POST-CONFERENCE REPORT

IN ATTENDANCE:

Thomas Abel, Taylor Basso, Cathy Chabot, John Coggon, Sarah Cunningham-Burley, Kate Frohlich, Mark Gilbert, Devon Greyson, Travis Hottes, Thomas Kerr, Rod Knight, Lisa McDaid, Jason Robert, Kate Shannon, Jeannie Shoveller, Sarah Viehbeck

REGRETS:

Erica Di Ruggiero, Yasmina Katsulis, Jennie Popay, Louise Potvin

May 1

1) INTRODUCTIONS AND WELCOME *(Jeannie Shoveller)*

MEETING OBJECTIVES

- identify knowledge gaps to inform a new research agenda related to population health ethics;
- examine how intervention approaches (e.g., population approach; high-risk group approach; vulnerable populations approach) exacerbate or attenuate young people's health;
- to identify and establish research partnerships to help launch a new PHE research agenda;
- to develop a plan for moving forward with a new research agenda related PHE.

2) CONTEXT SETTING: UNITED KINGDOM, CANADA AND THE UNITED STATES *(Sarah Cunningham-Burley, Kate Frohlich, Jason Robert)*

UNITED KINGDOM *(Sarah Cunningham-Burley)*

In the UK, PHE have somewhat limited saliency within practice and policy, although within the academy, relatively new opportunities are emerging, including the journal, *Public Health Ethics*, as well as other publications, such as the 2007 Nuffield Council on Bioethics report.

CANADA *(Kate Frohlich)*

Discussion emerged around the 'inequality paradox' whereby population health interventions may have the capacity to increase health inequities and privilege those who are at the lowest degree of risk. The question arose Is PHE a 'tool' for understanding the right thing to do? How is the most ethical act negotiated with the most efficient act within PHE?

UNITED STATES *(Jason Robert)*
PHE tends to suggest inequities require redressing and that this frequently runs counter to the socio-political discourses that demand individual rights over those of the collective – especially within the American context.

Discussion: What are the semantic differences between population health ethics and public health ethics? What constitutes a PHE 'framework'? How do we parse the difference between ethics in and ethics of public health?

3) OVERVIEW OF SCOPING EXERCISE *(Devon Greyson, Rod Knight, Jeannie Shoveller)*

The four scoping reviews under taken for the current workshop focused on papers concerned with discussions about ethics and population-level interventions. However, many other 'screened out' articles could also be analysed through a PHE rubric. For example, the search on long-acting reversible contraception (LARC), initially returned approx. 1,400 results, but only one of these remained relevant when an ethics filter was added. The group then overviewed the scoping paper that focused on ethical discussions related to various population-level HIV screening approaches (e.g., opt-out, mandatory, voluntary, seek and test).

Discussion: There was a general consensus that there is a lack of literature invested in the analysis of ethical concerns from a population and public health perspective in general, let alone with regards to more specific substantive areas, such as seek, test and treat models of HIV testing or treatment as prevention (e.g., identifying and treating people when not clinically necessary except as a 'public health' measure).

4) DISCPLINARY PERSPECTIVES ON CASE EXAMPLES *(Mark Gilbert, Jason Robert, Cathy Chabot, Kate Shannon)*

HIV TESTING *(Mark Gilbert)*
In Canada, many public health practices are adopting opt-out models, particularly with respect to prenatal testing. Acknowledging that guidelines around an HIV testing intervention need to be based on epidemiology of the disease, we should also consider the potentially polarizing and stigmatizing effects of the dominant discourses within public health.

HIV TESTING *(Jason Robert)*
Bioethics tends to focus on bedside decision-making. Testing and screening are population-level phenomena, not necessarily amenable to bioethical interrogation. We need new conceptual and methodological tools to more capably engage in ethics at the population level.

HPV VACCINATION *(Cathy Chabot)*
To date, the emphasis has been placed on personal autonomy rather than the broader population issues pertaining to the ethics of HPV vaccination programmes. Little attention has been placed on unanticipated consequences (e.g., reinforcing stigmatization of women's bodies as a site of disease control efforts).

HPV VACCINATION *(Kate Shannon)*
Much of the HPV discussions are centred on vaccination, particularly around mandatory/"opt-out" programs for young people. There is little empirical evidence to suggest what entails an effective HPV vaccination program, and policy decisions around HPV have been implemented in the face of an incomplete evidence base.

Discussion: Discussion also noted that there is a lack of clarity as to whether pharmaceutical companies are doing their due diligence in promoting the vaccine without knowledge of its long-term efficacy and risks. Another discussion point pertained to the promotion of HPV vaccinations solely for women and a discussion ensued around potential lost opportunities for prevention, especially for men.

