Going Digital

to deliver a healthier Australia

A health policy report
June 2018

CHF Consumers Health Forum OF Australia

The George Institute for Global Health

About the roundtable and this report

On 28 March 2018, The George Institute for Global Health and the Consumers Health Forum of Australia, with the support of the Australian Digital Health Agency (ADHA), convened a policy roundtable with key stakeholders across the health sector. The workshop was the first in a 2018-19 roundtable series, co-hosted by The George Institute and the Consumers Health Forum of Australia, #Consumers Shaping Health Thought Leadership Roundtable series.

In using the term 'consumer' we mean people who use health services, as well as their family and carers. This includes people who have used a health service in the past or who could potentially use a service in the future.

Attendees included consumer advocates, health care providers, clinicians, academics, industry, government and policy experts from across Australia. The purpose of the roundtable was to formulate independent recommendations on the implementation of Australia's National Digital Health Strategy: Safe, Seamless and Secure. There are seven priority areas in the Strategy:

1. Health information that is available whenever and wherever it is needed
2. Health information that can be exchanged securely
3. High-quality data with a commonly understood meaning that can be used with confidence
4. Better availability and access to prescriptions and medicines information
5. ***Digitally enabled models of care that improve accessibility, quality, safety and efficiency***
6. A workforce confidently using digital health technologies to deliver health and care
7. A thriving digital health industry delivering world-class innovation.

Roundtable participants focused on strategic priority area five, where several 'test beds' are being proposed to support digitally enabled models of care. The goals for the roundtable event were for participants to:

1. Establish principles to ensure test beds are ***co-designed*** with consumers, clinicians and other key stakeholders
2. Identify ***implementation issues*** associated with the test beds, including identifying critical ***change and adoption*** strategies, evaluation considerations and policy and governance issues
3. Formulate ***recommendations*** for test bed specifications and provide these to the ADHA as part of a roundtable report.

Small working groups in each test bed area were established on the day with clinician-consumer pairs appointed as co-leads for these groups. Structured discussion was based on Walt Disney's method for brainstorming and refining ideas.

Figure 1: Methods used in generating report recommendations

Dreamer	***Realist***	***Recommendations***
What are some future disruptors that would benefit health consumers dramatically	What conditions or building blocks must exist for your applications to become real?	What must be done, by whom, to implement these elements?
Propose 2–3 potential applications	Agree major required elements for success	Propose report recommendations

In developing recommendations for test bed activities, roundtable participants broadly identified three areas for consideration: ***(1) 'what we want' (dreamer)*** – aspirations for a digitally enable health care system; ***(2) what we have (realist)*** – current building blocks and limitations; and ***(3) 'how do we get there'*** – specific change and adoption activities needed to support these aspirations. This report summarises the discussions and recommendations arising from the event and subsequent follow-up with key stakeholders with knowledge of the strategy.

Acknowledgments

We acknowledge the lands of the First Peoples upon which this report was written and pay our respects to Elders past, present and future.

ABORIGINAL & TORRES STRAIT islander H•E•A•L•T•H

The George Institute for Global Health and the Consumers Health Forum of Australia would like to thank those who participated in the roundtable and the organisations they represented. We thank Andrew Hollo from Workwell Consulting for facilitating the roundtable. We also acknowledge the valuable contribution of the ADHA for the provision of an unrestricted grant to contribute to the running costs of the roundtable event. The recommendations presented in this report reflect the independent views of those who participated in the roundtable and are not in any way influenced or endorsed by the ADHA.

As the meeting was conducted under a version of the Chatham House rule, the views and recommendations in this report represent the outcomes of the group discussion and subsequent contributions from additional experts and advisers not able to attend the roundtable. The report does not necessarily reflect the specific views of individuals at the roundtable or the organisations they represented (some of whom may have official positions that differ from that represented in the report).

Thank you!

Leanne Wells

CEO
Consumers Health Forum of Australia

Professor David Peiris

Director, Health Systems Science
Office of the Chief Scientist
The George Institute for Global Health

CHF Consumers Health Forum OF Australia

The George Institute for Global Health

Proudly supported by

Australian Government
Australian Digital Health Agency

Summary of principles and recommendations

Cross-cutting principles

Principle 1: Apply a co-design framework to all test bed areas ensuring maximal engagement with a wide variety of consumers at every stage of development and implementation.

Principle 2: Develop a strategy to enhance digital health literacy for the Australian community, its care providers and health administrators.

Principle 3: Systematically appraise and reduce complexity where possible when designing test beds, embracing the need for flexible and iterative improvements over time.

Test bed recommendations

1. Chronic Care

Recommendation 1: Support new models of care for people with chronic and complex care needs that leverage digital health infrastructure, reduce care fragmentation and improve system performance (virtual professional networks, patient-powered networks, data platforms for secondary use).

Recommendation 2: Support access to high quality resources that empower consumers to better manage their health care needs (centralised chronic care resource gateway, 'open notes' access to all parts of the health record, gamification apps and apps for structured consumer stories).

Recommendation 3: Develop meaningful use criteria to assess provider engagement in the digital health eco-system and trial financial and non-financial incentives to support providers to enhance their digital health capacity.

2. Residential Aged Care

Recommendation 1: Invest in the provision of fit-for-purpose information technology infrastructure within and across all residential aged care facilities.

Recommendation 2: Ensure that residents' health and social services information is easily accessible by themselves and providers on an "anywhere, anytime, any device" basis.

Recommendation 3: Create a standardised set of indicators measuring client and staff experience and health outcomes and making facility-level information publicly available to support informed decision-making.

3. Emergency Care

Recommendation 1: Invest in the development of digital health technologies and care pathways that allow My Health Record data to be rapidly accessible to emergency providers in the health system.

Recommendation 2: Develop a standards compliant text/image message system, integrated with hospital record systems, to facilitate communication and workflow processes between emergency providers and other care provider teams.

Recommendation 3: Develop centralised electronic referral systems to make it easier for emergency providers to engage other care providers such as social care, aged care, hospital in the home services and non-government community agencies.

4. End of Life Care

Recommendation 1: Using a co-design approach with consumers and health professionals, develop and promote existing health professional and consumer-facing portals that provide information on care options, medical services and pathways for those nearing end of life.

Recommendation 2: Engage in targeted social media campaigns to encourage consumers and medical professionals to normalise conversations about death, and support carers by providing emotional and practical assistance including access to information, resources and guidance.

Recommendation 3: Make it easy for everyone to document their end of life treatment and care wishes and have these wishes available in a platform readily accessible to any member of the medical care or end of life care team as required.

Recommendation 4: Develop a health professional quality improvement program for end of life care.

Recommendation 5: Develop a rapid response team service to better support people's end of life care needs, particularly where palliative care services are not accessible or sufficient due to resource constraints.

Recommendation 6: Develop a telehealth support service for improving end of life care in rural and remote areas.

Introduction

Digital health technology has the potential to transform the way we deliver and receive health and social care. Advances in digital technology provide a tangible opportunity to improve health care quality, consumer outcomes and experience. Developments such as secure data exchange, interoperability of systems, telehealth services, and the use of mobile health technologies including apps and wearables are being implemented on a large scale.

The ADHA released the National Digital Health Strategy: Safe, Seamless and Secure, in August 2017, providing a five-year vision for national digital health activities. The strategy followed the guiding principle of 'putting users at the centre', a principle that continues through a national consultation phase inviting collaboration and co-production of the strategy's implementation plan – the Framework for Action. As part of this consultation process, The George Institute for Global Health and the Consumers Health Forum of Australia convened a digital health roundtable to bring together consumers and their advocates, clinicians, government, policy experts, researchers and digital technology specialists to provide advice on the implementation plan.

What are test beds?

A test bed provides a real world setting in which we can assess the performance of a new initiative under normal working conditions. Test beds are increasingly used to trial innovations in the health care sector, as they allow us to evaluate both integration and impact within the existing working practices and systems of our health services. The National Digital Health Strategy: Safe, Seamless and Secure identified six test bed clinical priority areas for testing digitally enabled models of care over the next four years. Proposed areas include:

- Telehealth
- Child health
- **Chronic disease**
- **End of life care**
- **Residential aged care**
- **Emergency care.**

It is expected that all six test beds will have projects launched by 2022, with four completed evaluations and two test beds implemented at scale nationally. At the roundtable, participants workshopped the last four of the above priority areas, given these are areas where digitally enabled models of care are least developed. There are, however, common elements to all test beds and recommendations in one area may have relevance across all priority areas.

How will test beds be developed?

The test beds should not be narrowly conceived as pilots to demonstrate feasibility. Rather, they are real-world models of care ("living laboratories"), designed with scale in mind from the outset. They are intended to allow digital technologies to be tested and continuously improved based on early and frequent user feedback, acknowledging that adaptability over time and in different contexts is essential to supporting adoption and sustainability.

The test beds should serve as a platform for consumers, health care providers, governments, industry and academics to 'co-create' digitally enabled models of care that can provide the greatest benefit to the greatest number of people in Australia. Test bed sites are likely to be facilitated by public and private providers from a range of sectors supported by local health networks. The National Digital Health Strategy outlined the following key features of the test beds:

- based in the priority health reform areas of chronic disease, telehealth, children's health, residential aged care, end of life care and emergency care
- implemented and evaluated over a two-year period to inform future scale-up and rollout plans
- cross-jurisdictional (spanning two or more state or territory health departments)
- developed with primary health networks involved as coordinators of care.

