Prato, June 2018

Making Biofutures

Anticipating the futures of biomedicine, healthcare, and life itself

Introduction

For many, it is axiomatic that human life and health are reimagined and remade in biomedicine. Biopolitical futures, however, appear to be emerging as complexly hopeful and bountiful yet deeply unequal and opened to dangers. The promise and optimism that surrounds bioscience and biotechnology underpins significant investments in health and the wider economy. Novel biological entities are being created and commercialised, institutions and regulations are being reconfigured, and identities and subjectivities are being refashioned in line with idealised visions of how medicine and healthcare will/may/should evolve in the future. Imagined futures are frequently bound up with 'nation-building' ventures, such as those associated with regenerative and personalised/precision medicine and the medical tourism industry. This hopeful, profitable imaginary, however, is counterposed with the apparent limits of biomedical knowledge and our conceptions of risk, as well as troubles with public trust in science. Economic constraints limit what public health systems can do, and a deepening of stratified biomedicalisations - across the globe and within nations - are emerging in relation to the roll out of biotechnologies. Iatrogenesis of health problems, emerging infectious diseases and the prospect of failed vaccination programmes and antimicrobial resistance also complicate the picture of the biofutures coming into being. This situation presents significant practical and conceptual challenges for public health systems and calls for new research approaches and theoretical resources that can be brought to bear on these concerns.

Here, we explore how human health and the production of human life are being transformed with these developments, and we address related socio-ethical and public policy questions. The event will provide the opportunity to reflect on the futures that are likely to materialise, to anticipate the potential tensions and opportunities within these futures, and thus to address the questions: what futures do we want? And, how may the social sciences and humanities contribute to the development of a more democratic science and technology?

Health and Biofutures

The Health & Biofutures Focus Program
Faculty of Arts

MONASH University

Monday, 11th of June

9:45 - Coffee

10:00 - Introduction & Welcome – Alan Petersen, Sam Taylor-Alexander

10:15 - Session One: Promissory Subjectivities & Identities

1. *CRISPR cowboys? Genetic self-experimentation and the limits of the person*
   Courteny Addison

2. *An Organism to Make a Future: Interspecies Chimera at the Frontiers of Life'*
   Amy Hinterberger

11:15 - Morning Tea

11:30 - Session One (cont.)

3. *CRISPR Genome Editing, Pigoons, and the Future of Organ Transplants*
   Silvia Camporesi

4. *Molecular futures: Disrupting cancer trajectories and compounding uncertainty*
   Julia Swallow

12:30 - Lunch

2:00 - Session Two: Kinship & Care

5. *Women as Fathers: "Reproductive" Technology (Re)creates Family Values*
   Barbara Katz Rothman

6. *Remaking motherhood: MRT and alterity in maternal relations*
   Catherine Mills

3:00 - Afternoon Tea

3:15 - Session Two (cont.)

7. *The 'New Hysteria': Wandering wombs and the re-making of reproduction*
   Andrea Whittaker

8. *Ethics, robots and the care of the elderly. A view from here to the future*
   Mattea Gelletti

4:15 - Panel discussion, with speakers from sessions one & two

6:00 - Refreshments on the Terrace

Tuesday, 12th June

10:00 -Refreshments

10:15 - Session Three – Political Economies of Biomedicine

9. *The unequal ecologies of extracorporeal living*
   Lenore Manderson

10. *Post-stroke disability: Access, technology and the lingering effects of biomedicalised stratification in Malaysia*
    Narelle Warren

11:15 – Morning Tea

11:30 – Session Three (cont.)

11. *A critical sociology of the rise of precision medicine: The case of oncology*
    Alex Broom

12. *Overdiagnosis and the uncertain risk of future harm*
    Stacy Carter

12:30 - Lunch

2:00 - Session Four – Health Imaginaries and the Future

13. *Taking us to the cloud: the promise of 'big data' in future medicine and healthcare*
    Alan Petersen

14. *Imaginaries of health and wealth: Accelerating innovation of Regenerative Medicines medicines in the UK*
    John Gardner

3:00 - Afternoon Tea

3:15 - Session Four (cont.)

15. *The EU General Data Protection Regulation: which imaginary for European biomedical data integration?*
    Luca Marelli

16. *The same but different? Identifying continuities and disruptions as a route to making responsible biofutures*
    Michael Morrison

4:15 - Panel discussion, with speakers from sessions three & four

Abstracts & Biographies

Session One: Promissory Subjectivities/Identities

1. *CRISPR cowboys? Genetic self-experimentation and the limits of the person*

Courtney Addison (Victoria University of Wellington)

The advent of CRISPR was heralded as signifying a new era of genetic modification (cheap! easy! DIY gene editing is here!). As issues around CRISPR's ownership and usage rights played out in the courts, another kind of activity has emerged on the scientific fringes. Self-experimenters with post-human aspirations have begun using CRISPR and related technologies to anti-ageing ends. Some have live-streamed their efforts, in a technological confluence that would have been hard to imagine even ten years ago. Others have pursued a route closer to traditional scientific progress, seeking strategic endorsements and selectively eschewing the conventions of 'legitimate' experimental science. This paper analyses popular accounts of genetic self-experimentation, showing how this activity troubles notions of health and medicine, and norms that dictate who gets to practice science, how, and within what bounds. The futures these individuals seek to attain for themselves conjure up much wider possible 'biofutures', which implicate existing institutions of science and medicine, and advance a very particular notion of how to live.

