

# EVERYDAY ETHICS IN PATIENT-ORIENTED KNOWLEDGE TRANSLATION

Jenny Leese, PhD Candidate

Rehabilitation Sciences, University of British Columbia

Arthritis Research Canada

April 11, 2019



a place of mind  
THE UNIVERSITY OF BRITISH COLUMBIA

van<sup>∞</sup>ouver  
foundation



# WEBINAR OBJECTIVES

1. Identify everyday ethical considerations in patient-oriented knowledge translation
2. Describe a case example illustrating ethical considerations in patient partner-researcher relationships
3. Reflect on practical implications of ethical considerations arising in the case example

# PATIENT-ORIENTED KT

- Forms a key part of patient-oriented research
- Research done in partnership with patients, that answers research questions that matter to patients and aims to improve health care

# KT APPROACHES

- End of Grant KT: Any activity aimed at diffusing, disseminating or applying the results of a research project
- Integrated KT: Knowledge users are members of the research team and participate in many stages of the research process

# DIMENSIONS OF RESEARCH ETHICS

1. Procedural Ethics
2. Everyday Ethics

# PROCEDURAL ETHICS

- Involves seeking approval from a relevant research ethics board (REB) to undertake research involving human participants
- Promotes research that is conducted to highest ethical standards to protect participants
  - Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2)
  - Tri-Council Framework: Responsible Conduct of Research
- Upholds core traditional principles of bioethics
  - Autonomy (Respect for Persons)
  - Beneficence (Concern for Welfare)
  - Justice

# EVERYDAY ETHICS

- Expands ethical considerations beyond arena of REB scrutiny
- Assumes the importance of acting ethically, regardless of formal requirement
- Refers to day-to-day ethical issues in “real life” that may not appear to be of great consequence from a traditional standpoint of bioethics
- Situated in common interactions between people

RESEARCH ARTICLE

# Patient engagement review

Juan Pablo Domecq<sup>1,2,5</sup>, Gabriela Prutsky<sup>1,2,5</sup>, T Nathan Shippee<sup>1,5,6</sup>, Juan Pablo Brito<sup>1,4,5</sup>, Kasey David Eton<sup>1,5,6</sup>, Jeff Sloan<sup>1,5,6</sup>, Victor Montori<sup>1,2</sup>, and Mohammad Hassan Murad<sup>1,3,5,6\*</sup>

### Abstract

**Background:** A compelling ethical rationale suggests that patient engagement will lead to research. However, it is unclear how to best conduct these questions: what are the best ways to identify and conduct research? What are the observed barriers to patient engagement?

**Methods:** We searched MEDLINE, EMBASE, PsycInfo, Search Premier, Academic Search Premier and size or design that described engaging patient environmental scan of the grey literature and non-quantitative, meta-narrative approach.

**Results:** We included 142 studies that describe patient engagement in most settings and most commonly done in primary care (development) and less commonly during the design of analytic studies to recommend a particular medication. The most commonly cited challenges were related to lack of resources, time, and an overarching worry of a tokenistic engagement.

**Conclusions:** Patient engagement in healthcare comes at a cost and can become a barrier to care. Achieving engagement to achieve engagement is lacking and clearly needed.

**Keywords:** Systematic review, Patient, Engagement, Patient centered outcomes research

# Patient and service user engagement: a systematic review and synthesis

Nathan D. Shippee PhD,\* Juan Pablo Domecq Garces MD,†† G MD,‡§ Zhen Wang PhD,¶ Tarig A. Elraiyah MBBS,† Mohammed Brito MBBS,†† Kasey Boehmer BA,‡‡ Rim Hasan MD,§§ Belal Erwin MLS,¶¶ Victor M. Montori MD, Msc\*\*\*,††† and M Hasa

**Correspondence**  
Nathan D. Shippee PhD  
Assistant Professor  
Division of Health Policy and Management  
School of Public Health  
University of Minnesota  
420 Delaware Street SE  
Minneapolis  
MN 55455  
USA  
E-mail: nshippee@umn.edu

**Accepted for publication**  
8 May 2013

**Keywords:** patient and public involvement, patient engagement, systematic review

### Abstract

**Background** There is growing attention to patient and service user engagement (PSU) in research. Existing variations in reporting and indexing, which are barriers to determining best practices.