Development of the test beds will require working closely with a broad variety of end users (consumers and carers with lived experience of the target health conditions, providers across many disciplines, and health administrators), to clearly define the problem to solve, identify which digital technologies can support or improve existing care processes, and develop mutually beneficial partnerships. It also should be noted that regional context will be critical to the implementation of the test beds. In particular, models specifically developed for rural and remote parts of Australia and for Aboriginal and Torres Strait Islander people will require close attention to these issues.

Cross-cutting principles

One of the greatest potentials for digital health to strengthen health systems is to improve the interface between health care sectors (home and self-care, primary and ambulatory, hospital, palliative and residential age care settings) and support people to transition smoothly between sectors. For consumers, a significant opportunity is to strengthen individual agency and activation so that they are involved in health care more as partners than as passive recipients of care.

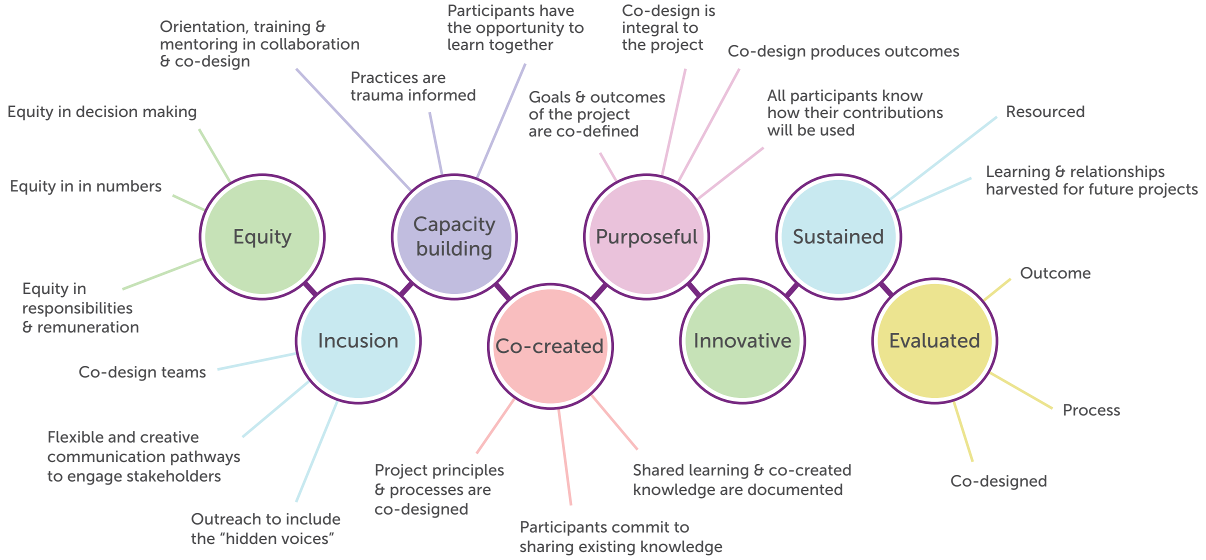
In recognising this, roundtable participants identified three 'cross-cutting' principles that were applicable to all test bed sites. These principles should be incorporated when considering test bed specification requirements.

Principle 1: Apply a co-design framework to all test bed areas ensuring maximal engagement with a wide variety of consumers at every stage of development and implementation.

While health care consumers continue to be involved as active participants in managing their own health, the focus is now moving to include consumers in value creation in health care planning and delivery. There was a strong view from roundtable participants that a greater level of disruption to current health care models is needed and that this will only be achieved when consumers play a substantive role in the design of such models. As the health system moves toward regional planning and commissioning arrangements, and multidisciplinary models of care, the need to focus on consumer needs and perspectives is increasingly important at both a policy and practice level. The growing body of literature on health value co-creation or co-design, and its benefits in the health sector, shows that value can be co-created for the individual consumers, clinical practices, health care organisations, and governments.

There are many approaches to co-design globally and in different industries. In this context, co-design means involving people who could be the future users of a service or policy in their development. It recognises that consumers are a diverse group with a broad range of experiences and that this diversity needs to be embraced when thinking about co-design processes. This involvement works best when it happens before policy options have been decided, is sufficiently resourced, and allows for the 'sharing of power'. Figure 2 shows one model highlighting the principles of co-design. It is strongly recommended that a co-design toolkit and framework such as this be utilised in the design of all test bed specifications. Further, it is critical that monitoring and evaluation frameworks incorporate consumer perspectives early and frequently to understand whether the models of care are meeting expectations.

Figure 2 – Principles of co-design, published by Consumers Health Forum of Australia and Australian Healthcare and Hospitals Association, commissionedby Prestantia Health and presented in *Experience-Based Co-Design: a toolkit for Australia*



Principle 2: Develop a strategy to enhance digital health literacy for the Australian community, its care providers and health administrators.

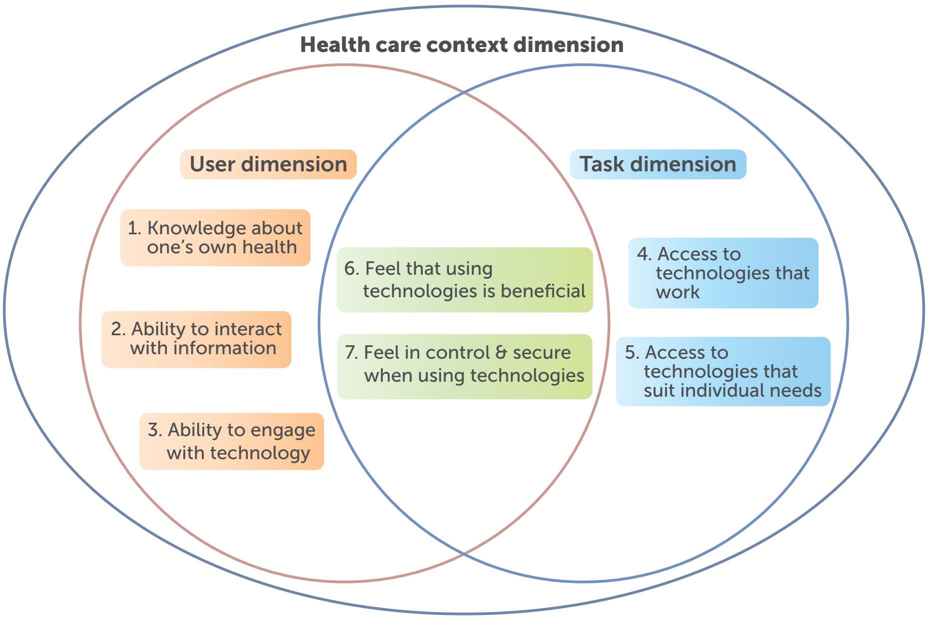
Australians are prolific users of digital technologies and many of these technologies have become indispensable in our daily lives. The health care system has been considerably slower than many other sectors to adopt these technologies. Many of the fundamental building blocks of Australia's digital health eco-system are being established (e.g. My Health Record, secure messaging, e-prescriptions, interoperability of systems). However, the majority of Australians have little exposure to useful ways to leverage these building blocks for health benefits. Although consumers need to be confident that these building blocks are built to a high standard, they are not in themselves useful until they are translated into everyday applications that have clear value in supporting health actions and health care experience.

Digital health literacy is the ability to seek, find, understand and appraise health information from electronic sources, and apply the knowledge gained to addressing or solving a health problem. It encompasses user, health care and task-oriented dimensions.

Strategies to increase awareness of digital health technologies alone are insufficient in increasing adoption. More intensive efforts are needed to understand and overcome digital health literacy gaps for particular population groups, particularly those from culturally and linguistically diverse communities. Frequently, social networks drive adoption of digital technologies and classical education approaches are not likely to be useful. Enhancing digital health literacy therefore requires: multi-sectoral collaborations across all the domains in Figure 1; adherence to user centred design principles (aligning with principle 1); and smart marketing strategies that leverage online social networks and the experience of avid users to support their uptake. Detailed market analyses are also needed to appraise which groups are missing out when technologies are implemented at scale. Incentives could be provided to industry by providing an expert "star rating" of digital health applications that are designed to cater for these groups.