Courtney Addison works at the cross-roads of Anthropology and STS. Her doctoral research (University of Copenhagen, 2017) explored the social and ethical dynamics of human gene therapy, and her current work maps the multispecies futures at stake in conservation genetics in Aotearoa. She is Lecturer in Science in Society at Victoria University of Wellington.

2. *An Organism to Make a Future: Interspecies Chimera at the Frontiers of Life*

Amy Hinterberger (University of Warwick)

Chimeric life forms constitute mergers between two or more distinct beings. In this talk, I will explore the making of interspecies mammalian chimeras in biomedical research where the availability of human embryonic stem cells and induced pluripotent stem cells has opened the way to radically humanize the biology of other organisms. By showing how chimeric life forms are foundational to biology, however, I loosen the compelling grip that chimeras have as liminal and monstrous. To the story of the chimera, I will reply with another story, that of the human as it is differently enacted at the levels of cells, tissues and organisms. Drawing on fieldwork conducted at a stem cell laboratory, farm animal research institute and primate research centre, I will show how meanings of the human become elusive and unknown when intertwined with chimeric life. In concluding the talk, I will reflect on what chimeras can tell us about the transforming politics of the human in biomedical research.

Amy Hinterberger is Associate Professor of Sociology in the Department of Sociology at the University of Warwick. Her research draws on sociology and the social studies of science to examine twentieth and twenty-first century life sciences and biomedicine. She is currently completing a Wellcome Trust funded project which investigates how the category human is defined, approached and governed in context of stem cell biology and regenerative medicine, looking particularly at interspecies mammalian chimeras.

3. *CRISPR Genome Editing, Pigoons, and the Future of Organ Transplants*

Silvia Camporesi (Kings College London)

One of the manifold promises of CRISPR genome editing technology is solving the shortage of human organs for transplantation through the development of humanised animal body parts (Feng et al 2015; Rashid et al 2014; Yang et al 2015). MIT guru George Church has been spearheading this research through the insertion of human genes into pig blastocysts, i.e. early embryos at the stage of 100-150 cells. Thanks to the editing in of human genes and the editing out animal genes, humanised animal models can be develop from chimeric human-pig blastocysts. This development is groundbreaking paves the way for growing pigs which are safe for xenotransplantation to humans.

Science fiction can sometimes be a precursor of biology imaginaries. In her 2003 book Oryx and Crake, British science fiction writer Margaret Atwood had seemingly anticipated George Church's experiments with her invention of the 'pigoons', i.e., engineered pigs for the mass-production of multiple organs for human transplants. The experiments did not end well, as those acquainted with Atwood's dystopias can imagine; the engineered pigs did not particularly enjoy being created for the purpose of serving humans, especially when they started developing higher neural functioning.

This paper will discuss the possible biofuture in which we will use gene edited pigs to serve as human organ donors. It will analyse the roles of science fiction scenarios in bioethics as "they become an increasingly important cultural resource through which we attempt to re-establish our narrative bearings and get a sense of where we are heading" (Shick 2016, 226). It will juxtapose the biofuture depicted by Atwood with the biofuture depicted by Kazuo Ishiguro in his 2005 book Never Let me Go, in which cloned humans are brought into being for the purpose of serving as living organ donors until their 'completion'. This juxtaposition will serve to unpack how a science fiction narrative-based approach to bioethics can bring to the fore the double temporality intrinsic in bioethics, whereby we influence the present time by anticipating possible biofutures. This double temporality shapes what kind of ethical and social questions we ask – and which we don't – about CRISPR genome editing technology.

Dr Silvia Camporesi is a bioethicist with an interdisciplinary background in biotechnology, ethics, and philosophy of medicine. She is an Assistant Professor in the Department of Global Health & Social Medicine at King's College London (UK), where she is also the Director of the MSc program in Bioethics & Society.Over the past decade, Silvia has written extensively about the ethics of emerging biotechnologies. She is author of From Bench to Bedside to Track and Field: the Context of Enhancement and its Ethical Relevance (UC Medical Humanities Press, 2014) and, with Mike McNamee, of Bioethics, Genetics and Sport (Routledge, 2018).Having completed a PhD at the Wellcome Trust Centre for Humanities & Health at King's College London directed by Professor Brian Hurwitz, Silvia has retained an ongoing interest in narrative approaches to ethics. Silvia sits on the UK Institute of Medical Ethics Research Committee and serves as Associate Editor (Reproductive Ethics) for the Journal of Bioethical Inquiry.

4. *Molecular futures: Disrupting cancer trajectories and compounding uncertainty*

Julia Swallow (University of Leeds)
Anne Kerr (University of Leeds)

Genomic medicine in oncology has led to the use of targeted therapies and treatments to manage cancer over time and also post-treatment monitoring such as molecular prognostic tools to predict future recurrence. Drawing on ethnographic data of a range of genomic based technologies and treatments being implemented in the UK, we explore how personalised molecular information is reshaping people's experiences of 'life with' and 'life after' cancer treatment alongside healthcare practitioners' roles and responsibilities in the clinic. We investigate how individuals, and the people involved in their care, experience these innovative health technologies and how this shapes their attitudes to and interventions in the future. We trace how efforts to increase precision can sometimes work to compound uncertainty regarding the future; producing new kinds of 'liminal' spaces for people living with and after treatment by disrupting and troubling cancer trajectories and pathways. We consider how these new 'liminal' spaces can (re)configure individuals' identities, subjectivities and responsibilities for managing cancer and keeping it at bay. We also trace how individuals and groups navigate multiple cancer and illness identities and reassert communitarianism and social justice in relation to these personalising agendas. Individuals living with and beyond cancer treatment draw on and develop a range of care work and identity practices to make sense of the new kinds of personalised certainties and uncertainties produced by genomic tools and techniques. Innovations in care work, identities and sociality are evolving alongside efforts to personalise and manage the molecular profile of cancer and predict future recurrence.

