Horizon Scanning Series
The Future of Precision Medicine in Australia

Consumer Engagement

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ABSTRACT

Understanding the consumer experience of health is a fundamental tenet to any long-term strategy in precision medicine. A scan of Australian consumer engagement in relation to precision medicine was developed based on the input of 5 key healthcare industry leaders (representing patient advocacy, personalised health, patient experience and healthcare research and development) and a review of recent literature on the subject.

The 6E framework of consumer engagement was used to structure the environment of consumer engagement. The current Experience of consumer engagement is set against challenges such as high out-of-pocket health expenditure and a lack of comprehensive structures and leadership in consumer participation. Specific to clinical research, there is an identified lack of translational platforms, patient cohort recruitment challenges, a lack of a centralised genomics data bank, siloed investments and funding from stakeholders.

More widespread consumer engagement can be undertaken by researching Emotions in terms of 'pain points' in societal health and building on the foundations of existing or siloed consumer Engagement frameworks. Understanding where engagement is needed is the first step i.e. governance, infrastructure, databanks, training and resourcing, tools, technologies and advocacy. Methods of engagement include information-delivery, consultation, placation on boards, government-agency partnerships and delegated decision-making power. Key Australian consumer advocacy groups include the Consumer Health Forum (CHF) and the Australian Patients Association(APA), the Health Consumers Council (HCC) and patient interest groups (PIOs). The diversity of consumers from an ethnic, socio-demographic or disease-specific is also a vital aspect of consumer engagement. Actual communication needs to be precise and 'mass-personalised'.

Where Execution processes are concerned, standardised clinical data is required as are 'anti-fragile', flexible policies. Excellence will be achieved through widespread PROMs and PREMs measurement and through genetic registries over the next decade. Success can be defined against the Healthcare Quadruple Aims (patient experience, health outcomes, cost per capita and staff experience). In Evolution of engagement, pilot 'test-beds' in populations for early trials of precision medicine is a key direction as are tools and technologies that 'personalise' medicine. Monitoring health behaviour, getting feedback and modifying behaviours, should be a key subject for exploration in consumer engagement particularly for rural communities.

Precision medicine, viewed holistically as personalised health presents a major opportunity for the public to decide what matters to them, and how the scientific agenda can be refined accordingly to deliver better health, wellbeing, productivity and happiness for the nation.

1. THE AUSTRALIAN PUBLIC IN THE CONTEXT OF HEALTH: DEFINITION

For the purposes of this input paper, members of the public refer to the population living in Australia who are citizens and non-citizens. In the context of precision medicine, they are referred to as 'consumers' and a key segment of that cohort are users of the health service system - the patient (the individual who has used a health service in the past or who could potentially use the service in the future), their family members and caregivers as well as the influencers of the system - the formal and informal consumer advocate, consumer advocacy groups and their members.

Precision medicine, gene editing and various other taxonomies of more targeted approaches to clinical care are subsets of a much larger opportunity for the public, which is personalised health and 'optimal living' conditions for each individual. Any discussion with the public should therefore contextualise the opportunity to the public beyond simply curative treatment approaches, as well as beyond purely gene-related sciences. Precision medicine therefore presents a major opportunity for the public to decide what matters to them, and how the scientific agenda can be refined accordingly.

> "*…it is now evident, more than ever before, to create population change in health outcomes and behaviours we need to shift the conversation to the individual, and strive to quantify each unique person and their (predicted and actual) responses to their ever-changing epigenetic daily choices that holistically encompass nutrition, exercise, climate, stress, sleep and the functions of the mind." - Matt Riemann, Health Scientist & Founder ph360, 2017.*

2. CONSUMER ENGAGEMENT IN PERSONALISED HEALTH: THE CONTEXT

The move towards consumer oriented business models is an unstoppable trend in all sectors of the global economy from Retail to Energy to Financial services. Increasingly, value is being co-created between system actors and consumers (patients) as consumers are no longer satisfied with being passive recipients of value created by firms or institutions.

The consequences of this shift are far reaching and the need for organisations in health to recognise that the power shift to consumers (in the form of choice and control in how services will be both delivered and consumed) signals a profound change on the horizon. For example, consumers will be more willing in the future to trade privacy for personalised benefit across all facets of the healthcare experience chain.

This power shift also comes at the expense of eroding trust in traditional institutions and incumbent systems. Stakeholders that are able to help consumers democratise their experiences and data whilst enabling more ownership of these experiences for the consumer will reap disproportionate rewards in the future. The ability of organisations in the health system to view the system horizontally (i.e., through the eyes of their 'customer') in combination with the traditional vertically oriented system is required (i.e., the current system is optimised for the firm or institution, not the consumer). Deeper consumer engagement is pivotal for this change to occur (Tice 2017).

