side: family and friends, the medical community, the industry community and government organisations. Participants were given a set of technology cards to fill in the details of the kinds of digital technologies they wanted to place on the map, as well as actor cards to contribute additional people. The technology cards invited participants to fill in details such as what the name of the technology was, what kind of technology it was (app/software, medical device, wearable technology, website or other), and to provide a description of what it does.

The five groups each created maps with many different technologies and relationships shown. They demonstrate the complex relations between individual consumers and healthcare providers, social groups, organisations and the digital health technologies that are currently used in Australia. The technologies included across the five landscapes that were created are shown in Table 1.

Current digital health landscape

Table 1: Technologies shown on the digital health landscapes

Apps and self-monitoring wearable devices such as Fitbits and smartwatches	Payment and health insurance systems
Fitness platforms like Strava	Medical training and education software
Online search engines (e.g. Google Search)	Online portals for registering healthcare providers
Online counselling services	Clinical diagnosis
Medical implants and internal monitoring devices (e.g. pacemakers)	Prescription and decision-making software
Medical websites like WebMD	Devices to promote mobility and safety
Blogs	Messaging services
Electronic health records and patient portals	Artificial intelligence
	Medical appointment and practice management software
Online health surveys	Telehealth technologies
Health-related games	Crowdsourcing platforms for medical funding
Rehabilitation activities	Video-sharing software
	Online communities for patient or carer support
Online direct-to-consumer medical testing facilities	Online clinical terminology and healthcare identifiers services
Augmented reality technologies	'Smart' devices linked to each other as part of 'smart cities' and the Internet of Things
Social media	Big data linkage and extraction software and national digital infrastructure

Current digital health landscape

In addition to the actors or groups already included on the map as involved in the digital health landscapes, participants added medical specialists, carers, government agencies, peak bodies, legislators and policy bodies, health advocates, researchers and academics, software and device vendors and entrepreneurs, advertising agencies and non-government organisations.

When each group presented their maps to the other groups and explaining what they considered to be working or not working in contemporary digital health, the following issues were raised:

Empowered patients who are able to seek and share health information pose a challenge and possible threat to the medical profession, allied bodies and government.

The relationship between the individual and their clinicians has changed quite dramatically, because there's a lot more power to that patient and they collect a lot more data [about themselves]. (Group 1)

What works about digital is the empowerment. And that's what digital is all about. It's about empowering people, no matter what industry you're talking about. You're seeing the medical establishment potentially threatened by having consumers empowered. And I think that's the sort of challenge that digital is going to have, because that is going to play out over the coming years – this tension between what's working on one side about empowering people. (Group 3)

The digital technology industry is able to work more quickly and take more risks than government agencies in developing and promoting their products.

The business community is very good at putting things out there – at trying new things and seeing what the community picks up on and what they don't, and what sells and what doesn't. Government haven't been quite so quick with that. (Group 5)

[Commercial technology developers] are pushing accountability, responsibility and risk onto the consumer by accepting terms and conditions and absolving themselves of liability, whereas government doesn't have that luxury to push responsibility as much onto medical practitioners as well as the individual. (Group 2)
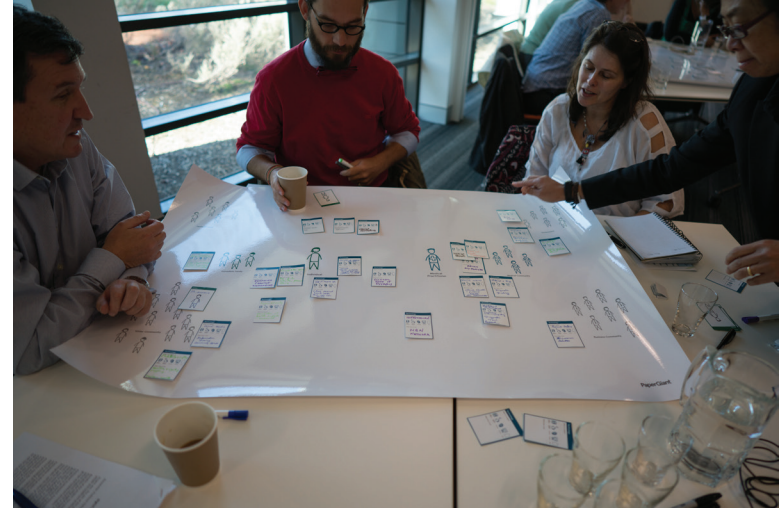
Current digital health landscape

Some elements of the Australian health digital data collection and sharing system and infrastructure are working well.

