

# Medical Education and Research Involvement with Patient and Public Partners

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### 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 and medical educators 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 in the protocol
- use participant partner involvement in your funding applications
- find, communicate with, train, conduct research and co-create with medical education partners
- Meet and manage expectations early and consistently for a good working relationship
- write the contribution of citizens to the research methods and in textbooks for publication.

### CONCLUSIONS

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

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 lifetime”. Abraham Verghese

<b>Strategies for working with patients/public as Research Partners</b>	
<b>From the beginning</b>	<ol style="list-style-type: none"> <li>1. Clarify roles and let your partners know who they are responsible to and how they can get help</li> <li>2. Write an intro email to research and clinical staff so the partner does not have to initiate first contact</li> <li>3. Involve members of the public at every decision-making level</li> <li>4. Introduce the patient caregiver and family perspective to each meeting</li> <li>5. Provide consistent oversight and support</li> <li>6. Share information and provide mentorship</li> <li>7. Pre-establish how to regroup, recover and reframe if things go wrong.</li> </ol>
<b>Find and cultivate</b>	<ol style="list-style-type: none"> <li>1. Identify partners through social media, advocacy groups, word-of-mouth, universities, within the community, schools, and forums</li> <li>2. Consider cultivating patient groups to work with you</li> <li>3. Think about how you will fund the involvement early and what the needs are, and 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</li> <li>4. Plan in advance, to build capacity and training, coordinate your resources and share with partners your work plan and time structure</li> </ol>
<b>Compensation</b>	<ol style="list-style-type: none"> <li>1. May vary depending on the level of involvement of a patient partner/collaborator</li> <li>2. Keep processes and paperwork simple so as not to burden patient partners/collaborators</li> <li>3. Need to consider local taxation laws/regulations and how these may impact compensation</li> <li>4. Have a share back plan for partners who do not want compensation</li> </ol>
<b>Reimbursement</b>	<p>Payment is designed to cover associated costs of participation including</p> <ol style="list-style-type: none"> <li>1. disability concessions,</li> <li>2. equipment</li> </ol>

	<ol style="list-style-type: none"> <li>3. travel, meals, and parking</li> <li>4. any out-of-pocket pre-agreed costs</li> </ol>
<b>Set the scene</b>	<ol style="list-style-type: none"> <li>1. Develop a climate for open communication of public and patient experience and how it will blend with clinical workflows.</li> <li>2. Change language from patients are involved to patients are partners</li> <li>3. Offer low-risk tasks and build trust. For example, having a patient partner write your abstract for publication is a high risk, sending patient-facing tools and asking partners to try this and share how they might make it better is low risk.</li> <li>4. 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, and be prepared to honour your partners on the level to which they can commit and respect their time.</li> </ol>
<b>Making it functional</b>	<ol style="list-style-type: none"> <li>1. Integrate involvement from the research to dissemination, to implementation, to further development, or refining the intervention and for long-term follow-up</li> <li>2. Integrate participant partners 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</li> <li>3. Use a Plan&gt;Build&gt;Test&gt;Reflect&gt;Refine approach and pilot everything. For optimal results do this early.</li> </ol>
<b>Ongoing implementation</b>	<ol style="list-style-type: none"> <li>1. Develop your publication and implementation strategy early - think of asking partners for plain language translation of your research findings and in the general knowledge translation of your work.</li> <li>2. Partners can build posters, infographics, presentations, peer-to-peer meetings, and recruitment materials and can edit documents for clarity and ease of reading.</li> <li>3. They can be trained to conduct interviews/focus groups with their peers.</li> <li>4. Involve participant partners in quantitative and qualitative research as this will assist them to identify good research questions that are scientifically valid.</li> </ol>
<b>Train/mentor, community and Capacity building</b>	<ol style="list-style-type: none"> <li>1. Provide training in research literacy, medical education per topic and ethics, there are multiple training programs available (see below for resources).</li> <li>2. At every meeting have a jargon bin, when an unfamiliar term comes up, define it and use it to build glossaries. This will also</li> </ol>

	<p>make people aware of when they are speaking in jargon and could make things clear and straightforward.</p> <ol style="list-style-type: none"> <li>3. Nurture a reciprocal learning relationship letting the team know that you have made a long-term commitment to patient and public partnership in research.</li> <li>4. Search out realistic expectations for participant partners and researchers and manage all relationships with respect and kindness.</li> </ol>
Inclusion process	<ol style="list-style-type: none"> <li>1. Involvement at multiple levels</li> <li>2. Shared informed leadership and decision-making, avoid silos</li> <li>3. Those who build and train together stay together</li> <li>4. Peer-to-peer mentoring and training</li> <li>5. Is the ongoing process of evaluation-is it working for everyone - how can we improve?</li> </ol>
Building trust and culture	<ol style="list-style-type: none"> <li>1. Build culture through shared understanding and cooperation</li> <li>2. Explore and take risks together</li> <li>3. Be transparent, keep volunteers informed</li> <li>4. Support collaborative research from the top</li> </ol>
Reinforce value and validate	<ol style="list-style-type: none"> <li>1. Give specific targeted, frequent and constructive feedback, thanks are not enough</li> <li>2. Let participants know how you are implementing their suggestions and why other suggestions will not work, be transparent, respectful and kind</li> <li>3. Adapt “teach back” and “promise back” mechanisms and remember to celebrate even small victories, this builds community.</li> </ol>

### Additional Resources:

Complimentary Initial ZOOM Consult with Dr Amy Price: [Add your organization in the subject line](#) We look forward to hearing more about your project and helping you to target this so it is most effective