**Objective** This paper utilizes a systematic scan to derive an evidence-based synthesis of research on patient and service user engagement (PSU).

**Design** A metanarrative systematic scan/manual search using scientific engines, along with feedback from patient and service user research.

**Eligible sources** English-language literature and other sources (including patient and service user research, public involvement in biomedical and health services research.

RESEARCH ARTICLE

# Early-career researchers' views on dimensions of patient engagement research

Jean-Christophe Bélisle-Pipon<sup>1,2\*</sup>, Geneviève Rouleau<sup>3,4</sup> and Stanislav

### Abstract

**Background:** Increasing attention and efforts are being put towards ensuring that some have even argued that patient engagement in research (PER) is a little empirical data on ethical issues associated with PER.

**Methods:** A three-round Delphi survey was conducted with a panel of PER. One of the objectives was to examine the ethical dimensions of PER preparedness to conduct PER ethically. The study was conducted among Unit in Canada, who represent the next generation of researchers involved throughout the study, such as definition, values, patients' roles, expected challenges (including ethical issues). Open-ended questions were used, through statements using 7-point Likert scales.

**Results:** Between April and November 2016, 25 ECRs were invited to participate in two second rounds, and 16 completed the third round. Panelists consisted of backgrounds (general practitioners and postgraduate students). The majority of Panelists' responses showed PER raises important ethical issues: 1) professional research (with risks of patients becoming less representative); 2) adequate recognition of patients' experiential knowledge; and 4) tokenism (engagement). While the panelists felt moderately prepared to confront these ethical issues, applying for an ethics certificate for a PER project.

**Conclusion:** If PER is an ethical imperative, it is vital to establish clear expectations for the PER community to identify and resolve ethical issues. Despite their overall not feel adequately prepared to address many of these issues. It is not enough and logistical imperatives. Additional research should focus on supporting what is not done, can undermine the credibility and feasibility of the entire PER project.

**Keywords:** Patient engagement, Patient-oriented research, Patient-centered outcomes, Ethical aspects, Tokenism, Authorship, Ethical preparedness

Qualitative Research

# Tokenism in patient engagement

David L Hahn<sup>a,\*</sup>, Amanda E Hoffmann<sup>a</sup>, Maret Felzien<sup>b</sup>, Joseph W LeMaster<sup>c</sup>, Jinping Xu<sup>d</sup> and Lyle J Fagnan<sup>e</sup>

<sup>a</sup>Wisconsin Research and Education Network, Department of Family Medicine and Community Health, University of Wisconsin School of Medicine and Public Health, Madison, WI, USA, <sup>b</sup>High Plains Research Network Community Advisory Council, Denver, CO, USA, <sup>c</sup>Department of Family Medicine, University of Kansas School of Medicine, Kansas City, KS, USA, <sup>d</sup>Department of Family Medicine and Public Health Sciences, Wayne State University, Detroit, MI, USA and <sup>e</sup>Oregon Rural Practice-Based Research Network, Oregon Health and Science University, Portland, OR, USA.

\*Correspondence to David L Hahn, Wisconsin Research and Education Network, Department of Family Medicine and Community Health, University of Wisconsin School of Medicine and Public Health, 1100 Delaplaine Ct., Madison, WI 53715, USA; E-mail: dlhahn@wisc.edu

### Abstract

**Background.** Patient engagement throughout research is a way to generate more relevant patient-important research questions, methods and results with the ultimate aim of facilitating translation of research into practice. Tokenism is defined as the practice of making perfunctory or symbolic efforts to engage communities or patients.

**Objective.** We wanted to explore how tokenism might influence engaging patients in research to help researchers work towards more genuine engagement.

