EDITORIAL

Testing for Life? Regimes of Governance in Diagnosis and Screening

ALAN PETERSEN and KIRAN PIENAAR

Testing—involving the analysis of blood samples or scans, colonoscopies, biopsies, or other procedures—is frequently the front door to healthcare. It often leads to further tests or treatments, perhaps hospitalisation, and sometimes unwelcome news about one's future. Consequently, being tested is fraught with meaning and is likely to evoke strong emotional responses in those subject to its regimes, including anxiety, fear and uncertainty. What if the test comes back positive? Should one gain a second opinion? Or confirm the results by undertaking further tests? If it is negative, should one feel relieved and get on with one's life?

While testing promises certainty—providing an objective, unequivocal indicator of an underlying disease or 'disorder', or susceptibility to such, and a clear path to treatment and care—it tends to give rise to many uncertainties and questions. In many cases, perhaps most, it calls for further investigation involving a cascade of other tests, which raise their own questions. It creates new categories and medicalised subjects (e.g., the 'at risk' or the 'genetically susceptible') and classifications (typically deriving from finer delineations of disease) that shape treatment and preventive approaches, and may profoundly impact individuals' sense of self and experiences of health. It almost always generates ethical dilemmas. Depending on the context, these may include 'the right to decide' (e.g., the individual or family in the case of tests for inheritable conditions); constraints on 'freedom of choice' in decision-making; what, if any action, to take on the basis of test results (especially in the case of genetic testing where test results do not equate directly with disease); and how to reconcile commercial interests with the broader 'public good'. It also has financial consequences as there are invariably associated costs and some procedures can be very expensive—which is an important consideration in healthcare systems where issues of cost-benefit often loom large. And it has politico-economic implications: testing itself or the results may serve broader governmental policy

Science, Technology & Society 26:1 (2021): 7–23
SAGE Publications Los Angeles/London/New Delhi/Singapore/Washington DC/Melbourne
DOI: 10.1177/0971721820964889

or commercial objectives (e.g., in decisions about who to exclude from insurance or who to target for treatments). In short, however one looks at it, testing is highly consequential and as much a socio-political phenomenon as a medical one.

This special issue explores the socio-cultural, politico-economic, policy and regulatory factors shaping the practices of testing in healthcare, and the implications of testing. The issue has its origins in a roundtable workshop, 'Testing for life? The sociology of diagnosis and screening', that we hosted at Monash University's Prato Centre in Italy, between 13 and 15 June 2018. All the articles are based on papers presented at that event. Not all the participants at that event chose to contribute, but we are pleased that many did since the issues raised there are significant, and even more so since the onset of the COVID-19 pandemic which has given rise to concerns about the accuracy of tests and the impacts of testing. We are delighted to also include interviews with two scholars who took part, Annemarie Jutel and David Armstrong, whose work is seminal in the sociology of diagnosis and screening.

Before we introduce the articles and the interviews, we begin with some observations on recent trends in the practices of testing and offer a broad perspective on this field, drawing on ideas from science and technology studies (STS) and insights arising from our workshop. The topic of testing in healthcare is not new in sociology and other social sciences, and we acknowledge the various important contributions made by colleagues to date, including investigations of population-based screening and routine diagnostic practices in the clinic, specifically prenatal genetic testing and direct-to-consumer genetic testing (e.g., Armstrong & Eborall, 2012; Hallowell, 1999; Jutel, 2011, 2019; Mol, 2000, 2002; Tutton & Prainsack, 2011). This work has focused on discrete diseases/conditions or specific populations, screening and/or diagnostic practices, and the experiences of those who receive or deliver diagnoses. However, there are other issues of great significance which are rarely if ever explored in the literature that we wish to highlight here.

The practices of testing, we contend, have far-reaching socio-political implications, constituting regimes of governance that guide, conduct and shape subjectivities in particular ways and with particular outcomes (see our interview with Annemarie Jutel). These outcomes include, crucially, decisions regarding processes of life such as when it begins and ends, and whether or not and when to intervene to alter its path: for example, through the use of biomedical treatments. We consider the dimensions and significance of this biopolitical governance, especially in light of a growing reliance of many contemporary societies on big data-based technologies of diagnosis using personal, genetic, medical, lifestyle and other information to identify and evaluate 'risk' and 'disease'. As we observe, while trends in testing are worrying in many respects, especially regarding growing intrusions into bodies and lives, the history of technologies indicate that paths of innovation are not inevitable and there is always scope to forge alternative, less technologically mediated futures. We conclude by discussing some potential scenarios for testing in the future.