> *What's working is there's some established mechanisms, like your interaction between community pharmacies and government on a transactional basis. So PBS [Pharmaceutical Benefits Scheme] online and those sorts of things are working. (Group 4)*

> *Australia has got off to a phenomenal beginning to get us to a point where we will just go in leaps and bounds beyond what other countries can do internationally, because we've established critical foundational pieces like the Healthcare Identifiers Service. The legislation that supports My Health Record is world-leading. We are well beyond a lot of other countries with respect to that. (Group 2)*

The accuracy and efficiency of collecting and sharing health and medical data across the health sector and with relevant actors such government agencies, the digital technology industry and health researchers needs much more work.

> *Particularly with things like My Health Record and a lot of the other apps that people are having, is that they are only as good and as valuable as the data that's being entered into it. So if people are having these fantastic My Health Records and it collects a lot of their medical data, it's not necessarily collecting a lot of information about the specialist that they went and saw. So unless the specialist is writing a discharge summary or transfer summary, and uploading, and then their GP's collecting it, and checking it out, reading it, and the patient's having a look at it and making sure it is accurate, then it's not necessarily being shifted from one person to another. Unless the hospital is uploading their discharge summary, and then the GP is collecting that from the device or the app in a timely fashion, then it's not necessarily being used or valuable. (Group 1)*

> *That whole area of data access and interoperability and data linkage is holding us back as a country. You know, there are parts of Europe where they've got much better access to their data and use their data much more intelligently. We're like 20, 50 years behind, and we obviously can't access that data for research.*

> *And it's frustrating that there's so much data that's collected administratively and routinely, but they're all there siloed into different areas, and we can't access it at the levels of aggregation that we would want. (Group 4)*

Better solutions need to be devised to find ways for all relevant stakeholders to be able to input data into the electronic medical record system.

> *There are a lot of allied healthcare practitioners and specialists, and particularly, the aged care sector, where the software is actually physically not present. So in order for them to connect with the national digital infrastructure, it's obviously critically important that we can think of other ways that they can do that, through technology that might be in their pockets. Everyone's carrying a pretty sophisticated piece of kit in their pockets. So we need to be cleverer about the way we can enable the community, consumers, but also the clinical community, who don't necessarily have the power to invest in the technology that they see might be needed to get connected to things like the My Health Record system. We need to offer lots of options for people to get on. (Group 2)*

Current digital health landscape

The government needs to work with industry, peak bodies and other agencies in developing solutions.

The peak bodies are important to work with the key government agencies and to work with the business community – the sector that's actually developing these apps and technologies – and how they work within the system, within the framework, standards and with compliance and privacy and all that. (Group 4)

Health consumers should be able to share their health data with healthcare providers, but also with chosen family members or carers. Consumers also need to be able to access the health data collected about them by their healthcare providers.

If, for example, you're looking at the individual, then the most important relationships would be with their immediate family and friends, and then their medical practitioner to share the data each way. (Group 5)

Relationships that are probably most important are about having that caring support group of peers and family. So that for individuals who are perhaps more vulnerable, having those people around them who know the information that's happening about them, and having access to some of that data and being able to share it … Patients are not necessarily having that capacity to feed the information back to their practitioners. And they're also having that change in power about the access to the medical information that the practitioner has that they don't necessarily have access to. (Group 1)

Health consumers are becoming concerned about the privacy and security of their personal data and want the government to protect their data.

People are more willing to trust – or are more ignorant of – sharing their data with the business community through apps and websites and stuff like that. But they seem to be more aware of the potential security risks of sharing their data with governments – say, with e-health records and things like that. And there's a trust issue there that's quite big. But it's interesting that they are more willing to share all that info with the business community. (Group 5)
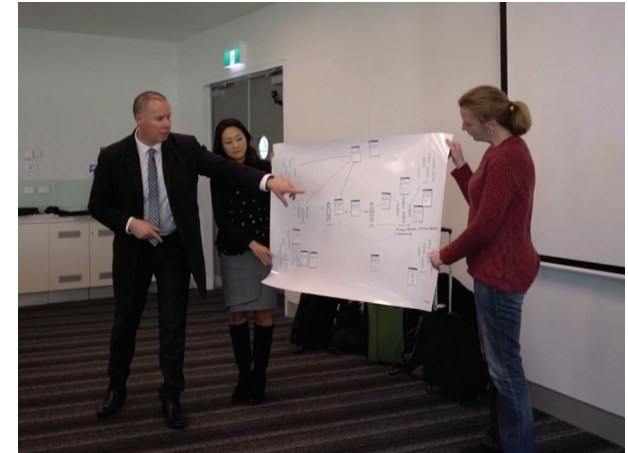
New digital health opportunities

In this activity, participants were given 'opportunity' cards that invited them to identify new digital technologies for future use. The cards included questions that asked participants to fill in details about the name of this new technology, the time-frame it was likely to take for this technology to emerge (five, ten or 20 years), what type of technology it was, what it would be used for, what it would do and what it might look like.