5) PERSPECTIVES ON RESEARCH GAPS *(John Coggon and Thomas Kerr)*

HIV TESTING *(Thomas Kerr)*
We need a radical change to the current state of research related to HIV testing, with more emphasis to be placed on the social, structural and ethical aspects. We need new methodological innovations (e.g., step-wedge designs) and concerted efforts to develop an evidence base regarding the social outcomes that should also "count" beyond the medical outcomes.

HPV VACCINATION *(John Coggon)*
Public health ethics imply a focus on both the individual and the community, in part, in order to determine political and ethical obligations to a community, which was viewed as being an important lens with which to interrogate public health actions.

Discussion: Discussions included hypotheses regarding the causes of the current "empirical impasse" in this area (e.g., dominance of medical model; lack of sufficiently sophisticated theory/methods; political will). Ultimately, the question emerged: why ethics in public health, and why now?

6) RESEARCHING THE ETHICS OF INTERVENTIONS AND 'UNINTENDED CONSEQUENCES' *(Lisa McDaid, Sarah Viehbeck, Thomas Abel and Travis Hottes)*

LISA McDAID

Efforts and interventions to reduce teen pregnancy may have unintended consequences. Despite overall gains, there remains a wide gap in reproductive health outcomes between young people in the most and least deprived areas of the UK. This illustrates the danger of taking a one-size-fits-all approach to interventions. We ignore the phenomena of cultural relevancy and normative thinking at our peril (consider the case of Hull, where cultural expectations dictate that women start their families young), particularly regarding intervention context and tactics that may miss the point entirely.

SARAH VIEHBECK

There are also unintended consequences surrounding tobacco control interventions in Canada. The enduring question, 'what is next for tobacco control?' implies that something further needs to be done, in spite of the success of current programs in reducing smoking. If we accept that further steps need to be taken, where are the boundaries? And, what sort of 'transitional interventions' need to be in place for smokers? The question arose: How far can you ban something without banning it outright?

THOMAS ABEL

Despite the 'best of intentions', some interventions may explicitly result in harm (e.g., exacerbate or insight violence, stigma, victim blaming). In these paternalistic approaches, the agency of the participants does not appear to be considered in a fulsome manner. Thus, a population/public health ethics needs to include a focus on distributive justice (e.g., structural interventions that more equitably distribute 'the freedom to choose').

TRAVIS HOTTES

In addition to unanticipated negative consequences, we must consider who/what is 'missed' by an intervention. For example, a focus on HIV testing may come at the cost of missing out on other relevant issues. HIV+ people are also affected by many other (potentially multiplicative) social inequities that have important implications for interventionists to consider as well.

Discussion: At this point in the discussion, it became clear that there are several other substantive examples that could be worked through an ethics lens (i.e., almost any population/public health intervention could be subjected to an ethics analysis); this could be a unique contribution because so few PHIs actually have been analysed from such a perspective. But, we also faced the challenge that in order to engage in these kinds of analyses that we would need to articulate an answer to the question (that also emerged during this discussion): What does a robust ethical position look like?

May 2

1) GENERATING AN INVENTORY OF POTENTIAL RESEARCH QUESTIONS, FUNDING OPPORTUNITIES AND/OR STRATEGIES FOR BUILDING CAPACITY

(Sarah Cunningham-Burley)

NOTE: Descriptions of publications and abstracts in which people might be interested in spearheading resulted in the to-do list, which can be found in the document Manuscript Follow-up from Public Health Ethics Workshop May Vancouver.docx. This file, along with the resultant abstracts, can be found in the Dropbox folder 'Manuscripts.'

2) SETTING THE STAGE FOR DISCUSSION GROUPS (*Rod Knight and Jason Robert*)

The group reviewed the proposal for the HIV testing operating grant and catalyst grant which has been submitted by Shoveller et al. to CIHR (March 2012 competition). Copies of the applications were included in the pre-workshop materials which may be found in the Dropbox folder 'Pre-workshop materials.'

3) IDENTIFYING PRIORITY RESEARCH QUESTIONS... CONTINUED *(Kate Frohlich, Kate Shannon and Sarah Cunningham-Burley)*

KATE FROHLICH

In the Montreal context, reflexivity is seen as a buzzword and is applied procedurally by people in order to 'do the right thing' (procedural) rather than to approach a problem differently (substantive).

KATE SHANNON
Discussion emerged around the topic of criminalization and enforcement around sex workers. When the Canadian Supreme Court ruled against laws criminalizing sex work, they determined that 'the collective goal [of the laws] is not strong enough to outweigh the individual harms the laws cause.' This is a PHE issue.

SARAH CUNNINGHAM-BURLEY
What do we want to achieve and why do we want to achieve it through ethics? How will our methodology be taken up by others? How do we keep our analysis infused with verve?