The Observed Rise in Testing

Our own research has its origins in part in the effort to make sense of the rising incidence of testing in a number of contemporary societies via both national cancer screening programmes and the clinical practices of medicine and healthcare. As many healthcare professionals have noted, and as statistics suggest, this rise has occurred over a period corresponding with—and apparently contributing to—burgeoning national healthcare costs. In Australia, for example, the use of pathology and diagnostic imaging services has risen sharply over the past decade, costing the publicly funded healthcare system, Medicare, AUD$5.25 billion in 2013, with GPs requesting 70 per cent of Medicare-funded tests (Alexander et al., 2015; Bayram et al., 2009). Imaging tests in particular have increased significantly with 7 million more imaging tests ordered nationally in 2014–2015 than in 2005–2006 (Britt et al., 2015). We have sought to understand the factors underpinning the optimism and expectations surrounding testing, which persist despite a lack of consensus on the value of tests and growing concerns about unnecessary testing (Carpenter et al., 2015; Moynihan et al., 2012).

The rise in testing may seem uncontentious in modern healthcare systems that share a strong preventive and early intervention ethos. It can be argued that there is nothing necessarily problematic about such a trend, which merely reflects improving standards of healthcare. However, while many people undoubtedly benefit from early diagnosis through testing, research shows that some tests may lead to unnecessary and costly, if not harmful, treatment. While these tests might lead directly to treatment and improved health outcomes, they might also prompt a cascade of further—and potentially unwarranted—tests (see Carter's contribution in this issue). Moreover, a growing body of evidence suggests that over-testing is becoming a significant problem in a number of countries with implications for patient care, clinical practice and the sustainability of healthcare systems (McGregor & Martin, 2012; Morgan & Coleman, 2014; Moynihan et al., 2012). While some individuals certainly benefit from undertaking some tests, from a cost-benefit perspective alone, one can question the overall value of testing in the population at large over the longer term, especially given the aforementioned cascade effect that tends to occur.

In recent years, within sections of the medical profession growing concerns have been expressed about the implications of over-testing and over-diagnosis, which led to the American Board of Internal Medicine launching the Choosing Wisely (n. d.) initiative in the USA, in 2012 (Cassel & Guest, 2012). This initiative aims to promote community debate and awareness about the use of unnecessary and potentially harmful tests, treatments and procedures, with a view to reducing inappropriate or low-value testing and treatment. Some of those who are involved in research related to this initiative attended our workshop. The Choosing Wisely initiative is no doubt underpinned by genuine concerns about the physical harms resulting from unnecessary tests and treatments. However, related public statements suggest that economic considerations, namely burgeoning healthcare costs and the

evident waste associated with excessive testing and the diversion of resources from other pressing areas of healthcare need, are also significant.

In this special issue, our focus is not restricted to 'over-testing' and the resultant 'over-treatment' that may occur which—as important as this is—provides a particular framing of issues that restricts investigation to matters of professional and policy concern. In our own research we have sought to bring a wider lens to the field of testing, to explore the array of factors that may account for the optimistic expectations for particular tests and for testing in general in healthcare, as well as the socio-cultural and political implications of testing for purposes of diagnosis and screening. In particular, we ask, what does the optimism for testing in healthcare reveal about contemporary processes of governance?

Widening the Lens

Scholarly work on testing thus far has been dominated by the perspectives of biomedicine, bioethics and psychology, which, while valuable in some respects, serve to narrow public debate and action on issues. Bioethics principlism, involving the application of abstract principles such as 'respect for autonomy', 'beneficence' and 'nonmaleficence' to particular areas of clinical practice, pervades virtually all scholarship on testing as well as other areas of medicine and healthcare, and underpins the regulatory framework governing related practices (Petersen, 2011). The widespread appeal of principlism is that it accords with the prevailing ideology of liberal individualism and the notion that individual freedom and rights should be paramount in health-related decisions.

