

**Design Session**

**Digitally-Enabled  
Informed Consent**

**Summary Report**

**INNOVATING**  
health

creating a new conversation

**INNOVATING** health series

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AUSTRALIA'S DIGITAL HEALTH COMMUNITY

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## About the Series

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HISA is delivering an ongoing thought leadership series - *Innovating Health: - Creating a New Conservation.*

Through an ongoing series of roundtable events, design sessions and other activities, we aim to lift and support the digital health innovation agenda in healthcare. Moving into 2018 we are *assisting leaders by examining practical change in the age of digital disruption.*

We seek to bring together health leaders with industry experts, challenge current thinking with new and different perspectives, harness our collective knowledge and ideas, and ultimately share topics and discussion with others to stimulate sector change. The series is in collaboration with and supported by **Accenture**.

Never has there been a time of such pressure on the healthcare system. The need to transform is vital.

Conjointly, the conditions and promise of innovative change are tangible through the development and application of new digital technologies, rapidly changing business models, Government policy reforms, the rise of health consumerism, and service led reform.

As the series has evolved it is clear that we have seen a shift in focus from participating health leaders and executives. There is general acknowledgement and understanding that digital change is occurring and health system needs to take advantage of the opportunity.

The questions are now about 'how'. How do I design new services? How do I respond to the dynamics of a digital and consumer society? How do I set an agenda for reform and change through digital? To this end a design session format has been implemented to provide a structured and facilitated process for designing and solving identified problems. We look forward to lessons and learnings from these sessions facilitated by leaders in the field.

*"Many of the ways we go about improving health and care were designed in a different mindset for a different set of circumstances.*

*Given the radical and complex nature of our transformational challenge, these 'tried and tested' methods increasingly won't deliver what we need to deliver for patients."*

*Helen Bevan and Steve Fairman NHS UK*

## Event 11 – Design Session – Digitally-enabled informed consent

Brisbane 19 April 2018

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### Overview

The Innovating Health Series was in Brisbane for another in its design executive events. A design thinking format has been introduced to these events as a way to move beyond discussion, harness collective experience, and strive to achieve practical outcomes and take-aways.

The problem statement introduced by Simone Finch, Founder of the **Westminster Initiative** focused on **digitally-enabled informed consent**. Simone was asked to define the problem statement as she has a wealth of experience across the health and social sectors. Among this experience, Simone has previously led a Hospital and Health Service, a PHN, as well as building strategies in mental health and providing advice on traversing the complexities of health and social care and the NDIS scheme.

Simone posed a practical case study problem that expressed the complexity across health and social services. The issues highlighted, while extreme, are experienced regularly by health providers, practitioners, carers and consumers. As digital systems and data become more pervasive in the health and care sector we are often still challenged by data governance and appropriate use. The session sought to focus on a specific case study example where there is potential for informed consent to be enabled by digital.

The design thinking session over lunch was then worked through on the stated problem with a group of 25+ health leaders and consumer group representatives. There was active discussion with a number of key outputs from the event.

### **Problem Statement:**

***“How do we use digital to enable informed consent across healthcare service provision – between patients and practitioners, between healthcare practitioners, and between consumers and services?”***

Simone posed the following case study to highlight the problem statement:

*Helen is a 46-year-old woman. She lives on her own in a privately rented house on the outskirts of a regional town. She is single and does not know where her two teenage children are – having lost contact with them after their removal as small children.*

*Helen is being treated by her GP for Type 2 diabetes and obesity. She has struggled with smoking all her life – it relieves the stress, but she knows it makes her sick plus it is very expensive. He doctor has referred her to the QUIT program through the local Hospital and Health Service.*

*She has ongoing, persistent mental illness and is seeing a psychologist on the Better Mental Health Plan. She is unable to work so receives a disability pension. She is hoping that she can access the NDIS but struggles to understand the system.*

*Her GP wants to refer her to the HHS for a diabetes care program but needs to share her information with them, particularly as sometimes her mental illness makes her anxious and paranoid. The program lead need to know, says the doctor, so they can respond appropriately.*

*Recently, her doctor noticed that she was losing weight. Helen admitted that she isn't able to eat because she has lost teeth. She got an appointment with the community dentist but cannot get to the appointment in the early morning as the bus doesn't arrive in town that early. The dentist sent her a letter. She cannot read it so she put it in the recycling bin as she is too embarrassed to ask for help.*

*Helen is functionally illiterate. She cannot read forms or understand what the doctors and nurses say about consent and her information. She worries that she will be laughed at.*

*She doesn't have an advocate or family member who can speak for her.*

*Helen needs care from a GP, psychologist, dentist and diabetes educator, in addition to support to maintain her rent and home – particularly when she is hospitalised with her mental illness.*

*She cannot read the consent forms and doesn't understand why she has to agree to the same thing everywhere she goes. Don't they all just share her medical records? Why do they keep asking?*

Yes, a rather complex problem, but one that the health and care system, practitioners, carers, patients and consumers deal with regularly.

