Course Title:

MT11: Building Public Participation in Research

Instructor(s) Information:

Amy Price, PhD, University of Oxford, and Research Fellow, *The BMJ*
(https://www.conted.ox.ac.uk/dphil-students?id=32)

Audience Level:

Materials can be adapted for all levels and forms of research.

Audience:

Anyone interested in public involvement, good scientific practice, and cooperation between scientists and the public.

Course Description:

The current model of research is being transformed by the crowdsourcing of research ideas and health data. To provide value, research must be ethical, methodologically sound, and clinically safe, and it must lead to practice based on real-world evidence. In addition, funders increasingly require research teams to involve the public in multiple aspects of research. Yet evidence shows that research teams struggle to include the public in activities such as systematic reviews, priority setting, research design, and evaluation.

This course shares solutions for starting from where we are to build research with public participation. We will offer practical methods to combine public involvement with science-based practice. Participants will learn manageable ways to invite the public to help prioritize, initiate, design, organize, and evaluate research.

Involving the public in scientific research offers untapped potential for improving public relations, science education, shared decision-making, and peer-to-peer knowledge. The time is ripe, the technology is ready, and the passion to engage the public is real!

Course Learning Objectives:

The course will show researchers and participants how to:

- ➔ Write public involvement into the research protocol.
- ➔ Use public involvement for funding applications.
- ➔ Find, communicate with, and train research volunteers.
- ➔ Meet with the public and manage expectations for a good working relationship.
- ➔ Write the contributions of citizens into research results for publication.
- ➔ Be ready for Patient Peer Review as a reviewer or as one being reviewed

Course Topics:

This course will cover the following topics:

- What is Public Involvement and who needs it?
- How Public Involvement can be a win/win proposition
- Accessing software resources
- Open data, protected data and sharing with participants

- Recognise and troubleshoot conflicts of interest and bias
- Relationships, conflict resolution and reality
- Problem solving
- How can we fix it and when do we need to
- Building the protocol to include PI
- Writing up the Research with PI in it. Looking at options
- Prepare for Peer Review, promises, perils and production

In all areas there will be time for questions, small group work and interaction

Course Schedule:

Day 1 - Monday:

- What is Public Involvement and who needs it?
- How Public Involvement can be a win/win proposition
- Accessing resources
- Whose data is it
- Avoiding conflicts of interest and bias

Day 2 - Tuesday:

- Making it Work
- What can go wrong
- How can we fix it
- Building the protocol
- Writing up the Research
- Prepare for Peer Review

Course Materials and Supplies:

Required:

- an open mind
- a willingness to interact and problem solve
- a laptop would be helpful

Other Resources:

Building Public Participation in Research

Workshop Developers| Amy Price, Homa Keshavarz, P. Lina Santaguida,

BACKGROUND:

The current model of health research is inundated by the crowdsourcing of research ideas and health data. To provide value, research must be ethical, methodologically sound, clinically safe and lead to real world evidence based practice. Funders increasingly require research teams to involve the public in multiple aspects of research. This presentation shares solutions for starting from where we are to build research with what we have. The evidence shows research teams struggle to include the public in preparatory forms of research like systematic reviews, priority setting, research design and evaluation. We propose practical solutions for combining research involvement with evidence based practice starting from ground zero.

OBJECTIVE:

To share manageable ways research investigators can invite members of the public to help researchers prioritize, initiate, design, organize and evaluate health research

METHODS:

Identify solutions for public involvement in research to:

- write research involvement into the protocol
- use research involvement for funding applications
- find, communicate with, and train, research volunteers
- meet and manage expectations for a good working relationship
- write the contribution of citizens into the research methods for publication.

CONCLUSIONS:

The public contains untapped potential for improving informed shared decision-making, education and methods in research. The time is ripe, the technology is ready, and the passion to engage the public is now!

QUOTABLE CONCEPTS:

In this digital age, we see a challenge for informed shared decision making in Research and Healthcare aptly expressed through these quotes;

"*The job of the human being [in the digital age] is to become skilled at locating relevant valid data for their needs. In the sphere of medicine, the required skill is to be able to relate the knowledge generated by the study of groups of patients or populations to that lonely and anxious individual who has come to seek help*." Sir Muir Gray, 2001

*"It is my aspiration that health finally will be seen not as a blessing to be wished for, but as a human right to be fought for***."** United Nations Secretary-General Kofi Annan

"*We are all fixing what is broken and it is the task of a lifetim*e". Abraham Verghese

BRIEF BIOGRAPHIES:

Amy Price PhD [dr.amyprice@gmail.com]

Amy Price worked as a Neurocognitive Rehabilitation consultant and in International