This emphasis on abstract principles and on individual liberty, benefit and safety diverts attention from profound socio-political and personal consequences of the instalment of regimes of testing. These include the creation or reinforcement of inequalities or discrimination associated with resulting biomedical classifications; the heightening of social anxieties among those who are tested, their families and the wider community; and the apportioning of responsibility to particular groups for health and risk management, who are liable to be blamed for their failure to engage with related practices or for expected health outcomes. With prenatal testing, for example, new technologies such as 'non-invasive prenatal testing' enable new ways of classifying 'healthy' and 'unhealthy' fetuses, and shaping citizens' sense of self and responsibility (in this case, mothers who give birth to a child with a disability that could have been 'prevented') (see Thomas et al., this issue). Those who are classified as being, say, 'at risk' of disease or being a carrier, or having a genetic 'defect', may be implicitly blamed for either having the disease/condition and/or not undertaking certain prescribed actions. In many cases, the outcome is stigma, and sometimes ostracisation and punishment (e.g., denial of treatment or of health insurance). In the history of testing, such outcomes are perhaps most evident in the case of those diagnosed with HIV/AIDS (see e.g., Banda, 2015; Pienaar, 2016) but are also apparent with those diagnosed with lung cancer and

certain other diseases or conditions (see e.g., Chapple et al. [2004] on lung cancer, and Fraser & Treolar [2006] on hepatitis C). COVID-19 has highlighted how the fear of stigma associated with a positive test result may shape behaviours, with reports that some patients have been deterred from getting tested and have also prevented others from gaining access to help because they feared that a positive result may result in stigmatisation (Cook & Dow, 2020). From almost the beginning of COVID-19, the World Health Organization and other public health authorities recognised that concerns about stigma could discourage people from being tested (IFRC, UNICEF & WHO, 2020).

Testing in Historical Perspective

Largely missing from the scholarship on testing are historical perspectives on the development of technologies and the contestations that invariably surround the adoption of particular tests and regimes of testing. These histories shape technological trajectories and outcomes—what tests enter mainstream practice, how they evolve and who gets to use them—and the meanings that are ascribed to them. Historical investigation of the practices of testing reveals the different interests involved in problem definition and the issues at stake in decisions surrounding the adoption of certain tests. The contestants may include the producers of tests, researchers, health professionals, and patients and their communities who demand action on their disease or condition. Such interests are evident in the case of PSA testing. As one of our contributors, Robert Aronowitz an eminent medical historian shows, once approved by regulators in 1985, PSA testing quickly reinforced the prevalence of the disease and preventive and treatment efforts—what he calls the 'looping effect'—along with fear among those detected with cancer. Historical investigation reveals how certain paths of technological development become settled and how this shapes subsequent innovations and investments. Once technologies are approved and enter clinical practice they very often find newer applications, and early reservations may be cast aside in light of the newly discovered or assumed benefits of their use. Professional groups undertake 'boundary work' in order to defend their preferred technologies drawing on particular kinds of evidence to provide credibility to their preferences (Gieryn, 1999).

The history of the development of pharmaceuticals, especially 'blockbusters', highlights that commercial influence may shape the practices of testing, particularly via the shaping (especially widening) of disease categories and the redefining of what counts as credible evidence. This can be seen in the case of Viagra, for which the 'little blue pill' for 'erectile dysfunction' was eventually repackaged and marketed as the 'little pink pill' for 'female sexual dysfunction', which considerably widened the market (and the profit margins) of its manufacturer (Loe, 2004; Moynihan, 2003, 2005). In this case, considerable efforts have gone into developing a new classificatory system for 'female sexual dysfunction' through, for example, changes to the International Classification of Diseases and a series of

(unsuccessful) drug trials, all of which are part of an effort to medicalise female sexual response and promote pharmacological treatments (Bancroft, 2002; Loe, 2004, pp. 138–143). However, as discussed at our workshop, professionals also play an important role in installing practices of testing through, for example, making diagnoses that fit the treatment they feel is most appropriate. One of our workshop participants, Ray Moynihan (in his own and collaborative research), offers many examples of the widening of medical categories and the impacts on policies and clinical practices, including restricting action on options that may ultimately prove to be more beneficial or less harmful. For example, the problem of 'brittle bones' suffered by many older people, especially women, has come to be defined as a medical problem ('osteoporosis'), whose treatment requires the use of hormone replacement therapy, rather than as an issue of, say, inadequate muscle strength, poor diets, 'risky' lifestyles or environmental designs that predispose to falls—which call for preventive actions (e.g., Moynihan, 2003; Moynihan & Cassels, 2005; Moynihan et al., 2002).

