

Horizon Scanning Series

The Future of Precision Medicine in Australia

Public Engagement

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1. Abstract

Meaningful and diverse forms of public participation will be essential to crafting a rich public dialogue concerning the family of approaches known collectively as ‘precision medicine’. We argue below that it will be essential to encourage a ‘participatory ethos’ in these deliberations, and to invest in public engagement initiatives in ways that enable such processes to play a significant role in influencing policy appraisals of both precision medicine and the technologies and approaches that underpin notions of targeted healthcare. We warn of the danger of treating public engagement as procedural ‘add on’, both separate from and subsequent to developments in precision medicine technologies, devices and approaches. We argue that such an approach is not only undemocratic but unsustainable politically. In contrast, we emphasise the importance of a fundamental participatory ethos for precision medicine to progress in Australia, as well as its embeddedness in wider health policy debates. We review key concerns around precision medicine in Australia and internationally concerning data commons and their enclosure, and health justice. We identify a number of avenues for engaging citizens as individual patients, as citizens and health policy makers, and the importance of considering these various subjects of engagement together.

2. Public engagement

2.1. The Promise of Precision Medicine

Precision medicine is often invoked as a solution to multiple issues: as a means of enhancing drug efficacy, reigning in increasing health spending, preventing drug side effects through personalised treatments, and boosting wealth creation within the medical technologies and pharmaceuticals (MTP) sector (Collins & Varmus 2015). Yet some analysts accuse precision medicine advocates of wishful thinking, warning that its promises rest on capabilities that do not yet exist (Joyner 2015; Maranto 2015). Moreover, they caution that any dedication of significant quantities of public funding towards the realisation of its promises may, in turn, have significant consequences for public spending on primary care and preventive health, while also distracting from efforts to address the social determinants and causes of ill health. Practitioners need to be wary of taking for granted promises regarding what precision medicine will in the future be or do, or predictions of its inevitable development.

As we will argue below, in approaching matters of public participation and engagement with precision medicine, it will be critical to ensure participatory processes are structured in ways that enable them to consider the broad social implications – and opportunity costs – that are likely to be precipitated by substantial investments in precision medicine. Approaching these matters historically, it is striking to note, that the formation of public health infrastructures – both in Australia and internationally – might be understood as much as a public and political accomplishment as a technological one. This suggests that, in the context of what De Voe & Short (2003) describe as “corporatist-style [and] institutionalized relationship between the state and the medical profession” (p. 345), and given the broader challenges for instilling public participation in contemporary health and clinical practice – where “deeply entrenched values, beliefs and practices of medical dominance in Australian hospitals still prevail” (Long et al. 2006, p. 516) – policy

consideration of precision medicine should extend to conceptualising this task as a matter of democratic appraisal.

There are three very different dimensions of public engagement concerning Precision Medicine:

1. engaging people as individuals in relation to health treatments and issues (including applications, consent and privacy);
2. engaging people as citizens to consider the futures that Precision Medicine may create; and
3. engaging people as health policy makers to consider the place of Precision Medicine in broader health futures and in contemporary health spending priorities.

In each of these cases, we should be mindful of the generative effects of engagement, and its potential to reinforce particular representations of the future despite their speculative nature. Nonetheless, the social dimensions of precision medicine as imagined by its proponents, and as enacted in emergent activities and policy settings, can usefully be explored. As envisaged, precision medicine is a 'disruptive' technology (McLoughlin et al. 2017), creating 'ontological novelties' (Jasanoff 2005) and perhaps 'wicked problems' (Garrety et al. 2016). In addition, each of the promises of Precision Medicine carries with it some new implied relationships: between groups, clinics, sensing technologies, databases, and research facilities. In the context of the increasing digitalization of health and medical records, such new relationships also disrupt the moral ordering of medicine (Baines, Hill & Garrety 2014). That is, new identities and hierarchies emerge.

Given its potentially significant implications for health care, and the more certain demand for public funding and policy support that its pursuit entails, any decision to prioritise precision medicine as a goal for Australian health policy requires a strong participatory ethos. Whilst there is some evidence to suggest that publics who are genuinely included in policy making, and therefore feel included in the polity, are more likely to feel positive about health and health policy more generally, public support should neither be taken for granted, nor treated as a binary ('yes/no') condition. As work in science and technologies has long shown public ambivalence towards new technologies can reflect the multi-faceted nature of both hopes and anxieties that offers a productive resource to policy makers rather than constituting a 'problem' that warrants redress (Kearnes & Wynne 2007; Kerr & Cunningham-Burley 2000). At the same time, and in the context of broad public skepticism with, and at times withdrawal from, processes of formal political representation (Eliasoph 1998), ill-conceived and narrowly defined processes of public consultation can themselves become the focal point for public controversy and concern (Wynne 2006).

