Arts-based approaches to KT in health policy development

Susan Cox, PhD
W. Maurice Young Centre for Applied Ethics
School of Population and Public Health
University of British Columbia
Vancouver, British Columbia

Creativity and innovation in knowledge translation
It might work out well…

Or it might not…
Learning objectives

- Explore the range of arts-based approaches to KT
- Identify challenges and opportunities related to using arts-based approaches in health policy development
- Consider examples of KT projects utilizing live theatre, found poetry and visual methods to inform health policy development
- Reflect on ethical and methodological issues arising from examples
### Arts-based Research

- Provides set of interdisciplinary methodological tools & practices used mainly by qualitative researchers but now more widely
- Can be incorporated in all phases of research from data collection to analysis and dissemination
- Poses range of new research questions & topics
- Expands diversity of audiences for research
- Enhances emotional & intellectual engagement

### Range of arts-based approaches

- **Visual:** collaborative mural making, digital storytelling, PhotoVoice, bodymapping; multimedia exhibitions
- **Performative:** live theatre, ethnodrama, dance, singing, music-making
- **Literary:** found poetry, storytelling, graphic novels, comics
"The 7,024th Patient" is an art exhibition that includes poetry and images to disseminate research findings from a study about patients' experiences of heart surgery and recovery. PROJECT TEAM: Dr. Jennifer Lapum, Dr. Gideon Cohen, Dr. Terrence Yau, Dr. Kathryn Church, Linda Liu (image retrieved from: http://the7024thpatient.com/events/)

Contact! Unload is a play co-developed by veterans telling the story of soldiers as they transition back to life in Canada. This theatre project is part of the Man/Art/Action initiative awarded to the Veterans Transition Network (VTN) by the Movember Foundation. Project Lead: George Belliveau, UBC Faculty of Education (image retrieved from: http://educ.ubc.ca/contactunload-in-vancouver/)
Climate for arts-based approaches

- Original emphasis on uses of ABHR for knowledge translation & exchange
- Increasing focus on use of ABHR as innovative & transformational mode of doing research
- Canadian Institutes of Health Research review of ABHR funding 2009-2014 (Boydell et al) reveals millions in funding to research using photo-elicitation, film, theatre and dance
Some factors influencing methodological innovation

- Rapidly changing socio-technical contexts and norms for how we communicate
- Theoretical shifts that argue for a focus on much more than just the ‘text’ (e.g., rise of sensory ethnography)
- Heightened desire on part of researchers to be more flexible and creative
- Need to capture ear of policy-makers or engage disenfranchised populations and communities
Examples of arts-based approaches to KT

• Theatre as an innovative approach to public engagement in development of health policy on assisted reproduction
• Multimedia performance piece about experiences of human subjects in health research as a method of sharing findings with key stakeholders to influence policy change
• Use of found poetry on reproductive tourism as a means of prompting policy-related questions and enhancing awareness of issues

Theatre as an Innovative Tool for Public Engagement in Health Policy Development

Project funded by:
Canadian Institutes for Health Research & Health Canada (2005-2008)

Susan M. Cox & Jeffrey Nisker, Co-PI’s
Magdalena Kazubowksi-Houston, Postdoctoral Fellow
Hubert Doucet, Collaborator

Research Assistants
Natasha Damiano
Celine Durand
Isabelle Gareau
Holly Longstaff

Margaret Dorazio-Migliore
Isabelle Ganache
Heather Greenwood
Marc Toppings
Objectives of public engagement:

- Provide Canadians with opportunity to learn about, debate and discuss complex issues arising from new reproductive and genetic technologies
- Provide Health Canada with results of process so that multiple and diverse perspectives can be used to inform policy on PGD, prenatal testing & genomics
Documenting the process

- fieldnotes and in-theatre observation (during 16 performances)
- demographics and audience feedback forms (70% response rate)
- moderated post-performance large audience discussions (N = 373)
- post-performance focus groups (N = 65 in 12 groups)
Complexity

“My overwhelming feeling from the play is I’m in constant conflict. When I watched the play, I just found it amazing how the play brought that out. And when you look at policy, the tricky thing is THAT. How do you put THAT complexity and THAT conflict, which results from these types of issues, into a policy?”

(Woman, Health Care Professional, LAD T9)

What makes live theatre an effective means of public engagement?

