Health Activism & the Knowledge Society: Engaging Consumer/ Citizens in Shaping Health

The ANZSOG Institute for Governance with The University of Canberra and the Health Care Consumers’ Association ACT

April 4th & 5th 2013

Clive Price Suite
Building 1, Level C
University of Canberra
Concept

The engagement and participation of health care consumers/citizens in policy-making and health care governance has been a clarion call of health activists over the past few decades. Hopes for this ‘democratizing of health’ have been high and the health consumer movement in Australia has achieved considerable success. Who gets sick, who dies early, and the quality of life of those living with disability and chronic illness are profoundly influenced by government policies and political decision-making. Empowering people to engage and participate in health activism matters. The voices of everyday people’s experience of health, illness and care services can inform better quality, more citizen-centric health-care, and health-promoting environments. Empowering the users of health care systems matters. Health care consumers can bring recognition of human rights to the forefront of policy and service governance decision making to improve the health of our communities.

This workshop will explore the changing dynamics of health care consumer activism in Australia.

What does it mean for health service consumer organisations to partner with governments, health professionals, and others to engage citizen participation in health policy and health system design and governance? How are health activists and their community-sector organisations negotiating the advantages and the pitfalls of being in-side the tent (when they are), without losing their integrity and independence as health activists, or their vision for broader agendas that cross the boundaries between government departments? The health care consumer movement is engaged in an arena where science and research are seen as central to decision-making. Yet the kinds of knowledge and expertise now recognised as integral to health have never been more complex. What does it mean for notions of democratisation and power sharing, to engage in arenas such as health traditionally dominated by scientific decision-making? At this 2-day workshop ANZOG Institute for Governance at University of Canberra and the Health Care Consumers’ Association of the ACT will bring together academic researchers and leaders of health care consumer organisations with health activists and those interested in the politics of citizen engagement and participation to consider such questions, and to reflect on how health consumer organisations can best contribute to the building of vibrant and politically and socially effective health activism for the future.

Social Purpose and Format

The aims of this workshop are to raise public awareness of the role of consumer health organisations in the politics of health; to bring together researchers and consumer health organisation leaders and activists to build understanding of the politics of citizen engagement and participation; to reflect on the history and future of health activism in Australia, the gains made and the conditions that make them possible or foster resistance; and to explore how health service users and citizens are shaping the ideas, knowledge, and expertise woven into health related policy processes. The workshop will be a mix of presentations from leaders in the field and participant discussion groups to enable maximum interaction between participants.

[Images of workshop participants engaged in discussion]
The Presenters

Helen Meekosha (UNSW)
[If you cannot make it to the workshop, Helen’s presentation at 4pm on April 4th is open to all]

Helen Meekosha is an Associate Professor in the School of Social Science at UNSW. Originally from the North of England, Helen worked as a community worker in the non-government sector until 1988 when she took a job teaching Community Work in the School of Social Work at UNSW. Her research is now located at the intersection between race, gender and disability relations. Her work in Critical Disability Studies has broken new ground in setting disability in a context of neoliberalism and globalisation, in particular arguing the case for an examination of global North/South relations that affect the incidence and production of disability. She is a currently one of three Chief Investigators on an ARC Discovery research project examining the nexus between Disability and Rurality, another unexplored field of inquiry in Disability Studies. This research also examines the almost untouched intersections between Aboriginality and Dis-ability in remote and rural Australia. She has recently edited a special issue of Third World Quarterly with Karen Soldatic (2011) on disability and a special edited volume of Critical Sociology is due out shortly (March 2013). Helen has been involved in Women with Disabilities Australia (WWDA) since its inception. As President of WWDA she accepted the prestigious National Human Rights Award in 2001. More recently, she spoke on behalf of the organisation at a High Level Panel at the 56th session of United Nations Commission on the Status of Women (UNCSW), New York in 2012. This was the first time in 56 years a panel on disability had been included in the UNCSW. Her research and public engagement has always been located in activist politics of policy change and the implementation of human rights.

