

POST-CONFERENCE REPORT

IN ATTENDANCE:

Thomas Abel, Stephanie Alexander, Thais Camargo, Ken Camargo, Anna Carson, Cathy Chabot, John Coggon, Sarah Cunningham-Burley, Rod Knight, Kate Frohlich, Mark Gilbert, Devon Greyson, Massudi Hakizamungu, Lisa McDaid, Eric Mykhalovskiy, Basia Pakula, Louise Potvin, Marie-Josée Potvin, Jason Robert, Erica di Ruggiero, Kate Shannon, Jean Shoveller, Sarah Viehbeck

REGRETS:

Jean-Baptiste Kakoma

MEETING OBJECTIVES

This workshop is a follow-up to a Symposium on PPHE held in Vancouver, 1-3 May 2012. The aim of the 2013 Montréal Symposium on PPHE was to continue the development of a framework for population and public health ethics. Specifically, the objectives of the 2013 Montréal Symposium on PPHE were to:

- Present, discuss and advance the manuscripts that were identified during the 2012 Vancouver Symposium on PPHE.
- Identify ongoing knowledge gaps to inform the continued growth of our research agenda (s) pertaining to PPHE.
- Solidify and expand research partnerships in this area.

May 6

1) OBJECTIVE 1: MANUSCRIPT DEVELOPMENT

Participants engaged in critical discussions related to six different manuscripts that were proposed during the 2012 Vancouver Symposium on PPHE. In order to provide the authors of each manuscript with a summary of the key points that arose during the discussion of each manuscript, please refer to Appendix A.

May 6–7

1) OBJECTIVE 2: IDENTIFYING KNOWLEDGE GAPS

A variety of different knowledge gaps were identified and discussed. The following is a summary of the key points that were surfaced during this discussion:

What and How?

- How do we characterize and fill the interdisciplinary space that we have created here?
- What is the role of empirical work in this realm, and, what concepts and theories are relevant and useful to advance our framework?

Reflexivity and positionality; values and vested interests

- What other work is occupying the space that we want to characterize and fill?
- What kind of networks and synergies are being generated (or need to be created)?
- Are we creating gaps by creating new ways of seeing things?

Geo-spatial and political considerations

- How do/should considerations related to various global contexts influence our research agenda(s) in the realm of PPHE?

Developing a set of working definitions

- How will we develop a common understanding of various working definitions within our work in PPHE (e.g., health, risk, equity, PPHE, disease, illness, (unintended) consequences)?

2) OBJECTIVE 3: SOLIDIFYING AND EXPANDING OUR EXISTING AND FUTURE RESEARCH PARTNERSHIPS AND ACTIVITIES

The following 5 points constitute the key points of action that were discussed in order to expand and advance our research activities:

1. Glossary Development

The development of a glossary that could be used to frame the field and shape the space that we would like to occupy was proposed. This glossary could be used as a basis for discussion and debate, and would help create a consensus on key definitions within PPHE.

Discussion: Although a glossary may sound like a simple idea, it is a complex and iterative process that serves to reflect the development of a guiding concept while shaping the research space through the definition of key terms. Here, it was discussed that the starting point of a PPHE glossary should be based around our common understandings of theory and methods within this area. By separating the key terms (population, public, health, ethics) we may also be able to distil meanings in ways that better reflect the nuances represented within each term, as well as how they converge together. The Journal of Epidemiology and Community Health publishes glossaries that contain definitions but are also analytical and it was considered a good ‘fit’ for the proposed glossary.

Action Items: At the next Symposium on PPHE (TBD), the proposed glossary will be added to the agenda for further consideration and development.

2. Criminal Law and Public Health Ethics Subgroup

The aim of this working sub-group was to explore the intersections of criminal law and public health as they pertain to PPHE.

Action Items: Eric, John, Kate F. and Kate S. will form a working subgroup to explore opportunities for working together in this substantive area and to identify key research questions within this area.

3. Framework/Position Paper

The aim of this proposed activity was to define our position and role as intellectuals engaged within the applied field of PPHE. Here, it was discussed that the relationships among public health, ethics, and bioethics should be clarified using a philosophical lens. A possible strategy in developing this paper could be to address key absences in the health sciences literature by drawing on concepts within social science that can inform both what is, or should be, addressed by PPHE.

Action Items: At the next Symposium on PPHE (TBD), this proposed paper will be discussed further, as it is likely that several of the emerging analyses (e.g., the ‘Why now?’ manuscript) will contribute to and inform our thinking in this area.