The Innovating Health design thinking event asked participants to bring their health professional focus as well as their consumer focus to the problem. The facilitated session was conducted to enable the health executive participants to access a different way of thinking about this 'wicked problem' using a co-design framework.

## Design Session

The design session was facilitated by Adrian Wilson, Senior Manager and Design Lead for 2<sup>nd</sup> Road, a design company based in Sydney. General format of the session in brief:

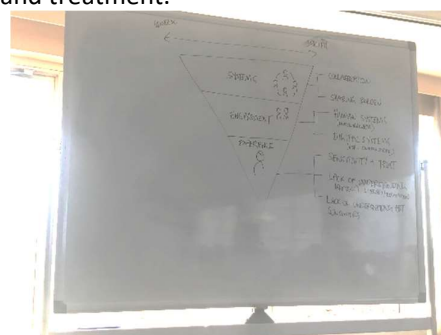
1. **Overview** of design thinking process and the **AcdB® model**
  - a. Four cognitive SPACES (explore the problem, envision a more desirable future, invent a solution, plan a way forward)
  - b. Immerse in each space – avoid jumping straight into solution mode
2. **A - SPACE. What's problematic / promising?** Exploring and reframing the problem
  - a. What's problematic about informed consent and the problem?
  - b. What are the key features of the problem? Why are they problems? Why do they bother us?
  - c. What do we really want to solve? What can we solve?
3. **B - SPACE. A vision of 'informed consent' in an ideal world**
  - a. What would "informed" consent look like if we truly had the patient at the centre of our thinking?
  - b. Reflect on our case study: what would it mean for Helen to be **truly informed**, and to **genuinely consent**?
  - c. Describe the experience of 'truly informed consent' – what would it look and feel like as consumer, clinician, health system as a whole
4. **C – SPACE. What can we do differently to realise this vision?**
  - a. Ideas for solving the problem (as we've defined it) that bring the desired experience to life, in a principled way.
  - b. What could we do differently to get the best of both worlds – technology and innovation in systems & services (that improve the quality and experience of care), while respecting

the inherent rights (e.g. right to privacy) and dignity of consumers; and empowering them to make good decisions about their health and treatment.

- c. How could digital/technology help us achieve this?
- d. Because the case study example was so complex, groups were asked to consider the problem in terms of 1) systems, 2) engagement, and 3) experience to frame their conversation.

#### 5. D – SPACE. Plan a way forward – Session summary.

The entire session was managed in just over 90 mins and was a great demonstration of thinking in groups through a design focus on the stated problem. Participants left with an improved understanding of the design process itself and some practical ways of thinking about a complex problem such as informed consent enabled by digital in a different way.



### Overview of Design Session:

A general discussion occurred in relation to the case study and defined problem and how it relates to informed consent. In summary, participants pointed out:

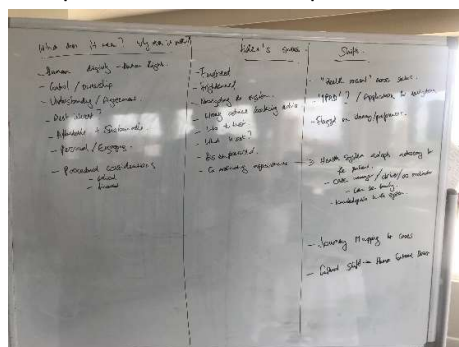
- Consent has never really been managed well in healthcare
- Effectively it's a procedural process covering requirements of the health organisation or practitioner involved
- Our systems do not cope well with consent, particularly when we focus on the patient / consumer experience
- There is to some extent a reliance on implied consent rather than express consent
- Clinicians will do the best for the patient but are working in the restrictions of their system