Julia Swallow is currently a research fellow on a Wellcome Trust funded project 'Translations and Transformations in Patienthood: Cancer in the post-genomics era' led by Professor Anne Kerr (University of Leeds) and Professor Sarah Cunningham-Burley (University of Edinburgh). This project involves exploring patients' and family members' experiences and perceptions of genomic based trials, treatments and therapies in oncology as well as examining practitioners' roles and responsibilities including how genomics is reconfiguring organisational boundaries and healthcare infrastructure. Prior to this I completed an ESRC funded PhD at the University of Leeds researching the role of technologies for diagnosing Alzheimer's disease in the clinic within the context of a growing ageing population (2012-2015). My research interests lie at the intersection of medical sociology and science and technology studies with a particular focus on genetic and genomic technologies, professional practice in healthcare and the sociality of diagnosis.

Session Two: Kinship & Care

5. Women as Fathers: “Reproductive” Technology (Re)creates Family Values’

Barbara Katz Rothman, (City University of New York - CUNY)

The first question which must be asked of any technology is what is the need it is meeting? In the world of what are called ‘reproductive technologies,’ the need is for a baby. But what is a baby? In a Patriarchal system (not just a system in which men rule, as they do in almost all societies, but those in which they rule as *fathers*) children are the seed of men, grown in the bodies of women. The baby that is being made is defined in terms of its seed. We now acknowledge that women have seed too, meaning that babies are ‘half his, half hers’ and might as well grow in the backyard – or a hired body in India, or an artificial robotic womb.

The history of Obstetrics and Gynecology is based on that premise that the child is the product of the seed, and the woman the container – or as the pregnant person is literally called in the literature of Obstetrics, the ‘maternal barrier,’ or in cases of high-risk fetus being transferred, ‘in situ,’ the site being the woman’s body.

We then develop technologies such as in vitro fertilization and what is called ‘gestational surrogacy,’ building upon this notion. The sellers of these services assure us there is no ‘genetic,’ and thus no ‘real,’ no ‘blood’ tie between the fetus and the ‘surrogate.’ As the blood of each is found in the veins of the other, as the fetus stirs inside the woman’s body, we are to understand that they are not ‘really’ related.

The consequences of this ideology can be found in more quotidian technologies of pregnancy, such as ultrasound imaging (accessing the fetal patient through the maternal barrier) presented as a moment of ‘bonding’ while eugenic screening takes place. This paper will build on our understandings of the origins and consequences of these technologies. I argue that Industry creates technologies which amplify biases. We create technologies to maintain systems of oppression, and then sell them as liberating.

Barbara Katz Rothman, PhD, is Professor of Sociology, Public Health, Disability Studies and Women’s Studies at the City University of New York. Her newest book is *A Bun In The Oven: How The Food And Birth Movements Resist Industrialization*. Her prior books include In *Labor*; *The Tentative Pregnancy*; *Recreating Motherhood*; *The Book Of Life; Weaving A Family: Untangling Race And Adoption*, and *Laboring On*. She is Past President of Sociologists for Women in Society; the Society for the Study of Social Problems, and the Eastern Sociological Society. She is proud recipient of an award for “Midwifing the Movement” from the Midwives Alliance of North America.

6. Remaking motherhood: MRT and alterity in maternal relations

Catherine Mills (Monash University)

For a long time, it has been understood that all human offspring have two genetic progenitors, who could be considered parents by virtue of that genetic relationship. Mitochondrial replacement therapy (MRT) challenges that presumption, since it involves the use of genetic material from three people in the creation of embryos. Consequently, there has been much scholarly and popular discussion about whether the offspring of MRT arrangements are justly thought of as ‘3-parent’ babies. In the UK, regulation of MRT has dealt with this by stipulating that egg donors in MRT arrangements are not genetic parents even though they contribute mitochondrial DNA to offspring. This is interesting because while it has long been recognised that being a genetic progenitor is not necessary to establish parenthood (as in adoption), it is something else to suggest that being a genetic progenitor is not sufficient to establish genetic parenthood. Other countries, including Australia, are still struggling with the issue of whether such donation undergirds parenthood in some sense at least, and the rights and obligations that may go along with it. My aim in this paper is to consider the implications of this situation for thinking about genetic parenthood more generally, and genetic motherhood in particular. I start from the view that the UK stipulation that donated mitochondrial DNA does not establish (genetic) parenthood reworks the maternal relationship. I argue that the legal cleavage of maternal relationships achieved in the UK regulation of MRT reflects a broader problem of the legal regulation of the co-option of the bodies and biological materials of others in reproductive projects. Further, it deals with this in a way that exteriorises and obscures the contribution of otherness in reproduction or generation. In effect, the UK regulation remains bound to a heteronormative imaginary in the very process of making legally permissible a technology that challenges the heteronormative family structure.

Catherine Mills is an Associate Professor and an Australian Research Council Future Fellow in the Monash Bioethics Centre at Monash University. Her disciplinary background is philosophy, and she uses feminist philosophy and bioethics to explore ethical issues that arise in human reproduction, especially relating to innovative reproductive technologies. In her current research, she is looking at the moral responsibilities of women in pregnancy, as well as examining the ethical, social and legal implications of inheritable genetic modification of humans. This includes the implications of technologies such as CRISPR-Cas9 and mitochondrial replacement therapy. She is a core member of the Health and Biofutures Focus Program at Monash University.