Alternatively, as one of our workshop participants commented, diagnoses may be made for diseases/conditions for which there is no available 'treatment'. Dementia screening is contentious because there is no widely accepted efficacious 'treatment' for the condition. Yet Dementia Australia emphasises the importance of 'assessment for cognitive impairment for dementia' because 'an early diagnosis means early access to support, information and medication' (Dementia Australia, 2019). Similarly, the UK's National Health Service (NHS) stresses the importance of an early diagnosis, which 'may help you get the right treatment and support in place in good time' (NHS, 2019). However, the 'treatments' currently on offer are limited to at best easing some of the symptoms, rather than 'curing' the condition or reversing memory loss. The testing itself is complicated and lengthy, often involving assessments of behavioural, functional and psychosocial changes, along with radiological and laboratory tests, undertaken over three to six months (Dementia Australia, 2019). Perspectives on age-related cognitive impairment have shifted over the twentieth century, from being seen as an inevitable part of ageing—according to some due to the isolation of the elderly and their deprivation of meaningful interactions with friends and relatives—to being defined as a clinical category, mostly attributable to Alzheimer disease, in the 1990s (Fotuhi et al., 2009). Viewed from a historical perspective, one may ask, how did this biomedicalisation of dementia come about? Who are the key stakeholders in the research on and diagnosis of dementia, and how have they shaped responses to and experiences of dementia? Could an alternative history of dementia have been written? If so, what would this have meant for how dementia is understood and addressed? (For examples of recent research that engages with these questions, see Grenier et al., 2017; Shakespeare et al., 2017).

As was also pointed out at our workshop, most applications of testing have no link to diagnosis: testing is often used for monitoring and surveillance (e.g., diabetics, cancer patients), sometimes without any consequences for treatment

decisions and clinical management. In such cases the mere potential of disease entails ongoing risk management: even in the absence of diagnosis, we are forever driven by the potential of diagnosis (e.g., via regimes of surveillance medicine (Armstrong, 1995) and the spectre of 'risk' (Aronowitz, 2015)). Once technologies of surveillance are introduced they may become subject to 'path dependency', with earlier decisions affecting later ones and 'lock-in', whereby it becomes difficult to change the general direction of technological development given the investments and stakeholder interests involved. Many examples of path dependency and technological lock-in can be found in the area of testing practice, including ultrasound and magnetic resonance imaging (MRI), both of which had limited applications to begin with but have found wider deployment supported by many vested interests over time. The adoption of tests may have, and very often has had, less to do with proven clinical effectiveness or patient safety than with socio-cultural, political, economic and historical factors; for example, cultural ideas about technologies and visualisation ('seeing is believing'), commercial imperatives, healthcare policies, health insurance premiums and pressure exerted by interest groups. Commercial interests have played a significant role in the adoption of many tests, which is clearly evident in the aforementioned case of PSA tests (Aronowitz's contribution) and MRI (Joyce, 2008).

The Blurred Distinction Between 'Diagnosis' and 'Screening'

As we discussed during our workshop, the boundary between 'diagnosis' and 'screening'—often viewed and analysed as distinct modalities of practice involving discrete populations—is becoming increasingly blurred. It was suggested that while professionals may draw a firm line between screening—where targets populations that are otherwise well (the asymptomatic) but may have an underlying disease, risk or 'susceptibility' of which they are not aware; and diagnosis—which generally occurs in clinical contexts where individuals report with signs and symptoms. This line is becoming increasingly indistinct for various reasons. In particular, whole genome sequencing, which some writers suggest may soon find routine application in healthcare, promises to provide comprehensive, potentially universal risk profiles covering the entire population for a whole host of conditions, which may indicate the need for treatments or changes in lifestyle much earlier than would previously have been the case. This predicted earlier intervention into our biophysical lives would seem to reflect a wider trend in biomedicine, noted by Aronowitz (2015), involving the blurring between 'risk' and 'disease'.

This convergence of 'risk' and 'disease' has a number of consequences. At the level of populations, it creates new categories of the 'pre-symptomatically ill': those who are presumed to potentially harbour disease and are in need of ongoing surveillance and likely early biomedical intervention. Thus, even those who feel well are drawn into biomedical surveillance and intervention, and called upon to play their role as presumed responsible citizens in the surveillance of health through engagement in practices of regular screening and self-vigilance. With economies

becoming increasingly reliant on technologies of prediction—founded upon big data analytics using citizens' personal genetic and other health information—and on automated systems of risk analysis, a growing number of citizens are likely to become subjected to and subjects of surveillance (Zuboff, 2019). (On this, see our interview with David Armstrong.)

