Monash University Prato Workshop, 13–15 June 2018

Testing for life?: The sociology of diagnosis and screening

Monash University Prato Centre
Palazzo Vaj
Via Pugliesi 26
59100 Prato (PO)

Monash Prato Centre Guide, including information on centre facilities, things to do in and around Prato, restaurants, medical facilities, services in Prato and transport

DRAFT PROGRAM

Tuesday 12 June, 19:00 Pre-workshop welcome dinner (à la carte, pay-as-you-go) – Il Decanter [TBC], Piazza delle Carceri, 1/2, Prato.

DAY 1: Wednesday 13 June

Venue: Sala Veneziana (includes standard AV equipment, comprising laptop, data projector, overhead screen and audio facilities). Access to wi-fi and computer labs.

09:00–09:30 Arrival and registration

MORNING TEA/COFFEE

09:30–09:45 Introduction, welcome and event format – Alan Petersen, Di Bowman, Kiran Pienaar, Stephen Derrick

09:45–10:00 Alan Petersen – Expectations in healthcare testing: a sociological perspective

10:00–11:00 Theorising diagnosis

- Annemarie Jutel – Diagnosis and social pattern analysis
- David Armstrong – Diagnosis: From classification to prediction

11:00–13:00 Perspectives on the rise of screening and diagnosis

- Robert Aronowitz – Inaction, failure and then evidence-challenged enthusiasm: The early detection and radical treatment paradigm for prostate cancer, 1906-present
- Ray Moynihan – Connecting across the literatures to understand and address our over-enthusiasm for screening the healthy [via video link]
- Stephen Derrick – Medical testing and screening in Australia: An historical overview and initial classification system
- Sarah Beth Evans-Jordan – Biological citizenship's youngest domain: Function shift in Norway's newborn screening program

13:00–14:00 LUNCH

14:00–15:30 What constitutes evidence in Australia's cancer screening programs?

- Kiran Pienaar – Medical optimism, evidence and the production of scientific 'facts': An analysis of Australian cancer screening policy
- Stacy Carter – Evaluating cancer screening: Context, evidence, values and ethics
- Jane Williams – Evidence-based cervical screening: Experts' normative views of evidence and the role of the 'evidence-based brand'

15:30–15:45 AFTERNOON TEA/COFFEE

15:45–16:30 Panel discussion [Panelists - day 1 presenters; chair TBC]

- Key epistemic, socio-cultural, political and ethical issues in diagnostic testing and screening

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- The role of socio-cultural forces in generating and sustaining optimism for testing and screening
- What constitutes 'evidence' for testing/screening practices?

19:00 Conference dinner (à la carte, pay-as-you-go) – **Venue**: Lo Scoglio [TBC], Via Verdi, 42, Prato. Restaurant menu

DAY 2: Thursday 14 June

MORNING TEA/COFFEE

10:00–11:30 From research evidence to practice: Exploring accounts from health professionals

- Nina Hallowell – Moving into the mainstream: Treatment focussed genetic testing, a screening tool or diagnostic resource?
- Kristen Pickles – GP use of mindlines in decision-making on prostate cancer screening
- Pierre Bossuyt – Evaluating medical tests: From results to consequences

11:30–13:00 Testing, diagnosis and the making of medicalised subjects and populations

- Thierry Jutel – *Safe* and *Breaking Bad*: Narrative, diagnosis and the modalities of individual transformation
- Chris Degeling – Individualising a public: Representation and intervention in diabetes, and the health of populations
- Alex Faulkner – Politics and activism in detection and testing for Lyme disease in the United Kingdom

13:00–14:00 LUNCH

14:00–15:00 Screening and informed decision-makers

- Marit Solbjør and Karen Willis – Free to choose? Informed choice and nudging in mammography screening
- John-Arne Skolbekken – A critical examination of the notion of informed choice in medical screening

15:00–15:15 AFTERNOON TEA/COFFEE

15:15–16:00 Panel discussion (Panelists - day 2 presenters; chair, TBC)

- The role of testing and screening in assembling populations and producing new kinds of medicalised subjects
- Connections between medical testing and contemporary forms of biological citizenship
- Evaluating the concept of 'informed choice' in the promotion of screening
- The role of medical testing in the management of risk and uncertainty

DAY 3: Friday 15 June

MORNING TEA/COFFEE

10:30–12:00 Roundtable discussion (Chair – TBC) (all participants): Reflections on key findings from workshop and issues for future sociological research

- What insights and/or conclusions can be drawn from the research presented?
- Why does medical testing and screening merit (continued/renewed) sociological attention?
- What contributions do different disciplines offer to our understanding of the various factors that shape testing and screening? Who are the key stakeholders in the field of healthcare testing and what are their interests?
- What is missing from the existing social scientific literature on diagnostic testing and screening? What issues should future research address?