Ensuring a high level of digital health literacy among health professionals and health care organisations is fundamental to the success of digital health initiatives. While pockets of digital innovation exist throughout our health services, many health care organisations require a significant cultural shift to accept and embrace digital technology. A workforce confident in using digital health technologies to support the delivery of health care is vital for the implementation of the National Digital Health Strategy. Achieving the necessary culture change and level of proficiency requires leadership from health managers and professional education bodies who could ensure digital health competencies are incorporated in health professional curriculum at all levels. Incorporation

Figure 3: Conceptual framework for understanding digital health literacy presented in *Knowledge Management & E-Learning*

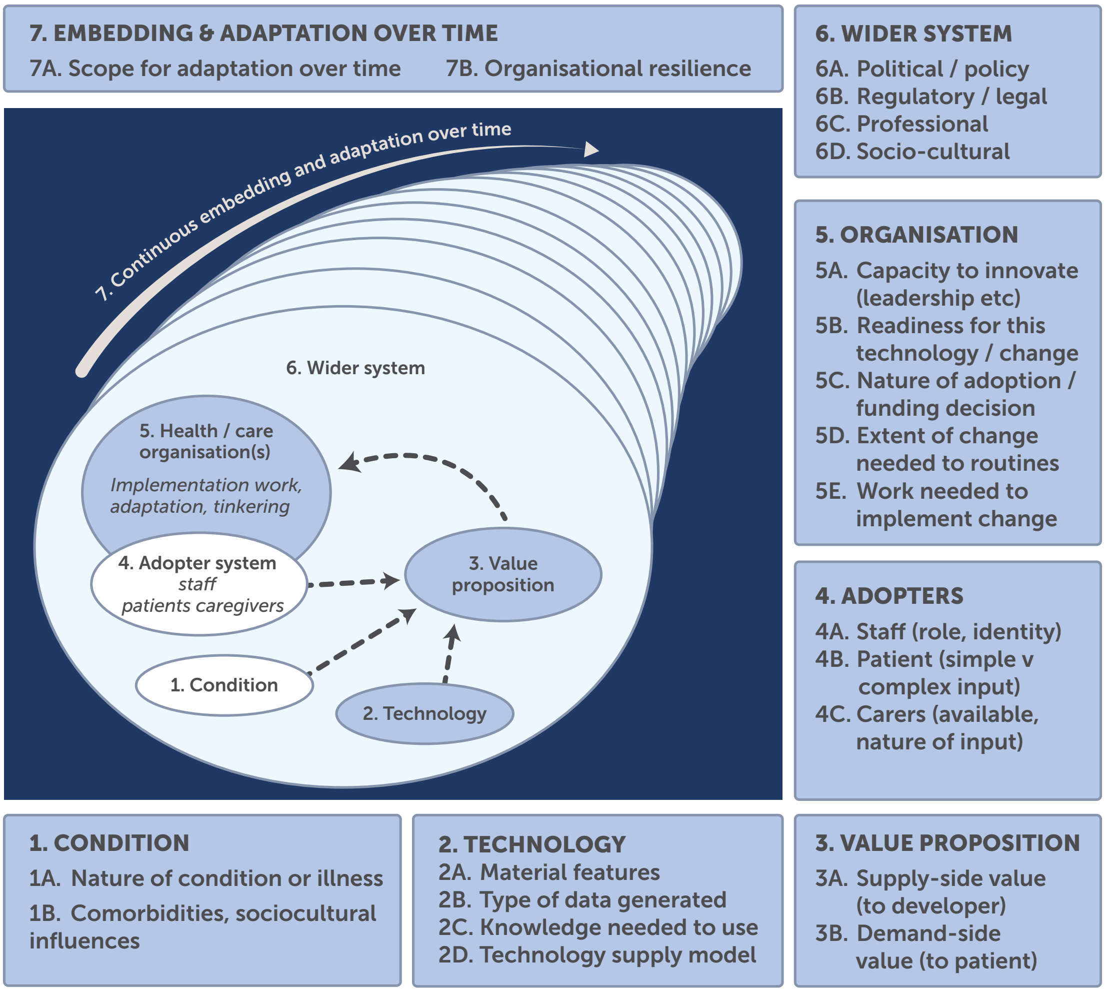


of digital health literacy into the *National Safety and Quality Health Service Standards* and promotion of resources provided by the Australian Commission for Safety and Quality in Health Care would be a useful starting point to support this culture change.

A multi-faceted digital health education program is recommended that includes the following components:

- Primary schools to standardise and implement a digital health program in their Personal Development, Health and Physical Education curriculum
- Make better use of peer support networks (e.g. high school, TAFE, university, retirees looking to upskill and get young people to teach them digital health literacy techniques)
- Through Science, Technology, Engineering and Mathematics curricula, provide an increased focus on entrepreneurship where students are challenged to build, design and critique apps, tools and marketing campaigns that promote digital health engagement
- Consumer digital health products that are co-designed with peak advocacy groups and disseminated via social networks as a 'grassroots' movement. If properly co-designed, such products would be high quality, evidence-based, narrated in languages appropriate to the community, cover health conditions that matter to the target population, and address everyday challenges with navigating the health system
- Provide digital health resource hubs in opportunistic spaces when people are thinking about health care (e.g. pharmacies, waiting rooms)
- A suite of secure mobile applications and electronic decision aids to support enhanced digital health literacy tailored towards self-management, improved decision support, and consumer activation for specific

Figure 4: The non-adoption, abandonment, scale-up, spread and sustainability *(NASSS) framework*



7. EMBEDDING & ADAPTATION OVER TIME
7A. Scope for adaptation over time
7B. Organisational resilience

6. WIDER SYSTEM
6A. Political / policy
6B. Regulatory / legal
6C. Professional
6D. Socio-cultural

5. ORGANISATION
5A. Capacity to innovate (leadership etc)
5B. Readiness for this technology / change
5C. Nature of adoption / funding decision
5D. Extent of change needed to routines
5E. Work needed to implement change

4. ADOPTERS
4A. Staff (role, identity)
4B. Patient (simple v complex input)
4C. Carers (available, nature of input)

1. CONDITION
1A. Nature of condition or illness
1B. Comorbidities, sociocultural influences

2. TECHNOLOGY
2A. Material features
2B. Type of data generated
2C. Knowledge needed to use
2D. Technology supply model

3. VALUE PROPOSITION
3A. Supply-side value (to developer)
3B. Demand-side value (to patient)

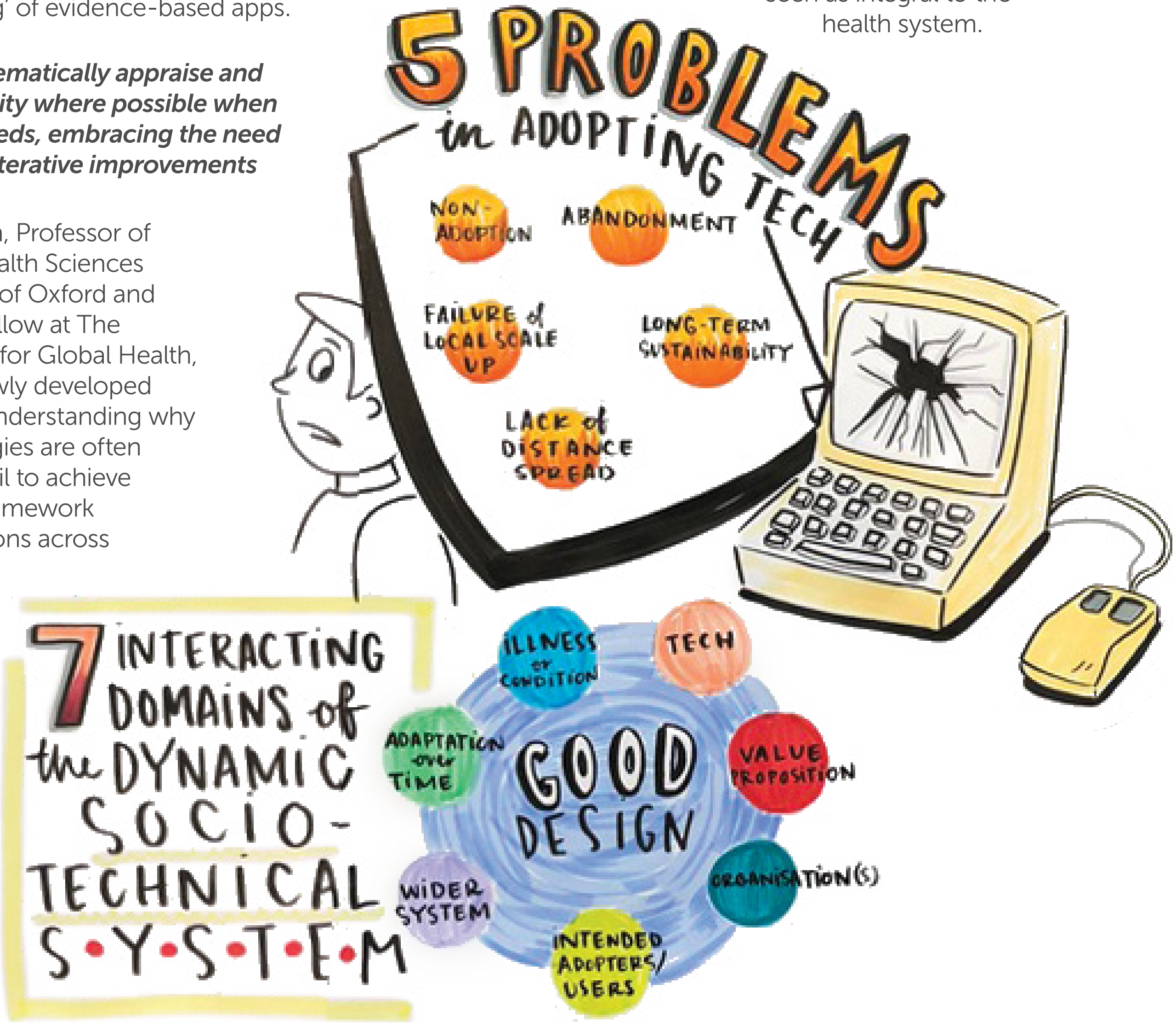
target population groups. Resources that adhere to good practice health literacy principles could be promoted by a star rating system hosted on Healthdirect Australia

- The inclusion of digital health competencies in curriculum at all levels from undergraduate to continuing professional development, linked to accreditation standards. This will ensure that health care providers commit to cultural change to realise digital health benefits, enhance their capacity within the context of digital tools, capabilities and interoperability
- Review of Medicare Benefits Schedule (MBS) items numbers to allow practitioners to spend more time engaging people in use of high quality digital health apps and potentially having item numbers to support prescribing of evidence-based apps including the 'prescribing' of evidence-based apps.