As the concept of 'precision medicine' has gained traction, especially in US biomedical policy discussions, participatory discourse has been much more prominent than in earlier biomedical paradigms (Blasimme & Vayena 2016). Yet this participatory ethos may be embedded within a broader normative 'project' for precision medicine that *remains unscrutinised and undemocratic in its aims*. This broader project needs proper public scrutiny. In the context of precision medicine, a participatory ethos is variously defined through concepts such as 'patient centred medicine', or through increased sharing of data (participation in 'knowledge commons') between various clinics, research facilities and biobanks (National Research Council 2011). Yet such approaches are typically constrained by an *a priori* positing of the individual citizen as patient, and as an individual 'rational health consumer', rather than someone who identifies first and foremost with many social groups (McLoughlin et al. 2017).

The promises made for precision medicine imply a significant reordering of relations in health care, which require participatory ethos that is both broadly defined, and capable of considering questions of purposes, responsibility and the opportunity costs of investing in precision medicine infrastructures. We suggest that a comprehensive participatory approach would also involve wider publics in discussions surrounding the objectives of health policy more broadly, and the envisaged place of precision medicine in addressing the nation's health: who cares for whom and how? In this way, public engagement would usefully locate itself in the context of broader discussions surrounding the future and future priorities of health care, recognising the plurality of future health trajectories.

2.2. Review of Key Precision Medicine Public Engagement Issues

The scope and intent of public engagement initiatives on precision medicine vary from ‘bottom up’ rethinking of medical expertise to more ‘top down’ public deliberation and outreach initiatives (Woolley et al. 2016). A lack of clarity around the ambition for public involvement – who is being engaged and to what ends – has been evident in some precision medicine and health data initiatives, such as Care.data (Carter, Laurie & Dixon-Woods 2015; Woolley et al. 2016). Care.data was part of a broad effort to override the Data Protection Act and enable all NHS patient data to be accessed for reasons other than patient care (such as research) without their permission (Woolley et al. 2016). Concern that reidentifiable data could end up with private operators was a key source of public backlash to the project (Woolley et al. 2016).

The decision by the administration of President Barack Obama to launch the US Precision Medicine Initiative (PMI) has raised the profile of precision medicine above and beyond earlier targeting approaches, such as pharmacogenetics. Within this, the participatory approach adopted by the PMI has helped it secure wider political support. As Blasimme and Vayena (2016) argue, “the launch of a Precision Medicine Research Cohort and the incorporation of a participatory ethos into the fabric of the [Precision Medicine Initiative] proved to be crucial determinants of the political support for precision medicine.” A public survey was conducted showing broad support for and interest in the concept (Kaufman et al. 2016). At the same time, that the PMI has also been the focus of significant public and policy scrutiny – which in part has questioned both its inclusiveness and its broad public mandate (Bonham, Callier & Royal 2016; Juengst et al. 2016; Newkirk II 2016; Reardon 2017; Woolley et al. 2016) – highlights the danger in assuming that investments in public engagement processes will necessarily lead to unquestioning public acceptance.

Beyond government and institutional-backed efforts to support ‘invited engagement’ in the form of surveys and consultative forums with wider publics, there are five broad areas in which we can see the emergence of new forms of social relations and sites of patient/ citizen engagement:

1. **Responsibilisation of patients:** “Precision medicine ... not only embraces a general trend towards expanding the scope of research participation. It also seeks to promote a culture of personal responsibility for one’s own health, and does so by using the language of empowerment” (Blasimme & Vayena 2016, p. 183). This ‘responsibilisation’ can be understood in a wider set of shifts devolving power from governments to individuals (Shamir 2008), and thus changing the ways in which members of the public and patients are engaged in their own health care.
2. **Consumer devices and sensors** are often imagined as the vehicles for this shift in power relations, and a site at which relationships between patients/ consumers, the state and markets are renegotiated. Where many critics see the shift in locus of health power from government to market as something to fear, others see a dismantling of old hierarchies as a source of liberation. For example, Eric Topol’s group at UC San Diego has been a significant recipient of PMI funding. He foresees a radical transformation in healthcare based on new technologies such as the Apple Watch (Topol 2016), whilst also warning of potential market power issues (Wilbanks & Topol 2016).
3. **Data sharing and commons:** an important dimension of precision medicine includes the creation of new data repositories with novel regimes of access and governance. Hood and Friend’s notion of P4 medicine (prediction, prevention, personalization and participation) emphasises the new sharing of data between laboratories. The creation of a data commons is a central theme of National Research Council’s (2011) report that prefigured President Obama’s Precision Medicine Initiative. These initiatives are crucial to public engagement insofar as they promise patients’ shared data will benefit a wider social group. As discussed above with the care.data project, a cross-cutting concern around data sharing is its enclosure by large corporations, who can then “trade people’s disease profiles, unbeknown to the patients ... or aggressively market health-related services to people regardless of whether those services actually benefit their health” (Wilbanks & Topol 2016).
4. **Justice:** there are wider concerns relating to the potential for precision medicine to inflame, rather than reduce, racial injustices around health, perpetuating longstanding mistrust between racial minorities and state health agencies (Bonham, Callier & Royal 2016). These concerns and broader issues surrounding health and social inequality are regularly canvassed in communities, in the media,

by social services and advocacy groups, and in academia, constituting a form of civic engagement that we may describe as ‘uninvited engagement’

5. **Embeddedness of hopes and concerns about precision medicine in wider health systems:**

Questions of justice surround not only the potential implications of precision medicine, but also the very effort to bring it into being, and to dedicate public funding to do so. The public controversy that surrounded the introduction of Australia’s Medical Research Future Fund, and particularly regarding the proposed \$7 GP co-payment which was intended to be a major MRFF funding stream, is a case in point. Health practitioners, health economists, patient and community groups argued publicly that cuts should not be made to primary and preventive health care to fund biomedical research. Again, this may be considered as a site of ‘uninvited engagement’ in the development of health policy.

Box/Appendix: Key Australian Precision Medicine Public Engagement initiatives

- Australian Genomic Health Alliance: ‘Genomics in the Community project’ centred on patients with education/information, and professional ethics consultation.
 - Queensland Genomic Health Alliance – no engagement initiatives
- Australian Law Reform Commission – Essentially Yours <https://www.alrc.gov.au/publications/1-introduction-inquiry/essentially-yours>
- [Australian](https://www.digitalhealth.gov.au/) Digital Health Agency ‘Conversation’ portal: <https://conversation.digitalhealth.gov.au/>

2.3. What have we learnt from Public Engagement on emerging and health technologies

There have been examples of public engagement in a range of emerging technologies and in healthcare, over the last few decades, both internationally and in Australia. There are lessons to be learned from these. Some engagement processes have engaged a range of people and shaped policy and regulation, others have alienated members of the public and been labelled as lip service. Because precision medicine has the potential to lead to significant controversy within public as well as professional groups, it needs to be considered carefully, and not rushed in to use.

One of most significant lessons from the introduction of genetically modified food and crops, particularly in Europe, was that members of the public will not automatically adapt to and adopt new technologies when they are introduced into society (Einsiedel & Goldenberg 2004; Kearnes et al. 2006). This is also the case for health technologies such as electronic health records in Australia, Scotland or England (Aitken, Cunningham-Burley & Pagliari 2016; Baines, Hill & Garrety 2014; McLoughlin et al. 2017), which were not embraced by patient and professional groups as expected.

Analyses of these unsuccessful attempts at introducing new technologies often invoke the assumption that the main reason people do not adopt technologies is because they misunderstand them, and that education will create support. This ‘deficit model of public understanding of science’ (Wynne 2006) has been strongly critiqued; instead, there have been calls for better *engaging* with a range of public and professional groups (Delgado, Lein Kjølberg & Wickson 2011; Durant & Jerome S. Legge 2005; Felt & Wynne 2007; e.g. Hagendijk & Irwin 2006; Marks 2016; Stilgoe, Lock & Wilsdon 2014).