Taking Healthism to a New Level

This blurring of 'risk' and 'disease' has the potential to radically transform citizens' conceptions of self and their relationship to 'health' and 'risk'. Writing some decades ago, in the US context and before social media and the widespread use of self-tracking devices, Crawford (1980, 1994) observed the rise of an obsessive attention to healthy lifestyles, which he termed 'healthism'. Healthism, he noted, promised salvation of the self: a resurrection or transcendence through intensive work on the self by attention to correct diet, exercise, lifestyle and so on. Crawford (1994) characterised healthism as a political ideology enabling the middle-class, who at the time were experiencing an identity crisis linked to falling real incomes and standards of living, to distinguish a distinct identity, 'the healthy self'. As one of us (AP) has pointed out elsewhere, this ideology prescribes pursuit of an idealised conception of health that is both unattainable and may lead to an unhealthy obsession with diet and weight (Petersen, 2015, pp. 7–8). If new technologies of prediction find general adoption in healthcare, as anticipated by many commentators, citizens' anxieties about 'health' and 'risk' will likely be raised to unprecedented levels, and help underpin a new, consumer-driven economy of testing. As testing becomes increasingly reliant on big data-driven algorithms—that are inherently biased (e.g., Noble, 2018; O'Neill, 2016)—the potential for insidious surveillance, discrimination and exclusion will increase. One does not need to look too far into the future to envisage some of the likely implications. A 'breakthrough' announced at the time of writing, namely a genetic test for obesity, provides some pointers in this regard.

The Case of Testing for Obesity

The search for the 'obesity gene' has a long history, but has been given considerable impetus by developments in genomics, IT and data science over the last two decades. Research on the genetics of obesity has been used to argue that genetic factors may be involved in 40 to 70 per cent of the development of obesity (e.g., Herrera & Lindgren, 2010). Developing a test for obesity has evident great appeal to policymakers in contemporary societies who seek economic efficiencies, using technological solutions to complex problems and shifting more responsibility onto citizens for health and other matters. The idea of a genetic test also holds great appeal among the many commercial interests who aim to capitalise on major health problems such as the purported 'epidemic of obesity'. Not surprising then

that the news of a new genetic test that uses several million genes to 'predict' obesity, published in the journal *Cell* in 2019, has attracted great interest (Khera et al., 2019). The test is described as a 'prognostic test' whose value depends on its ability to achieve prevention of the condition by providing a warning of the need for changes in lifestyle or the use of specific drugs (Torkamani & Topol, 2019, p. 519). The researchers drew on data from a previous genome study, that examined the genomes of 300,000 people for 2.1 million genetic variants affecting body mass index (BMI), to develop a single number—the 'polygenic risk score'. The 'breakthrough' promised to enable scientists to understand why those exposed to the same or similar diets may end up with very different weights. It also suggested that individual 'will-power' may not be enough and that some may find it more difficult than others to control their weight (Guglielmi, 2019).

According to the researchers, the polygenic risk score has particular application with children when preventive opportunities are optimum, and will enable those at high risk to be targeted (Khera, 2019). However, the editors of the issue in which this article appeared offered some qualifications: there is 'no proven medication or intervention for obesity', the score relies on BMI as a proxy for obesity when there are known to be better metrics to quantitatively define obesity, and the study is limited to only those of European ancestry (Torkomani & Topol, 2019, p. 520). One issue not mentioned in the original article, the editorial, and the associated media commentary is that obesity is heavily stigmatised. Developing a test for obesity has the potential to reinforce the stigmatisation and marginalisation of those so classified, especially children for whom—according to the test's inventors—the test will have most applicability. One reporter commenting on the findings points out, 'Detecting health problems before they start is a major selling point for consumer genetics'; however, people may not recognise that the test is likely to be inaccurate and a poor indicator of future health (Flam, 2019, para 3). Setting aside questions of accuracy, if the test were to become routinely used it will likely serve as a tool for genetically discriminating against those classified as 'obese', denying them insurance coverage, future healthcare for perceived related diseases, or exclusion from certain types of employment. Asymptomatic 'obese' individuals will be targets of active surveillance, creating a new class of citizens denied what are currently considered to be basic rights to privacy and self-determination. The idea that a genetic test for 'obesity' could be useful for preventive health is underpinned by a series of highly questionable assumptions regarding this purported problem, and effectively shifts blame on to individuals for their failure to meet a culturally normative, ascribed ideal of body size and weight.