Celia Roberts (Lancaster University)

In 2001 Celia has been in the Department of Sociology, Lancaster University, in the northwest of England. Originally from Sydney, she did her PhD at the Department of Gender Studies, Sydney University and was a project officer at the National Breast Cancer Centre, working with consumers to deliver consumer advocacy training nationally. Over the last 8 years Celia has been involved in several European Commission-funded projects around health and citizen participation in science and biomedicine. Most recently, she has participated in a 3 year project called ‘European Patient Organisations in Knowledge Society’ (EPOKS) which compared health activism in 4 health areas (ADHD, Alzheimer’s disease, Rare Diseases and birth) across 4 countries (England, France, Portugal and Ireland). She will report on this project at this workshop.
Evelyne de Leeuw (Deakin University)
evelyne.deleeuw@deakin.edu.au

Professor Evelyne de Leeuw is Chair in Community Health Systems and Policy for the Faculty of Health at Deakin University. Professor de Leeuw did a PhD on the feasibility of true health policy public and private policies for health, not restricting itself to the health care sector or public health in The Netherlands (Maastricht, 1989). She has been involved in World Health Organization (WHO) health promotion endeavours since the 1986 Ottawa Conference. Her current research interest focuses on the interface between knowledge, health, urbanisation, globalisation and policy development. Recent books include *Democratising Health* with Lofgren and Leahy, Edward Elgar, 2011), *Health Promotion and the Policy Process* (with Clavier, OUP, 2013), and a forthcoming major volume on Healthy Cities (with Simos, Springer, 2014).

Anni Dugdale (University of Canberra)
Anni.Dugdale@canberra.edu.au

Anni Dugdale is Associate Professor of sociology in the School of Government and Policy at University of Canberra and a research fellow with the ANZSOG Institute for Governance. Anni completed a PhD in the Social Studies of Science, Technology and Medicine at University of Wollongong in the mid-1990s during which she spent a year as a PhD Fellow at Johns Hopkins University in the School of Hygiene and Public Health. Anni’s interest in health consumer activism began as a consumer representative on a Therapeutic Goods Administration committee in the 1990s. Anni’s current research is focused on the role of information and communication technologies in citizen participation and engagement in health, e-democracy and e-government, and the politics and social contribution of patient/healthcare consumer organisations. She has contributed to *E-Health Communities and Online Self-Help Groups* (Smedberg), and is currently researching and writing on the history and impacts of the Health Care Consumers’ Association of the ACT.

Catherine Settle (ANU)
catherine.settle@anu.edu.au

Catherine’s passion for health reform and her interest in health activism initially arose from her experiences and observations as a healthcare professional in nursing, midwifery and naturopathy. Over the last 10 years, Catherine has been developing her capacity and skill as a more effective change-agent by being deeply involved in the work of the health consumer movement, along with completing a Master’s degree in Community and Health Development at University of Canberra. Catherine is currently writing-up her PhD thesis at the Centre for Health Stewardship at ANU, which has been part of an Australian Research Council Linkage Project exploring the participant experience of deliberative methods of engaging citizens in health policy development.
The Panellists

Anne McKenzie: Consumer Advocate at the Telethon Institute for Child Health Research and until recently Chair of the WA Health Consumers Council

Darlene Cox: Executive Director at the Health Care Consumers Association of the ACT

Demos Krouskos: Chair Health Issues Centre Board, Victoria.

Melissa Fox: Executive Committee Health Consumers Queensland and a Maternity Coalition consumer representative

Morag Morrison: Executive Director Health Consumers NSW

Stephanie Miller: Executive Director Health Consumers Alliance SA

For further information contact
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Anni.Dugdale@canberra.edu.au

The workshop is free but you will need to pre-register

TO REGISTER GO TO
http://www.governanceinstitute.edu.au/engagement-program/symposiums-conferences
## The Program