**Methods.** The Community Clinician Advisory Group and Patient and Clinician Engagement program held a workshop at the 2015 North American Primary Care Research Group meeting titled 'How Do We Move beyond Tokenism in Patient Engagement?' Patients, clinicians and academic researchers contributed examples of genuine and token engagement characteristics based on personal experience and knowledge. Data were iteratively collated and categorized into domains and items.

**Results.** Examples of genuine and token engagement were categorized into three domains: **Methods/Structure of engagement, Intent and Relationship building.** Members with experience in patient-engaged research projects felt that longitudinal engagement was a key element to effectively translating research into local community and practice.

**Conclusions.** The group (i) highly valued genuine intent and relationship building as elements to combat tokenism; (ii) noted that early genuine attempts at engagement may superficially resemble tokenism as researchers build enduring and trusting relationships with patient/community partners and (iii) emphasized the importance of seeking and utilizing patient experiences throughout research. These observations may contribute to more formal methods to help researchers (and reviewers) evaluate where engagement processes sit along the 'genuine-token' continuum.

**Key words:** Culture and disease/cross-cultural issues, doctor-patient relationship, faculty development, health literacy, primary care.

Domecq et al. *Health Services Research* (2014). Shippee et al. *Health Expectations* (2013); Pipon et al. *BMC Medical Ethics* (2018); Hahn et al. *Family Practice* (2017)

# GENUINE PATIENT PARTNER-RESEARCHER RELATIONSHIPS

**Table 1.** Domains from the 2015 Community Clinician Advisory Group workshop with examples along the ‘genuine–token’ engagement continuum

Domain	More ‘genuine’	More ‘token’
III. Relationship building	<p>Sense of trust; developing an atmosphere patients feel comfortable in; valued and respectful relationship</p> <p>Making research purposeful—customize to patient needs having full disclosure between all parties</p> <p>Mutual benefits</p> <p>Delving deep into roots of perspectives, cultures, beliefs, myths, needs and ensuring they are addressed</p>	<p>Lack of trust/feeling from patient of ‘what I say doesn’t matter’</p> <p>Not having full disclosure</p> <p>Benefit is not mutual</p> <p>Patients are a means to an end</p>
Before project	Active dialogue prior to starting/developing research question/project; developing research question together with community/patient and what matters to them	No active or pre-existing relationship with patients
During project	Partnerships are promoted and nurtured	No attempt to create a partnership
After project	Sense of partnership that is sustained beyond specific grant or project; longitudinal ongoing partnership/relationship building	Relationship ends at the end of the project

# OUR FOCUS

- Lack of empirical evidence on patient partners' experiences of everyday ethical issues relevant to patient-oriented KT
- “It IS About Us! Patient Engagement in Health Research”
- Use a relational ethics lens to examine everyday ethical issues in patient partner-researcher relationships, based on the experiences of patient partners living with arthritis

# RELATIONAL ETHICS

- Used to bring attention to everyday ethical issues in relationships between patients and researchers in health research
- Supports careful consideration for the quality of relationships in the context of everyday life situations
  - Is that the way I should treat someone?
  - Is that the way someone else should treat me?

### PREPARATORY PHASE:

- Identifying and prioritizing research questions
- Acquiring Funding

- Patient partners approach academic partners with research idea
- Patient and academic partners formulate pertinent research questions
- Patient and academic partners write, review and provide feedback on funding application documents

### EXECUTION PHASE:

- Study designing
- Undertaking

- Academic partners revise interview guide and recruitment strategy based on insights shared by patient partners
- Patient and academic partners develop memorandum of understanding to represent an agreement to collectively own all data (subject to a participant's approval), results and research outputs generated by the study
- Patient and academic partners discuss themes emerging in the data to inform ongoing analysis and interpretation

### TRANSLATION PHASE

- Disseminating
- Implementing
- Evaluating Impact

- Academic partners create lay summaries using guidelines provided by patient partners, and revise lay summaries according to patient partners' feedback
- Patient and academic partners act as co-authors in preparing presentations and publications to present findings from the study