12:00–13:00 Workshop close, future plans and evaluation

- Do we wish to plan future events of this kind? Ideas for pressing topics/themes for related workshops?
- Do we wish to build international networks or collaborative research in this field?
- Any interest in convening an international conference panel on the workshop theme or a topic related to one of the themed sessions?
- Do we wish to publish a special issue and/or edited collection?
- Participant feedback/evaluation to guide planning for future workshops of this kind?

13:00–14:00 LUNCH

Key objectives and anticipated outcomes of the workshop

1. To increase understanding amongst the workshop participants and more widely in the scholarly, medical, policy and patient communities of the socio-cultural, political and ethical implications of the growing use of medical testing technologies;
2. To explore the distinctive contributions that sociology makes or may make to this topic;
3. To stimulate further research on the socio-cultural, political, ethical and regulatory dimensions of medical testing, screening and diagnostic practices;
4. To produce publications – e.g. a special issue of an international peer-reviewed journal or an edited collection – that will contribute much-needed sociological perspectives on the rise and expansion of medical testing and screening. While the focus of each publication will be unique, together they will offer new insights into diagnostic testing and screening as *social* interventions as much as medical ones.

Timeline

DAY 1: Welcome, format of event and participant introductions; identification and delineation of key issues for discussion (a brief discussion document will be distributed before the event); discussion of the socio-cultural forces generating and sustaining optimism for the use of testing technologies in healthcare; what constitutes 'evidence' for testing/screening practices?; panel discussion of key epistemic, sociocultural, political and ethical challenges/issues in diagnostic testing and screening.

DAY 2: Discussion of the role of testing and screening in making medicalised subjects and populations; consideration of the concept of 'informed choice' in screening discourses; identification of relevant socio-ethical principles governing screening and the tensions inherent in maximising the participation of target populations.

DAY 3: Reflections on key insights and findings from the workshop and consideration of future directions for critical social scientific research on healthcare testing; identification of key stakeholders in the field of healthcare testing and their interests; exploration of the contributions of different disciplines to understanding the socio-cultural, ethical, political and regulatory factors shaping medical testing and screening; planning for possible future events and international collaborative research on healthcare testing and screening; begin to map outline of planned publications (e.g. a special issue of an international peer-reviewed journal or an edited collection).

SPEAKERS – in order of presentations

Alan Petersen, Monash University
Expectations in healthcare testing: a sociological perspective

Over the last decade or more testing in healthcare has grown significantly. Testing includes such diverse interventions such as ultrasounds, MRIs and CT scans, colonoscopies, and testing for vitamin D and vitamin B12 deficiencies. In our research, we aim to understand the dynamic role played by expectations in the development and operations of testing practices. Specifically, we examine the sociocultural and politico-economic factors that underpin the rise in testing in healthcare, focusing on the Australian national cancer screening programs and the routine use of tests in clinical practice. In healthcare, testing is generally seen to provide unquestioned benefits, in both clinical diagnosis and in preventive screening. However, testing may also produce harms, through the interventions themselves or resulting treatments; further, the growing use of tests contributes to burgeoning healthcare costs and the misallocation of scarce healthcare resources. This paper will describe our approach to understanding the rise and practices of testing in healthcare, and discuss some findings and implications from our work thus far.

Annemarie Jutel, Victoria University of Wellington
Diagnosis and Social Pattern Analysis

Diagnosis—whether it be the classification of disease, or the process by which a patient's disease is named—is profoundly social in its enactment, with important social consequences. Yet, to illuminate the social function of diagnosis, one must go beyond common sociological precepts. In this presentation, I explore how a sociological understanding of diagnosis is enhanced by situating its analysis in multiple social contexts, rather than focussing on its particular and idiosyncratic instantiations. Using the example of diagnostic "truth-disclosure" (the revelation to a patient of a life-threatening diagnosis) and relying on Zerubavel's "Social Pattern Analysis," I show how the transformative social power of diagnosis can be generalised via the use of, and discussion about, diagnosis in popular culture, historical texts, and transnational medical approaches to naming of serious disease.