All participants agreed that there more that can be done here, it is complex, there is work underway, but when we approach it from consumer point of view the extended system of health and social care systems and system interaction becomes evident. This set the context for the design session which applied the AcDb® approach. Participants were divided into four groups to work through specifics in regards to the case study and problem area posed. A snapshot of group discussion is provided below:

#### 1. Group 1:

**The problem** - when asked: “why is informed consent important?” and “walking in Helen’s shoes”,

Group 1 discussed the importance of building new models of healthcare which afforded the



individual more dignity and rights. Acknowledging procedural considerations, there needs to be more focus on consumer engagement in healthcare transactions providing the opportunity for greater awareness and understanding toward individuals involved. The current process would see Helen frightened, unsure about what is happening, not trusting and a general feeling of helplessness. We need to shift to a model which adopts advocacy for the

patient / consumer, provides a clear pathway, and the opportunity to understand and increase health literacy for treatment and accessing the health and care system.

*The approach* – Group 1 focused on engagement as a way forward to address the problem Helen’s case study highlighted. Propose to focus on **health literacy** specific to a health service. This could include nurse support facilitated by iPad gazing to assist with education including the use of patient journeys which contextualise the example for the patient – what it means to them. Linking the consent process into the **patient journeys** was proposed as valuable approach. This is fundamentally designed to build ‘trust’ and working on the assumption that engagement begins at the community level. Target areas of biggest need, tailor messages which are specific to what’s important, and includes cultural change at the local level.

*“Building trust and engagement starts at the local community level.”*  
*IH Design Session Participant*

## 2. Group 2:

*The problem* – Group 2 identified that recording and sharing of information was problematic across the health sector. There is education and consent process tied up around awareness and



understanding, many providers working with a process and fear of losing a benefit, a general lack of trust in authority, sensitive privacy areas, and time pressures of clinicians that make this issue more problematic and difficult to change current systems. To answer why does it matter, to solve some of these complex problems the system needs to be more than a process – it needs to show empathy. It can do this through smoothing pathways for information sharing, applying ‘**standing**

**consent processes** except for certain agreed conditions and social situations. The shift to change needs to occur from moving away from paper form, to focus on process linked to a pathway, which is multi-modular, multi-language and allows easy access (such as mobile phone access).

*The approach* – Group 2 proposed a ‘**dream change solution**’ which was pitched as quick to implement to address system problems. It was to develop digital health pathways inclusive of the ability to define a health pathway, obtain conditional consent for that pathway from the individual, document interactions allow that health pathway, and allow ongoing access to individuals and their approved health providers to address systematic issues of double handling and fragmented service experience. The tool would be online, supported by visual and auditory content catering for multiple languages. Its implementation would be focused on target groups / populations of existing programs through a practical outreach process with Federal and State Governments providing stewardship over the model.



*“Define health pathways and standing consent processes for better individual engagement and system efficiencies.”*

*IH Design Session Participant*

**3. Group 3:**

*The problem* – Group 3 approached the problem from the perspective of risks to patients and consent path at different life events and through clinical pathways. Whilst its aspirational, it is difficult to build trust across the system as we are not all equal and all have different needs which create the complexity. Enabling consent across these myriads of scenarios ensuring the different aspects of the individual and the range of services and practitioners that one would need to see is problematic. It highlights that the system is under and over servicing clients, its not efficient, its difficult to navigate, and there are minimal people to assist and advocate for individual care treatments and pathways. Among other things, the Group explored whether ‘one consent is enough?’

*The approach* – A **Care Concierge** was proposed which focused on personalised care and delivering public good to address systemic problems. It would seek to ensure consistent identity



of individuals, provide a regulatory framework to allow for system data sharing through a consent engine which individuals sign up to and pre-authorize, enabling consent across health and social care services. The Care Concierge model would be built around 1) trusted information – which enables everyone to act diligently, 2) appropriate to models of care – nurse practitioners, GPs, carers, 3) governance which allows for clinical quality control, monitoring and

judgement in decision making, 4) consent engine enabling consent across defined pathways, and 5) allowing for the care concierge service to be enabled. The Care Concierge would be reliant on a health CRM system, to advocate for patients / individuals, to build trust in the model. The system would require the infrastructure to enable digital and a proof of concept approach to implement.