Whilst engagement is important, it needs to be more than tokenistic; otherwise, it risks further alienating people (Kearnes et al. 2006; Wynne 2005). Public engagement therefore needs to be meaningful. It cannot only take place once a technology is ready for launch – it should be further ‘upstream’ in the development process (Einsiedel & Goldenberg 2004; Felt et al. 2009; Joly & Kaufmann 2008). It also needs to ‘open up’ (Stirling 2008) broader questions about the desirability of the technology, how it might be embedded within existing practices, how it risks disrupting existing ethical and professional norms, how it can cause patient or consumer alienation, how it should be regulated and who has responsibility, how it might reinforce existing inequalities, what options would not be pursued/funded if this particular technology went forward, or about broader risks and uncertainties (Carter, Laurie & Dixon-Woods 2015; Fan 2015; Garrety et al. 2014; Soulier, Leonard & Cambon-Thomsen 2016; Wynne 2014).

Public engagement and historical health controversies have revealed that people may want to influence the research, implementation and governance of technologies; therefore the outcomes of engagement (e.g. passive public support) should not be pre-determined (Callon & Rabeharisoa 2008; Corrigan & Tutton 2009; Epstein 1996; Nicol & Critchley ; O’Doherty et al. 2011; Sandler & Kay 2006). Trust-building thus becomes central: many participants in consultations regarding biobanks for instance do not want to be involved in day-to-day management of the database, but do want to know that their data, health and privacy are looked after (Haddow et al. 2008). Trust cannot be instrumentalised, however, and public engagement does not automatically lead to public trust; trustworthiness needs to be enacted and performed, not expected (Aitken, Cunningham-Burley & Pagliari 2016; Bates et al. 2010; Carter, Laurie & Dixon-Woods 2015; Marks 2011; Salter & Salter 2017; Stranger, Chalmers & Nicol 2005; Wynne 2006).

Public engagement then becomes a process and a political commitment to openness and listening, rather than a one-off event. It is not an easy task (Felt et al. 2009; Haddow et al. 2008; Katz et al. 2009; Salter & Salter 2017) and will require tinkering and care (Gill, Singleton & Waterton 2017; Marks & Russell 2015; Puig de la Bellacasa 2011)

2.4. Framing of Precision Medicine as an object of Engagement

With what are the public being engaged in? Precision medicine is “a family of approaches” to medicine (Blasimme & Vayena 2016, p. 173) and also to health. Whilst precision medicine is often presented as a transformation in genomics that heralds new forms of clinical diagnosis and treatment (see section 2.1) its promise includes prediction of disease emergence, prevention of disease progression and public participation (e.g. crowd sourced citizen driven trials) (Hood & Friend 2011). Thus, in addition to the personalisation of treatment, its implementation requires comprehensive datasets and new systems of data management, data-linkage and data interpretation. As outlined above, public engagement exercises often miscarry when the agenda is constrained to immediate concerns about quality and safety, and fails to engage with public investment in *future* trajectories of new technologies or approaches. Thus, optimal PE needs to both invoke these emerging and future trajectories and countenance the uncertainties they entail (Wynne, 2006).

2.4.1. What could Precision Medicine be? Ethical issues and beyond.

The wide ranging, fundamentally disruptive potential of precision medicine for health systems means debates about traditional ‘ethical’ considerations – such as informed consent, privacy and confidentiality, and personal autonomy – are unlikely to be sufficient. Ethics considerations often rest on balancing public good with individual autonomy in the introduction of medical technologies, when and how to achieve patients’ consent and so forth. However, as discussed above, such a patient-centred approach elides many of the significant questions that engagement should properly address. For example, if publics understand precision medicine as one of many pathways for future care, how can public spending on prevention, treatment, research be balanced; what priorities should inform research; what differences exist in the benefit distribution for the population at large of spending in each area?

The aspiration that precision medicine spans prediction, prevention, personalisation and participation has implications for engagement and consultation with:

- The creation of health infrastructure. In Australia the National eHealth Transition Authority oversees the My Health Record System and eHealth transformations e.g. Healthcare Identifiers Service and HealthConnect (transitioning to digital records). Slow public uptake of the digital My Health Record (11% of the population in March 2016) has led (2017) to an opt out approach. Yet notwithstanding the rationale for having taken a closed approach to developing E-Health in Australia, a recent National E-Health Transition Authority report signals the limitations this introduces for community engagement (National E-Health Transition Authority Ltd. 2016, p. 42).
- Transformations in training and job specifications for medical staff and healthcare workers whose future roles are envisaged to involve handling and interpreting of data so complex

that AI, algorithmic medicine, will play an increasingly integral role (National E-Health Transition Authority Ltd. 2016).