David Armstrong, King's College London
Diagnosis: From classification to prediction

For the last two centuries or so the primary role of diagnosis has been to classify the patient's illness, better to understand its cause, appropriate treatment and likely prognosis. During the last 60 years, however, the role of diagnosis has begun to change as medicine has conceptualised illness in temporal terms and evaluated diagnostic labels for their predictive ability. The temporal canvas of medicine can be seen in the growth of screening, primary prevention, anticipatory care and chronic illness, all of which emphasise the temporal trajectory of illness. Perhaps the dominance of the risk factor in modern medicine is the best illustration of these changes. The risk factor gained its importance not from its impact on understanding the cause or best treatment of illness but from prediction (based on population statistics). Attempts to further the predictive role of diagnosis include the promotion of molecular or stratified medicine that seek to 'personalise' the predictive algorithms based on risk factors. One effect of these changes has been to move

the human body – and identity – from its previous structured 'anatomical' arrangement to a temporal space of possibility.

Robert Aronowitz, University of Pennsylvania
Inaction, failure and then evidence-challenged enthusiasm: the early detection and radical treatment paradigm for prostate cancer, 1906–present

In order to better respond to current controversies in prostate cancer diagnosis, screening, and treatment, we need a more nuanced understanding of the history of the disease. Like our clinical responses to the disease itself, the historiography of prostate cancer has lagged behind that of breast and cervical cancer. I will use this contrast to highlight the social, economic, and professional factors which shaped 20th century American efforts to prevent and treat the disease.

My overall investigation is divided into 3 periods: (1) 1900-1940, when urologists developed but rarely performed radical prostatectomies; (2) 1940-1970, focused on one problematic proto-screening program; and (3) 1970-1990, when small bits of technical innovation in diagnosis and treatment led to the diffusion of a mass screening and radical treatment paradigm *prior to* rigorous evidence of its overall safety and efficacy. What emerged was a stable and self-reinforcing set of beliefs about the efficacy and safety of the screen and radical treatment paradigm. These beliefs have been largely immune to challenge by evidence from randomized clinical trials. Instead, they have been sustained by routines which simultaneously create fear and promise to relieve it.

Overall, the history of prostate cancer represents a significant case study of the social and psychological efficacy of modern medical interventions. This history provides insights into the cost/quality crisis in health care testing and other aspects of Western medicine and suggests we should expand our bioethical and policy gaze to the blurred boundary between practice and experiment, where so much problematic change occurs.

Ray Moynihan, Bond University -- via video link
Connecting across literatures to understand and address our over-enthusiasm for screening the healthy

Background
Overdiagnosis is recognised as a threat to health and health system sustainability - and screening is regarded as a key driver of the problem. Understanding the forces driving increasing screening and testing activities is critical to any effective collective response.

Together with colleagues at Bond University, I recently produced and published in *BMJ* a landmark map of drivers of overdiagnosis and potential solutions – created as part of the development of a national response in Australia to overdiagnosis and related overuse, involving multiple stakeholders: professionals, consumers, researchers, civil society groups and policy-makers. A limitation of our map, and our nascent national response, is an over-reliance on bio-medical literature and framing.

Methods and Results

Our literature search and analysis identified around 40 key drivers and solutions for overdiagnosis, within multiple related domains – culture, health system, industry, professionals and public. Enthusiasm for testing and screening programs were key drivers, while reform of screening and enhanced evaluation and regulation of diagnostic tests were identified as key solutions. In developing this Roundtable presentation, relevant sociological literature will be analysed and synthesized with the results of our published analysis, and employed to enhance development of Australia's national response.

Discussion
This presentation will develop connections between medical and sociological literatures, deepening understanding of our enthusiasm for screening, and how to address overdiagnosis. It will advocate more multi-disciplinary work like this Roundtable, and enhanced engagement with consumer and civil society organisations, to help facilitate a deeper societal conversation about iatrogenic harm and how to respond to it.