New digital health opportunities

As shown in Table 2, 37 digital health opportunities were created. The participants presented ideas for a diverse range of new digital health opportunities they imagined could contribute to improving healthcare into the future. The ideas can be clustered around three major types of technologies:

- Health services-oriented data integration

- Medical testing, diagnosis and treatment

- Consumer-oriented health and medical information

The importance of making health data systems easy to operate, including the data entry and sharing functions was again prominent in these ideas for new digital health technologies. Several participants imagined current systems like My Health Record working better than they do currently. The 'Linked Health Data' proposal included the following features:

For the research community and population health. Software that links health data across healthcare and social services such as the National Disability Insurance Scheme and

aged care. Provides greater information for all to provide appropriate healthcare to connect communities. It will improve care provision and data integration and decrease silos.

Others proposed new technologies that could be developed to facilitate entering health data. One example is the 'Vocal Documentation and Transmittal of Health Records' technology. This was described as:

Software for clinicians. It looks like a microphone linked to CIS. Codes using spoken language (natural language processing) and electronically stores via My Health Record. Eliminates need for manual entry of electronic health records (data).

Some people created ideas for new devices that could contribute to preventive health and diagnosis as well as treatment efforts. These included a better sleep apnoea machine, a 'smart' toilet that could use human waste to test for disease, various types of monitoring devices that could be worn on or implanted in the body, and robots for offering healthcare and diagnostics. The 'Balance Tester', for example, was described as:
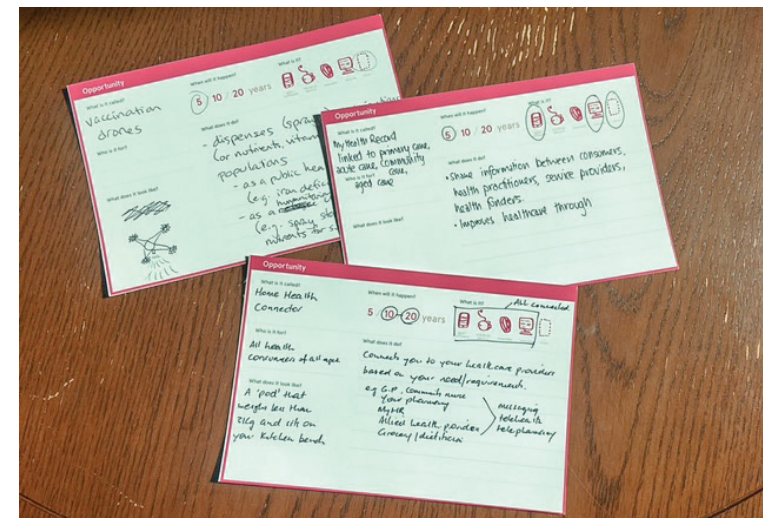
New digital health opportunities

Software for elderly, people after concussion. Includes smart home technologies and a smartphone app. Unobtrusively measures balance and gait parameters as people walk down the corridor (at home or in aged care facility) to access small changes over time that indicate an increased likelihood of a fall occurring.

More speculative ideas included the 'Vaccination Drones':

The drone dispenses (sprays) vaccinations (or nutrients, vitamins) on populations as a public health measure (e.g. iron deficiency) and as a humanitarian tool (e.g. spray starving people with nutrients for survival).

a 'Baby Transporter':

Teleports baby out of pregnant woman safely, so she can give birth without pain (like in Star Trek).

and 'Nanites':

For consumers. A medical device using nano-scale particles to facilitate the visibility of mechanisms

(e.g. how cancer works), provides invasive procedures without bad side effects and ongoing monitoring and modulation of bodily functions.

Other people imagined devices that facilitated health consumers to have better access to information. These included platforms for consumers to rank and rate providers or view details relating to their competence. One example is the 'Health Professional Rater':

Website for consumers to rate/grade health professionals and health facilities (like My Hospital but with better data thus more user friendly). Like Trip Advisor. It will improve consumer awareness and choice and patient outcomes and drive continuous healthcare improvement.

There were also several suggestions for devices that consumers could use to generate or access health information about themselves. The 'Home Health Connector' was a device for this purpose:

For all health consumers. A 'pod' that weighs less than 3kg and sits on your kitchen bench. Connects you to your healthcare providers based on your need/requirements (e.g. GP, community nurse,

New digital health opportunities

your pharmacy, My Health Record, allied health provider, grocery store, dietician). A messaging system that connects all devices and software used by the consumer.

The 'Digital Clone' was even more imaginative, described as:

A virtual reality device or software for patients. Stores all data generated by an individual – similar to the human brain.

Here again, the ideas presented in this future-facing activity demonstrated the value the participants placed on developing a health digital data system that is interoperable and allows access from all relevant parties, including health consumers. Participants could imagine several possibilities for digital technologies to improve health and medical diagnosis and care and prevent illness and disease. They developed ideas for facilitating access by consumers to their own personal health data but also to information about health services and providers, so that they could make informed decisions.