*Patient and academic partners corresponded regularly by email throughout each phase of the research process, and held bi-annual progress meetings (attended in-person and remotely)*

# ARTHRITIS PATIENT ADVISORY BOARD

- Founded at Arthritis Research Canada in 2001
- Volunteers living with arthritis
- Goals to ensure the patient perspective is represented on research matters and communicate research findings to patients, professional organizations and the general public



# QUALITATIVE APPROACH

- A one-to-one, semi-structured interview (approx. 60 mins)
- Eligible: Past or present members of the Arthritis Patient Advisory Board
- Thematic analysis uses iterative, constant comparison methods to identify commonalities and differences within and between transcripts
- Themes considered were considered in light of the relational ethics lens

# RESULTS

- Recruited 22 out of 33 eligible participants
- 21 (95%) were female, aged 26 – 68 years (with a median of 60 years)
- 10 (45%) employed, 9 (41%) retired, 2 (9%) students, 1 (5%) did not report
- 13 (59%) had at least one university degree
- Between 1 month to 10 years experience as a member of the board



## 3 MAIN THEMES

1. Being heard
2. Co-building social relations
3. "Adding another spinning plate to an already busy life"



# THEME 1: BEING HEARD

*Chloe: I'm not ready or know enough yet... I hope to be able to go to the conferences and to talk to the researchers eventually, when I feel ready.*

***Jessica: there's a mutual respect... patients sometimes need encouragement and reinforcement that their views are not lesser...***  
*that's really important because patients are going to be reticent to contribute if they feel it's tokenism. If they feel it's really valued then that's going to encourage them to speak and contribute more freely without fear.*



*Marie: there have been some research projects where **our feedback has made a difference** in how the research was designed... that's showing respect to the patient perspective... the researcher has treated me like a colleague in terms of sitting and talking and asking questions.*



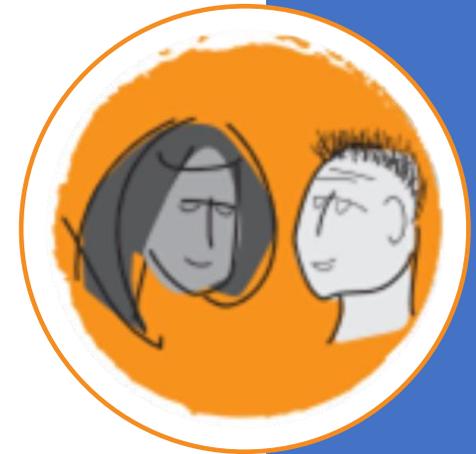
Olivia: *I've seen patients shape some projects... what I saw these investigators had at the end was a much less generalizable project... I don't think that you can discount years of research training for patient experience... we need to figure out the best way to give them both critical weight and maximize each one... **The patient is just as important as the researcher, and the researcher is just as important as the patient.***





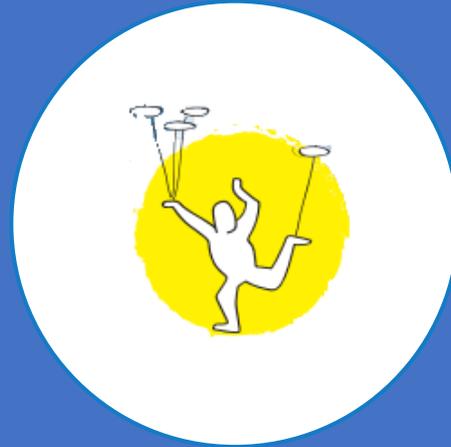
# THEME 2: CO-BUILDING SOCIAL RELATIONS

Phoebe Lewis: ***Everybody was on a first-name basis and right away that power hierarchy is dismissed.*** So when you're sitting across the table from a researcher and he's just talking about his research as casually as if he was at a Sunday picnic, all of a sudden your comfort level as a patient partner goes up... [researcher] would just sit down like the rest of us and eat and talk and sometimes share confidences... We felt quite comfortable passing them in the hall and saying hi. We knew a little bit about their families. They knew about ours.