Discussion: It has been increasingly unclear what does and does not constitute public health – is everything public health? Discussion centred around the importance of reflexivity in developing an ethical research agenda and methodology. What are the risks of assuming moral high ground as a service provider or researcher, without engaging in meaningful reflexive practice? What happens when the public's idea of what is ethical and the service providers'/researchers' diverge?

4) MOVING PRACTICE INTO ACTION *(Lisa McDaid, Thomas Abel, Sarah Viehbeck and Travis Hottes)*

LISA McDAID
Establishing buy-in, effectively learning a lexicon and creating a network of collaborators are all part of moving practice into action. We must ask what policy makers want and how our research fits that agenda.

THOMAS ABEL
We need more theoretical guidance and we need to ask ourselves how we use these theories to help us with regards to PHE? Part of moving ahead in PHE will be finding a balance between theory and practice.

SARAH VIEHBECK
Potential applicants for funding should look for 'buried' language around ethics in funding opportunities which may not seem to be immediately relevant.

Discussion: Discussion centred around possible outlets for new PHE research including an upcoming IPPH casebook regarding ethical concerns in public health, a forthcoming Springer Press series on PHE, and expressions of interest regarding PHE from European and American Public Health Associations, CPHO of Canada, and TCSP2.

TRAVIS HOTTES
What happens when individual practitioners resist policy and institutional practice ("conscientious objectors")? Ethics may be seen as a kind of 'four-letter word' and ethics training requirements may only go as far as learning how to pass an IRB.

5) IDENTIFYING PRIORITY RESEARCH QUESTIONS... CONTINUED *(Sarah Cunningham-Burley)*

Discussion focused on the various funding opportunities that each of our working contexts provides. Clearly, each participant will have access to different funding opportunities and there may be differing funding priorities in each context (or even levels of appetite within our own group). These will affect our capacity to facilitate ongoing research partnerships and training activities within this field. Further discussion resulted in a list of manuscripts which people might be interested in spearheading and various potential co-authors adjourned from the workshop to pursue their 'pitches' for Day 3.

May 3

1) PITCH TIME

Abstracts of the papers outlined below can be found in the Dropbox folder 'Manuscripts.'

WHY NOW? *(Sarah Cunningham-Burley, Sarah Viehbeck and Kate Frohlich)*
An overview of the intellectual and policy processes that have led us to where we are now within the field of population and public health ethics. This paper will consider whether population and public health ethics is merely an extension of bioethics to a wider level of application or a new field in and of itself. The authors will describe the trans-national influences on population and public health ethics, exploring the space that has been occupied particularly by American philosophical and political positioning. Possible journals: *Population Health Ethics, Critical Public Health, Journal of Epidemiology and Community Health, American Journal of Public Health.*

HPV SCOPING REVIEW / HPV AND GENDER PAPER (*Jason Robert and Lisa McDaid*)
In the present iteration of the scoping review, gendered issues are only occasionally raised. Is this a robust result or is it an artifact of our use of MEDLINE as our primary database? We may need to search other databases. *Discussion:* It will guide these papers to have an HPV content expert onboard – for example, someone like Gina Ogilvie (BC Centre for Disease Control)

ON PHIRE *(Jason Robert)*
A paper which considers how ethics collaborators are involved in the research process. The proposed manuscript would be divided into four parts: (1) diagnosis of PHIRE; (2) primary, secondary, and tertiary prevention of PHIRE; (3) resolution/management of PHIRE; and (4) evaluation of PHIRE, and lessons learned.

HOW FAR CAN WE BAN SOMETHING WITHOUT BANNING IT? ("VICE, ADVICE AND GOVERNMENT POLICY") *(John Coggon, Sarah Cunningham-Burley, Kate Frohlich, and Sarah Viehbeck [authors listed alphabetically until order is negotiated])*
This paper will investigate the distinction between practical limits on freedoms, the role of state action or inaction with regards to health behaviours and the consequences of different types of interventions. It will also analyse the effects of tactics such as stigma, labelling, criminalization, social exclusion and the characterization of 'vulnerable persons.' Case studies may include smoking, cannabis, emergency contraception and alcohol. A possible journal could be *Sociology of Health & Illness*.

PUBLIC HEALTH PARTISANSHIP AND POLITICAL STANDING *(John Coggon)*
Empirically demonstrable, systematically entrenched inequalities in health status have become a source of central political and ethical concern, a concern that is heightened by practical moral theories that demonstrate the clustering of health disadvantages alongside other socially determined inequities. This politicisation raises questions about the role and standing of public health practitioners, both individually and through professional associations, in public debates. The purpose of this project is to examine, compare, and interrogate the issues raised by a (potentially) partisan role for public health as a pressure group.

2) NEXT STEPS

We reviewed our jointly developed plan related to new publications and further collaborations that were identified during the workshop, including: products (e.g., manuscripts); timelines; and, additional research questions to be explored.