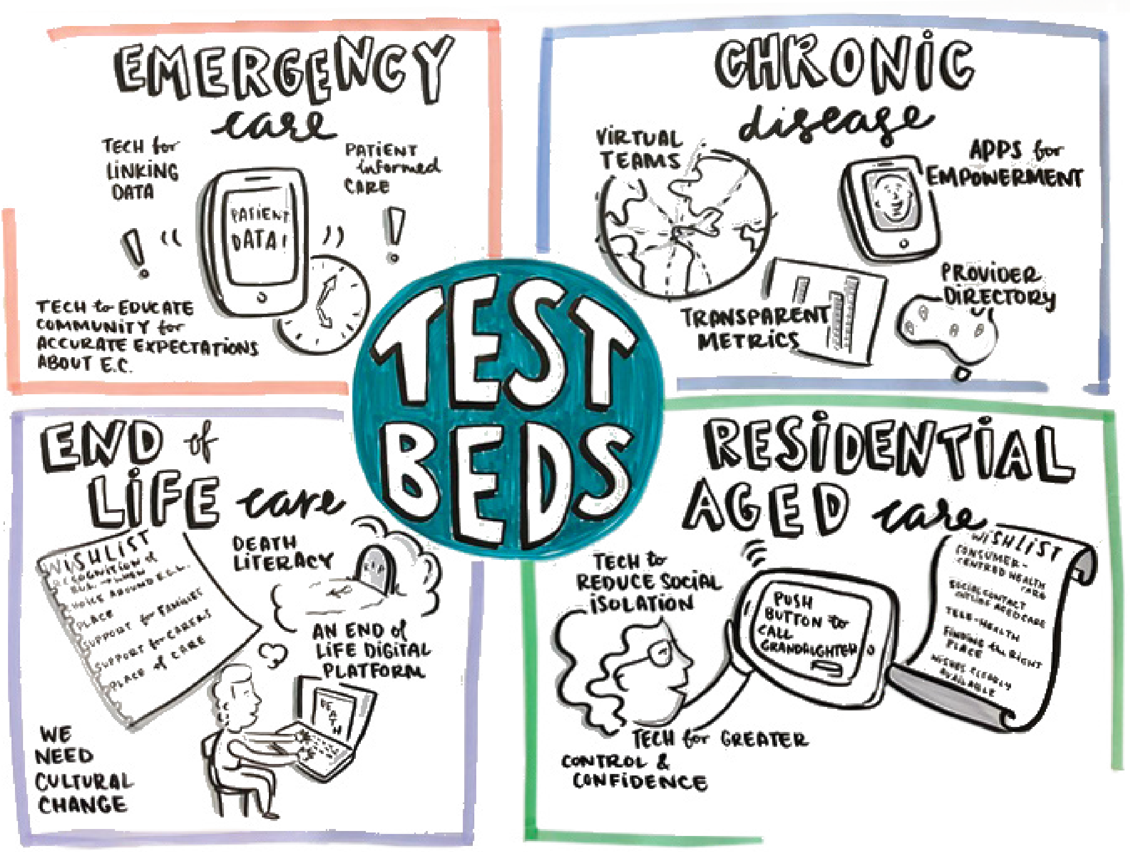
Principle 3: Systematically appraise and reduce complexity where possible when designing test beds, embracing the need for flexible and iterative improvements over time.

Trish Greenhalgh, Professor of Primary Care Health Sciences at the University of Oxford and Distinguished Fellow at The George Institute for Global Health, introduced a newly developed framework for understanding why health technologies are often abandoned or fail to achieve scale-up. The framework proposes questions across seven domains (Figure 4) and postulates that as complexity increases in and across each of these domains, the likelihood of failure increases.

It is recommended, therefore, that regular assessments of complexity be conducted across these domains. It is also recommended that there be clear action plans to reduce complexity in as many domains as possible. It is recognised that health care is inherently a complex environment and that considerably larger than anticipated resources may be needed for highly complex test bed sites. Further, it is critically important to embrace flexible designs that are iteratively shaped over time based on user feedback. When implementing digital strategies in complex systems, there will inevitably be unintended consequences. It is important that a learning system is developed that can identify adverse outcomes early, make improvements as needed and monitor for the impact of these improvements. More than simply an incident monitoring system, a learning system is a continuous improvement process that is seen as integral to the health system.



Recommendations



1. Chronic care

> *As a health consumer with a chronic illness I have at times found it difficult to understand my illness and its implications while managing a full family life. I longed to be an active partner in my illness management.*
>
> *Digital health care has provided me with personalised emergency help when needed; just-in-time decision making support in difficult situations; and enhanced my health care partnership. I feel that my opinions are valued and safer because of it.*
>
> *Yet, I would like more interaction, resources and care management options from a digital 'one-stop-shop'. In all the years I have attended multiple outpatient and other healthcare services I have never discussed my illness situation with any other patient or heard their story - it is such a siloed and isolating experience! But we now have the technology to share our stories, and provide consumers with resources, rather than them becoming experts in 'googling' information and determining reliable websites, as I have learnt to do.*
>
> *My Health Record is a visionary move in the right direction. I feel safe in knowing that my medical information is in one place and accessible by others when needed, but it still feels like a repository of information 'about' me. I look forward to the time when it will have more interactive features and I can feel that I have 'real' partnership in my illness management.*
>
> ***Christine Slade***
> ***Consumer Advocate***

Digital health is a fundamental enabler to improve care for people with chronic and complex care needs. There has been much attention both in Australia and internationally in developing health care home models for this group. Key principles of such models include improved access to a health care provider of choice, co-ordinated care across sectors, whole person care, promotion of teamwork, and a commitment to quality and safety are. Digital health strategies such as population registries, health information exchanges, electronic shared care plans, consumer portals, and personal health records have potential to support these principles.

What we want	*What we have*	*How do we get there*
• Care is consistent across all sectors of the health system and leverages both private and public health infrastructure • Clinicians have ability to safely and easily share information • The right information is available at the right time and in the right place • Information that is actionable through better access to services • People do not have to repeat their story to multiple providers • People are able to connect with others digitally to share health and health care experiences • People are able to pose research questions that matter to them • Data can be safely accessed and analysed to improve health system quality • People feel included as a member of the care team • Care needs to be contextually relevant to rural and metropolitan environments	• My Health Record • E-prescriptions • Risk stratification tools and predictive analytics • Shared care plan software products • Population and disease specific registries • Third party apps that interface with health record systems and My Health Record • My Aged Care • National Cancer Screening Register • State integrated care initiatives (e.g. Victorian eReferral program, NSW Integrated Care Program, Tasmania real-time drug reporting system)	• New funding models that support value over volume • Support for multiple types of specific and connected interventions • Communities of practice for health care providers and consumers • Access to curated resources • Secure messaging between providers and consumers • Recognise deficte in health outcome that people in rural and remote communities experience

Recommendation 1: Support new models of care for people with chronic and complex care needs that leverage digital health infrastructure, reduce care fragmentation and improve system performance (virtual professional networks, patient-powered networks, data platforms for secondary use).

1.1 Implement trials of virtual care teams to support integrated care for people with high health needs

- Electronic shared care plans should be enhanced with additional elements to support team-based care. Better utilisation of existing MBS team care arrangements is needed, however, new funding models that support team-based care are needed in the longer term
- Accelerate progress to making national provider directories accessible via care planning software applications
- Provide funding for virtual case conferences and other mechanisms to support both real-time and non-immediate interaction between care providers
- Develop quality and safety programs and indicators that provide personalised feedback to teams rather than individuals on their performance
- Encourage and support professional knowledge sharing networks by establishing virtual learning communities of specialists, general practitioners and other primary care providers *(e.g. Project ECHO approach)*
- Establish trials to promote connectivity of health and social care providers building on existing partnerships (e.g. The Social Services Institute)
- Work with consumers to develop personalised sick day action plans that are easily accessible by all team members during periods of being acutely unwell.

1.2 Trial a national "Patients Like Me" style platform to allow consumers with chronic and complex care needs to safely connect and share experiences with one another

- Industry should work with peak bodies to co-create with consumers a platform that facilitates the development of interactive networks of people with expert knowledge and first-hand experience of relevant health conditions. This would include common symptoms reported by people with these conditions, experience of particular treatments and testimonials on the benefits and risks associated with these treatments
- Leverage these networks to develop, test and evaluate digital content
- Provide access to latest research and clinical trials that are actively recruiting
- Create an advocacy platform that brings together multiple advocacy groups for stimulating national conversations and policy debates for tackling the growing burden from chronic illness.