7. The 'New Hysteria': Wandering wombs and the re-making of reproduction

Andrea Whittaker (Monash University)

Hysteria no longer exists as a disease category in the DSM. But Western medical obsession with the need to control the wombs of women remains. What disturbs us about 19th century images of hysteria: the latent sexism, medical paternalism, masculine rationality and patriarchy still remains the experience of many women in their encounters with biomedicine. In this paper I consider the advent of new means exist to correct the defective female body: uterine transplants. I consider how these new technologies might re-make our reproductive futures and how they will not. I call this focus upon new manifestations of moving uteri, the 'new hysteria. ' Like the old hysteria, the new focus upon the reproductive tract continues traditions of medical experimentation, gendered stereotyping and paternalism towards women's bodies. We find a complex and risky surgical intervention being justified and driven by social, religious and legal concerns and obstacles created around surrogacy.

Andrea Whittaker is Head of Anthropology in the School of Social Sciences, Faculty of Arts. She has achieved international standing in the field of medical anthropology. Her current research projects include the study of global medical trade and mobility, reproductive travel and biotechnologies in the Asia Pacific, including issues of gender, religion, bioethics and global regulation of the trade, and social isolation among HIV positive people in Queensland. Her research spans the disciplines of anthropology, international public health, Asian studies and gender studies.

8. Ethics, robots and the care of the elderly. A view from here to the future

Matteo Galletti (Università degli Studi di Firenze - University of Florence)

According to the UN, world life expectancy has dramatically increased in recent years: "Globally, life expectancy at birth has risen from 65 years for men and 69 years for women in 2000-2005 to 69 years for men and 73 years for women in 2010-2015". The large disparities across countries rise important ethical and political issues in terms of equal access to and distribution of healthcare services.

Data are relevant under another aspect. In rich countries the improvement of life prospects intersects the biotechnological innovations in healthcare and, especially, in the care of the elderly. In the (near) future "care robots" could be diffusely employed in assisting human caregivers in institutional and private settings and this scenario raises a lot of questions relating to its costs. Could the introduction of this kind of technology be financially sustainable for public healthcare services? Could it generate inequalities between citizens who can afford it and citizens who can't?

In this paper I don't deal with such urgent political issues, but I focus on ethical questions related to the impact of care robot on human relationships and ethical values traditionally defended by philosophical ethical theories.

"Robo-ethics" is a fairly novel specialization in the field of applied ethics. In a 2017 survey paper, Vandemeulebroucke, Dierckx de Casterlé, and Gastmans present a useful map of prominent ethical approaches to care robots. In particular, in their discussion they point out that care ethics turns out to be the most fruitful approach to investigate human-robot relationships in care contexts.

In this paper I argue for a mixed approach, articulated on two levels: On a more general level, arguments like those set forth by Robert Sparrow could serve to deal with dystopian "futures," as in the fully automated aged care facility he describes. In the intermediate steps between current reality and "extreme dystopian scenarios" we can adopt a care ethics approach with the aim of assessing case by case which transformations of care relationships the introduction of robots brings about.

Matteo Galletti is research fellow at the Department of Letters and Philosophy of Florence. In 2006 He completed a PhD in bioethics at the University of Bologna, where he worked on several research project on end of life issues and ethics and genetics. He taught Ethics and Bioethics in Degree Courses and Masters. He published many papers in moral psychology and bioethics and he is the author of a book on moral responsibility (in Italian, Reciprocally Responsible Agents. Moral Responsibility, Naturalism, and Normativism). He’s currently working on ethical and political implications of “Libertarian Paternalism” and nudging and on the ethical and social impact of new biotechnologies.

Session Three – Political Economies of Biomedicine

9. *The unequal ecologies of extracorporeal living*

Lenore Manderson (Brown University and University of the Witwatersrand)

Political economies and social structures combine to manipulate the consequences of bodily difference, injury and disease, locally and globally. Each point of difference loads onto another, shrinking the physical and social impacts for some and exacerbating unequal outcomes for others. My purpose is to map difference as experienced in clinical settings, through focus on extracorporeal technologies. I am interested specifically in objects, products and systems, for although their use presumes access to and acquisition of skills and resources, I take for granted the body of knowledge, the methods, theory, and practices of the use of these technologies.

Depending on diagnosis, prognosis and technical availability, a range of extra- as well as in-corporeal technologies are used by people living with different conditions. Most extracorporeal technologies – even quotidian objects like hearing aids and glasses – are increasingly treated as provisional; internal technologies or procedures obviate or render them invisible either in the present or in an imaginary future. Glasses and contact lenses are replaced by intraocular lenses, corneal grafts, whole eye transplants, and in the future but at an accelerating pace, by electronic eyes. Body system functions too are displaced by technology.

In tertiary care settings in South Africa, extracorporeal technology proves the points of difference in the availability and affordability of care, marking out inequalities, destabilizing bio-environments and systems, and raising questions of ethics and rights. I address this by discussing ECMO – extracorporeal membrane oxygenation – as used in high care private hospital settings in South Africa as elsewhere. ECMO is a life support technology for people with respiratory and/or cardiac failure. In the same way that a dialysis machine functions as an artificial kidney, so ECMO is an artificial lung to which blood is diverted from and returns to the patient. In both cases the machinery is intended to be short term in theory, replaced as soon as possible by a transplanted organ. But as I illustrate, ECMO and its component parts are high risk, create unrealistic expectations, and are of questionable benefit for most patients and wider publics. By mapping out ECMO’s micro-ecologies and interactions, I show how the technology disrupts the ecosystems of patients, hospitals, and environments at large.