- Decisions about the role of the public health system in developing expertise to manage, interpret and use health data, and the extent to which private bodies and actors are involved not only in systems design but in its use. For instance, in the UK, the NHS provision of 1.6 million patient records to Google DeepMind for the purpose of app development was deemed to be in breach of UK privacy law by the Information Commission Office in July 2017 (See also (Woolley et al. 2016).
- Decisions about to whom benefits from the sharing of data from national records will accrue. An independent review of the UK life sciences sector, signalled the vital importance of health data as a public asset that enables the rapid growth of the health technology industry and called for the establishment of “capture for the UK the value in algorithms generated using NHS data” (Bell 2017, p. 60) to that the value of this public resource could be acknowledged and better captured.
- Decisions about other aspects of regulation.

In essence, the turn towards precision medicine is driving significant shifts not only for individuals’ diagnosis and treatment, but in the collaborative research, development, design and delivery of health care systems. This change, as signalled by (Bell 2017, p. 5), calls for “[a]new philosophy of collaboration and trust: underpinning relationships between government and industry”. We would suggest that what this new philosophy could or should be needs to emerge from social deliberation and engagement, if it is going to contributing to building the social licence for harnessing the possibilities of precision medicine.

2.5. Opportunities for meaningful public engagement and responsible innovation in precision medicine.

2.5.1. How should we engage members of the public about precision medicine?

As we have signalled, there are three very different dimensions of public engagement re precision medicine – engaging people as individuals in relation to health treatments and issues (including applications, consent and privacy); engaging people as citizens to consider the futures that precision medicine may create; and engaging people as citizens to consider the place of precision medicine in broader health futures and in contemporary health spending priorities. The former is necessary and important, and likely to happen. However, meaningful democratic involvement of the wider community in decisions about precision medicine requires the latter two, which may be harder and less likely to be supported by those with a stake in precision medicine. Deliberative methods – such as citizen juries, deliberative and multi-criteria mapping, planning cells, deliberative polling and consensus conferences (Burgess et al. 2007; Dryzek 2010; Mansbridge et al. 2012; Stirling & Mayer 2001) – are useful for enabling for citizen engagement process to encompass broader questions concerned with the societal dimensions and implications of new technologies. These methods bring a diversity of views and experiences, shift participants from a role as health consumers to a role as citizens, and can bring a public interest lens to consideration of the benefits, risks and opportunities of precision medicine (Hagendijk & Irwin 2006; MacLean & Burgess 2010). The most well-known deliberative method in Australia currently is the citizens’ jury (Russell 2016), but in its pure form, this method is unsuited to the kind of complex, nuanced discussion that is needed for this area of health policy. Citizens’ juries tend to focus on a single judgement or choice of options – reaching a verdict. Even the question of whether precision medicine is worth going ahead with is not a simple choice because it’s not clear what precision medicine is or what it means for individuals and health systems. The contested nature of what ‘precision medicine’ actually refers to – whether narrowly defined as pharmacogenomics or much more broadly to refer to targeted population health strategies involving a range of sensing and data gathering technologies – presents challenges for public engagement.

The consensus conference is better suited to a complex issue of this kind. It was used in numerous countries in the 1990s and 2000s, particularly to explore genetically modified foods (Dryzek & Tucker 2008; Joss 1999;

Joss & Durant 1995; Laurent 2009; Sclove 2000). These processes provided useful insights that have informed regulation and innovation in some of those countries, but there was a tendency to apply the model unthinkingly.

In recent years the use of these methods across an array of policy domains has been the focus of critical scrutiny, focused on the ways in which the drive to produce consensual outcomes from public dialogue processes may shield power asymmetries between social groups (Horst & Irwin 2010; Mouffe 1999). In addition, more recent scholarship has pointed to the ways in which this work is characterised by a 'residual realism' whereby both democracy and the public are rendered as pre-given categories that are imported into the design and evaluation of participatory practices (Chilvers & Kearnes 2016, 2017). If adopted in the social appraisal of precision medicine these methods should be designed reflexively in ways that mitigate their potential to reinforce pre-existing asymmetries between social groups, and in ways that are flexible and adaptive in light of the remaking of contemporary democratic practice.