1.3 Establish national data platforms curated by trusted custodians to support research and new learning that will enhance the quality and safety of Australia's health system

- Australian health care has a depth of public health care information which, due to various reasons (e.g. legislation, consent, technology, cybersecurity, jurisdictional), is not being adequately utilised. Consequently trials of strategies to mobilise data safely are needed
- A data brokerage model should be developed which allows trusted organisations to access national and jurisdictional data repositories for public good purposes via a data platform that complies with national standards.

Recommendation 2: Support access to high quality resources that empower consumers to better manage their health care needs (centralised chronic care resource gateway, 'open notes' access to all parts of the health record, gamification apps and apps for structured consumer stories).

2.1 Co-design with consumers a centralised gateway to access resources for chronic conditions

- Work with key stakeholders to establish information repositories (akin to www.headtohealth.gov.au mental health gateway, indigenoushealthinfonet) that are linked to other curated specialist resource sites (e.g. disease specific information repositories managed by peak bodies, healthdirectaustralia.gov.au)
- Establish a process to rate these information repositories both by consumers (a "trip advisor rating") and by trusted professional bodies such as Primary Health Tasmania's Digital Health Guide. Mobile app rating scales such as those developed by the Young and Well CRC could serve as a model for how to implement this
- Promote access to these resources by integration with HealthPathways projects nationally and application-programming interfaces to My Health Record.

2.2 Implement an OpenNotes trial where consumers have 100% access to all health information entered into their health records across all parts of the health system

- OpenNotes allows consumers secure portal access to read all of their health notes. Studies have found that more extensive access has the potential to support consumer/provider relations, support continuity of care, reduce waste and increase the quality and safety of the health system
- OpenNotes portals should allow for two-way communication where consumers can highlight errors and inaccuracies and provider feedback.

2.3 Conduct trials of gamification to enhance self-management of chronic conditions

- Gamification is the use of game elements and techniques in nongaming contexts. Although gamification to support self-management of chronic diseases holds promise, it remains relatively under-explored and many gamification apps do not follow any standardised guidelines
- Existing gamification apps should be quality appraised using a standardised framework
- Support the integration of a suite of gamification apps with My Health Record to promote consumer adoption and engagement and rigorously evaluate their impact.

Recommendation 3: Develop meaningful use criteria to assess provider engagement in the digital health eco-system and trial financial and non-financial incentives to support providers to enhance their digital health capacity

3.1 Develop and implement tools to assess organisational digital health capacity and trial a financial incentive program to improve capacity

- Implement structured assessments to capture the large variation in the level of digitisation across the health system
- Establish national meaningful use standards and tools that allow health care organisations and providers to rate their current capacity to engage with the digital health system
- Provide peer-ranked feedback to providers on their rates of meeting meaningful use standards and incorporate these measures into public reports
- Develop targeted incentives, depending on level of digital maturity, that will support organisations and providers to progressively increase adherence to meaningful use criteria
- Align incentive programs with existing policy reform initiatives such as the Practice Incentives Program eHealth Incentive.

3.2 Trial personal health budgets that provide discretionary funding to consumers with chronic care needs to enhance their engagement with the digital health system

- A personal health budget is an amount of money to support the health care and well-being needs of an individual which is jointly agreed upon between the individual or their representative and the funder. In most models, the personal health budget tends not be new funding, but rather a re-allocation of existing funding that is primarily controlled by the individual

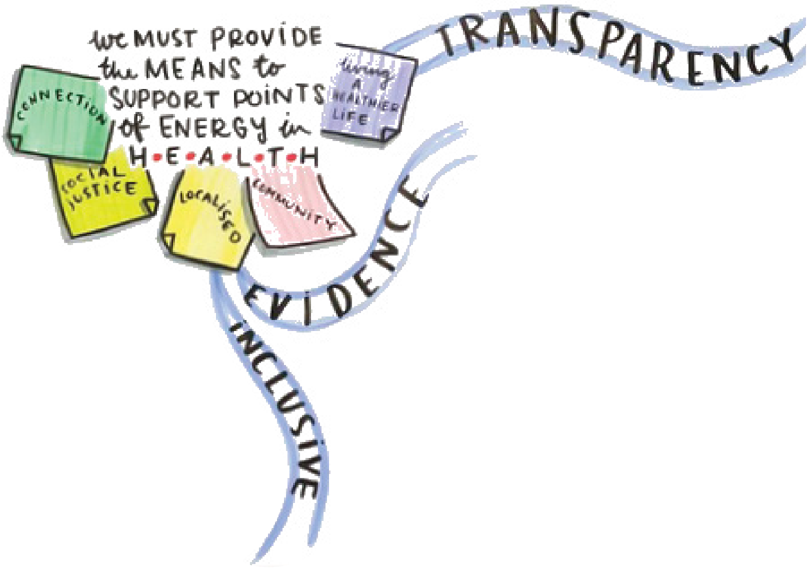
- Although traditionally personal health budgets have been used for specific services such as therapies, personal care and equipment, a novel use would be to allow consumers to use discretionary funds for greater digital enablement. This may include purchasing of digital hardware, broadband access, devices in the home or training in use of particular software applications
- A trial of personal digital health budgets should be considered for those who currently experience a ‘digital divide’ in equitable access to digital health technologies.

2. Residential Aged Care

> *A resident & carer-centred aged care system is one that first asks ‘What matters to you?’ and not ‘What’s the matter with you?’”*
>
> *The challenge for residential aged care is how to improve the quality of life of residents. One important way is to reduce the social isolation and loneliness of older people once they leave their established homes. There is a need to harness the technology and use it to enable older people living in residential care to stay in regular contact with their grandchildren, friends and family. We also need to optimise communication by enabling older people and their carers to communicate with multiple care providers (treating doctors, general practitioners, hospitals, rehabilitation services, nursing and general care staff, family members) and, importantly, between these providers and the resident.*
>
> *Digital health and a My Health Record with up to date information also has the potential to enhance safety, in relation to the quality use of medicines. Benefits such as reducing adverse drug reactions, identifing potential problem medicines and triggering medicine reviews by clinical pharmacists will help all health consumers, and especially those in residential aged care.*
>
> ***Jan Donovan***
> ***Consumer Advocate***

There are significant opportunities within the residential aged care system to support a resident and care focused health system. The first opportunity is to embrace a broader definition of “health” to include wellbeing. Residents often have complex physical, health and social needs that all need attention to maintain “health” and quality of life. Nutrition, exercise, falls prevention and avoidance of social isolation underpin better health. A structured care plan driven by the resident’s goals that includes screening and monitoring is also needed. This plan must be easily shared with providers and carers within and outside the walls, and must contain the resident’s advanced care plan/directive.

Navigation of the aged care system is often a complex process for consumers. Complex health issues, disabilities, physical limitations, and isolation can make it difficult for elderly Australians to access health services and support. Further, moving to a residential aged care facility may be associated with feelings of loss of control, which can be mitigated by enhancing the involvement of residents in decisions around their care. Digital health initiatives have potential to improve continuity of care, reduce adverse drug events in residential aged care, provide greater support for people living with dementia and improve adherence to treatment plans. Central to this is a clear need to ensure older persons and their carers have access to the appropriate information and resources. Digital health initiatives within this test bed need to support the current health issues of aged care residents (including complex and multiple comorbid conditions), social and emotional well-being, functional capacity, the prevention of further complications, and effective end of life planning.



What we want	*What we have*	*How do we get there*
• Reduction of social isolation, loneliness and enhanced social contact • Resident/carer-centred, moving from "What's the matter with you" to "What matters to you?" • Ready access to information, wishes and preferences at any time on any device • Smooth transition of care for residents between aged care home, hospital and other health services • Enable virtual health care, removing the requirement of provider and consumer to be physically present together • An improvement focussed organisational culture with a particular emphasis on medicines safety and prevention of falls • End of life wishes are known, documented and clearly communicated • Care needs to be contextually relevant to rural and metropolitan environments	• Some national standards in place (e.g. identifiers, data sharing, privacy) • My Aged Care online portal, but low awareness of its potential • My Health Record medicines list • Consumer medicines information (e.g healthdirectaustralia, NPS MedicineWise) • Variable use of electronic medical record systems by aged care providers • Lack of interoperable systems • Limited paperless communication between general practitioners and aged care providers	• Leadership and incentives to enhance organisational digital health maturity • National minimum software specifications requirements for IT vendors • Fit for purpose IT infrastructure in health care facilities and tools for self-assessment of IT capacity • Integrated digital systems to facilitate inter-operability and communication between aged care, hospital, primary care, pharmacy and other providers • DHS/DOH/DSS systems communicate (i.e. social, financial and health information able to be cross-referenced) • Measure and share - consumer and staff reported experience and outcomes; health outcomes that are meaningful to consumers and carers • Recognise deficte in health outcome that people in rural and remote communities experience

Recommendation 1: Invest in the provision of fit-for-purpose information technology infrastructure within and across all residential aged care facilities.