The entrenchment of market-oriented healthcare creates strong imperatives to develop and use technologies such as AI-driven diagnostic devices and genetic tests that promise predictive precision and 'empowerment' through 'choice'. AI-powered devices are already in development, such as mobile apps that 'can listen to coughs' and 'make diagnoses' (Eddy, 2019) or have been approved by regulators, such as the first FDA-authorised autonomous AI-diagnostic system in medicine that will allow the detection of diabetic retinopathy (Abràmoff et al., 2018). However,

many technologies are marketed with little or no effective regulatory oversight. Increasingly, tests are advertised directly to consumers via the internet on the basis of claims that are difficult if not impossible to verify and arguably involve deception (Akerlof & Shiller, 2015). Genetic testing companies constitute an especially thriving segment of this market. One of the most well-known and controversial, 23andMe, advertises itself as an online-based 'ancestry service' offering a relatively quick, painless, personalised means of gaining information on one's identity (23andMe, 2019); however, the company originally (in 2007) just offered genetic health tests, until it ran foul of regulators in the USA (Herper, 2013). Since 2014, the company has included both ancestry and health-related components in its tests. But are identity-based data and health-related data so easy to disentangle? And can individuals ever undertake genetic tests without there being implications for others to whom they are genetically related but who wish not to be tested?

The routinisation and normalisation of the use of such tests in the population may pave the way for a consumer-led, or 'weak' eugenics with the genetic selection of particular traits occurring through individual 'choices' exercised with the aid of the internet rather than via coercive or state-sponsored, 'top-down' eugenic programmes of the kind seen and overtly supported by all sides of politics in many countries in the past. This 'eugenics by the back door' has been identified by Duster (1990) as a potential outcome of the 'mainstreaming' of genetics in healthcare influenced by a combination of market forces and consumer desire. When considering potential eugenic futures one needs to clearly distinguish between intentions and outcomes of policies and practices, with an eye to historical and politico-economic trends (Petersen, 2007). While a resurgent, consumer-driven eugenics may seem far-fetched, Allen's (1996) historical research reveals that eugenic arguments have reappeared in different guises during periods of economic hardship, gaining support from both Left and Right. While we may not see a return of Nazi theories of 'racial hygiene'—which identified particular groups (especially Jews, the mentally ill and homosexuals) as sources of 'infectious disease' and legitimised their killing in the name of 'public health' (Glass, 1997), eugenics may take a more subtle guise via genomics-driven ventures that employ big data to establish a reference for 'normal' health and functioning. The strong preventive ethos in healthcare indeed creates an imperative to use technologies that offer the prospect of saving costs and reducing suffering (see interview with David Armstrong). Testing may find applications that go beyond those that are strictly health-related, involving genetic selection according to particular desirable traits. It is noteworthy that, at the time of writing, there are growing debates about whether prospective parents should be able to select the gender of their children using preimplantation genetic diagnosis (Foong, 2019). In one case, described by critics as 'what the Nazis wanted to do', an Australian couple was reported to have spent AUD$20,00 to travel to the USA to choose the gender and eye colour of their babies through IVF (Talbot, 2019). As consumer-driven healthcare becomes ever more entrenched, it is likely to become increasingly difficult to deny citizens their 'right to choose', even where this involves selections that prove discriminatory and contribute to eugenic outcomes

(see for example, Thomas et al., in this issue on the ethical issues surrounding the 'screening out' of disability through non-invasive prenatal testing).

The Uncertain Future of Testing

One of the key lessons to be drawn from STS is that technologies, as social products, rarely develop as envisaged. Innovations may, and often do, diverge from expected paths and are inclined to have unforeseen, unintended consequences. The potential implications of the recent trends we have described will only be realised if individual citizens continue to contribute their personal information to the big data projects that underpin genomics research and consumer genetics—and this ultimately relies on generating and sustaining public trust in the new technologies. Future 'digital healthcare' is ultimately reliant on citizens' 'active' engagements with new technologies, including social media platforms, apps and mobile devices that are required to harvest and share personal data. It presupposes certain practices of the self, whereby individuals use technologies in certain prescribed ways. The Cambridge Analytica scandal in 2018 and the My Health Record controversy in Australia the same year (see Confessore [2018] on Cambridge Analytica and Kwan [2018] on My Health record) highlighted considerable public concerns about the collection and sharing of personal data, and a growing mistrust in the big tech companies that exist only by virtue of monetising citizens' personal data (Petersen, 2019).