International Population Health Ethics Research Collaboration

6–7 May, 2013 Montréal, Canada

4. United Kingdom Hosted PPHE Symposium

In order to advance our partnerships and activities in PPHE together, Sarah C.-B., Lisa and John proposed that the UK contingent should apply for funding to host the next Symposium on PPHE in the UK. Here, two possible foci for the next proposed Symposium were discussed: (1) to initiate the development of a PPHE monograph or series of manuscripts; and (2) to develop an agenda that addresses the question of empirical research within PPHE, including how we want to develop our research questions and where to seek funding.

Action Items: Sarah C.-B., Lisa, and John will identify potential funding opportunities to host the next Symposium on PPHE in the UK. If needed, Kate F. will consider submitting a Meetings, Planning and Dissemination grant to CIHR to help supplement the funds raised by the UK team.

5. Engaging Students

In order to foster training within our group, it was decided that we should promote opportunities for international exchanges with students related to PPHE. It was also discussed that, if funding permits, we will continue to encourage and foster student participation in the 2014 UK Symposium on PPHE.

If you would like any additional information related to the discussions that took place during this Symposium, please contact Rod Knight at rod.knight@ubc.ca.

ACKNOWLEDGMENTS

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Appendix A

A SUMMARY OF THE DISCUSSION RELATED TO EACH PAPER

1) **ADVANCING POPULATIONS AND PUBLIC HEALTH ETHICS REGARDING HIV TESTING: A SCOPING REVIEW**

(Rod Knight, Jean Shoveller, Devon Greyson, Thomas Kerr, Mark Gilbert, Kate Shannon)

Discussants appreciated the treatment of stigma as a spectrum, rather than a binary concept, but also suggested that one needs to be aware of clustering anything that is problematic under the label of stigma. Instead, it may be beneficial to draw on other sets of literature, including literature from the substantive areas of breast cancer screening, mental health, vulnerability and social disadvantage. In addition, the complexity of measuring stigma arising from PH interventions (e.g., various approaches to HIV testing) was raised. It was also discussed that a PPHE framework could have been helpful within positioning this analysis. Finally, a “parking-lot issue” was raised: we are still left wondering whether bio-ethical principles or frameworks are necessary but not sufficient for PPHE.

Another critique of this manuscript was that it lacked a global (Southern) perspective and certain aspects remain underdeveloped (such as the relational dimensions of stigma). In scaling up any intervention, the ethical implications of ‘doing stuff to lots of people’ (which is not necessarily structural) arises. In moving these ideas forward, it was suggested that it may be necessary to be more reflexive in considering the values inherent within various definitions and key terms that are surfaced in our writing. Finally, it was suggested that many of the critiques addressed during this discussion could be a direct result of not having a set agenda for PPHE more broadly.

RECOMMENDED RESOURCES

- Powers, M. and Faden, R. 2008. Social Justice: the moral foundations of public health and health policy. *Oxford University Press*, New York, NY.
- Bayer, R and Stuber, J. 2006. Tobacco control, stigma, and public health: Rethinking the relations. *Am J Public Health* 96(1):47-50.
- Parker, R. and P. Aggleton. 2003. HIV and AIDS-related Stigma and Discrimination: A Conceptual Framework and Implications for Action. *Social Science & Medicine*. 57(1):13-24.
- Young, I and McDaid, L. How acceptable are anti-retrovirals for HIV prevention?: A review of research on the acceptability of pre-exposure prophylaxis and treatment as prevention. Currently under review.

2) EXPLORING TARGETED 'DISCOURSES' WITHIN CANADIAN AND AMERICAN HIV TESTING GUIDELINES: A CROSS-COMPARATIVE ANALYSIS

(Rod Knight and Jean Shoveller)

The comparative nature of this piece was described as being weak and it was recommended to include an international comparison between UK (or other European nations) and North American guidelines (e.g., how definitions of risk are constructed). On the other hand, it was suggested that, rather than drawing comparisons between country guidelines, considerations related to how groups are constructed within a set of guidelines might be more revealing. A further examination of HIV testing guidelines for partners of pregnant women was suggested. Finally, in moving the manuscript forward, it was recommended that the authors carefully consider how texts create risk categories, delineate why these categories were selected, consider the role of guidelines, and remain cognizant of the potential to conflate public health practice with the text. In addition, the authors should position themselves within the text and provide a discussion of why they chose to examine guidelines.

Other themes that arose included the importance of including literature on risk and risk management, a recognition of the definitions used within guidelines, an analysis of how identities are created through framing and how vulnerable groups can be used as an alias for at-risk groups (and how to approach this ethically). It was also recommended to consider the history and creation of categories, as well as the careful consideration of sex and gender. Finally, the question of whether considering notions of heterogeneity within PH practice is a social justice or PPHE issue was raised.