- The peak bodies representing Australia's aged care industry – Leading Age Services Australia, Aged & Community Services Australia, The Royal Australian College of General Practitioners, Council on the Ageing and Consumers Health Forum of Australia – must advocate for digital health initiatives within residential aged care, in addition to a digitally literate aged care workforce
- As a first step, residential aged care providers should install high-speed, reliable internet infrastructure as standard, to allow connectivity for residents as well as staff
- Aged care providers should be provided with tools to self-assess their level of digital maturity Digital health minimum standards in residential aged care facilities should be incorporated into national quality assurance processes including accreditation standards
- Aged care providers must adopt a commitment to workforce training and development in order to create a digitally literate aged care workforce. This will support staff to be confident in the application of digital health initiatives and provide the necessary support for residents as they embrace digital health technologies for information and communications.

Recommendation 2: Ensure that residents' health and social services information is easily accessible by themselves and providers on an "anywhere, anytime, any device" basis.

- Government should engage aged care providers and consumers to establish minimum standards for accurate identification of an individual, data sharing and release of information
- Support should be provided to health care providers to standardise the use of the individual health care identifier (IHI) in consumer-health service interactions. This will ensure that consumers and providers can be confident that the right information is associated with the right individual at the point of care
- Establish national minimum standards for software vendors to support exchange of information between different aged care, primary care and hospital software systems
- Data sharing processes should also be implemented to support information exchange between information systems of the Department of Health, the Department of Human Services and the Department of Social Services. Data needs to be available and safely accessed in varying and appropriate formats for service managers, health care providers and consumers (residents and their carers). Digital platforms supporting mobile access (phone and tablets), centralised online

information repositories, and text and notification messages are required

- Existing case studies of excellence in digital health initiatives relevant to the aged care should be leveraged (e.g. pharmacy-led de-prescribing initiatives for antipsychotics and anticholinergics, such as Webstercare Medication Managament Software and Veteran's Affairs programs)
- Collaborative partnership models need to be developed that more effectively integrate industry and academic research and development programs while at the same time closely engaging consumers in these programs.

Recommendation 3: Create a standardised set of indicators measuring client and staff experience and health outcomes and making facility-level information publicly available to support informed decision-making.

- Aged care regulators (e.g. Australian Aged Care Quality Agency) should support aged care providers to engage residents and their carers in the routine collection of Patient Reported Experience Measures (PREMs) and Patient Reported Outcome Measures (PROMs), in addition to other service quality indicators
- A system should be established to enable timely feedback of consumer experience and other quality metrics to aged care providers. This information can then be used to drive quality improvements activities in both experience- and outcomes-focused health care
- Aged care providers should make transparent and accessible digital information about the quality, performance and acceptability of their services so that consumers can make more informed choices about their residential aged care options.

3. Emergency Care

> *Consumers in an emergency expect to come in contact with a continuous flow of highly qualified health professionals, all with equal respect for each other and access to the patient's medical history and treatments. This expectation is far from the fact with great variation between jurisdictions around Australia. A national policy would be desirable and achievable with paramedic registration.*
>
> *An emergency to a consumer often means calling on an ambulance service, a critical health service for emergency care, yet few consumers are aware of the gaps in the relationship between the health service and ambulance services.*
>
> *Digital health records offer a solution to part of this problem by giving more health professionals access to our important health information. There are many questions to address to make this a reality. For example, when dealing with a distressed or unconscious patient how would a paramedic access the appropriate health record? Should access to My Health Record include retinal scans or finger printing?*
>
> *Addressing these questions together will lead to a better connected health system, that provides improved continuity of care for all consumers.*
>
> ***Richard Brightwell***
> ***Consumer Advocate***

Digital health in emergency care has the potential to offer improved access to an individual's health information, aid clinical decision making by emergency clinicians, reduce error and improve quality of care. Evidence suggests that the integration of digital health into emergency care will be particularly useful for improving the quality and timeliness of treatment especially for people with complex and chronic conditions and those that experience cultural and language barriers. Although the situation is improving, in most Australian states there is limited linkage between health information systems (including emergency department systems) both within and between hospitals, nor between emergency departments and ambulance information systems. Consequently emergency care providers are unable to readily access digital health records held by general practitioners, or relevant information stored in My Health Record. Further, paramedics and other first responders are not currently authorised to access My Health Record data which perpetuates information siloes and fragmented care processes.

In a context where time-critical, often life or death, decisions must be made for people with minimal information, the ability to easily access information has the potential to make a major impact on the quality and efficiency of emergency care. There is a pressing need for interoperable health information systems allowing data for an individual to be integrated, linked and readily accessible. There are also particular issues when considering accessing information in rural and remote area emergencies that need addressing and these need to be separately considered when developing test beds in this area.

What we want	*What we have*	*How do we get there*
• Wide use of unique identifiers to ensure rapid identification of the correct person from multiple data sources • Ready access to relevant data about the person including health summaries from GPs, discharge summaries from other hospitals, allergies, medication prescribed and dispensed, diagnostic imaging and pathology results • A system that knows critical information about people in an emergency that would lead to improvements in the care provided • A system that reduces information siloes between providers in different disciplines both within the hospital and the community • Care needs to be contextually relevant to rural and metropolitan environments	• Multiple information repositories that are inconsistently available and accessed • Site specific identifiers • Limited real-time access to information after-hours • Paramedics and other first responders have limited access to current health information • Reliance on facsimile machines to communicate information between providers	• Encourage providers and consumers to maintain up to date information in their records and upload information to My Health Record • Support assisted upload of Advanced Care Plan/Directives to My Health Record • Support paramedics and other first responders to access essential information • Improve workflow and referral processes in the emergency department to assist with timely access to other care providers and supporting post-discharge care • Recognise deficte in health outcome that people in rural and remote communities experience

Recommendation 1: Invest in the development of digital health technologies and care pathways that allow My Health Record data to be rapidly accessible to emergency providers in the health system.

- Government, health care funders, providers, consumers and researchers should collaboratively support implementation of the opt out model for the My Health Record system
- Innovative strategies to identify a person in the My Health Record database are needed to support rapid, accurate identification of people rather than relying on traditional search criteria using Medicare and demographic information (e.g. biometric scanning)
- Attention should also be given to allowing paramedics and other first responders "break glass" permissions to access My Health Record data in an emergency. This would include smart search features and management algorithms based on key information delivered at the point of care
- As the amount of clinical information increases in the My Health Record, it will be essential to make sure that the information is searchable and can be presented appropriately in the clinical context. Software developers need to co-design with providers and consumers digital applications that interface with the My Health Record infrastructure to make "emergency care summaries". Areas to focus on in these summaries would include allergies, recent investigation results, medication and problem lists, and Advanced Care Plan/Directives.

Recommendation 2: Develop a standards compliant text/image message system, integrated with hospital record systems, to facilitate communication and workflow processes between emergency providers and other care provider teams.

- Current intra-hospital referrals and consultations made from the emergency department mainly operate on a pager/phone system that has been unchanged for decades. There is large wastage in the system as a result of these archaic information systems
- It is recommended that secure, compliant mobile message systems that are integrated with the hospital electronic medical record be trialled to support referrals and consultations within the hospital. Such systems should be able to accommodate text, images and multimedia information
- Point-to-point secure messaging also needs to be augmented to support timely transfer of care from the emergency department back to the community or aged care facility. Whilst such systems are in place for communication with GPs they remain variably used and there is little provision to include other care providers.

Recommendation 3: Develop centralised electronic referral systems to make it easier for emergency providers to engage other care providers such as social care, aged care, hospital in the home services and non-government community agencies.

- Emergency department referral to external agencies currently relies on phone calls, paper form filling and fax machines. Such processes tend to only work if an appropriate person on the receiving end is opportunistically available

- Relatively simple digital innovations including electronic bookings, appointment tracking, integration with digital calendars and smartphone maps for directions could help to assist with post-discharge follow up care from the emergency department care. Such apps would also need to be integrated with existing information systems
- Develop online marketplaces for support services that engage a broad network of service providers who may be able to address urgent social and physical care care needs.

4. End of Life Care

Dying is an inevitable part of life. Almost 160,000 people die each year in Australia and it has been estimated that about 75% of all deaths are expected. Recognising that 'one size does not fit all' and that different models of care are likely to be required for different individuals depending upon their illness trajectory is imperative.

Digitally enabled models of care can play a key role in the future of end of life care delivery to be strongly responsive to the needs, preferences and values of people, their families and carers. We all need to communicate better, not just in conversation but in how we share information about ourselves and make documents like Advance Care Plans available when needed.

If dying and death were talked about more, there would be much less stress, conflict and regret for all involved and people could get on with ensuring that they are making the most of their time right up until their death. These topics need to be part of everyday conversation.

If clinicians were able to communicate more effectively with their patients regarding end of life care and people in general had access to more information and resouces around these issues, they would understand what to expect, be able to plan more effectively and hopefully could be reassured that their wishes would be respected and followed.

With improved communication between all parties involved, the grief and bereavement that follows death would be less complicated and less costly in terms of health dollars.