New digital health opportunities

Table 2: New digital health opportunities created by participants

Name and type of new technology	What it does	Time-frame (years)
Health Services-Oriented Data Integration		
Linked Health Data	For the research community and population health. Software that links health data across healthcare and social services such as the National Disability Insurance Scheme and aged care. Provides greater information for all to provide appropriate healthcare to connect communities. It will improve care provision and data integration and decrease silos.	5
My Health Record	Medical data software linked to primary care, acute care, community care, aged care. Used to share information between consumers, health practitioners, service providers, health funders. Improves healthcare.	5
National Digital Child Health Record (linked to My Health Record)	Unified and digitally accessible child health record.	5
Open API Interoperability Framework	For everyone. It connects all the technology in a way like Uber does with Google Maps with PayPal with calendar apps.	5
Vocal Documentation and Transmittal of Health Records	Software for clinicians. It looks like a microphone linked to CIS. Codes using spoken language (natural language processing) and electronically stores via My Health Record. Eliminates need for manual entry of electronic health records (data).	10
Precision Medicine Digital Systems	Software to stratify healthcare – combines genomic and phenotypic information and individualises care.	20
Medical Testing, Diagnosis and Treatment		
Balance Tester	Software for elderly, people after concussion. Includes smart home technologies and a smartphone app. Unobtrusively measures balance and gait parameters as people walk down the corridor (at home or in aged care facility) to access small changes over time that indicate an increased likelihood of a fall occurring.	5
Sleep Apnoea Device	Medical device for sleep apnoea suffers (and their partners). It does effectively what existing machines do but because of advances in technology, they will be less restrictive and terrifying.	5

New digital health opportunities

Table 2: New digital health opportunities created by participants

Vaccination Drones	The drone dispenses (sprays) vaccinations (or nutrients, vitamins) on populations as a public health measure (e.g. iron deficiency) and as a humanitarian tool (e.g. spray starving people with nutrients for survival).	5
Dr Toilet	A smart toilet for everyone. It provides diagnostic data, at the individual or population level. Tracks 'samples' [human waste] and identifies indicators of conditions: i.e. bowel cancer, pregnancy, medication use/overuse etc. Feedback to users or government.	5
HD Ultrasound Scan	An app or wearable for 24/7 surveillance of baby in utero. Parents can see (and healthcare providers can monitor) baby's health from conception to birth.	10-20
Wearable Diabetes Monitoring Device	For patients with diabetes. Generates data for blood glucose monitoring: e.g. contact lens.	5
Educated Lifestyle Assessment	For medical practitioners. Software and devices combine to provide information about people's everyday life routines and assessment of their environment. Helps to assess state of health holistically (social determinants). Improves advice system for preventive health	5-10
Apple Medical Service	For anybody using Apple technology: e.g. phones, other wearables, sensors and implants. Apple will establish a franchise of medical professionals and people using Apple technologies have their health data collected and uploaded in real-time to Apple. Trends in their data are monitored, and specific changes generate alerts or acute changes are flagged for immediate action.	20
Life Length Predicator	Software to integrate information – genetic diagnostic, treatment and lifestyle – to predict life expectancy. By changing behaviours and community engagement, individuals can extend their life expectancy if they choose.	10
Personal (DNA) Medicine Proteomics Predictive	Allows self-diagnosis, prediction and prescription using DNA analysis and dynamic constant self-quantification.	10
Proactive Predictive Information	Used for decision-making about individual health. Not only provides information on likely outcomes but tracks and enables change using precision health. Consumer empowerment: removes uncertainty, opens up bounded rationality.	5-10
Nanites	For consumers. A medical device using nano-scale particles to facilitate the visibility of mechanisms (e.g. how cancer works), provides invasive procedures without bad side effects and ongoing monitoring and modulation of bodily functions.	20