RECOMMENDED RESOURCES

- Mykhalovskiy, E. and L. Weir. 2004. The problem of evidence-based medicine: Directions for social science. *Social Science and Medicine*. 59(5):1059-1069.
- Timmermans, S and Berg, M. 2003. *The Gold Standard: The Challenge of Evidence-based Medicine and Standardization in Health Care*. Temple. Philadelphia.
- Teghtsoonian, K. 2009. Depression and Mental Health in Neoliberal Times: A Critical Analysis of Policy and Discourse. *Social Science & Medicine*, Vol 69. No. 1 (July), 28-35.
- Garoon, J and Duggan, P. 2008. Discourses of disease, discourses of disadvantage: A critical analysis of National Pandemic Influenza Preparedness Plans. *Social Science and Medicine*, 67:1133-1142.
- Hacking, I. 2007. Kinds of People: Moving targets. *Proceedings of the British Academy*. 151:285-318.
- Patton, C. 1986. *Sex & Germs: The Politics of AIDS*. Montreal-Buffalo: Black Rose Books.
- Oppenheimer, G.M. 1988. In the Eye of the Storm: the Epidemiological Construction of AIDS. In *AIDS: The Burdens of History*. (eds) E. Fee and D.M. Fox . University of California Press: Berkeley, California. Pp. 267-300.
- Schellenberg, E.G., J. Mantler Keil, and S. L. Bem. 1995 'Innocent Victims' of AIDS: Identifying the Subtext. *Journal of Applied Social Psychology*. 25(20):1790-1800.

3) HOW FAR CAN WE BAN SOMETHING WITHOUT BANNING IT?

(John Coggon, Sarah Cunningham-Burley, Kate Frohlich, Sarah Viehbeck)

It was suggested that the title, framing and structure of this paper could be refined and clarified, and that the three proposed cases may each require a very different set of discussions. One possibility could be to develop a comparative approach that contrasts normative and laissez-faire approaches. It was discussed that the use of various theories (e.g., theories of class dominance, power, empowerment) could be employed to structure this paper. It was also suggested that the authors could provide some additional information related to various interventions (e.g., accumulation of softer measures vs. a ban; what are the comparative outcomes in terms of social and political implications, and determining effectiveness?).

Finally, as public health practices can contribute to the (re)production of stigma and the health-related effects of stigma, the question was raised: What will need to happen for PH and communities to respond to and be compelled by PPHE to address these issues within this area? In addition, the following questions were raised: What makes this a PPHE paper? What counts as a PH intervention in the authors' view? Who has the 'right' (e.g., communities; judges) to participate in formulating PH interventions to address complex social problems? It was also raised that, because banning is a drastic structural intervention, it is also a means of regulation that creates pressure at the margins (locally and globally). As such, the geography of marginalization and PPHE could be more clearly incorporated into this discussion. Further, it was recommended that more nuance related to the intersections of the criminal justice system and PH could be provided (e.g., consider speeding laws). Finally, the issue of licensing was discussed as being an interesting PH intervention, as a license is usually conferred based upon an acquired skill.

4) PUBLIC HEALTH PARTISANSHIP AND POLITICAL STANDING

(John Coggon)

It was suggested that other definitions of public health could be considered (e.g., John Last's or Rudolph Virchow's definitions of PH), in part because the definition that is chosen/presented will have implications for how the rest of the paper will unfold. In this light, examining the history and evolution of PH definitions may be of particular use. The scope of PH action was surfaced by the author as an important consideration (e.g., at what point does the WHO become the "WEO" – World Everything Organization?).

It was also suggested that values are what separate professions from other kinds of work, and that (particularly within the Canadian setting) advocacy is considered a core competency in PH. The question as to whether advocacy is a black and white issue (or is there room to 'play in the grey'?) was raised, as well as the need to remember that PH efforts are not inherently good (e.g., eugenics). It was also suggested that some reflexivity could serve to improve why this paper seeks to advance this conversation. It was recommended that distinguishing between PH as a collective and PH as a space (e.g., a political space) could potentially reveal some new and important insights within this paper. As a corollary, by including a PH contributor as a co-author, it would be easier to attend to the 'language luggage'; further, this could position the paper as an exemplar of interdisciplinarity, thereby contributing to the space this group is trying to generate. The importance of distinguishing between PH practitioners and researchers was also discussed.