Rosemary Dillon
Consumer Advocate

Despite most Australian preferring to die at home, only a minority achieve this. Conversations about death and dying are inherently difficult, even though, when asked, most people have clear preferences for the type of care they would like and where they want this delivered. Although death is more predictable now and is mostly driven by slow deterioration of chronic conditions, the trajectory of illness can vary greatly ranging from short periods of evident decline, through to longer term limitations with intermitted serious episodes, through to periods of prolonged low functional levels with disability and a reduction in function. These differing trajectories can make planning difficult for consumers and their family and carers, and for many medical professionals who find raising and discussing important issues regarding prognosis, treatment options and dying difficult. These difficulties prevent early and open discussions about the treatment and care we would prefer at the end of our lives. As a result, families and carers are often forced to make difficult decisions on behalf of a person who is seriously ill without having had previous conversations or support, causing them greater stress and uncertainty in an already difficult time. Consequently, the majority of people do not have their preferences met when it comes to end of life care planning.

If dying and death were incorporated into everyday conversations, there would be much less stress, conflict and regret for all involved. It would allow those who are dying and those who care for them to make the most of their time right up until their death. Providers also need to communicate more effectively with consumers, their families and carers regarding end of life care.

Advance care planning promotes care that is consistent with a person's goals, values and beliefs, and is an essential tool in enabling Australians to communicate their preferences regarding their end-of-life care. Whilst advance care planning discussions are valuable in their own right, a written Advance Care Plan (ACP) or an Advance Care Directive (ACD) increases the likelihood that the person's preferences will be known and followed. ACPs/ACDs should be living documents, regularly reviewed, updated and made available to all those involved in the care of the person dying.

Access to high quality resources to support decision making could assist with knowing what to expect, enable more effective planning and be greatly reassuring to people that their wishes will be respected and adhered to. With clear plans in place, there would be less conflict between family members and other carers. It would enable them to advocate confidently on their behalf and they would know who to contact if there was anything they were unsure about. Clear plans would also lead to less confusion between clinicians working in different sectors of the health care system (e.g. GP, emergency department, ambulance services etc.). With improved communication between all parties involved, the grief and bereavement that follows death would be less complicated and less costly in terms of health dollars.

Although the evidence base for digital health solutions supporting end of life preparation is relatively new, digital health could support consumers, caregivers and health care providers to develop and implement ACP/ACDs, improve access and continuity of care, and support palliative care best practice. State-wide strategies now underpin the provision of quality end of life care in all jurisdictions, however these acknowledge that successful implementation will require consideration of the redesign of the end of life care pathway.

What we want	*What we have*	*How do we get there*
• Dying and death are spoken about in an informed manner by all and social stigma is removed • End of life care is delivered with dignity and privacy and in accordance with the dying person's wishes • People are able to make informed choices over where end of life care and death occurs • Everyone has a clearly enunciated, up to date ACP/ACD that is accessible by all members of the care team including paramedics • High quality palliative care is accessible in any location when needed and symptoms related to death and dying, particularly pain and breathlessness, are effectively managed • Carers have access to information and resources, support when needed, and can confidently advocate on behalf of the person they are caring for • Health professionals have appropriate communication skills to provide end of life care with respect, compassion and sensitivity • End of life care is well coordinated between different sectors of the health care system and people experience seamless transitions between community, residential and acute care • Rapid access to palliative care expertise is available via online resources and specialist advice is available to the treating health care provider when needed • Care needs to be contextually relevant to rural and metropolitan environments	• Ability to upload and refresh ACPs/ACDs to My Health Record • ACPs/ACDs are accessible on different systems, e.g. My Aged Care, aged care provider systems, GP and hospital electronic medical record systems • Sub-optimal rates of people receiving end of life care that reflects their choices and needs • Difficulty for consumers to access high quality end of life care and services • Low completion rates of ACPs/ACDs (15% nationally) • Low rates of people dying at home (14%) despite 70% of Australians preferring this • Timely provision of palliative care services is low • Carers are not well supported in their role and have difficulty accessing help. • Variable skills amongst health professionals in having end of life care conversations with consumers and carers	• Normalise advanced care planning discussions and foster organisational cultural change in health services • Prompt consumers at various life milestones (e.g. driver's licence, making a will) or provide incentives (e.g. private health insurance rebates, funeral/life insurance, tax rebate, CPD points) to improve death literacy, normalise conversations of death, and encourage ACPs/ACDs to be established • Create partnerships with high risk industries, i.e. mining, manufacturing, defence force (5,000 recruits each year in defence force), targeting different demographics (e.g. younger men) • Make a requirement for ACPs/ACDs to be immediately accessible to those providing care (i.e. first responders) • Improve access to end of life care information, support and resources for carers • Establish quality improvement initiatives to regular review gaps in care and develop strategies to overcome them • Provide emotional and practical support for carers and facilitate navigation of complex health care systems • Recognise deficte in health outcome that people in rural and remote communities experience

Recommendation 1: Using a co-design approach with consumers and health professionals, develop and promote existing health professional and consumer-facing portals that provide information on care options, medical services and pathways for those nearing end of life.

- Widely promote existing guided decision-making platforms such as MyValues to assist with creating ACPs/ACDs online and ensure they are embedded in the Advanced Care Planning Australia website
- Provide improved access to information and resources regarding end of life care and planning regarding treatment options including carer support services. Examples include: *CareSearch*, *PalliAGED*, *ELDAC*, *Carers toolkit*, *Palliative Care Australia*, *Dying to Talk*
- Ensure these resources are readily accessible via Primary Health Network *HealthPathways* links and hospital intranets.

Recommendation 2: Engage in targeted social media campaigns to encourage consumers and medical professionals to normalise conversations about death, and support carers by providing emotional and practical assistance including access to information, resources and guidance.

- Support collaboration between government, industry, consumers and providers to co-design social and traditional media strategies to address stigma-related barriers to providing optimal end of life care building on existing campaigns such as *National Palliative Care Week and Dying To Know Day*
- Engage multi-sectoral agencies (e.g. Roads and Maritime Services, Department of Social Services, Department of Human Services, legal services) to prompt consumers to engage in end of life planning at specific milestones (e.g. driver licence, making a will)
- Work with industry and government to implement an incentive program to improve death literacy and encourage ACPs/ACDs. Examples include discounts on private health insurance and funeral/life insurance, loyalty programs, tax rebates
- Workplaces should be encouraged to implement campaigns that incorporate ACPs/ACDs as part of overall employee wellbeing
- Widely promote existing e-learning such as *PCC4U*, *End of Life Essentials and Centre for Palliative Care* and invest in gaps in health professional workforce development and training to build the capacity of all health care providers to engage in end of life and advance care planning discussions. Training could be effectively linked to incentives (i.e. Continuing Professional Development points).

Recommendation 3: Make it easy for everyone to document their end of life treatment and care wishes, and have this available in a platform readily accessible to any member of the medical care and end of life care team as required.

- Ensure that all residents newly entering an aged care facility have ACP/ACDs uploaded to My Health Record within 28 days of admission
- Build on the current functionalities of My Health Record to simplify end of life documentation that is easily understood and located by consumers. General Practitioners should work with consumers to assist the uploading of ACPs/ACDs into My Health Record
- Ensure functionality of My Health Record that enables care providers quick access to an individual's ACP/ACD. Make it a requirement for essential information from the ACP/ACD to be immediately accessible to those providing care (see emergency care section)
- Incorporate ACP/ACD data into digital technology (e.g. bleeper or wearable device) which can be read by paramedics or other health care providers
- Allow carer/guardian access to ACP/ACDs (power of attorney/guardianship board)
- Support sharing of consumer information from multiple sources, including service records, My Aged Care client records, National Disability Insurance Scheme participant plans and My Health Record
- Partner with high risk industries, i.e. mining, manufacturing, defence force, to promote acceptance and adoption of end of life care planning among employees
- Ensure that consumer preferences, including cultural and spiritual customs and beliefs, are respected and embedded in digital strategies for end of life care.

Recommendation 4: Develop a health professional quality improvement program for end of life care.

- Establish local and national end of life registries that report on quality outcomes and incorporate appropriate key performance indicators into health services accreditation. Such a registry would build on existing initiatives, engage multiple stakeholders, establish clear data requirements, have appropriate consent and administration rights and provide training for health care providers to engage with the registry
- Ensure that health record data extraction tools are able to report indicators such as the proportion of an eligible population with ACPs/ACDs implemented, updated and acted on at aged care facilities, hospices, and general practices. This information could be extracted from electronic health record and My Health Record data

- Conduct random sample surveys to assess carer and consumer experience and outcomes and incorporate these data into quality indicator datasets. Use this information to prioritise and drive change in the delivery of end of life services
- Increase access to education and training resources for carers in aged care facilities to support delivery of high quality end of life care.

Recommendation 5: Develop a rapid response team service to better support people's end of life care needs, particularly where palliative care services are not accessible or sufficient due to resource constraints.

- The default care pathway is hospital-centric and when a person experiences an acute deterioration the current system encourages transfer to hospital regardless of the person's end of life care wishes
- Rapid response teams who have ready access to all necessary information, including ACPs/ACDs, are needed to facilitate additional support and adjust care to match the needs of a person during acute deteriorations
- Given a major requirement in times of deterioration is often social support rather than clinical support, rapid response teams should also comprise paid formal carers to supplement the work of unpaid informal carers at home or paid formal carers in aged care facilities
- Technology-assisted, stepped care approaches to escalate or deesclate care as needed have been trialled in *other settings* and similar strategies should be tested for end of life care settings
- Rapid response teams would also have real-time access to an on-call specialist to provide management advice and avert the need for unnecessary hospital admissions
- The rapid response team could also inform general pracitioners and other members of the care team of the latest management plan via secure messaging services.