Personalisation and precision medicine in health are a natural waypoint on the path to 'horizontal' or holistic, integrated and person-centered healthcare directed at improving individual patient and population outcomes. These key factors represent the biggest single opportunity in our lifetimes to restructure the health system on a more economically sustainable and outcomes based platform.

3. THE 6E FRAMEWORK: A STRUCTURED METHODOLOGY FOR CONSUMER ENGAGEMENT IN HEALTH

A framework that encompasses key methods of consumer engagement and patient experience has been used to discuss the considerations for public engagement in the health sector (Ratnanesan 2015). It covers:

THE 6E FRAMEWORK

E1. Experience - defining the current experience in the health sector against a backdrop of precision medicine

E2. Emotions - the importance of understanding person-centered frustrations and delights in individual and population health and wellbeing

E3. Engagement - planning for and stimulating levels of active participation including key engagement elements to consider

E4. Execution - considerations for policy development and solutions for implementation including tools and techniques

E5. Excellence – clarity on the target outcomes and experiences the impact of PROMs, PREMs and genetic registries

E6. Evolution - outlining the future of consumer engagement in precision medicine

3.1 E.1 EXPERIENCE

Healthcare remains to be one of the top 3 election issues in Australia (Blumer 2016) and therefore understanding the consumer experience of health is a fundamental tenet to any long-term strategy in precision medicine.

The Australian health care system was ranked 4th out of 11 developed countries (after UK, Switzerland and Sweden) by the Commonwealth Fund in 2013. Australia was also ranked 2nd for quality, whilst the worst health care ranking was access to services (7th). This is in some degree driven by higher health costs as the Australian public pays more for their health care than most other developed countries. The only other country with a higher proportion of patient paying excessive out-of-pocket costs was the US (Cutler & Olin 2017: p.5).

With such challenges, there is a significant baseline of interest for public engagement in health. This trend provides a significant opportunity for precision medicine, however, it reinforces that the discussion should involve areas of consumer priority and out-of-pocket expenditure such as individual wellbeing and optimal living.

In addition, the big picture of Australian healthcare (Ratnanesan & Howarth 2015: p.9) does pose some challenges for consumer engagement:

- A ‘fee-for service’ funding system: Doctors are incentivised by treating patients quickly and seeing a large volume of patients rather than their contribution to larger health outcomes. This is creating an environment where patients are treated for their presenting symptoms rather than root causes. Essentially, there is no ‘reason’ to engage and no ‘time’ to engage for clinicians and/or service providers.
- Lack of integration: A patient’s care is passed on from one clinician or service provider to another - there is no one person who has ownership or responsibility for managing the entire pathway of a his or her care, giving rise to incidences of errors, duplicated tests and inefficiencies and a lack of accountability
- Variable degrees of consumer empowerment: Patients in the public system do not generally pay for publicly funded services apart from co-payments with their medications (Medicare). They are, essentially, dis-incentivised from seeing private primary care practitioners or specialists. For the service provider, there is less motivation for services to improve to meet the needs of a passive consumer. For the consumer, this translates to a perception that there is a ‘lack of choice’ or a loss of empowerment as a consumer, particularly for a patient with an ongoing illness who may want to see a clinician in the private sector. This ‘lack of choice’ would be one of the reasons why consumer engagement exercises would be met with some cynicism by patients. Initiatives in precision medicine would need to illustrate very clearly the influence consumers would have on decision-making.

Other key reasons that limit the practice of engagement or affects engagement processes, cited by researchers that developed an engagement framework for South Australia Health and Medical Research Institute (SAHMRI), include (Miller et al 2017):

- A lack of structures and mechanisms in supporting consumer and community participation in health and medical research (p.2)
- A lack of leadership in consumer engagement in Australia that enables consumers to be meaningfully involved in initial stages of research (p.2)
- Very few examples of a comprehensive systemic approach to consumer participation in health and medical research (p.5)
- Almost no documented studies of participation of consumers in the more traditional scientific research endeavours (p.5)

There have been some success areas in certain silos e.g. HIV, breast cancer, Aboriginal Health however, influenced by factors such as social activism (p.5).