New digital health opportunities

Table 2: New digital health opportunities created by participants

Enhancing Implants for Patients	Medical implant devices for people with disabilities/chronic conditions. They solve conditions such as neurological vision/hearing problems, epilepsy, Parkinson's. They can relieve mental health symptoms: e.g. by triggering serotonin or inhibiting cortisol. They prompt healthy behaviours: e.g. exercise, controlling over-eating, sleep to prevent relapse.	5-10
Enhancing Implants for People in Good Health	Implants that enhance ability to perform physical or neurological tasks: e.g. triggering hormones in brain, forcing muscle activity etc.	10-20
Service Robots	Humanoid robots that provide services around the home, including detecting health indicators.	20
Modelling for Community Sports	Software for sports players and coaches. Helps them to work out ways to improve gameplay/not break rules without injuring players or incurring penalties in the game.	5
Baby Transporter	Teleports baby out of pregnant woman safely, so she can give birth without pain (like in Star Trek).	10
Energy Scanner	Wearable device that measures energy intake for weight loss or gain. Measures energy in a meal or food item by scanning it. Can also calculate nutrients and other nutritional information.	10-20
Consumer-Oriented Health and Medical Information		
Health Professional Rater	Website for consumers to rate/grade health professionals and health facilities (like My Hospital but with better data thus more user friendly). Like Trip Advisor. It will improve consumer awareness and choice and patient outcomes and drive continuous healthcare improvement.	5
Personal Life Data Communicator	A wearable device that looks like something familiar – phone, watch, ear-piece, glasses, jewellery etc. It collects personal health data for logs stored in the cloud. Sends alert to doctor/family if risk to life: e.g. heart attack. Can log all health data so individual can choose to easily share with medical professionals or for health insurance refunds, pharmaceutical benefit scheme.	5
Care Navigator	App and website for consumers and carers. It will support consumers to make better decisions about access to care and treatment. It will provide an antidote to our complicated, fragmented systems across the public and private sector. Tracks our interactions with all health services, sends reminders, helps us maintain motivation and gives us confidence to act. Links our information from different providers. Tracks our medical observations and results. Like a GP on our desktop.	10

New digital health opportunities

Table 2: New digital health opportunities created by participants		
Safer Care	Website for consumers and carers. Provides data on clinical competence of registered health professionals: e.g. how many times they have performed the surgery, infection rates, complication rates and return to theatre, unplanned readmission etc, so consumers and carers can make more informed decisions about who they see and let operate on them.	20
Open Notes	Software for patients to provide them access to their health info in their clinicians' records. It will empower patients and improve their understanding and adherence to treatments and potentially allow co-creation of clinical records between people and their care providers.	5
Push Health Prompts	Provides notifications to about their health and care to patients from mobile apps supported by My Health Record and clinical information systems.	5-10
Insights Through Data	A range of devices and software that can deliver insights through intuitive interfaces that lead to new behaviours related to health. E.g. reduces obesity or alcohol consumption.	5
Personal Blockchain	Used by consumers – allows them to control access to their own data, which is distributed across multiple systems. Controlled via your smartphone. Empowered individuals. As records created across the ecosystem an entry needs to be made to the personal blockchain. You then control who gets to see what.	10
Health Data Integrator	Capacity for IT systems to integrate data from a range of sources for monitoring health status. Health and health outcomes for the end user.	5
Integrate You	For consumers and medical professionals. It places all your medical stuff in one place so that it can be accessed and you don't have to continue to share with everyone. Can only access areas specific to the condition: e.g. mental health records.	10
Digital Clone	A virtual reality device or software for patients. Stores all data generated by an individual – similar to the human brain.	10
Home Health Connector	For all health consumers. A 'pod' that weighs less than 3kg and sits on your kitchen bench. Connects you to your healthcare providers based on your need/requirements (e.g. GP, community nurse, your pharmacy, My Health Record, allied health provider, grocery store, dietician). A messaging system that connects all devices and software used by the consumer.	10-20
Databot	A small device or software for patients. Fills in the gaps of data silos. Uses predictive technology based on partial data. Collects all conscious and unconscious data and links it to a larger system.	10

Opportunity storyboards

In this final activity, participants were given storyboard templates. They were asked to choose one of the new opportunities identified by the group, and work in pairs to create a narrative in which this technology was used. Five boxes were included in the storyboard, with the headings 'Set the scene', 'What happens?', 'Then what happens?', 'What happens next?' and 'What happens after?'.

Opportunity storyboards

The participants were asked to fill the boxes with simple drawings and provide some text below each box explaining what was happening. The purpose of this activity was to encourage participants to further consider how the new technologies they had invented would work in the context of end-users' everyday lives. When they were completed, the storyboards were placed on the wall. As they helped themselves to the lunch that was provided at this end-part of the workshop, participants were invited to move around the room viewing and discussing the other storyboards.

Eleven storyboards were created by the group. They are as follows:

Home Health Connector

"Mrs Smith, aged 75, with co-morbidities, has come to the end of her prescription and repeats of medication and needs to see her GP for a new script. She is alerted by the device. Mrs Smith uses the device to book telehealth consultation with GP. GP confirms appointment for 3pm and calls Mrs Smith and conducts telehealth review of Mrs Smith's conditions. GP writes a new script. Script is sent to Mrs Smith's pharmacy where script is verified and filled at 4pm. Pharmacist finds issue with potential drug interaction on one of Mrs Smith's OTC [over-the-counter] meds. Contacts GP to resolve. GP and pharmacist resolve issue and a new script is written and re-sent to the pharmacy. Pharmacy delivers med to Mrs Smith's home and refills dose administration and within device and also refills any other authorised repeat medications. All activity is then recorded and reconciled on Mrs Smith's My Health Record. All other notifications for medication delivery are re-set. Confirmation message sent to Mrs Smith's GP when the device has completed the tasks."

