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

<table>
<thead>
<tr>
<th>Dreamer</th>
<th>Realist</th>
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</thead>
<tbody>
<tr>
<td>What are some future disruptors that would benefit health consumers dramatically?</td>
<td>What conditions or building blocks must exist for your applications to become real?</td>
</tr>
<tr>
<td>Propose 2–3 potential applications</td>
<td>Agree major required elements for success</td>
</tr>
<tr>
<td>Recommendations</td>
<td>Propose report recommendations</td>
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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.
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 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.

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.

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.
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.

**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
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

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

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 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.

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.

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.
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 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. 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.

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).

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.
- Consumers a platform that facilitates the development of interactive networks of people with expert knowledge and first-hand experience of relevant health conditions.
- 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.

What we want

- 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)

What we have

- 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 deficit in health outcome that people in rural and remote communities experience

How do we get there

- 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.
1.3 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 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, indigenoussentinelhealthinfonet) 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, suitability and application of care, reduce waste and increase the quality and safety of the health system

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 ecosystem 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 reallocation 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 & care-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 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, identifying 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.

Naviagation 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 wellbeing, functional capacity, the prevention of further complications, and effective end of life planning.
What we want | What we have | How do we get there
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- 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 interoperability 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 deficit in health outcomes 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 reliable 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 antidepressics and anticoagulancers, such as Webstercare Medical Management 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.

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

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 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 or inpatient 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 advanced care planning 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 bookkeeping, 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.

Recommendation 4: 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 caregivers. 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 where and when needed.

If dying and death were incorporated into everyday conversations it would be much less stressful, 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 and their families if 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.

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.

- Make it a requirement for essential information from the ACP/ACD to be immediately accessible to those providing care (see emergency care section)
- Ensure functionality of My Health Record that enables carers 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
- Ensure that consumer preferences, including cultural and spiritual customs and beliefs, are respected and accepted by health services
- Support collaboration between government, industry, consumers and providers to co-design and trial digital 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
- Widen 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 complete an ACP/ACD and upload this 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

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.

What we want

- 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
- 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 caring for/ 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 deficit in health outcome that people in rural and remote communities experience

What we have

- 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
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How do we get there

- Provide improved access to information and resources regarding end of life care and planning regarding treatment options including carer support services.
- Examples include: CareSearch, PallAGED, 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
- Widen 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).

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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 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 deescalate 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 aver the need for unnecessary hospital admissions.
- The rapid response team could also inform general practitioners 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.

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?
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.

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Thank you

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