• Power of story in co–construction of knowledge (versus provision of information)
• Actors and audience members are mutually responsive (i.e., not passive) participants
• Performance creates empathy and stimulates imagination yet allows for multiple interpretations
• Shared experience of play becomes basis for dialogue, discussion and intervention
Challenges

• Creating a process: conceptualizing how to do theatre for public engagement
• Constraints: need for ‘balanced’ perspective
• Budgetary issues and competing priorities: quality of production vs assessing engagement
• Evaluation: absence of suitable standards
• Ethical issues: around identifiability of citizen voices, emotionally volatile situation, accessibility for persons w/disability
• Implementation: black hole at Health Canada

Centering the Human Subject in Health Research

CIHR Funded Project (2005-2012)
Susan M. Cox (PI)
Michael McDonald (Co-PI)
Anne Townsend, Pat Kaufert and Joe Kaufert (Co-Investigators)

What are the experiences of human subjects in health research?

The Psychograph (antique phrenology machine, circa early 1900s)
Centring the Human Subject. Theatrical performances at the Arts-Based Methods in Health Research dissemination event, November 19th & 20th, 2009. Leading Playwriter and Director: Graham W. Lea

YOU ARE THE OFFICIAL YOU HAVE THE NAME TAG AND THE WHITE COAT

WHEN MY MOTHER DIED I HAD AN APPOINTMENT THE NEXT MORNING AND IT WAS VERY EARLY SO I WENT AND I SAID YOU KNOW I HAVE NOT DONE THE BLOOD WORK BECAUSE MY MOM DIED YESTERDAY AND I JUST COULD NOT CALL SO I AM HERE NOW SHE SAID WHEN DO YOU THINK I COULD DO THE BLOOD WORK AND I SAID WELL I DO NOT KNOW MY MOM JUST DIED YOU KNOW I HAVE TO MAKE ARRANGEMENTS AND THINGS WELL SHE SAID SHE WOULD NOT WANT IT TO BE ANY LATER THAN THURSDAY LADY LISTEN TO ME MY MOM JUST DIED SHE WAS VERY INSISTENT SO I WENT DOWN AND HAD BLOOD WORK ABOUT TWO DAYS LATER

(Visual art created by: Donal O Donoghue)
Challenges

• Difficulties of negotiating appropriate forms of interdisciplinary collaboration between researchers and artists
• Methodological aspects of ‘creating’ the performance & weaving together all the pieces
• Differing priorities of researchers around accuracy in portraying findings and artists in aesthetics of performance
• Varied audience response and clinician/researcher concerns about ‘lack of balance’

Listening deeply:
Understanding experiences of reproductive tourism through poetic inquiry

Susan Cox, Heather Walmsley, Carl Leggo
University of British Columbia
The Odds (Heather Walmsley)

We did donor IVF:
15 mature eggs; 8 fertilized.
By day 3, down to 1 embryo.
We transferred that one.

I can’t help feel disappointed. 
We hoped to have something 
To freeze. 
Just in case.

But that was not to be

Why the other 7
Didn’t make it?
The universe, 
Giving me the middle finger.

I really thought
Taking my crappy eggs
Out of the equation
Would be the magic bullet.

For once, the odds in my favor
Challenges

- Issues of voice and methodological uncertainty of ‘creating’ poems that adequately represent participant experiences and perspectives
- Task becomes one of raising troubling questions but being unable to provide answers
- Tolerance for ambivalence and ambiguity in policy context

Cautionary notes

- Start small and keep it simple. These kinds of interdisciplinary collaborations are labour intensive and complex!
- Aim for early involvement of artists in conceptualization of arts-based approach; can’t just add on at the end of a project
- Be prepared for unforseen challenges, differing paradigms and competing priorities
- Audience impacts can be unpredictable and difficult to assess; no accepted standards for evaluation
References from examples


Resources

Books

• Daisy Fancourt (2016) Arts in Health: Designing and Researching Interventions, Oxford University Press.


Journals
• Arts and Health: An International Journal for Research, Policy and Practice
• Art/Research International: A Transdisciplinary Journal
Guidelines for:
• Visual researchers
• Ethics committees

Authors: Susan Cox, Sarah Drew, Marilys Guillemin, Catherine Howell, Deborah Warr, Jenny Waycott (alphabetical order)

Visual Research Collaboratory

Thank you!
I welcome your comments and questions.
Email: susan.cox@ubc.ca