Supersize Me

The text in this storyboard was: "Born/pre-birth. Blood drawn. Genome sequenced and shared, stored. Predisposition, risk profile established. Get sick. Genome used (shared securely) for pharmacogenomic prescribing." [Problems are:] "Personalised pharmaceuticals facilitate complete decadence and hyper-indulgence. Gattaca?! Breaking the mind/body connection. White/worried/well."

Opportunity storyboards
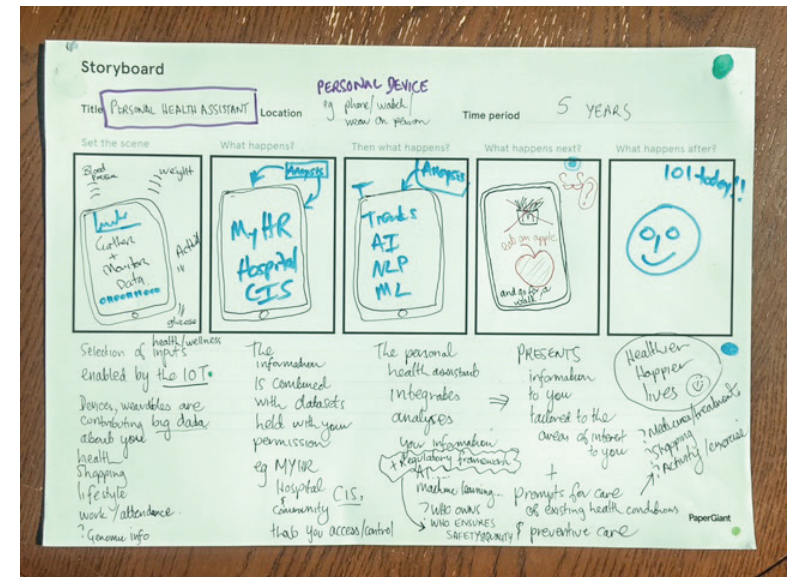
Better Social Connection and Health Via Technology

No text was supplied with this storyboard – the narrative was conveyed by graphics and accompanying dialogue. These showed an individual dealing with a bad day and wanting to talk to someone to receive emotional support. The person considers who s/he might be able to trust and feels safe to talk to, but knows that 'I get to choose what and when I share'. The person uses a smartphone to talk to peers, knowing that 'I can decide what action to take' based on their advice. The story ends with the person living 'happily ever after'.

Nanites/Nanobots

The drawings show a cancer patient injected with nanites [robots at the nano scale], that then attack the cancer and stay in the body to attack any new cancers. Questions raised in the accompanying text included: "What is the energy source for these nanites? What if the nanites go rogue or become contagious? iRobot 2.0. Who develops the technology, injects them, and talks to the individual? Who is responsible for the maintenance/fixes? Who funds/pays for this expensive technology? How do we decide which cancers get treated by nanites? If you engage in risk behaviour, do you get excluded from access to this treatment?".

Predict My Health

This storyboard included a diagram showing an end-suer with implants and wearable device, with data emanating from the devices, integrated and then returned to the user, as well as shared with healthcare providers. The text gave the following details: "Smart use of data. Connecting siloed health providers. Effective feedback on health issues. Wearables/implants/devices (smart) send data to central hub. Using predictive technology, they are monitored, analysed and distributed. Alerts and warning are delivered to the individual and health providers, [leading to] recommendations and appropriate action. Risks [include] security, privacy, misuse, non-use, excluded users, affordability. [Benefits include] preventive measures and healthy lifestyle and cost savings".

Opportunity storyboards
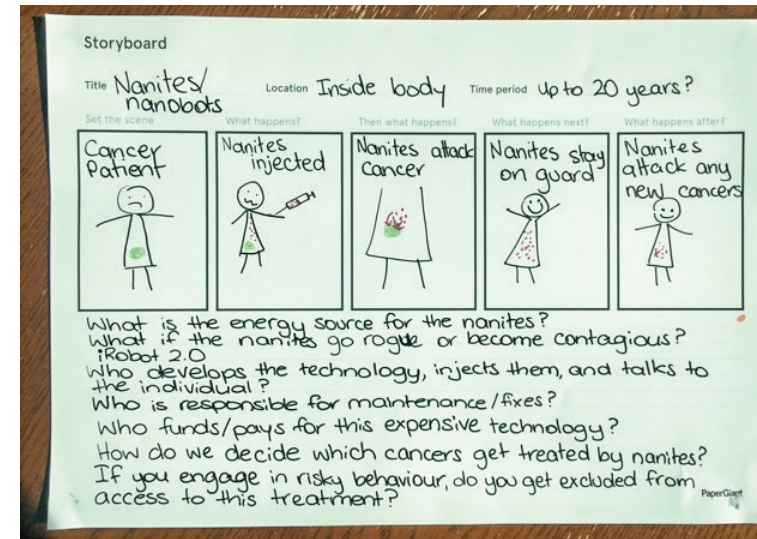
Too Much Information

This storyboard showed a person whose head hurts. S/he uses a smartphone to conduct a "full body scan". "The report from the phone says: 30% risk of stroke, 50% chance of brain tumour, 75% chance of Alzheimer's in the future, 25% chance of diabetes, 60% chance of cancer, 50% chance of brain damage, 10% chance of headache." This person decides that "There doesn't seem much point in living," and commits suicide by leaping off a bridge.