*“There are 28 different interventions for consent in Helen’s example.*

*It is currently complex”*

*IH Design Session Participant*



#### 4. Group 4:

**The problem** – Group 4 described the problem of why informed consent is important by recognising that the current system causes harm whether intentional or not. There is no consistency across the system, i.e. not all consent is the same, not all “sharing” is the same, not consistent across medical or care providers. The “problem” of engagement – digital highlights the problem, but mindset needs to change. We need to understand how we engage better to individuals. We cannot overcomplicate health and social care. Need to over-emphasise literacy as part of social communications. There is a need to share this problem across health and social services – not just a health problem. Consent matters because it is a) a right to understand and agree to something that will affect you (not just clinical) and that you have the capacity to understand and agree. Everyone should be afforded that right and in what context it can be sought, as well as how long it remains valid.



**The approach** – Group 4 focused on a systematic approach to engagement and change in informed consent tied to currently programs and initiatives already underway. They proposed Government saying ‘here is your data – this is what we know.’ There needs to be a process of validation and building trust with the consumer, but it is important people see the benefits and long-term outcomes from doing this exercise. It would be an incremental and share with consumer – what is next. To build trust an alert when health records are accessed would increase patient engagement and use of tools. This could be focused on targeted groups initially but it could include areas and groups to obtain data for research which currently occurs through other mechanisms.

*“Let’s validate the data – ask consumers – here is your data, this is what we know.”*

*IH Design Session Participant*

#### Conclusion - HISA Reflection on the Event

We were delighted with the proactive involvement and animated discussion through the design thinking process. We want to thank all health leader participants. We also thank Simone Finch and Adrian Wilson for their time, participation and expert facilitation of the session.

Our key take-aways as participants and observers at the event were:

- **Informed consent is problematic** – information sharing and consent is problematic across health before we even look at the social care sector and related interactions as we currently know it. There is recognition that this is not sustainable as we move increasingly into a digital future. Consumer focus will drive procedural change as we move forward.



- **Focus on the individual** – focusing on individuals involved in any health and social care transaction whether they are providing the care or receiving it is powerful in changing perspectives on the potential changes and solutions required.
- **Health pathways and consent matching** – all participants and groups highlighted health pathways and consent models as key approaches for change. These may have merit and there are examples where some of these models are already evolving.
- **Health literacy and consumer understanding** are key ingredients for change but we must make the systems simpler and provide appropriate support to better engagement to make a difference. A cultural change is required within healthcare to address individual engagement requirements of consumers.
- **Design thinking** continues to be a useful tool to gather new ways of thinking for well-established problems – of which we have many in healthcare. In terms of informed consent, it allows for HISA is continuing to host these sessions and refine the format taking the learnings and feedback from this session. Most participants commented on the process and its usefulness.

We look forward to our next instalment in the series in June when the series visits Canberra. Health Leaders in attendance for this Session were:

- Simone Finch, Founder Westminster Initiative (Problem Statement Facilitator)
- Adrian Wilson, Design Lead, Second Road (Design Facilitator)
- Kris Trott, CEO, Queensland Alliance for Mental Health
- Brentyn Parkin, CEO, MyCommunity Directory
- Dr Mal Thatcher, Healthcare Executive / CIO
- David O'Driscoll, Director Innovation and Development, Australian Digital Health Agency
- Dr David Evans, Deputy Director Medical Services, PAH, Queensland Health
- Anita Lee, Managing Director, Accenture
- Travis Hodgson, Program Director, Australian Digital Health Agency
- Anton Cush, Business Development Manager, Tunstall Healthcare
- Cory Monaghan, Senior Director, Architecture, eHealth QLD
- Dr David Hansen, CEO, Australian eHealth Research Centre
- Anne Curtis, Senior Engagement Advisor, Health Consumers Queensland
- Connie Land, Director Clinical Informatics and Digital Solutions, Mater Health Services
- Sallyanne Wissmann, Director Information Management, Mater Health Services
- Mitch Carre, Director, Digital Applications Support, Mater Health Services
- Dr Josie Di Donato, Leadership and Advocacy Director, HISA
- Ian Manovel, Principal Innovation Accenture
- Terry McNerney, Information Manager, Gold Coast phn
- Dr Alyson Ross, Director of Commissioning, Gold Coast phn
- Gil Carter, Principal, Vironi
- Narelle Doss, A / Chief Digital Strategy Officer, eHealth QLD
- David Bunker, Executive Director, QLD Genomics Health Alliance
- Greg Moran, HISA Host
- Joanne Scarfe, AAPAC Health Marketing Manager

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