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<tr>
<th>Time</th>
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| 9.30 - 10.00 | WELCOME & INTRODUCTION  
Welcome to Country: Roslyn Brown (Ngunnawal Centre)  
Welcome & Introduction: Janne Graham (HCCA)  
Workshop Aims: Anni Dugdale (ANZSOG Institute for Governance) |
| 10.00 - 10.45 | CELIA ROBERTS (Lancaster University)  
Evidence-based activism: Exploring birth politics in Europe |
| 10.45 - 11.15 | Morning Tea |
| 11.15 - 11.45 | PANEL 1: MORAG MORRISON (HCNSW) & MELISSA FOX (HC Qld)  
EXPLORING THE MAKING OF HEALTHCARE CONSUMERS/CITIZENS/ACTIVISTS AND GROWING EFFECTIVENESS IN THE POLITICS OF HEALTH SYSTEM CHANGE. |
| 11.45 - 12.45 | WORKSHOP 1: EXPLORING THE MAKING OF HEALTHCARE CONSUMERS/CITIZENS/ACTIVISTS  
How do healthcare consumer representatives’ play roles as patients, users, advocates, citizens, and activists? How do skills and capacities develop? How can healthcare consumer organisations facilitate the effectiveness of consumer representatives as agents of change? How do contemporary politics of healthcare consumer representation shape processes of advocating for change? |
| 12.45 – 1.00 | REPORT BACK |
| 1.00 – 1.45 | Lunch |
| 1.45 – 2.15 | EVELYNE DE LEEUW (Deakin University)  
Health activism for better health policy – a discourse around evidence |
| 2.15 – 3.15 | WORKSHOP 2: NEGOTIATING THE ADVANTAGES AND PITFALLS OF PARTNERING WITH GOVERNMENT  
What are the advantages and pitfalls of partnering with governments? What are health consumer organisations’ experience of evidence-based policy? How do health care consumer organisations and consumer representatives make experiential knowledge valued? How are the imperatives of new governance which emphasise consumer representation experienced in different parts of the health system? What are the dynamics and pressures that health consumer organisations face with the increased call for inclusion of the consumer voice in formal health decision-making processes? Is ‘Localism’ (devolving more power to local areas to make decisions shaping health services in their areas) impacting on Health Care Consumer organisations, how? (How) are coalitions and alliances becoming more important to achieving healthcare consumer led change? |
| 3.15 – 3.30 | REPORT BACK |
| 3.30 – 4.00 | Afternoon Tea |
| 4.00 – 4.30 | PUBLIC TALK: HELEN MEEKOSHA (UNSW)  
Activism on the margins: the involuntary sterilization of disabled women and girls |
<p>| 4.30 – 5.30 | DISCUSSION FOLLOWED BY DRINKS |</p>
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<tr>
<td>9.00 – 9.30</td>
<td>HEALTH ACTIVISM IN THE ACT</td>
<td>Anni Dugdale (University of Canberra)</td>
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<td>9.30 - 10.00</td>
<td>PANEL 2: STEPHANIE MILLER (HCA SA) &amp; DEMOS KROUSKOS (HIC VIC)</td>
<td>PARTNERING WITH GOVERNMENT - THE DYNAMICS OF CONSUMER-LED CHANGE IN COMPLEX LOCAL, NATIONAL AND GLOBAL HEALTH LANDSCAPES</td>
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<td>10.00 – 11.00</td>
<td>WORKSHOP 3: FUTURE CHALLENGES</td>
<td>How can health care consumer and health activist organisations best position themselves in the face of the increasing privatisation of health? How can health consumer organisations develop new forms of representation and ways of using new technologies and techniques to mobilise healthcare consumers? How can healthcare consumers strengthen their role in shaping research and data? How can healthcare consumer organisations and Universities work together to strengthen the political effectiveness of healthcare consumer action?</td>
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<td>11.00 - 11.30</td>
<td>Morning Tea</td>
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<td>WORKSHOP 3 REPORT BACK</td>
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<td>12.00 – 12.30</td>
<td>CATHERINE SETTLE (ANU)</td>
<td>DEVELOPING DELIBERATIVE CAPACITY: ENGAGING CITIZENS IN DELIBERATIVE METHODS OF HEALTH POLICY DEVELOPMENT</td>
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<td>1.30 – 2.30</td>
<td>PANEL 3: DARLENE COX (HCCA ACT) &amp; ANNE MCKENZIE (Telethon Institute WA)</td>
<td>FUTURE CHALLENGES \ PLENARY DISCUSSION &amp; WRAP-UP</td>
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<td>2.30 – 3.00</td>
<td>Afternoon Tea</td>
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<td>3.00 – 4.30</td>
<td>POSTGRADUATE &amp; RESEARCHERS WORKSHOP</td>
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UC ACCESSABILITY

UC AccessAbility continues to promote students with disability and/or health conditions. This support can be seen through the provision of reasonable adjustments which allow equal access to the university.

Below is a Campus Map to assist people with a disability. It shows lift access, disabled parking spaces, location of accessible toilets and location of ramps.

We hope that this map assists you during your time at the Health Activism & the Knowledge Society: Engaging Consumer/ Citizens in Shaping Health workshop at the University of Canberra on the 4\textsuperscript{th} and 5\textsuperscript{th} of April 2013.

Ashleigh Rumble & Alannah Brady
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Recommended all-day Parking