Stephen Derrick, Monash University

Diagnostic testing and screening in Australia: An historical overview and initial classification system

The use of pathology tests and procedures and screening tests has risen steadily in Australia over the past two decades. The number of pathology tests undertaken has grown from just over 40 million in 1993-94 to over 135 million in 2016-17. Consequently, there have been mounting concerns about whether all these tests are necessary and the costs to the public. In 2016-17 the cost to Medicare (Australia's universal health scheme) of all pathology tests was over $2.7 billion, up from around $700 million in 1993-94, an average annual increase of 5.6%. The numbers of some tests such as Vitamin D, Vitamin B12 and iron studies have grown much faster than this. For example, Vitamin D tests have increased at an average annual rate of 41%; Vitamin B12 at 14% and iron studies at 13%. The substantial growth in these tests attracted significant attention and the Australian Department of Health undertook major reviews of Vitamin D and B12 tests. Regulatory changes were then implemented in November 2014 designed to restrict use of the tests. This paper examines growth in a range of pathology tests, procedures such as colonoscopies, imaging procedures and screening tests for major cancers and presents information on numbers and costs of tests; use by age and gender and regional variations in testing rates. These data, extracted from the Medicare database, raise significant socio-economic issues about the rise in use of testing. Drawing on these data and information about the processes involved in each test, an initial classification framework has been developed. The aim of the framework is to develop a set of interpretive criteria that will inform the selection of tests for more detailed sociological analysis. In this paper, I will present the framework and invite feedback on its utility for categorising and assessing diagnostic and screening tests across different healthcare contexts.

Sarah Beth Evans-Jordan, Norwegian University of Science and Technology (
Biological citizenship's youngest domain: Function shift in Norway's newborn screening programme

Norway's newborn screening program (NBS) is having growing pains. As recently as 2011, the screening panel was expanded from 2 to 23 conditions. Just six years later, two more conditions are being added. At each crossroads, white papers are written, public comment is invited, and final regulatory texts are produced. There is discussion, but not much discord, about the conditions tested for. But some of the voices emerging in the public debate seem eager to introduce wording into the law that would serve to advance a research imperative by making NBS samples available for non-screening-related purposes. They argue that the potential benefit to the public good should outweigh concerns about privacy, consent, and ultimately, choice. Screening personnel fear hidden agendas may weaken public trust in the screening program, which currently enjoys participation rates of virtually 100%. This document and interview study reveals some of the processes that actors can employ that would turn the newborn screening program into a national DNA database. How might the aims of NBS and of epidemiological research both be served? Must the preservation of one jeopardize the other?

Kiran Pienaar, Monash University
Medical optimism, evidence and the production of scientific 'facts': an analysis of Australian cancer screening policy

Australians have high expectations of national screening programs as effective tools for early disease detection. But are these expectations higher than warranted? While many people benefit from early diagnosis through screening, research shows that some screening tests may lead to unnecessary, sometimes harmful, treatment. In this paper, we draw on theoretical concepts from science and technology studies to analyse how screening is presented in policy documents for Australia's breast and cervical cancer screening programs. Our concern is to explore how scientific 'facts' about the potential benefits and risks of screening are presented in policy to enact particular realities, with important effects for those who are the targets of screening. Focussing on policy claims about the effectiveness of screening, we analyse the ways in which these claims are authorised via appeals to 'evidence'. We argue that presenting evidence as neutral and objective obscures the political choices involved in generating evidence and scientific 'facts'. Importantly, some of the claims presented in the policy documents have a tendency to emphasise the benefits and minimise the risks and harms of population-based screening. In doing so, we suggest that national policy may be contributing to generating, and sustaining, higher expectations of screening than are warranted. Higher expectations bring with them societal and economic costs to the public.