Dr Toilet

In this storyboard, the 'smart' toilet idea is used. The graphics show a man with a stomach ache. The man visits the toilet and receives a message on his smartphone: "Go see your doctor soon. Love, Dr Toilet." He visits his GP, who already has received his test results and is ready to discuss them with the man.
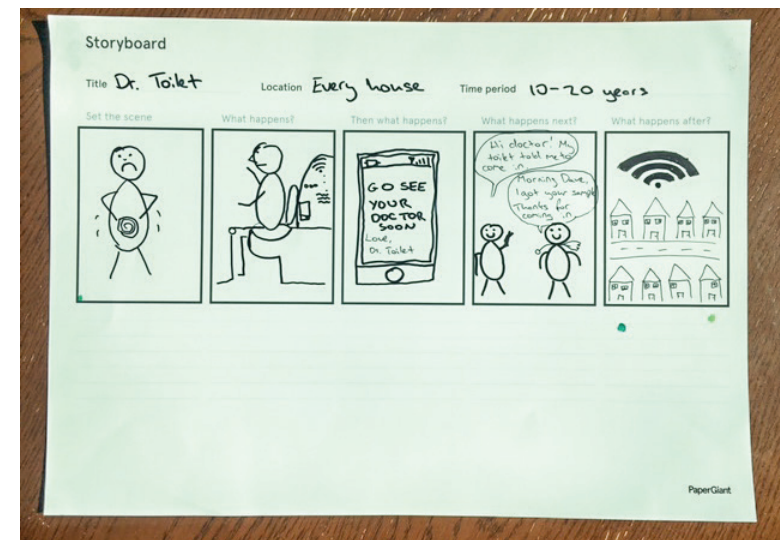
Companion Robots

The idea of the companion robot is included in a narrative. The robot is shown interacting with an elderly person in the home, performing cleaning duties and sending health data to other parties.

A medical problem is detected and the person is taken by ambulance to hospital. Benefits identified are a "focus on elderly, keep at home for as long as possible, quality of life, social interactions, sensing health states – raising alarm, providing services".

Personal Health Assistant

This storyboard details how a personal health-monitoring device used on a smartphone or smartwatch can be used. The images show the device monitoring the user's blood pressure, weight, physical activities and blood glucose levels, sending the data to My Health Record and hospital CIS [Clinical Information System]. The user receives notifications about the preventive actions they should be taking and lives to 101 years. The accompanying text provides further details: "Selection of health/wellness inputs enabled by the IoT [Internet of Things]. Devices, wearables are contributing big data about your health, shopping, lifestyle, work/attendance, genomic info. The information is combined with datasets held with your permission: e.g. My Health Record, hospital CIS and community that you access/control. The personal health assistant integrates and analyses your information – AI, machine learning. Presents

information to you tailored to the areas of interest to you and prompts for care of existing health conditions and preventive care. Medicines/treatment, shopping, activity/exercise. Healthier, happier lives. Regulatory framework – who owns [the data], who ensures safety and quality?"

Allocation of Resources in a Digitised World

In this storyboard, issues of "information equity" are raised. A person is shown "challenging the norm" [wearing boxing gloves ready to strike a punching bag labelled "Norms"] and society is shown as being divided into "the healthy and unhealthy people". This leads to an "ethical debate" in which questions are raised relating to "fair and cost-effective allocation of resources".

Monitoring Pregnancy

A digital device for monitoring pregnancy is shown in this storyboard. The text explains: "Women at home, universal extension of what is already happening – monitoring and surveillance. Gets rapid support and early intervention from midwife. Becomes pre-

occupied with machine rather than with baby. Anxiety/stress, hypervigilance. Medicalised, technologized, disconnected from own body."