Lenore Manderson is Distinguished Professor of Public Health and Medical Anthropology in the School of Public Health at the University of the Witwatersrand (Wits), Johannesburg, South Africa, and Distinguished Visiting Professor at the Institute at Brown for Environment and Society (IBES), Brown University, Providence RI, USA. I took up these positions in 2014, after working in Australian universities for 40 years. Relevant to this symposium, my publications include *Sickness and the State* (1996), *Surface Tensions*: *Surgery, Bodily Boundaries and the Social Self* (2011), and *Technologies of Sexuality, Identity and Sexual Health* (ed., 2012). At Wits, I am working particularly on medical interventions, technology, access and equity, in relation to both chronic and acute health conditions. I edit the international journal *Medical Anthropology* and a new book series on medical anthropology for Rutgers University Press. In 2016 I was awarded the biennial Career Achievement Award of the Society for Medical Anthropology for my theoretical and methodological contributions to the field.

10. Post-stroke disability: Access, technology and the lingering effects of biomedicalised stratification in Malaysia

Narelle Warren (Monash University)

Disability after stroke can be reduced by access to timely diagnosis and treatment, and this is recognised in the Malaysian health guidelines for best practice stroke management, which are based on those from health systems in highly industrialised settings. In rural Malaysia, however, these 'ideal types' of post-stroke management are rarely achieved: limited diagnostic equipment and infrastructure leads to delayed diagnosis. This is further complicated by state-based policies which give some groups (largely based on ethnicity) access to services that others do not. In this paper, I draw upon the lens of 'biomedicalised stratification' (Clarke, Mamo & Fosket, 2009) to consider how such structural factors are brought to bear in stroke diagnosis and treatment in Malaysia, and how this has downstream effects, transforming people's futures and producing long-term disability after stroke.

Narelle Warren is a Senior Lecturer Anthropology and Sociology at Monash University. Broadly, my research is concerned with everyday experiences of chronic conditions and disability, including how care is arranged, negotiated, and deployed in practice. Her current program of research focuses on understanding the relationship between the lived experience of neurological conditions, biomedical representations of the brain and temporality, from both the perspectives of people living with such conditions and their informal carers. She is also interested in the social construction of ageing, and the role of gender in this. Much of my work to date has been concerned with understanding how (and what mechanisms underlie) people's experiences of chronic conditions, including disabilities, vary by gender, age, geographical location, and culture.

11. *A critical sociology of the rise of precision medicine: The case of oncology*

Alex Broom (University of New South Wales)

Precision medicine is radically transforming the character of healthcare. In this paper I will outline some of the (emerging and enduring) social implications of this turn toward 'precision' - as articulated in cancer care where it has its strongest foothold. In particular, I will focus on questions of value, cost, risk and vulnerability in the lived experience of precision, as well as the 'professional projects' (and evolutions) and politics driving the rise of precision therapeutics. I will outline the importance of further examining its evolving and diverse social impacts across the life course for cancer patients, carers and professionals, and improving our capacity to ensure lay/community engagement and participation in the evolution and character of precision medicine.

Alex Broom is Professor of Sociology and Co-Director of the Practical Justice Initiative, Centre for Social Research in Health, The University of New South Wales (UNSW), Sydney. He is recognised as an international leader in the sociology of health and illness. His current focus is on developing critical analyses of the social dynamics of cancer and palliative care and the global challenge of antimicrobial resistance across contexts and cultures.

12. Overdiagnosis and the uncertain risk of future harm

Stacy Carter (University of Wollongong)

In this paper I consider the counterintuitive concept of overdiagnosis, the way that the risk of overdiagnosis-related harm arises from practices that pursue fictional expectations, and the conditions under which imposing such risks may be ethically justifiable. My analysis of overdiagnosis draws on Jens Beckert's 2016 investigation of the role of imagined futures in late modern capitalism, Robert Aronowitz's 2015 analysis of risky medicine, and Sven Ove Hansson's proposals regarding the ethics of risking harm to others (e.g. 2003). The construction of the late modern healthcare consumer and the promises of risky medicine, I will argue, have doubled on themselves, ironically imposing risk of the very harms that they ostensibly aim to limit. Based on work in progress with Wendy Rogers and Vikki Entwistle, I will apply Hansson's analysis to argue that imposition of these risks of harm is unlikely to be ethically justifiable. Changing risk-imposing practices, however, may require both a refashioning of healthcare professional routines and the construction and promulgation of new fictional expectations of healthcare and human embodiment. Such corrective shifts seem at odds with the enhanced healthcare futures often promised by biomedicine, but are arguably more responsive to the uncertainties and limitations that arise when attempting to predict and limit future harms.