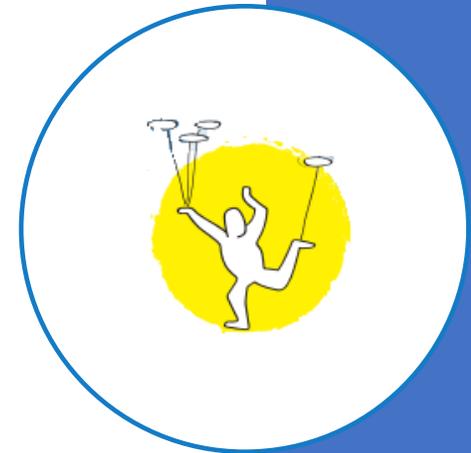
Jessica: *There's an ongoing relationship that enables more in-depth partnership... **true engagement is a continuing two-way dialogue, it's not just project-specific***



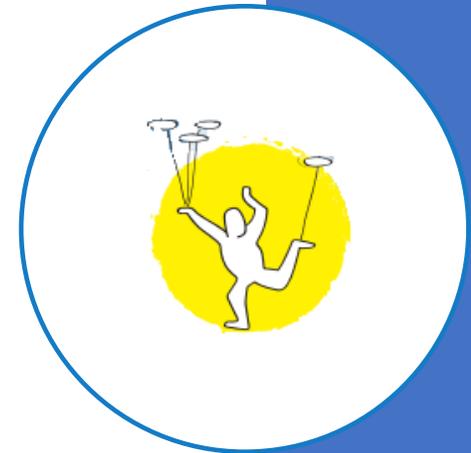


THEME 3:  
“ADDING ANOTHER SPINNING PLATE TO AN  
ALREADY BUSY LIFE”

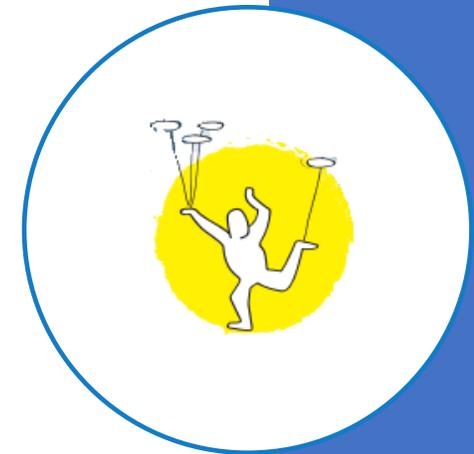
Sarah: *[there is a] **constant guilty, nagging feeling that I'm not doing enough...** I have thought about [stepping down from being a patient partner] for that reason... basically I felt pressure... I have no personal time... my job has been very time consuming. So between all those things, it gives me very little time for my husband [laughs].*



Mary: ...you're already dealing with so much yourself, personally in your home life, your own health, your own work life... if you're not able to contribute to the same degree because you're in a flare, there's a level of understanding and appreciation [from researchers] that you don't have to feel guilty... nobody is going to make you feel bad at all when you can't do it... **The researchers understand you need to look after yourself and that's what they want for you personally as well.**



Jessica: ... *[I was] sent a draft of the newsletter [by a researcher]. Would you have some time to review it before I send? So I think that's really nice... you're not just sent something without a warning and then expected to be able to find time in their deadline to do it... I replied back that **I have a number of commitments, was the deadline flexible... and right away the response was yes... again, the communication indicates that there's respect.***



# MUTUAL RESPECT

- Underscores how everyday ethical issues of power and vulnerability are experienced by participants
- Valuing patient partners' and researchers' distinct contributions as equally important
- Actively seeking, listening to and acting on patient partners' contributions