2.5.2. Opening up precision medicine conversations

Citizens have demonstrated again and again that they are able to provide reasonable and useful answers, even about highly technical topics, when asked sensible questions (Burgess 2014; Fischer 1999). Asking people, "What do you think about whole genome sequencing?" or "Do you have concerns about precision medicine?" is just public opinion gathering, disconnected from the realities of science, technology and innovation. If we accept a post-deficit rationale for public engagement, we need to think about where democratic and technological imperatives meet; where values and technologies collide (Felt et al. 2009; Korthals 2011; Laurent 2017). We need to begin with a much more sophisticated understanding of the social, moral and political economy dimensions of innovation in this area to have a sophisticated conversation with citizens about what precision medicine might and should look like, and its place in our health system (Kerr, Hill & Till 2017).

This means opening up precision medicine, including opening up into a discussion of what 'precision health', and 'precision health systems' might look like (Stirling 2008). But also opening up 'precision' to understand how imaginaries and realities of this new thrust have implications for choices, relations, markets and trajectories and how these interact with existing arrangements and vulnerabilities (Bayer & Galea 2015; Kerr, Hill & Till 2017). Public dialogue needs to consider not only what precision medicine can/should do for individual health choices and outcomes, but also what it could/should do for health professions, markets and systems (Raisio 2010), and whether Australia should prioritise limited health funding in efforts to realise its promises. This is engagement that goes beyond success stories to conversations about what success looks like for society as a whole. These conversations absolutely have to address equity, not as an ethical side effect or risk of precision medicine, but as a central pre-condition and implication of personalised medicine, and as key to a public consideration of the extent to which precision medicine should receive priority public funding and policy support (Bayer & Galea 2015).

Though not used in Australia, Technology Assessment provides a range of approaches and methods to engaging publics that integrate engagement with other methods to consider more fully, and from a democratic perspective, the societal implications of emerging technology and innovation (Felt et al. 2009; Hennen & Nierling 2014). This integrated approach resonates with Responsible Research and Innovation in bringing public engagement from the margins and integrating it with analysis, anticipation and reflexivity amongst scientists and decision makers (Chilvers & Kearnes 2017; Guston 2014; Stilgoe, Owen & Macnaghten 2013).

2.5.3. Public engagement opportunities going forward

Some of the drivers and opportunities for public engagement activities include:

- Low uptake of e-health (arguably attributable to poor engagement, along with uncertainties in relation to data access and management), which has significantly eroded the capability of these new systems (Baines, Hill & Garrety 2014; Garrety et al. 2016; Garrety et al. 2014).

- Concerns about the implications of precision medicine for health care professionals (Garrety et al, 2014)
- Genomic Health Alliances and State-supported genomics initiatives, currently have limited focus on public engagement beyond patient engagement, but have investments in communication and engagement
- The Responsible Research and Innovation (RRI) agenda – currently weak in Australia but strong in Europe, connects with rhetoric regarding responsibility in these areas, building on past ethical, legal and social aspects (ELSA) work on GMOs, synthetic biology, genomics (Fisher et al. 2012; Jacob 2013; Owen, Macnaghten & Stilgoe 2012; Stilgoe, Owen & Macnaghten 2013; von Schomberg 2011)
- Technology assessment provides methods and cases (projects on personalised medicine in Sweden, Switzerland, UK - <http://www.eptanetwork.org/>)
- The *Science & Technology Engagement Pathways* program developed by the Department of Industry and Innovation (Department of Industry Innovation Science Research and Tertiary Education 2013) provides principles, approaches and cases (Russell 2013).¹
- The *Research Impact and Engagement Agenda* (under the National Innovation and Science Agenda) provides incentives for researchers, particularly in universities, to engage, including with publics.²

Some of the challenges and obstacles for public engagement include:

- Hype, promise, rhetoric – incentives for powerful groups in health systems to perpetuate
- Lack of understanding, and of methods and capability to understand, societal implications
- Ageing – pressure, urgency, economic drivers

Precision medicine, like other emergent fields such as artificial intelligence, is seemingly moving forward in ways that are both produced by conscious choices, funding decisions and policy settings, and, in more decentralised fashion, by scientific and medical discoveries, technological architectures and commercial networks that sometimes appear to resist straightforward policy intervention. As advocates for precision medicine, policy makers and other health stakeholders grapple with the great challenge of how to productively shape health and medicine to meet societal needs, public engagement has much to offer in helping illuminate the aspirations, anxieties and preferences of individuals and collectives, and providing a site at which they may seek to collaboratively co-create health futures.

¹ See: <https://industry.gov.au/industry/IndustrySectors/nanotechnology/Publications/Community-Engagement/Pages/default.aspx>

² See: <https://www.innovation.gov.au/page/measuring-impact-and-engagement-university-research>

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