Missions before sustaining serious injury and years of rehabilitation. She emerged with a goal to build a bridge between research methods, research involvement and public engagement where the public is trained and empowered to be equal partners in health research. She is a Doctoral Candidate at the University of Oxford and has worked in many areas of research and development. Amy's experience has shown her that shared knowledge, interdisciplinary collaboration, and evidence based research will shape and develop the future. She serves on multiple boards and charities including as a BMJ Research Fellow and as a member of the BMJ Patient Panel. For publications see Research Gate Profile

Homa Keshavarz PhD [homa.keshavarz12@gmail.com]

Homa Keshavarz was awarded her PhD in Epidemiology from MRC, Cambridge, UK. She is currently working as a consultant methodologist/epidemiologist on clinical practice guidelines for the Canadian Thoracic Society while also working as a co-lead of PENTEC (pediatric normal tissue effects in the clinic), international multi-center Systematic Review. She worked as a **senior scientist**/Epidemiologist with the University Health Network (UHN) where she serves as a methodologist and project manager for clinical practice guidelines, systematic review, and observational studies.

She worked at the Evidence-Based Practice center at McMaster University for over 10 years working on various large-scale systematic reviews and clinical practice guidelines. She also worked extensively on the 8-year pilot phase of the Canadian Longitudinal Study on Aging, the largest cohort study of aging in the world. She has also taught health research methodology and statistics to graduate students at McMaster University. She has an interest in continuing her work in multi-centered health research. She worked through the SARS outbreak as an Epidemic Intelligence Service Officer (EIS) at the Centers for Disease Control and Prevention from July 2000 – June 2002 in Atlanta, Georgia, USA. She has a keen interest in public health and the methods used to bring evidence into practice including citizen research involvement. Research Gate Profile

P. Lina Santaguida PT, PhD [santag@mcmaster.ca]

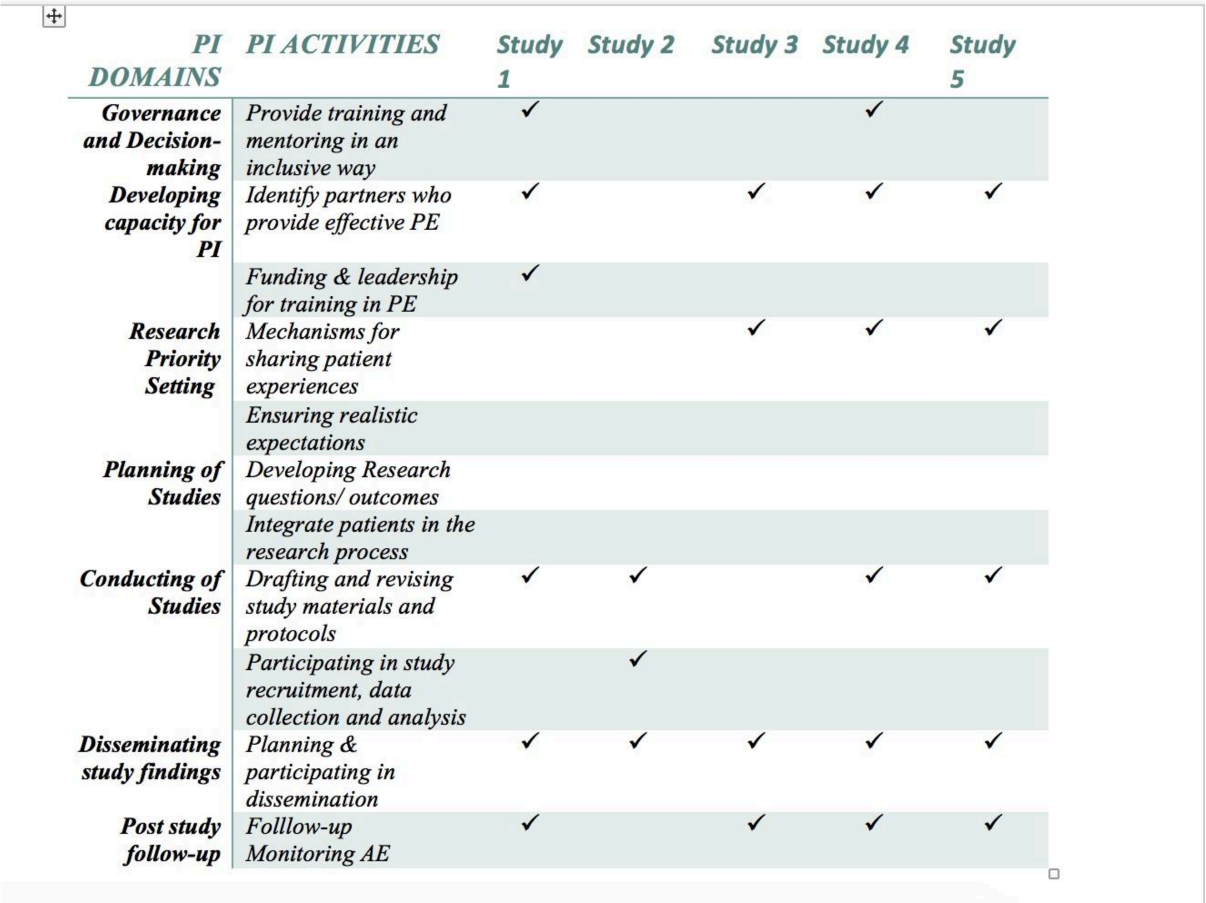
Pasqualina (Lina) Santaguida is an Assistant Professor at McMaster University in the Department of Health Evidence and Impact. Her research interests are broad and include work in four main areas: knowledge translation (knowledge syntheses methods, systematic reviews, rapid reviews, meta-epidemiologic methods, risk of bias assessment, reporting of harms); aging and mobility related disorders (cervical spine disorders, use of orthoses, musculoskeletal related disability, osteoarthritis, physical therapy; utilization of complementary and alternative therapies); health outcomes (measurement properties of patient specific instruments, criteria to select outcomes); and accessing online health information.