Stacy Carter is Professor and Director of Research for Social Change, a research centre of the Faculty of Social Science at the University of Wollongong. Her research focuses on the political, social and ethical dimensions of public health and human wellbeing. Her work is designed to bring the perspectives of the public and health professionals into policymaking in domains including vaccination, screening, de-implementation and especially overdiagnosis. She is a member of the Wiser Healthcare Collaboration (wiserhealthcare.org.au), an NHMRC-funded program of research to address overdiagnosis and overtreatment. She tweets sporadically: @stacymcarter

Session Four – Health Imaginaries and the Future

13. Taking us to the cloud: the promise of 'big data' in future medicine and healthcare

Alan Petersen (Monash University)

'Big data' is widely portrayed as underpinning future medicine and healthcare. Many predict that data contributed by patients themselves and/or gained from other sources such as clinical trials, medical records and medical imaging, and analysed at great speed by computers will soon 'transform' medical research, the prevention and treatment of disease, and the practices of care. Data, unlike other resources (e.g. oil, coal) can, in theory, be infinitely replicated, stored via cloud computing, and moved around the world at great velocity and put to new uses. Its health and economic value is seen to derive from the aggregation of diverse and otherwise valueless data. But can 'big data' deliver what is promised; namely improved health, and more efficient, effective diagnosis, treatment and care? This paper examines the politics of the promissory discourse underpinning the anticipated 'health data revolution'. As I argue, many of the claims about 'big data' and its applications and benefits can be questioned on various grounds. Nevertheless, its promissory discourse is profoundly shaping policies and practices, including investment decisions. The paper considers the implications of the datafication of health and medicine and the prospects for citizen resistance and contributions to forging alternative futures.

Alan Petersen is Professor of Sociology and Research Coordinator, School of Social Sciences at Monash University. He is also Co-Convenor of the Health and Biofutures Focus Program. His research covers the sociology of health and medicine, science and technology studies, and gender studies. He is currently leading two Australian Research Council Funded projects: one on patients' use of digital media to access treatments; the other on testing in healthcare, focusing on Australia's national cancer screening programs and the routine use of testing in clinical practice. His recent books include *Hope in Health: The Socio-Politics of Optimism* (Palgrave, 2015) and *Stem Cell Tourism and the Political Economy of Hope* (Palgrave, 2017) (with Megan Munsie, Claire Tanner, Casimir MacGregor and Jane Brophy). He recently completed *Digital Health and Technological Promise* (Routledge, forthcoming)

14. Imaginaries of health and wealth: Accelerating innovation of Regenerative Medicines in the UK

John Gardner (Monash University)

Regenerative medicines are championed as having considerable clinical and economic potential. In order to realise this potential, governments are supporting various 'innovation acceleration' initiatives such as regulatory changes and new interdisciplinary collaborations. Using the UK as an example, this talk explores the imaginaries of health and wealth that are animating these initiatives, and it focuses on several particular initiatives – including the establishment of the innovation accelerating 'catapult' agencies – to explore some of the values and tensions that appear to be shaping the emerging biomedical landscape. The talk will argue that some innovation-accelerating initiatives appear to conflict with egalitarian notions of distributive justice that underlie many healthcare systems.

John Gardner is a Research Fellow in the Health & Biofutures Focus Program at Monash University. John's research is situated at the intersection of sociology and STS, and it explores the social dimensions of medical innovation. So far he has undertaken research on the implementation of neurotechnologies in healthcare settings (funded by the Wellcome Trust); the emerging regenerative medicine industry; and the way in which hospitals are being reconfigured within emerging bioeconomies. His recently published monograph *Rethinking the Clinical Gaze* (Palgrave, 2017) explores the intersection of biomedical innovation, patient-centred medicine, and power.

15. The EU General Data Protection Regulation: which imaginary for European biomedical data integration?

Luca Marelli (Katholieke Universiteit Leuven)

May 25, 2018 marks the coming into force of the European Union (EU) Regulation 2016/679 on data protection, also known as the General Data Protection Regulation (GDPR). Geared to harmonize data protection legislation in the EU so as to provide regulatory support for the establishment of a full-fledged Digital Single Market – a policy cornerstone of the Juncker Commission – the GDPR is also bound to impact biomedical research and digital health technologies very significantly, in Europe and beyond, given the global reach of EU-centered R&D. At its core, the GDPR drives a major shift towards a flexible regime of governance in the field of EU data protection, promoting a decentralized and accountability-based model, while assigning an enhanced role to institutionalized ethics in the standardization of emerging fields and technologies (Marelli and Testa 2018).

Against this backdrop, this paper is aimed at probing, and critically examining, the GDPR's underpinning imaginary for European biomedical data integration, as on the one hand it is poised to provide significant leeway for increased value-extraction from personal data in the name of 'scientific research' (thus enabling the further entrenchment of forms of so-called 'platform capitalism' in the EU (Srnicek 2017)), while, on the other hand, it could be seen as fostering the protection of data subjects and promoting their substantive rather than merely tokenistic engagement in research. Additionally, in order to test the GDPR's prospective impact on these issues, this paper conducts a forecast exercise focusing on a major legal controversy that have recently erupted around the property of the Shardna database – a genomic biobank storing sensitive data of over 10,000 people.

