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Susan Dodds • Rachel A. Ankeny  
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# Big Picture Bioethics: Developing Democratic Policy in Contested Domains

 Springer

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**Donald Chalmers** is Distinguished Professor of Law and Director of the Centre for Law and Genetics at the University of Tasmania. His major research interests are in medical research ethics and the regulatory aspects of genetics. He is a Fellow of the Australian Academy of Law. With colleagues, he has been awarded several ARC and NHMRC research grants. He was Chair of the NHMRC Australian Health Ethics Committee from 1994 to 2000, Deputy Chair of the NHMRC Embryo Research Licensing Committee (2003–2012) and a member of the NHMRC Human Genetics Advisory Committee (2006–2009). He chaired the Gene Technology Ethics Community Consultative Committee (2001–2010). He was Law Reform Commissioner in Tasmania (1991–1997). Internationally, he serves on the HUGO Ethics Committee, the International Cancer Genome Consortium Access Committee and the Global Alliance Regulation and Ethics Working Group.

**Susan Dodds** is Professor of Philosophy and Dean of Arts and Social Sciences at the University of New South Wales (UNSW Australia) and Adjunct Professor of Philosophy at the University of Tasmania, where she was Dean 2009–2016. Her research explores the intersections of ethics, political philosophy, moral psychology and feminist theory. She has served as Chair of the National Enabling Technologies Strategy (NETS) Stakeholder Advisory Council and was a member of the Australian Health Ethics Committee (AHEC) of the National Health and Medical Research Council (2012–2015). Dodds is a Chief Investigator and Ethics, Policy and Public Engagement theme leader in the Australian Research Council Centre of Excellence in Electromaterials Science (ACES).

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**Eliza Goddard** is a Research Fellow in the Ethics, Policy and Public Engagement programme within the Australia Research Council Centre of Excellence for Electromaterials Sciences (ACES) at the University of Tasmania. Goddard completed her PhD on the impacts of emerging bionic medical technologies on selfhood and social relations. Her current research draws on moral psychology, feminist philosophy, phenomenology and bioethics to explore questions concerning the role of the first-person perspective, and understandings of disability, in emerging medical technologies. She has published in neuroethics and feminist philosophy and authored reports for government and professional bodies, including on emerging technologies and community engagement frameworks.

**Matthew Herder** is Professor in the Faculties of Medicine and Law at Dalhousie University. Professor Herder's research interests cluster around biomedical innovation policy, with particular focus on intellectual property law and practices connected to the commercialization of scientific research.

**Holly Longstaff** specializes in applied ethics and policy analysis from a social science perspective. She is a Partner at Engage Associates Consulting Group and the ethicist for the BC Cancer Agency Research Ethics Board. She has also served as the Interim Associate Director for the Office of Research Ethics at Simon Fraser University and as the Communications Officer for the national board of the Canadian Bioethics Society. Holly has presented her research at conferences across North America and has published her work in a variety of journals including *Cell Stem Cell*, *Global Environmental Change*, and *Accountability in Research*.

**Fiona J. Mackenzie** completed her honours degree in history and philosophy of science at the University of Sydney, and was a research assistant on the Big Picture Bioethics project. Mackenzie is currently a freelance academic editor in Sydney.

**Helen Marshall** is Associate Professor in the School of Paediatrics and Reproductive Health and Robinson Research Institute, University of Adelaide. Marshall is a medical researcher who has completed a Bachelor of Medicine and Surgery, Doctorate of Medicine, Master in Public Health and Diploma in Child Health at the University of Adelaide and completed the Advanced Vaccinology Course at the Pasteur Merieux Institute, France. She is an Associate Professor in Vaccinology, in the School of Paediatrics and Reproductive Health and is the Medical Director of the Vaccinology and Immunology Research Trials Unit, in the

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**Cheluchi Onyemelukwe** is Senior Lecturer at the School of Law, Babcock University, Nigeria. She is also the Executive Director of the Centre for Health Ethics Law and Development. Her work has included experiences in health law reform, health policy development and evaluation, and governance and regulation. Her experience has also included developing, drafting and researching health policies, legislation and regulations in university and government positions and legal practice in Nigeria and Canada. She is currently a member of the Advisory Council on Immunisations and Vaccines of the National Academy of Science, and a member of the Taskforce on Community-Directed School Health and Feeding Program in Nigeria. She has particular interests in regulation, research ethics, patients' rights, legal and ethical issues around HIV/AIDS and violence against women, and has published articles in these areas.