Jane Williams, The University of Sydney
Evidence-based cervical screening: experts' normative views of evidence and the role of the 'evidence-based brand'

Organised cervical screening programs are a combination of social and clinical arrangements designed to maximize benefit and minimize harm associated with cervical cancer at the population level. Many organised programs are described as 'evidence-based', reflecting an expectation that healthcare should be based on the tenets of Evidence Based Medicine (EBM). EBM is both normalized and contested. As part of a larger study of how cervical screening came to be the way it is, we conducted a qualitative study of cervical screening experts' perspectives on evidence and its use in guideline development processes. We found that the 'evidence-based' descriptor was used rhetorically to indicate scientific trustworthiness; in short 'evidence-based' indicated 'good'. Experts held ideal, scientistic, conceptions of evidence and its use as objective and value-free, yet reported experiences that suggested those ideals were unattainable in practice. This produced pronounced attention to matters of efficacy and effectiveness of cervical screening *tests*, and neglected decisions relating to the social arrangements that combine to produce an organised screening program. Such arrangements include who to screen, who carries out the screening and how often, how to categorise risk, what data to collect and how to collect it. Rhetorical use of the "evidence-based brand" appeals to a particular kind of authority: one which is difficult to achieve in practice, and belies the variety of information that is required and the socially negotiated nature of policy and program decisions.

Stacy Carter, The University of Sydney
Evaluating Cancer Screening: Context, Evidence, Values and Ethics

From 2012 to 2016, we conducted a large values-based social science project: *Evaluating Cancer Screening: Context, Evidence, Values and Ethics*. We aimed to explain cancer screening as a social practice, with attention to the mobilisation of evidence, processes of guideline formation, routines of testing, and—especially—the values underpinning stakeholders' reasoning and action. We selected three contrasting case studies (prostate cancer screening, breast cancer screening and cervical screening), used interpretive social science and deliberative democratic methods, and engaged with policymakers, clinicians and members of the public.

We found that the construction of *evidence* about cancer screening entailed epistemic and practical paradoxes that seem both morally compelling and unresolvable. These paradoxes contribute to diverse *uncertainties,* which are underplayed in public-facing rhetoric but evident and troublesome for clinicians in particular. Institutional cancer screening discourses imply that it is a unified practice with clear goals and coherent justifiability. Contra this, we discovered extensive *variation* and *contest*: in understandings of the purpose of screening, in the values animating stakeholders, in routine practices of screening, in conditions underpinning these practices, and in the resulting consequences.

Consequences must be central to any substantive normative justification of screening activities, but the selection, prioritisation, conceptualisation and measurement of these consequences are all contestable and tend to be non-transparent. Meanwhile, public support for cancer screening is often strong and resolute. I will conclude by describing our current deliberative work on understanding this apparent tension between the justifiability and perceived legitimacy of cancer screening interventions.

Nina Hallowell, University of Oxford
Moving into the mainstream: Treatment focussed genetic testing a screening tool or diagnostic resource?

For many years clinical geneticists used *BRCA1* and *2* genetic testing as a screening test to identify those who had a genetic susceptibility to develop breast and ovarian cancer. More recently *BRCA* testing is used to direct the treatment of patients with breast or ovarian cancer, either informing their adjuvant chemotherapy regimes or surgical management. Thus, the role of BRCA testing in patient management has changed from that of a screening tool, used by a small group of specialists, to a diagnostic resource employed in mainstream cancer care (oncology and breast surgery). Using interview data, this paper will explore how healthcare professionals – oncologists, breast surgeons and clinical genetics professionals - conceive of this new application of *BRCA* testing. We will show that healthcare professionals prioritise treatment focussed *BRCA* testing very differently from the way it is intended within the patient pathway. We will argue the introduction of *BRCA* testing in the mainstream raises issues for professional identity and that in describing their engagement with *BRCA* testing healthcare professionals involved in the treatment focussed testing pathway engage in boundary maintenance (Geiryn), as demonstrated by their reconfiguration of the purpose of *BRCA* testing in this context. This paper, will thus, enable us to interrogate the screening-diagnosis.

Kristen Pickles, The University of Sydney
GP use of mindlines in decision-making on prostate cancer screening

Background: Australia and the UK draw on the same contested evidence base for prostate screening yet have notably different rates of PSA screening; they are the two locations of this research study. Gabbay and le May developed the concept of 'mindlines' to explain how clinicians use research evidence in practice. This qualitative analysis of GP perspectives on PSA screening draws on Gabbay and le May's theory.

Methods: An empirical study using grounded theory methodology. Data were generated from in-depth interviews with 69 GPs practising in Australia and the United Kingdom.