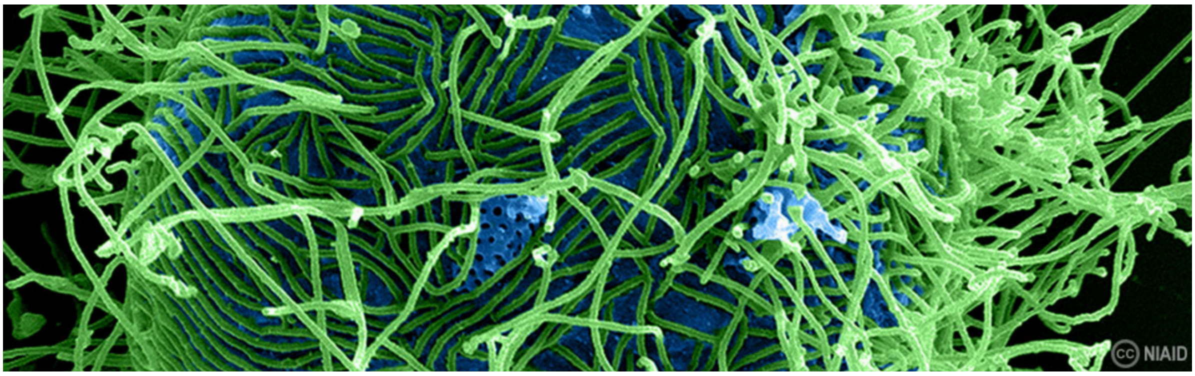
Luca Marelli is a Marie Skłodowska-Curie fellow (2018-2020) with the Life Sciences & Society Lab at KU Leuven, researching on the politics and imaginaries of biomedical innovation of the European Union. After graduating in philosophy at the University of Milan, he completed a PhD (2016) in Foundations and Ethics of the Life Sciences at the European School of Molecular Medicine and University of Milan, with a dissertation on the co-production of scientific and governance innovation in translational induced Pluripotent Stem Cell (iPSC) research in the European Union and the United States. In 2013–2014, he was a Visiting Research Fellow in the Program on Science, Technology and Society at the John F. Kennedy School of Government at Harvard University. As a post-doctoral fellow with the STS Unit at the European Institute of Oncology (IEO) in Milan, he was involved in the Italian Epigenomics Flagship Project (EPIGEN) and was also part of the expert group drafting the incidental findings policy for genomic research of the Italian National Research Council.

16. The same but different? Identifying continuities and disruptions as a route to making responsible biofutures.

Michael Morrison (University of Oxford)

Ideas of 'responsible research and innovation' (RRI) emphasise early engagement with emerging technologies to steer them in socially desirable directions. However, this is challenging to achieve in practice for a number of reasons. Experimental research in the life sciences is both highly technical and inherently uncertain so expectations can be hard to assess, much less open up to democratic debate. Moreover, a focus on the 'revolutionary' and 'disruptive' aspects of new technologies and fields tends to present existing knowledge, practices and organisational arrangements as irrelevant and outdated. A more nuanced approach to (bio)futures 'in the making' recognises that *which* properties of emerging technologies come to be seen as desirable owes a lot to existing policies, institutional commitments and criteria for evaluation and assessment. Looking at what is stable and enduring as well as what is novel and disruptive in making new fields and technologies can provide a way for ethicists and sociologists to get to grips with emerging technologies even as their impact remains uncertain. We can use our expertise to identify similarities with existing cases that have already been subject to detailed empirical scrutiny, providing a basis for offering advice about pitfalls to avoid and possible ways to proceed. Drawing on familiar cases from my own work - stem cells, biobanks and genomics – I describe some emerging therapeutic, diagnostic and infrastructural trajectories and suggest comparisons and continuities that could usefully inform critical analysis and RRI activities.

Michael Morrison is a sociologist working primarily in the domains of medical sociology and Science and Technology Studies (STS). He is based at the Centre for Health, Law and Emerging Technologies (HeLEX) at the University of Oxford and is also an affiliate member of the Institute for Science, Innovation and Society (InSIS) (also at Oxford) and the Health, Technology and Society research group at the University of Exeter. His work has examined the development of innovative biotechnologies including regenerative medicine, biobanking, and issues of human biomedical enhancement, with a view to understanding how these challenge existing organisational, regulatory, and cultural practices and foster the emergence of new ones. Michael is currently PI on the ESRC-funded project "Biomodifying technologies and experimental space: organizational and regulatory implications for the translation and valuation of health research" which is a collaboration between researchers at the universities of Oxford, Sussex and York.



The Health & Biofutures Focus Program
Faculty of Arts
Monash University

The Health and Biofutures Focus Program engages with the scientific, technological and socio-political transformations of human health and the production of human life. It builds on contemporary currents in academic and applied research to address major public policy questions and challenges in Australia and internationally.

This multifaceted program explores the growing digitalisation of health care; emerging reproductive and sexual health technologies; preparedness policy and communications on global health threats; the impacts of globalisation and deregulation on practices of health and healthcare (e.g. health and medical tourism); and how discourses and narratives of promise, hope and expectation shape bioscience, biotechnology and biomedicine.

People:

Andrea Whittaker (Anthropology)
Alan Petersen (Sociology)
Mark Davis (Sociology)
Catherine Mills (Philosophy)
Sam Taylor Alexander (Anthropology)
John Gardner (Sociology)