She has conducted a number of knowledge syntheses (n=29) over the past 14 years funded by

a variety of agencies that include Canadian Institute of Health Research (CIHR) and Agency for Healthcare Research and Quality (AHRQ). She was the Co-Associate director of the McMaster University Evidence-based Practice Centre (MU-EPC) for over 5 years. She is a member of the Cervical Overview Group that has published Cochrane reviews on the management of neck pain. She is a member of the Cochrane Methods and Cochrane Adverse Effects groups and a member of the Cochrane committee that developed a new risk of bias tool for non-randomized studies (ROBINS-I (www.riskofbias.info)). She has developed a tool for assessing risk of bias in harms (McHarm) and was part of Steering Committee that developed the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) Harms extension.
http://www.fhs.mcmaster.ca/ceb/faculty_member_santaguida.htm

HELP FOR STRUCTURING:

For complex grant applications that often contain multiple projects (for example, in the table below there are 4 studies included in the application) or even just one study with different areas of research involvement/public engagement, P. Lina Santaguida developed this table (Adapted from PCORI and CIHR SPOR criteria) which may be helpful to refer back to in a protocol, grant application or when considering what needs to go in a publication.



PI DOMAINS	PI ACTIVITIES	Study 1	Study 2	Study 3	Study 4	Study 5
Governance and Decision-making	*Provide training and mentoring in an inclusive way*	✓			✓	
Developing capacity for PI	*Identify partners who provide effective PE*	✓		✓	✓	✓
	Funding & leadership for training in PE	✓				
Research Priority Setting	*Mechanisms for sharing patient experiences*			✓	✓	✓
	Ensuring realistic expectations					
Planning of Studies	*Developing Research questions/ outcomes*					
	Integrate patients in the research process					
Conducting of Studies	*Drafting and revising study materials and protocols*	✓	✓		✓	✓
	Participating in study recruitment, data collection and analysis		✓			
Disseminating study findings	*Planning & participating in dissemination*	✓	✓	✓	✓	✓
Post study follow-up	*Folllow-up Monitoring AE*	✓		✓	✓	✓

STRATEGIES TO INCORPORATE FOR RESEARCH INVOLVEMENT

Strategies for working with patients/public as Research Partners	
From the beginning	1. Involve members of the public at every decision-making level 2. Introduce the patient caregiver and family perspective to each meeting 3. Provide consistent oversight and support

Find and cultivate	1. Identify partners through social media, advocacy groups, word-of-mouth, universities, within the community, schools, and forums 2. Consider cultivating patient groups to work with you 3. Think about how you will fund the involvement and what the needs are, build this into your funding proposals. If you don’t have money brainstorm what can you offer of value to volunteer research partners be transparent and ask volunteer partners for ideas 4. Plan in advance to build capacity and training, coordinate your resources and share with volunteers your work plan and time structure
Set the scene	1. Develop a climate for open communication of public and patient experience 2. Change language from patients are involved to patients are partners 3. Have patients/members of the public choose their levels of involvement, be realistic as patients may be ill, have other jobs, be fine for part of your research and then have a health crisis, be prepared to honor your volunteers on the level to which they can commit and respect their time.
Making it functional	1. Integrate involvement from the research, to dissemination, to implementation, to further development, or refining the intervention and for long-term follow-up 2. Integrate research volunteers into all research processes with a sensitivity to their ability and capacities, do not assume because they are members of the public that they are unable to contribute 3. Use a Plan>Build>Test>Reflect>Refine approach and pilot everything