While in the past ordinary citizens have played an active, 'bottom-up' role in the development of some new tests and treatments—as seen most clearly in the case of breast cancer and HIV/AIDS communities—it is by no means certain that they will play such a role in the future. Growing calls for 'algorithmic accountability', pockets of data activism (with citizens developing their own databases to offer alternative sources to those offered by technology companies), and calls for greater regulatory control of Facebook, Amazon and other big tech companies, point to limits on some of the developments flagged above. Since, as STS scholars observe, technologies and users are 'co-produced' (Oudshoorn & Pinch, 2005), citizens may use innovations in totally unexpected ways. If we just examine one sector that is projected to increase in the future, the personal wearable market, while this appears huge (according to the marketing hype of the producers of FitBits and other wearables), the compliance rate is poor, with reports of a large number of people abandoning them over time because they do not find them useful or get bored with them (Petersen, 2019, p. 85). If the future testing economy is to be a personal data-driven one then new ways may need to be found to encourage citizens to contribute their data. The question is, will citizens comply?

Introduction to the Articles

This special issue brings together a diverse collection of research that draws on different disciplinary perspectives to explore the social, political and ethical

implications of the rise and expansion of testing in healthcare. Topics addressed include the role of testing in governing uncertainty and risk; historical and current practices of screening and the ethical issues they raise; and how testing technologies and practices in different healthcare contexts produce new, medicalised subjects. In reflecting on these topics, the articles contribute to debate about contemporary issues in areas of healthcare that affect us all—diagnostic testing and population-based screening.

In the first article, Stacy Carter draws on a large study of breast, cervical and prostate cancer screening to examine the persistence of cancer screening despite growing evidence of its potential to cause harm. Combining insights from the sociology of screening and overdiagnosis literatures, she identifies three possible reasons why support for cancer screening remains so strong. In its multi-faceted account of the persistence of screening, the article highlights how proponents of screening draw on persuasive promissory discourses to promote screening as an identity-shaping consumer service and as part of a collective effort to control biofutures. Faced with an uncertain future and the sceptre of cancer, it is perhaps unsurprising that healthcare consumers are swayed more by the promise of early cancer detection than by sober consideration of the potential harms of screening. However, as Carter concludes, there is a pressing need for conceptual and policy shifts to make cancer screening programmes more responsive to the potential for harm.

Robert Aronowitz' article, 'Prostate cancer: People transforming a diagnosis, a diagnosis transforming people' also explores the persistence of screening, but through a historical analysis of one of the most controversial types of screening, prostate cancer screening. Applying Ian Hacking's concept of 'looping effects' and drawing on a wide range of sources, Aronowitz traces the transformation of prostate cancer diagnosis from 1904 to the present day. In line with recent STS and sociological scholarship, Aronowitz argues that efforts to understand disease are inextricably entangled with measures to prevent, diagnose and treat it. In the case of prostate cancer, this means that attempts to resolve current screening controversies will require an understanding of the ways in which screening and radical treatment approaches have impacted knowledge of the disease. While acknowledging the role of unproven promise, fear and uncertainty in shaping problematic screening practices, the article ends on a hopeful note suggesting that it is possible to respond to the challenges of prostate cancer with more humility and greater attention to the role of screening in shaping the disease in unanticipated and sometimes harmful ways.

Also focusing on cancer screening, in their article entitled 'Informed choice and nudging in mammography screening', Marit Solbjør and Karen Willis conduct a discourse analysis of breast screening information on Australian and Scandinavian health authority websites. Applying Thaler and Sulstein's (2008) concept of 'nudging', they argue that despite appearing neutral and factual, screening information is presented using normative scripts which work to nudge women towards screening. However, the article also draws attention to the competing priorities that screening

websites juggle: on the one hand, they aim to encourage high participation by depicting screening as the default option, and on the other, they present it as an individual choice. In navigating this tension, breast cancer screening discourses in both the Australian and Scandinavian contexts use strategies of persuasion to encourage women to participate, while presenting the decision to be screened as an active, informed choice.

The next article, by Gareth Thomas, Barbara Katz-Rothman, Heather Strange and Joanna Latimer, shifts the focus to foetal screening, specifically non-invasive prenatal testing (NIPT), which is used to predict the risk of a foetus having a genetic condition such as Down Syndrome. Drawing on the authors' collective empirical research on earlier screening technologies (Katz-Rothman), Down syndrome screening (Thomas), genetic screening/testing (Latimer) and NIPT (Strange), the article outlines the unresolved issues that NIPT poses in relation to informed choice, abortion, and conceptions of disability and 'normalcy'. Despite its promise of safe and early diagnosis, the practice of NIPT raises a host of challenging questions about what a 'screen positive' result means, what action to take, and how to navigate the choice of 'therapeutic' abortion and its unsettling relationship to disability. As Thomas et al. argue, NIPT is inflected with moral, ethical and social concerns that bear directly on the bio-politics of procreation. In this respect, NIPT is a paradigm-shifting global technology: it represents a mainstreaming of genomics and as such, careful consideration needs to be given to how it is used and regulated, and how it shapes conceptions of disability and 'selective' termination, or in short, what constitutes an 'acceptable' life.