# EMBODIMENT

- Recognizing risks of possible negative impacts of being a patient partner
  - Feelings of discomfort (e.g., insecurity, guilt)
  - Stress
  - Aggravated symptoms
- Valuing informal acknowledgement of each other as people beyond roles within a project

# INTERDEPENDENCY

- Situating the individual within a community, connected with other individuals and institutions that influence their choices
- Building relationships with researchers among existing priorities in daily lives
- Acknowledging what was being juggled in participants' lives beyond the research setting

# STRENGTHS AND LIMITATIONS

- A rich sample of patients with arthritis who have a wide range of experience as patient partners
- Detailed description in a real world context
- Transferability may be restricted to similar contexts

# FURTHER WORK

1. Patient Engagement in Research (PIER) Framework
2. PIER Workbook to facilitate high-quality partnerships between researcher and patient partners



# CONCLUSIONS

- Findings illuminate some important everyday ethical issues in building relationships in patient-oriented KT, based on experiences of patient partners
- Better understanding of these ethical issues could support researchers and patient partners to build genuine relationships in everyday practice of patient-oriented KT
- Critical step in supporting an ethically-sound practice of patient-oriented KT that prioritizes patient perspectives

# ACKNOWLEDGEMENTS

- Study participants
- Linda Li, Professor, Department of Physical Therapy, University of British Columbia
- Sheila Kerr, Member, Arthritis Patient Advisory Board, Arthritis Research Canada
- Alison Hoens, Co-Chair, Arthritis Patient Advisory Board, Arthritis Research Canada
- Lianne Gulka, Co-Chair, Arthritis Patient Advisory Board, Arthritis Research Canada
- Wendy Lum, Member, Arthritis Patient Advisory Board, Arthritis Research Canada
- Bao Chau Tran, Former PhD student, Department of Physical Therapy, University of British Columbia
- Graham MacDonald, Research Assistant, Arthritis Research

# REFERENCES

1. British Columbia SUPPORT Unit. (2018). *What's patient-oriented research?* Retrieved from <http://bcsupportunit.ca/> [Accessed April 1 2019].
2. Canadian Institutes of Health Research. *Knowledge Translation*. (2016). Retrieved from <http://www.cihr-irsc.gc.ca/e/29418.html#5.1> [Accessed April 1 2019]
3. Natalie Zizzo *et al.* What Is Everyday Ethics? A Review and a Proposal for an Integrative Concept. *The Journal of Clinical Ethics* 2016;27:2:117-28.
4. Domecq JP *et al.* Patient engagement in research: a systematic review. *BMC Health Services Research* 2014;14:1–9
5. Shippee ND *et al.* Patient and service user engagement in research: a systematic review and synthesized framework. *Health Expectations* 2015;18:1151–66.
6. Rouleau G *et al.* Early career researchers' perspectives and roles in patient-oriented research. *Research Involvement and Engagement* 2018;4:35.
7. Hahn DL *et al.* Tokenism in patient engagement. *Family Practice* 2017;34:290–5.
8. Ellis C. Telling secrets, revealing lives: Relational ethics in research with intimate others. *Qualitative Inquiry* 2007;13:3–29.
9. Austin W. Engagement in contemporary practice: a relational ethics perspective. *Texto & Contexto - Enfermagem* 2006;15:135–41.
10. Hamilton CB *et al.* Framework for advancing the reporting of patient engagement in rheumatology research projects. *Current Rheumatology Reports* 2017;19:38.
11. Leese, J *et al.* 'Adding another spinning plate to an already busy life.' Benefits and risk in patient-researcher relationships: a qualitative study of patient partners' experiences in a Canadian health research setting. *British Medical Journal* 2018;8.
12. Hamilton C, *et al.* An empirically based conceptual framework for fostering meaningful patient engagement in research. *Health Expectations* 2018;21:1:396-406.

*Thank you!*

**Jenny Leese, PhD Candidate**

[jleese@arthritisresearch.ca](mailto:jleese@arthritisresearch.ca)

@jen\_leese