Ongoing support & implementation	1. Develop your publication and implementation strategy early - think of asking volunteers with plain language translation of your research findings and in the general knowledge translation of your work 2. Volunteers can build posters, infographics, presentations, peer-to-peer meetings, recruitment materials and can edit documents for clarity and ease of reading 3. Volunteers can be trained to conduct interviews/focus groups with their peers 4. Involve research volunteers in quantitative and qualitative research as this will assist them to identify good research questions that are scientifically valid
Training/mentoring/capacity building	1. Provide training in research literacy and ethics, there are multiple training programs available 2. At every meeting have a jargon bin, when an unfamiliar term comes up, define and use to build glossaries. This will also make people aware of when they are speaking in jargon and could make things clear and simple 3. Nurture a reciprocal learning relationship letting volunteers know that you have made a long-term commitment to patient and public partnership in research. 4. Feel realistic expectations in volunteers and researchers and manage relationships with respect
Inclusion process	1. Involvement at multiple levels 2. Shared informed leadership and decision-making, avoid silos 3. Build together 4. Peer-to-peer mentoring and training 5. Ongoing process of evaluation-is it working for everyone - how can we improve?

Building trust and culture	1. Build culture through shared understanding and cooperation 2. Explore and take risks together 3. Be transparent, keep volunteers informed 4. Support collaborative research from the top
Reinforce value and validate	1. Give specific targeted, frequent feedback, thanks is not enough 2. Let volunteers know how you are Implementing their suggestions and why other suggestions will not work, be transparent, respectful and kind 3. Adopt "promise back" mechanisms to put in place

ADDITIONAL RESOURCES:

PCORI has a useful document about implementing patient engagement http://www.pcori.org/sites/default/files/Engagement-Rubric.pdf

HOLE IN THE WALL: Sugata Mitra shares how kids teach themselves in this TED Talk, now translated into 30 languages, https://www.ted.com/talks/sugata_mitra_shows_how_kids_teach_themselves

CITIZEN SCIENTISTS DEVELOP A GALAXY Citizen Science in The Zooniverse - YouTube

THE SCIENCE OF ENGAGEMENT McCracken G, Oullier O, Ramsoy T.. 2013. http://webershandwick.co.uk/wp-content/uploads/2014/03/SofE_Report.pdf

THE PUBLIC HELPING THEMSELVES: The public has great ability to solve research problems, they are a committed force in need of a plan for innovation that works. http://blogs.bmj.com/bmj/2014/10/17/amy-price-patients-doing-research-for-themselves

BACKGROUND ON MARIE CURIE: Amateur, scientist and Nobel Laureate https://www.mariecurie.org.uk/who/our-history/marie-curie-the-scientist

CASP UK: Free critical appraisal checklists and learning tools http://www.casp-uk.net/casp-tools-checklists

Amy Price: Developing tools for practice that support patient choice – The BMJ http://blogs.bmj.com/bmj/2017/05/24/amy-price-developing-tools-for-practice-that-support-patient-choice

BMJ PATIENT PARTNERSHIP:
http://www.bmj.com/campaign/patient-partnershipAND
http://www.bmj.com/about-bmj/resources-reviewers/guidance-patient-reviewers
and to see a blog on patient review
http://blogs.bmj.com/bmj/2015/06/23/amy-price-and-marilyn-mann-on-the-pros-o

f-patient-peer-review
RAYYAN FREE SYSTEMATIC REVIEW APP https://rayyan.qcri.org/
THINKWELL: Videos on using free apps and resources http://www.ithinkwell.org/finding-answers/crisp/
MENDELEY: Free app and slideshow explain how to use it http://www.ithinkwell.org/mendeley-and-more-for-systematic-reviews/

Price A, Schroter S, Snow R, *et al.* Frequency of reporting on patient and public involvement (PPI) in research studies published in a general medical journal: a descriptive study. *BMJ Open* 2018;**8**:e020452. doi:10.1136/bmjopen-2017-020452

Price A, Albarqouni L, Kirkpatrick J, *et al.* Patient and public involvement in the design of clinical trials: An overview of systematic reviews. *Journal of Evaluation in Clinical Practice* 2017;:1–14. doi:10.1111/jep.12805

Price A, May S, Nelken Y, *et al.* Mind the gap in clinical trials: A participatory action analysis with citizen collaborators. *JECP* 2016; **In-Press**:1–7. doi:10.1111/jep.12678

Price A. Public led online trials and participatory action research: Why do we need them? *Eur J Pers Centered Healthc* 2016; **4:340**–5. doi:10.5750/EJPCH.V4I2.1095

Abelson J. Patient Engagement and Canada' s SPOR Initiative. 2015;**2015**.