Recommendation 6: Develop a telehealth support service for improving end of life care in rural and remote areas.

- Rural and remote consumers experience inequitable access to end of life care services when compared with those in urban areas
- Telehealth services could better support consumers and and help carers respond to particular care needs
- Services that can be assisted with technology based solutions include: consumer and carer education, decision support, psychosocial support including problem solving training, social support and augmentation of clinical care delivery
- Telehealth specialist support could provide further expertise and give consumers, carers and health care providers confidence to implement management plans without the need for physical referral.

Summary

Test bed evaluation

It is essential that detailed evaluations be conducted for each of the test beds to assess safety, acceptability (to consumers, providers and organisations) and impact. This will enable active refinement and adaptation of the test bed models of care throughout the implementation process and support broader adoption and sustainability of successful digital health care models. Adhering to the cross-cutting recommendation of co-design, the monitoring and evaluation frameworks for these test beds should be developed prior to implementation, and incorporate consumer perspectives early and frequently to understand whether the models of care are meeting expectations.

Some key questions to consider in evaluating their impact include the following:

- What results were achieved by the test bed?
- Have consumers and health care providers been effectively involved and established as key design partners in the design and implementation of the test beds?
- To what extent has the specific health system context been considered in the development of the test bed (e.g. attention to rural and remote specific needs)?
- Are multi-stakeholder partnerships strengthened as a result of the test beds?
- Will providers support the test beds, what will they have to do differently to support implementation and what are the consequences of these different work practices?
- What changes were made during implementation and why?
- Were there any unintended consequences from test bed implementation?
- What are the criteria for test bed failure and when should a test bed be abandoned or undergo major modifications?
- Did the test beds improve consumer/carer health outcomes and experience?
- Are the benefits of test beds equitable across different user groups?
- What is the business plan for implementing the test beds at scale?
- What policy enablers are needed to support scale up of promising test beds?
- Do the test beds include a rural and remote model?

Conclusion

The recommendations in this report provide guidance on implementation of four digitally-enabled models of care as part of Australia's National Digital Health Strategy: chronic disease, residential aged care, emergency care and end of life care.

Navigating our fragmented health system of public and private services with its many players, funding structures and disease siloes can be overwhelming for many people. The disjointed nature of these services means that health information is equally fragmented. Digital health offers the bold promise of harmonising information flows, transforming conventional service delivery models, overcoming fragmentation and making health care more equitable. This would make care more accessible, support comprehensive and longitudinal care and aid critical time-dependent decisions during an emergency and at end of life.

However, we know that many digital health technologies struggle to get adopted at scale and sustained over time. Key factors include lack of sustainable funding models, leadership, and the complexity of the interventions themselves and the environments in which they are implemented. Critical success factors include sustainable funding models, supportive leadership, trust and security assurance, strong consumer and clinician engagement and governance, and collaborative learning – each of these require engagement of multiple stakeholders at their core. Through appropriate, co-designed strategies, digital health can more effectively engage consumers and carers, reduce complexity where possible and be flexibly adapted over time in response to dynamic environments.

Australia now has many of the critical infrastructure building blocks in place to support a digitally enabled health care system. Major progress is being made with My Health Record, population registries, shared care portals, state-based digital health strategies and linked hospital information systems. The time is now ripe to leverage this maturing digital health capacity in ways that are meaningful to both consumers and providers. If done well, it has potential to be transformative for Australia's health system bringing about rapid enhancements in quality, safety, accessibility and efficiency.

Host Organisations

About The George Institute for Global Health

The George Institute for Global Health is an independent global medical research institute, established and headquartered in Sydney, with major centres in China, India and the UK. The George is focused on reducing the burden of the leading causes of death and disability around the world – chronic disease and injury.

Our research has driven major improvements in the prevention and treatment of heart disease, stroke, diabetes, kidney disease, and many other conditions, and our researchers have been recognised among the world's best for scientific impact and excellence. Affiliated with world class universities such as UNSW Sydney, we have over 650 staff globally, a global network of collaborators, projects in more than 50 countries, and have raised over $730 million for global health research. In 2017, we celebrated 10 years of impact in China and India.

To have the greatest impact on health outcomes, The George also convenes health policy forums in Australia, China, India and the UK to contribute to health care debate and evidence-based policy reform. The George Institute for Global Health has established a commercial subsidiary, George Health Enterprises to expedite the translation of some of its research findings into practice, while generating profits to support the Institute.

www.georgeinstitute.org

About the Consumers Health Forum of Australia

The Consumers Health Forum of Australia (CHF) is the national peak body representing the interests of Australian health care consumers and those with an interest in health care consumer affairs. CHF works to achieve safe, quality, timely health care for all Australians, supported by accessible health information and systems.

CHF does this by:

- advocating for appropriate and equitable health care
- undertaking consumer-based research and developing a strong consumer knowledge base
- identifying key issues in safety and quality of health services for consumers
- raising the health literacy of consumers, health professionals and stakeholders
- providing a strong national voice for health consumers and supporting consumer participation in health policy and program decision making.

CHF member organisations reach thousands of Australian health consumers across a wide range of health interests and health system experiences. CHF policy is developed through consultation with members, ensuring that CHF maintains a broad, representative, health consumer perspective.

CHF is committed to being an active advocate in the ongoing development of Australian health policy and practice.

www.chf.org.au

Project team

The roundtable and independent report was a joint production of The George Institute for Global Health and the Consumers Health Forum of Australia.

David Peiris
Director, Health Systems Science
The George Institute for Global Health

Leanne Wells
CEO
Consumers Health Forum of Australia.

Anna Palagyi
Research Fellow (Health Systems)
The George Institute for Global Health

Maya Kay
Head of Stakeholder Engagement and Communications
The George Institute, Australia

Chelsea Hunnisett
Communications & Stakeholder Engagement Coordinator
The George Institute for Global Health

Dean Hewson
Digital Health Advisor
Consumers Health Forum of Australia

Alexander Baldock
Design Manager
The George Institute for Global Health

Working group co-leads

Chronic disease – Christine Slade, Marcus Tan

Residential aged care – Jan Donovan, Steve Hambleton

Emergency care – Richard Brightwell, Paul Middleton

End of life care – Kelly Gourlay, Rosemary Dillon

Expert input

Paresh Dawda, Jane Burns, Kirsten McCaffery, Brian Oldenburg, Chi Li, Trish Greenhalgh

Note takers:

John Mulley, Alison Coenen, Joanna Forbes

Thank you

The George Institute for Global Health and the Consumers Health Forum of Australia are grateful for the participation of the following representatives in the roundtable discussion, and in subsequent consultation and feedback, that form the basis of the recommendations provided in this report.

Anja Ebker White
Royal Prince Alfred Hospital

Bernard Borg
Consumer Advocate

Chris Leahy
Australian Commission on Safety and Quality in Health Care

Chris Whipps
National LGBTI Health Alliance

Christine Slade
Consumer Advocate

David Hansen
Australian e-Health Research Centre, CSIRO

David Peiris
The George Institute for Global Health

Dean Martin
Consumer Advocate

Emily McNeil
AHMAC & Digital Health Branch, Department of Health

Emma Hossack
Medical Software Industry Association

Fiona Tuttlebee
Black Dog Institute

Harry Iles-Mann
Consumer Advocate

Jan Donovan
Consumer Advocate

Jane Burns
University of Sydney

Kelly Gourlay
Palliative Care Australia

Kim Webber
Australian Digital Health Agency

Kirsten McCaffery
Centre for Medical Psychology and Evidence Based Decision Making

Keziah Bennett-Brook
The George Institute, Australia

Leanne Wells
Consumers Health Forum of Australia

Marcus Tan
HealthEngine

Marienne Hibbert
Precedence Health Care

Mark Diamond
National Rural Health Alliance

Mary Foley
Telstra Health

Melissa Cadzow
Consumer Advocate

Michael Costello
HealthDirect Australia

Michael Frost
Australian Institute of Health and Welfare

Nicolle Marchant
Consumer Advocate

Paul Middleton
Take Heart Australia

Paul Nicolarakis
Lorica Health

Phil Offer
George Health Technologies

Rami Weiss
Healthshare

Riaz Ahmed
Central Queensland , Wide Bay and Sunshine Coast PHN

Richard Brightwell
Consumer Advocate

Richard Royle
PricewaterhouseCoopers

Rosemary Dillon
Consumer Advocate

Steve Hambleton
Avant Mutual

Tamsin Cockayne
Northern Territory PHN

Teng Liaw
University of New South Wales

Tim Kelsey
Australian Digital Health Agency

Going Digital

to deliver a healthier Australia

For more information about this report and related roundtable, contact the event hosts:

Dean Hewson
Digital Health Adviser
Consumers Health Forum of Australia

E: d.hewson@chf.org.au
P: 02 6273 5444

www.chf.org.au
CHFofAustralia
CHFofAustralia

Chelsea Hunnisett
Communications and Stakeholder Engagement Coordinator
The George Institute, Australia

E: chunnisett@georgeinstitute.org.au
P: 02 8052 4402

www.georgeinstitute.org
georgeinstitute
thegeorgeinstitute