The narratives developed by the participants again drew attention to both the potential benefits offered by digital health and the harms and risks that can be involved. The benefits identified in these stories included opportunities to deal with mental distress by receiving support from peers, having individualised medical assessments conducted, filling prescriptions more easily, curing cancer and receiving information to assist preventive health efforts and to live to a happy and healthy old age. However, some of the stories raised questions of whether too much information about their health delivered to consumers can make them complacent – or conversely, demoralise or depress them, or divert attention from their own knowledge of their bodies. Issues of the costs of offering the technologies, their maintenance, which conditions might be appropriate to treat with them, who might be excluded from access to new technologies or which social groups might be privileged over others were included in some narratives.
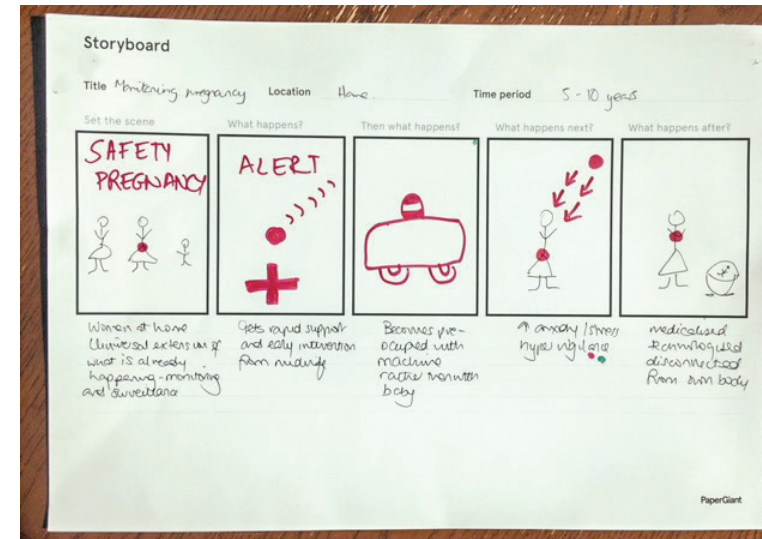
Conclusions

The digital health stakeholder workshop provided an opportunity for a diverse range of stakeholders interested in digital health to come together and co-create ideas about what is and is not working in current digital health and where the future lies. Representatives from health consumer, health-care provider, government, industry and research groups shared their knowledge and experiences.

Conclusions

The activities and ensuing discussions within the group generated the following key insights:

- Digital health technologies offer valuable ways for health consumers, healthcare providers, community groups and health industries to create and share information about health, medicine and healthcare. These technologies can effectively provide information, support and social networks for health consumers and improve healthcare access and delivery.

- Ethical and social issues need to be considered, including whether some individuals or social groups might be stigmatised by a focus on self-management of health.

- Some consumer groups and providers are currently excluded from full participation in the digital health ecosystem, due to lack of necessary infrastructure, social disadvantage or economic factors, their health status, lack of skills or interest, or because their needs are not adequately recognised.

- Health data are potentially valuable to all stakeholders, albeit in different ways.

- Establishing a system for the effective collection, protection and sharing of health data is highly complex. While Australia is leading the way in some respects in terms of developing the legislation, digital infrastructure and systems required, there is much that still to be accomplished.

- Mechanisms for facilitating further consultation between the various stakeholders involved in digital health, including consumers and carers, need to be established, so that their needs and interests can be incorporated into future policy development and planning.

- The rights and responsibilities of the different stakeholders involved in connected digital health need to be better identified and highlighted.

- It is important to find an effective and ethical way to connect health data with all involved stakeholders. Siloed data needs to be better shared across sectors and parties.

- At the same time, personal data privacy and security need protection. Health consumers need to be able to invest their trust in government and other stakeholders to protect their personal data.

The group focused for the large part on issues relating to diagnosis, testing and medical care technologies, medical and self-monitoring apps and devices, electronic health records and the digital data all these technologies generate. How online discussion forums, websites and social media (e.g. Facebook, Twitter, Instagram and YouTube) provide opportunities for consumers and other stakeholders to create and share health information and health-related experiences received far less attention. There was also very little specific mention or discussion of the digital health needs of unpaid carers and marginalised groups such as people who identify as LGBQTI or as indigenous Australians, or those from culturally and ethnically diverse communities.

Recommendations for future research

Recommendations for future research

- What are the socioeconomic determinants of digital health use in Australia, for consumers, healthcare providers and other stakeholders?

- What value do different stakeholder groups attribute to health data and how do they use these data? What are the similarities and differences between groups? How can different needs and values be balanced across the digital health ecosystem?

- What is the role of online discussion forums, websites and social media in creating and sharing health information and health experiences for stakeholders as part of the broader digital health ecosystem?

- What issues are most important to consumers when they are considering signing up to My Health Record? What are the facilitators and barriers they experience?

- What are the needs of unpaid carers and marginalised groups such as people who identify as LGBQTI or as indigenous Australians, or those from culturally and ethnically diverse communities?

- How can health and medical data generated across the health system, be more effectively and ethically collected, stored and shared, ensuring their validity and usability?

- Who should be given access to consumers' personal health data, and how will this be facilitated?

- How can the security of personal health data and consumers' privacy be adequately protected?