Results: GPs' described structural and organisational conditions in their respective healthcare systems that partly explained their varied screening approaches. We propose from this comparative analysis that GPs in Australia and the UK are following different mindlines, shaped by their individual cultures, contexts, and experiential knowledge. UK GPs agreed with the professional guidance they received and implemented relatively similar versions of evidence-based practice. Their mindlines were seemingly embedded in their organisation. Australian GPs were accustomed to a noisy marketplace of conflicting professional advice. Their mindlines were independently constructed based on individual experiences, strongly influenced by contextual considerations, and likely vary considerably from one GP to the next.

Conclusion: If GPs construct mindlines in interaction with their broader care environments, then it may not be sufficient to focus efforts to alter established screening practices of Australian GPs on micro level influences in isolation. It is likely that influences embedded at the meso level will require attention in policy and practice support interventions.

Patrick Bossuyt, University of Amsterdam
Evaluating medical tests: From results to consequences

Like all other interventions in health care, medical tests should be thoroughly evaluated before they are introduced into daily clinical practice. There should be sound evidence to support the recommendations about testing in clinical practice guidelines, to provide coverage through reimbursement decisions, or to invest in testing technology at the hospital level.

For a very long time, tests were introduced based on a generic promise that new technology will improve things. In laboratory medicine, the available evidence largely focused on the analytical performance of medical tests: to what extent can results be trusted? In imaging, reader studies were expected to convince potential users about the reproducibility of findings.

Increasingly, there is shift towards patient outcomes in the appraisal of health care interventions. In more and more countries reimbursement decisions are guided by considerations about effectiveness and cost-effectiveness: will these interventions improve the health of patients and other citizens, or simplify health care while not affecting quality?

We argue that the evaluation of medical tests cannot and should not escape from this consequentialist transition. Yet accepting this transition poses specific challenges, as trials that document the effects of testing on patient outcomes are relatively few in number in most areas of clinical medicine. The reasons for this evidence gap, and solutions for overcoming it, will be discussed.

Thierry Jutel, Victoria University of Wellington
Safe *and* Breaking Bad*: Narrative, Diagnosis, and the Modalities of Individual Transformation*

Imagining ourselves in the world implies telling ourselves stories about compelling transformative moments. The diagnostic moment is one which linguist Suzanne Fleischman refers to as transformative, when a simple utterance cleaves life indelibly into “before” and “after.” Diagnostic processes and pronouncements provide ready-made inciting narrative events in popular media. In this presentation, I compare and contrast two media texts which draw narrative, visual and aesthetic cues from the diagnostic process, or lack thereof, follow the subsequent transformations of their main characters, and reflect on the imaginative capacities and limitations of their characters to reshape their lives.

In the television series, *Breaking Bad* (2008-2013), a diagnosis of lung cancer leads character Walter White to transform from high school teacher and failed scientist into drug lord. In contrast, in Haynes’ *Safe* (1995), it is the absence of diagnosis which leads Julian Moore’s character to abandon her social role in pursuit of a safe refuge from the industrialised world which, she thinks, is poisoning her. Both texts explore the powers of self-transformation and limits of self-agency in the context of diagnostic and non-diagnostic pronouncements.

They are explorative ("what if?") and experimental in the sense that they align narrative, oral and visual forms with transformative processes. They are indicative and reflexive of societal expectations about the modalities of individual transformations.

Using textual and visual analysis, I will present how diagnosis and its absence offers modalities for individual transformation which extend beyond the impact of the diseases themselves, and work as pretexts to imagine the limits of the social.

Chris Degeling, University of Wollongong
Individualizing a public: representation and intervention in diabetes, and the health of populations

Diagnostic tests and diagnostic laboratories often play a central role in constituting and framing public health problems. Further, results from diagnostic data provide evidence that justify and direct public health action. A close examination of the discourse and practices surrounding the use of Hemoglobin A1C titres in the diagnosis and monitoring of type 2 diabetes mellitus (T2DM) illustrates how laboratory technologies perform four interrelated rhetorical and epistemic functions. At various levels and units of analysis—pathology, patient or population— the tests performed by diagnostic laboratories work to: *generate differences*, *constitute entities*, *transform knowledge* and *connect meaning with matter*. Rather than simply being an objective description of dysfunction, the knowledge created by diagnostic tests helps to translate descriptions into

individually directed actions, and to imbue people's everyday practices with beliefs and values. At the same time, the magnitude of need—in population terms—bestows value on a diagnostic test and the interventions that it intends. This way of linking patients and populations is aggregative: populations comprise large numbers of individuals. The notion that populations arise from and intersect with complex social or economic systems receives implicit acknowledgement in representing future needs-qua-incidence, but not when it comes to interventions. Instead, for T2DM at least, the scope for intervention remains focussed on clinical practice and self-management.