Continuing the focus on natal screening, Sarah Beth Evans-Jordan and John-Arne Skolbekken examine newborn screening (NBS) in their article 'Scientific citizenship's youngest domain: Function creep in Norway's newborn screening programme'. In the 1970s, the Norwegian government introduced newborn screening for genetic disorders and several years later in 2017 it sanctioned the secondary use of NBS samples for epidemiological research on conditions not related to NBS. Such use has been enabled by developments in genomics and biobanking, but it is not without controversy. Indeed as Evans-Jordan and Skolbekken argue, the secondary use of newborn blood samples for research purposes is an example of function creep with significant implications for the ways in which newborns are constituted in the eyes of the state. The expanded programme enacts infants as scientific citizens, subject to duties and responsibilities which were previously the sole preserve of competent adults, capable of giving informed consent. What are the implications of bestowing this form of citizenship on infants who are unable to advocate for themselves? How do we balance the need to protect the youngest, most vulnerable members of society with the pursuit of scientific progress through genomic research? As the article makes clear, there are no simple answers to these questions, but they need to be reckoned with if we are to guard against the potential adverse consequences of biobanking and protect those most at risk of harm.

The final article by Alex Faulkner, Kate Bloor and Vahsti Hale also grapples with challenging questions about the management of risk and uncertainty in relation to

testing. Using the case of Lyme disease, Faulkner et al. examine how governance institutions in the UK deal with diagnostic uncertainty in developing guidelines on testing for this highly contested illness. The article draws on the concepts of 'participatory governance' and patient 'group activism' to explore patient groups' participation in the development of new clinical guidelines on Lyme disease testing. While the analysis reveals high levels of patient group participation in the policy and evidence review processes, the extent of their influence is equivocal, suggesting that patient groups play a symbolic, rather than materially significant, role in guideline and policy development. The authors attribute this to the technical processes of the systematic review method and narrow definitions of what counts as evidence: together these features of the consultation process serve to limit the influence of patient groups, sidelining patient experience in health policy formation. It seems to us that the reliance on credentialed scientific evidence in health policy formation suggests a need for broader, more capacious understandings of 'evidence' that treat patient experiences as valid forms of knowledge, capable of informing policy.

Read together, the articles in this collection explore and extend many of the issues that prompted us to invite an interdisciplinary group of scholars to discuss medical testing and screening as regimes of governance with far-reaching political, social and material effects. While this collection was completed before the onset of COVID-19, the issues raised remain equally if not more salient when viewed in light of the unprecedented challenges that the pandemic poses. We are pleased that we were able to attract such engaging speakers exploring a diverse array of topics, and we are delighted that most were able to contribute to this special issue. We thank all of them for their contributions. We are grateful to the reviewers for their constructive, engaged feedback on the articles. Special thanks to David Armstrong and Annemarie Jutel for their insightful comments and reflections on surveillance medicine, the sociology of diagnosis and diagnostic practice. Their perspectives provide a rich contextual backdrop to the issues canvassed in the articles. And finally, we thank Amit Prasad and Venni Venkata Krishna for the opportunity to edit this special issue and for helping bring it to fruition. We hope it offers some insights into the socio-technical, political and ethical implications of the rise and expansion of testing in healthcare and encourages future research from diverse disciplines as well as ongoing public debate and discussion.

DECLARATION OF CONFLICTING INTERESTS

The authors declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

FUNDING

The roundtable workshop which formed the basis for this special issue was funded by an Australian Research Council Discovery Grant (DP170100504), awarded to Alan Petersen and Diana Bowman for a project entitled, 'Expectations of Healthcare Testing: A Sociological Study'.

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Alan Petersen
Sociology Program,
School of Social Sciences
Monash University, Australia
E-mail: alan.petersen@monash.edu

Kiran Pienaar
Department of Sociology
School of Humanities and Social Sciences Deakin University, Australia
Sociology Program
School of Social Sciences
Monash University, Australia
E-mail: kiran.pienaar@deakin.edu.au