**Wendy A. Rogers** is Professor of Clinical Ethics at Macquarie University and Deputy Director of the Macquarie Research Centre for Agency, Values and Ethics. Her current research interests include the ethics of surgical research and innovative surgery, research ethics, vulnerability, public health ethics and issues to do with defining disease and the ethics of overdiagnosis. Rogers has published widely in leading bioethics and medical journals, and contributes to policy debates through membership of the Australian Health Ethics Committee and the NSW Ministry of Health Clinical Ethics Advisory Panel.

**Kerry Ross** is the Manager, Archives at the University of Wollongong. From 2005 to 2009, she undertook PhD research that explored the intersection of science and politics in the Federal and State policymaking debates around the introduction of genetically modified food crops in Australia. Kerry also worked as a long-term research assistant on a number of ARC projects in the years 2005 through to 2012.

**Gene Rowe** is an Independent Consultant at Gene Rowe Evaluations, Norwich, United Kingdom. Gene gained his first degree in Psychology at the University of

Bristol and a PhD at the Bristol Business School, University of the West of England. His research interests have focused on human judgement and decision making in a variety of contexts, and he has conducted research into knowledge elicitation methods, the quality of judgement, forecasting (especially using the Delphi technique), risk perception/communication and management, and public engagement in agenda setting/policymaking (etc.). Later, he has been interested in developing schemes to evaluate public and stakeholder engagement events. Since 2010, he has been an independent consultant (previously having been Head of Consumer Science at the Institute of Food Research, Norwich). He has published around 100 journal articles and book chapters.

**Philip Ryan** is Emeritus Professor in the School of Public Health at University of Adelaide. Ryan is a biostatistician and public health physician. He has a special interest in the design and conduct of intervention trials and all aspects of data collection and management in health research. He has been a member of many trial management committees and independent DSMBs.

**Cobi Smith** is a PhD candidate in the Australian National Centre for the Public Awareness of Science at Australian National University. Smith is researching how international law and human rights shape governance of science, technology and sustainable development, with a focus on participatory and deliberative methods. She is interested in theories of participatory governance, deliberative democracy and collaborative learning. She has led or facilitated deliberative processes about science and technology policy for universities, government departments and non-governmental organizations.

**Jackie M. Street** is Senior Lecturer in the School of Public Health, University of Adelaide. Street is an Australian National Preventive Health Agency Fellow 2013–2015 and a team member of the multidisciplinary NHMRC Capacity Building Grant-funded project, HealthCare in the Round 2009–2015. Her research focus is community participation in decision making in policy and health technology assessment. With a PhD from the University of London, she has qualifications and experience in both biomedical and social sciences and draws on both in her work.

**Colin Thomson** is Professor of Law and Academic Leader for Health Law and Ethics in the Graduate School of Medicine at the University of Wollongong. He has been a member and chair of several research ethics committees (1984–2004, 2010), a member and chair of the Australian Health Ethics Committee (1998–2002 and 2006–2009) and of NHMRC working parties that drafted the National Statement (1999 and 2007). He developed accreditation standards for leading HRECs (NSW Health) and conducted certifications of institutions for the NHMRC national approach to single ethical review of multi-centre research.



# Abbreviations

AHEC	Australian Health Ethics Committee
AHMPPI	Australian Health Management Plan for Pandemic Influenza
ARC	Australian Research Council
ART	assisted reproductive technology
CAUT	Canadian Association of University Teachers
CIHR	Canadian Institutes of Health Research
SCOC	CIHR Stem Cell Oversight Committee
CEO	Chief Executive Officer
COAG	Coalition of Australian Governments
CMA	Canadian Medical Association
hES cells or HESC	human embryonic stem cells
NBCHR	Council of Bioethics on Human Research
NHMRC	National Health and Medical Research Council
iPS cells	induced pluripotent stem cells
PRE	Interagency Advisory Panel on Research Ethics
ICSCN	International Consortium of Stem Cell Networks
MRC	Medical Research Council
MREC	Medical Research Ethics Committee
NHRDP	National Health Research Development Program
NSERC	Natural Sciences and Engineering Research Council of Canada
PI	Pandemic influenza
PIPEDA	Personal Information Protection and Electronic Documents Act
PEPPPI	Public Engagement Pilot Project on Pandemic Influenza
RCTs	randomised clinical trials
RCNT	Royal Commission on New Reproductive Technologies
REB	Research Ethics Board
SSHRC	Social Sciences and Humanities Research Council of Canada

SSHWC	Social Science and Humanities Special Working Committee on Research Ethics
HOS	South Australian Health Omnibus Survey
SCN	Stem Cell Network
SCC	Supreme Court of Canada
TGA	Therapeutic Goods Administration
TCPS	<i>Tri-Council Policy Statement</i>