RECOMMENDED RESOURCES

- Dawson, A. (ed.) 2011. *Public Health Ethics: Key Concepts and Issues in Policy and Practice*. Cambridge University Press: Cambridge, UK.
- Fassin, D. 1996. *L'espace politique de la santé: Essai de genealogie (Sociologie d'aujourd'hui)*. Presses Universitaires de France: Paris, France.
- Labonte, R. 1994. Death of a program: Birth of a metaphor. In Rootman, I (ed.) *Health Promotion in Canada: Provincial, National and International Perspectives*. Saunders, Toronto.
- Collins, H. And Evans, R. 2009. *Rethinking Expertise*. University of Chicago Press, Chicago, 176pp.

5) POPULATION AND PUBLIC HEALTH ETHICS AND LONG ACTING REVERSIBLE CONTRACEPTION: A SCOPING REVIEW OF THE BIOMEDICAL LITERATURE

(Devon Greyson, Rod Knight, Cathy Chabot, Jean Shoveller, Jonathan Contreras-Whitney)

Discussants suggested that, as currently presented, there are several papers that could be developed from the data set. It was recommended that the authors identify several key frameworks and audiences for a set of related papers (e.g., write one for a biomedical audience identifying gaps in the literature and a separate paper for a social science audience). It was also recommended that the authors could consider including an analysis of vested interests within the papers, as well as young women's own perspectives; in doing so, the authors could examine adverse effects more thoroughly (e.g., if the available evidence does not back up the complaints made by young women, their experiences are more likely to be dismissed). In framing the gender issues, it was recommended that caution be

exercised, as access to LARCS by disadvantaged populations is very limited (as sexual health within these populations is often limited to STI/HIV prevention).

The difficulty of employing scoping reviews was discussed due to some inherent limits (e.g., excluding social science literature as data). However, in this case, a strategic and purposive decision was made to utilize the scoping review as a tool in the examination of how these pertinent conversations and questions are presented within the biomedical literature, as social scientists should not carry the full burden in this area (e.g., questioning the morality of 'taken for granted' PH actions). Further, this approach allows publication within the biomedical arena, where the message is most needed. Interest was expressed in understanding if this research agenda applies within the South, and whether the debate can be adapted to benefit the Southern context. Some discussion arose around whether this is PPHE, including if and how we can use the papers generated by these scoping reviews to build our research agenda.

6) WHY NOW?

(Sarah Cunningham-Burley, Sarah Viehbeck, Kate Frohlich)

Rather than an attempt to reinvent some space within bioethics, this paper represents an attempt to search for the authors' own identities within this space and to challenge the 'hegemony of bioethics' by considering it through a set of interdisciplinary approaches. Thus, it was discussed that this paper is much broader than previous work (e.g., intervention research). The paper is entitled 'Why Now?', but it was suggested that it should instead refocus on why PPHE (and how this is different from other fields), which will lead naturally into how it is different from other fields (namely, bioethics).

It was also suggested that, by refocusing the analysis on upstream health determinants, mechanisms and processes, this paper could be further removed from the bioethics paradigm. In addition, it was discussed that this paper could serve to shape the discourse and provide an opportunity for 'bumping up against' the limits of other agendas and interests. By writing this paper, a public dialogue becomes possible based on others' understanding of our work. It was discussed that, because this paper will represent an important 'agenda setter', it should be both reflexive, but also describe why reflexivity is so important within the realm of PPHE.

OTHER RECOMMENDED RESOURCES

Special Issue- Symposium: Global Health and the Law. *The Journal of Law, Medicine and Ethics*. 2013; 41(1):9-379. <http://onlinelibrary.wiley.com/doi/10.1111/jlme.2013.41.issue-1/issuetoc>

McDougall CW. 2009. National Collaborating Centre for Healthy Public Policy List of Public Health Ethics Researchers and Instructors Across Canada. http://www.nchpp.ca/docs/EthicsList_short_EN.pdf

Canadian Institutes of Health Research – Institute of Population and Public Health. (2012). Population and Public Health Ethics: Cases from Research, Policy, and Practice. University of Toronto Joint Centre for Bioethics: Toronto, ON. <http://www.jointcentreforbioethics.ca/publications/documents/Population-and-Public-Health-Ethics-Casebook-ENGLISH.pdf>

Aceijas C, Brall C, Schröder-Bäck P, Otok R, Maeckelberghe E, Stjernberg L, Strech D, Tulchinsky TH. Teaching ethics in schools of public health in the European Region: findings from a screening survey. *Public Health Reviews*. 2012; 34: 1.