Alex Faulkner, University of Sussex
Politics and activism in detection and testing for Lyme disease in the UK

Lyme disease has recently become a growing matter of concern in the UK, as elsewhere in the world, with new patient groups being formed and increased policy attention, notably a current review by the National Institute for Health and Care Excellence (NICE), the health technology assessment 'gatekeeper' of technologies proposed for adoption in the public health care system. Media attention is increasing with frequent reports of high profile individuals allegedly contracting it, and reports of regional hotspots where the ticks carrying the bacteria appear to be prevalent. The disease is very controversial among public health professions and the Health Protection Authority, and the existence of a 'chronic' Lyme disease is disputed. For many patients, it appears to be an 'illness that you have to fight to get' (Dumit, 2006). Based on extensive collaboration with a Lyme disease information and campaigning organisation, led by an 'expert patient', this paper draws on a wide array of published documentary material and personal commentary, to describe the anomalies and uncertainties that characterise the prevailing testing

regime and diagnostic policy and practice. This is undertaken by juxtaposing official public health policy positions and healthcare policy statements against information and positions derived from the most prominent patient organisations, to reveal the wide range of disputed aspects both of the (official and unofficial private) testing technologies and clinical Lyme detection policy and practice. Conceptually, I shall discuss the account in terms of matters such as identity (patienthood, citizenship); diagnostic labelling; evidence-based activism; and the stakeholder politics of uncertain evidence.

Marit Solbjør, Norwegian University of Science and Technology
Karen Willis, La Trobe University
Free to choose? Informed choice and nudging in mammography screening

The debate about individual versus population benefit of cancer screening is contentious, particularly when referring to the screening of asymptomatic individuals. However, screening programs, such as mammography, are reliant on large numbers of individual women choosing to participate, in attempting to show evidence of benefit at the population level. This raises issues around the construction of choice, informed consent, and in particular, what information screening programs provide to potential participants.

The nudge approach advocates that 'choice architects' provide information about how to make healthy choices at the same time espousing that each woman must make her free choice about participation. Such an approach appears to be consistent with what Rose (1999) calls the *ideas of freedom that define the ground of our ethical systems and our practice of politics*. However, previous research shows that many participants in breast cancer screening are less concerned about making an individually focused free informed choice and more likely to respond on the basis of trust, experience of the healthcare system, or community values. The way screening providers design programs towards choice and uptake could therefore substantially impact on participants' decision making.

In this paper we explore the construction of participation in mammography screening programs by examining web pages for government funded mammography screening programs in Australia and Norway. We examine the how they position the choice to be screened, the notion of informed consent, and the strategies used to balance their own interest of high proportions of population participation alongside individual women's rights to freely choose.

John-Arne Skolbekken, Norwegian University of Science and Technology
A critical examination of the notion of informed choice in medical screening

Mammography screening is a widely applied tool in public health efforts to reduce breast cancer mortality. It is a technology in demand among women, despite considerable controversy among medical experts about its efficacy as a public health instrument. In addition to the debate over its usefulness, there is also an ongoing ethical debate about the information provided to enable women to make an informed choice about their eventual participation in a screening programme. It is the aim of this paper to examine this latter debate, to scrutinize the arguments and positions taken by the involved parties. Based on an initial analysis three positions have been outlined: 1) A pragmatist position argued by the screening providers and enthusiasts, focusing on the information that gives the largest participation rate. 2) A sceptic position, favoured by supporters of evidence based medicine, stressing the importance of providing a balanced information on the pros and cons of screening. 3) An ignorant position, expressed by screening participants, claiming that information is of minor importance, as long as mammography screening is provided. The latter position inevitably raises the question of how we are to understand women's position, as it perhaps indicates that ignorance is a bliss in this context. Hopefully, this question can be reflected on by the scholars attending the Prato workshop.

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