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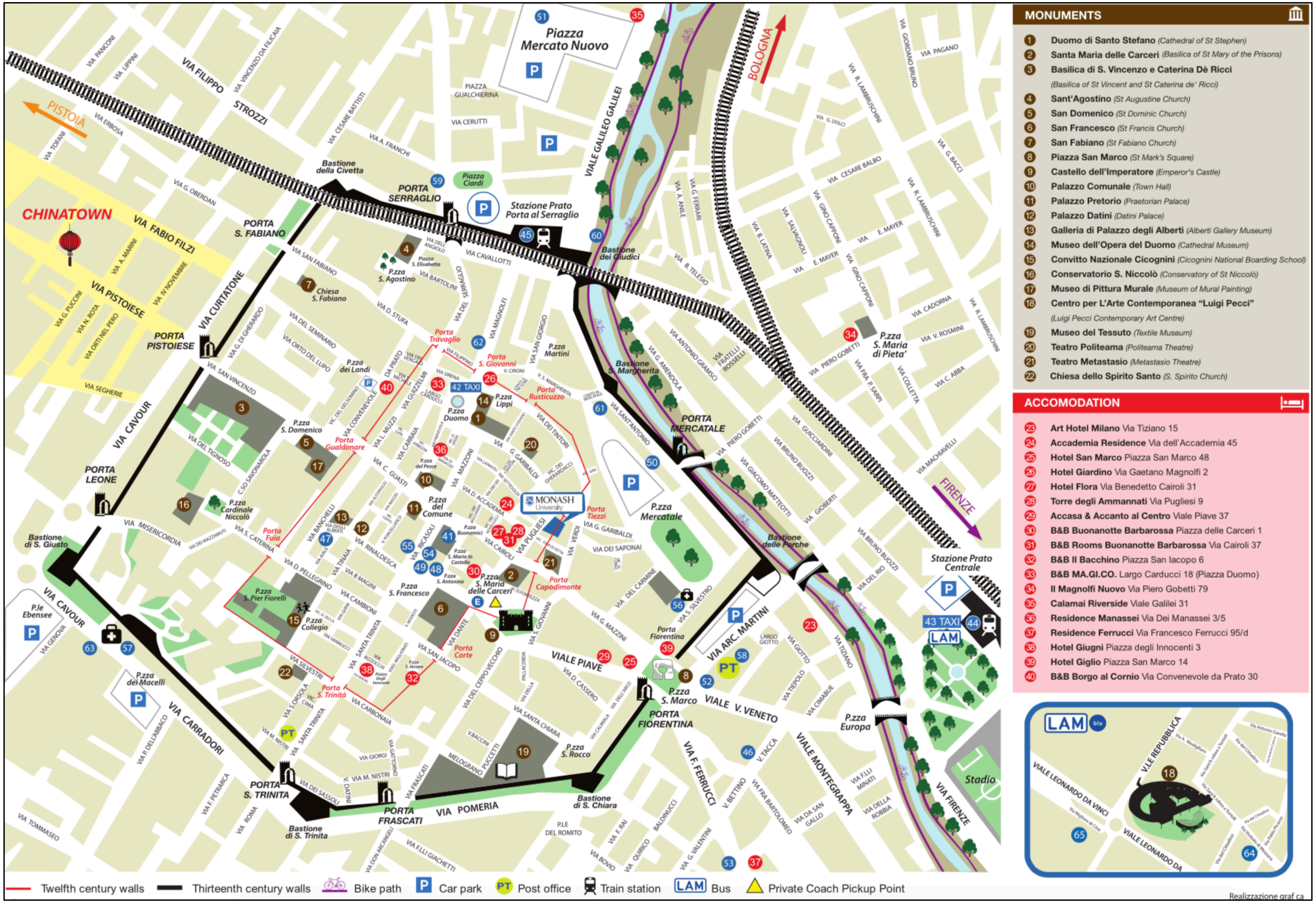
Prato, June 2018



MONUMENTS

1. **Duomo di Santo Stefano** *(Cathedral of St Stephen)*
2. **Santa Maria delle Carceri** *(Basilica of St Mary of the Prisons)*
3. **Basilica di S. Vincenzo e Caterina Dè Ricci**
   (Basilica of St Vincent and St Caterina de' Ricci)
4. **Sant'Agostino** *(St Augustine Church)*
5. **San Domenico** *(St Dominic Church)*
6. **San Francesco** *(St Francis Church)*
7. **San Fabiano** *(St Fabiano Church)*
8. **Piazza San Marco** *(St Mark's Square)*
9. **Castello dell'Imperatore** *(Emperor's Castle)*
10. **Palazzo Comunale** *(Town Hall)*
11. **Palazzo Pretorio** *(Praetorian Palace)*
12. **Palazzo Datini** *(Datini Palace)*
13. **Galleria di Palazzo degli Alberti** *(Alberti Gallery Museum)*
14. **Museo dell'Opera del Duomo** *(Cathedral Museum)*
15. **Convitto Nazionale Cicognini** *(Cicognini National Boarding School)*
16. **Conservatorio S. Niccolò** *(Conservatory of St Niccolò)*
17. **Museo di Pittura Murale** *(Museum of Mural Painting)*
18. **Centro per L'Arte Contemporanea "Luigi Pecci"**
    (Luigi Pecci Contemporary Art Centre)
19. **Museo del Tessuto** *(Textile Museum)*
20. **Teatro Politeama** *(Politeama Theatre)*
21. **Teatro Metastasio** *(Metastasio Theatre)*
22. **Chiesa dello Spirito Santo** *(S. Spirito Church)*

ACCOMODATION

23. **Art Hotel Milano** Via Tiziano 15
24. **Accademia Residence** Via dell'Accademia 45
25. **Hotel San Marco** Piazza San Marco 48
26. **Hotel Giardino** Via Gaetano Magnolfi 2
27. **Hotel Flora** Via Benedetto Cairoli 31
28. **Torre degli Ammannati** Via Pugliesi 9
29. **Accasa & Accanto al Centro** Viale Piave 37
30. **B&B Buonanotte Barbarossa** Piazza delle Carceri 1
31. **B&B Rooms Buonanotte Barbarossa** Via Cairoli 37
32. **B&B Il Bacchino** Piazza San Iacopo 6
33. **B&B MA.GI.CO.** Largo Carducci 18 (Piazza Duomo)
34. **Il Magnolfi Nuovo** Via Piero Gobetti 79
35. **Calamai Riverside** Viale Galilei 31
36. **Residence Manassei** Via Dei Manassei 3/5
37. **Residence Ferrucci** Via Francesco Ferrucci 95/d
38. **Hotel Giugni** Piazza degli Innocenti 3
39. **Hotel Giglio** Piazza San Marco 14
40. **B&B Borgo al Cornio** Via Convenevole da Prato 30