Where precision medicine's clinical research engagement is concerned, industry experts assert that (Damiano 2017):

- There is a lack of translational platforms that that would engage the university, hospital and industry (pharmaceutical, biotechnology, medical devices) communities
- A significant amount of time has to be invested to create a cohort of patients to engage in clinical research. Often universities, hospitals or pharmaceutical companies are pressed to either flex or simplify their inclusion criteria or alternatively going overseas to research, leading to an exclusion of Australian participation in the process.
- There is a lack of a centralised, shared Australian 'Genomics Data Bank' that can enhance clinical trials. Whilst this is the case, there will be an inability to achieve 'economies of scale' as well as 'scientific benefits of scale'. The current industry infancy stage presents an opportunity. It is critical that further research and strategy development is required in relation to how best to communicate and engage with the public on these issues.
- There is a lack of funding from the 'right' stakeholders; consumers engage widely in fund-raising events for certain specific diseases and comorbidities whilst the industry (with more significant research funds) may be unwilling to participate in commercially unattractive niche areas of unmet needs.
- There is an individualistic perspective in terms of funding – dollars are invested in certain silos of research; therefore, the industry is not developing overall, nor is the investment evidence-based.

''We need to spend money in what will develop the industry not in what a certain sector wants. Community engagement cannot be done without translational practices, and without genomic data banks we cannot develop precision medicine that will drive the research and science to the next horizon. The community cannot be engaged because we work in our own realm and …. instead of help, (we) segregate more. Not because we are not capable, it is because we invest without observing what others have done successfully'' – Daniel Damiano, Healthcare Manager ANZ, Oracle

Whilst there is an overall lack of infrastructure to support more widespread public engagement in both clinical research and social research, the opportunity exists to address this issue by involving the consumer in the development of the ideal infrastructure. This infrastructure would relate to government policy, planning, reforms, resources, databanks, tools and technologies to optimise ongoing and future health of the nation. There is also an opportunity to communicate the urgency of such an initiative to industry from a future focus standpoint. Setting this strategy in motion is likely to be impactful across all healthcare silos, not just precision medicine.

In making the case for this opportunity, the fact that precision medicine opens the door not just to curative treatment or illness prevention, but also optimal living conditions for health and wellbeing. This is a broader paradigm shift that would bring significant outcomes in public productivity, longevity, happiness and national economic prosperity.

‘Precision medicine is a 'means to an end', not an end in itself. Therefore, the focus should be on delivering improved health and wellbeing outcomes and experiences for the public good, rather than to introduce precision medicine approaches purely for its potential. Members of the public should be involved earlier in helping determine such strategies particularly in light of the immensity of social, ethical and legal considerations involved in divulging a lifetime of personal data – Dr Avnesh Ratnanesan, Energesse

3.2 E2. EMOTIONS

The Australian healthcare system is a fragmented one – primary care vs secondary care, public vs private and state vs federal. These cause ‘fault lines’ whenever patients, budgets and resources shift from one part to another, resulting in system-wide inefficiencies, variable standards of care and information asymmetries (Ratnanesan & Howarth 2015: p.9). Consumer engagement needs to take place to identify the depth of these ‘fault lines’, the details and stories where a patient’s health has been affected by these inefficiencies and therefore the implications, and opportunities, for precision medicine.

Budin-Ljøsne & Harris (2016), in a study on patient engagement and precision medicine which included patient interest organisations (PIOs) in Norway, the UK and US found that ‘PIOs interpreted the meaning of “personalized” medicine (PM) slightly differently from the promoters of PM. Although the PIO representatives largely agreed that focusing on the biological and environmental factors that may affect the health of the patient is important, they also believed that “personalizing” health care means that greater attention should also include taking the time to listen to the patient, learn about her values, assess her mental and spiritual well-being, understand her personal circumstances, and improve her quality of life and ability to function in society with a condition………and that no technological advancement or biological instrument can substitute the importance of the doctor-patient relationship’. Their views run concurrent with the patient experience emphasis on compassion, empathy and respect.

In this regard, public engagement is required in understanding the social determinants of health and which consumer journey touchpoints affecting a person’s health are not typically addressed by health systems. Such 'pain points' and frustrations in societal health could be addressed by personalised healthcare & medicine via more targeted approaches.

The challenge is balancing the addition of further complexity to diagnostic procedures for the front-line, which could incur greater cost, workload and stress for consumers (and health professionals), in the interest of better long-term outcomes.

3.3 E3. ENGAGEMENT

In identifying how to optimally realise public engagement in precision medicine in Australia, an initial literature review included, in particular:

a) Patient and Interest Organisations’ Views on Personalised medicine – A qualitative study,

b) A consumer and community engagement framework developed for the South Australia Health and Medical Research Institute's (SAHMRI) (co-designed with consumers and researchers) and

c) Arnstein's Ladder of Citizen Participation.

It was clear that the ideal infrastructure and engagement processes identified overseas (Norway, UK and US) matched the research outcomes of the Australian context. Arnstein's participation methods provide further guidance on channels to employ at each stage of engagement.