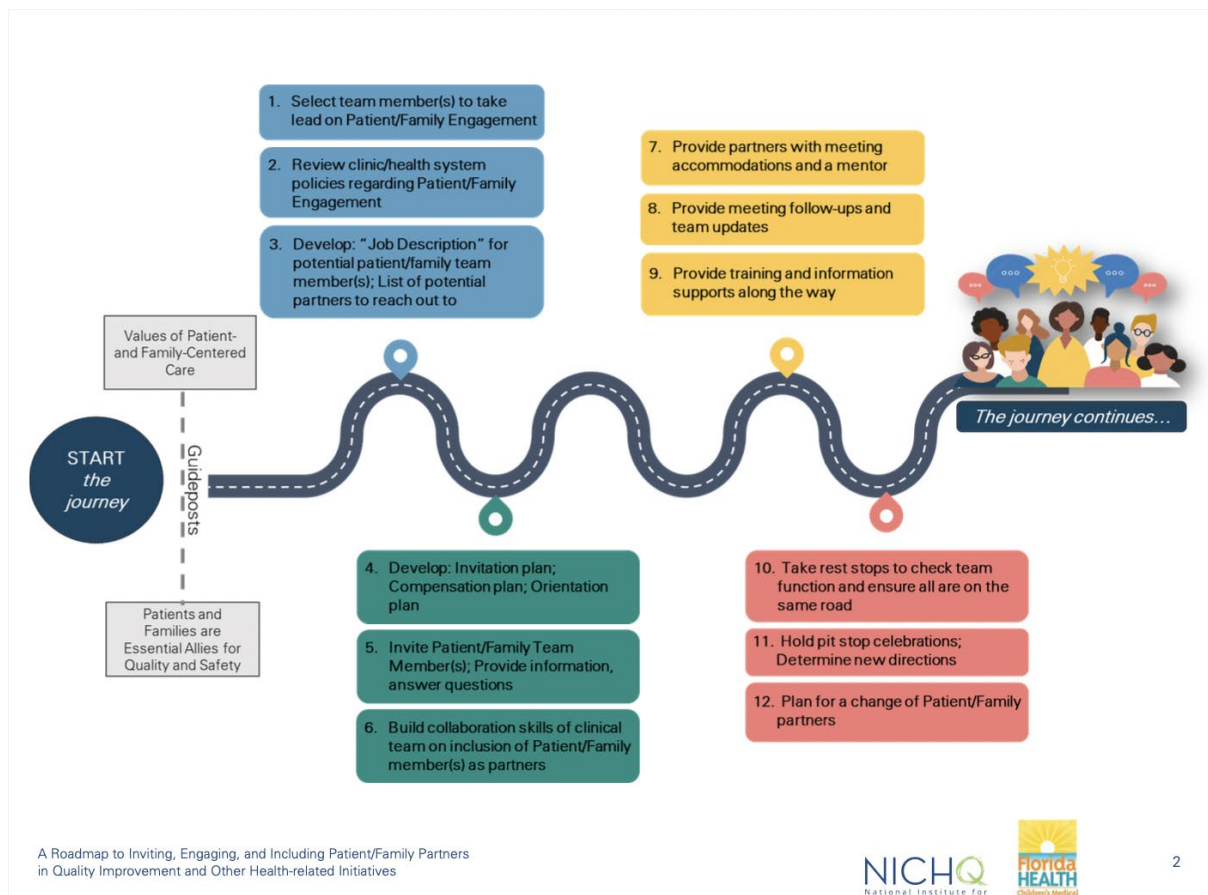
## Introductory Tools for Co-Production

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# Best Practices for Virtual Patient Engagement

The COVID-19 pandemic has shifted many patient engagement activities in health research online. The following practices offer strategies for research teams to uphold the values and principles set out in Canadian Institutes of Health Research's Strategy for Patient-Oriented Research while patient partners **#stayhome**.





## Take Our Course

### Partnering with the Public and Patients in Medical Research

There are many benefits to partnering with patients in medical research. Yet despite much to be gained, patients and researchers often fail to meaningfully partner to advance medical science. How might we create trusting relationships between patients and researchers? What models exist to enable inclusivity and respect for all relevant stakeholders in the medical research enterprise?

These are just some of the topics we will cover in this [Stanford Online course](#).

### PCORI Research Fundamentals

People new to health research or patient-centered research have many questions: What is patient-centered outcomes research? How does the research process work? How can I be an effective partner in a research study?

PCORI's on-demand training package, Research Fundamentals, answers those questions

and more. It is designed to help you understand the language and logic of the research process in an engaging and easy-to-grasp way.

### [View Research Fundamentals](#)

The training package's advantages include:

1. Free, convenient access—PCORI offers the training at no charge, 24/7 via our website
2. Easy to understand—The activity is written in plain language to make it clear and easy to remember
3. Modular format—The training is split into modules that take you through the research cycle from beginning to end
4. Set your own pace—You can complete each module one at a time or stop and start a lesson as your schedule allows
5. Mark your path—The Navigator tool allows you to personalize your learning journey

## NIHR INVOLVE

As you learn about partnering with the public and patients in medical research you may become curious about how to implement successful co-production partnerships in your own work. The NIHR has been leading efforts in the science of community engagement and co-production of research in the UK, and they have prepared a series of informative action-oriented handouts. These materials are provided courtesy of NIHR INVOLVE.

Special thanks to [Simon Denegri OBE](#) for directing us to these resources.

We encourage you to explore these tools during our course and to also learn more about the organization, INVOLVE. [Four helpful booklets and cheat sheets are freely available here](#)





Co-production in healthcare research is the activation of public and patient involvement in which patients and members of the public work with clinicians and researchers to create, redesign and build medical research. Involvement and co-production can also be initiated by the public as they seek researchers and clinicians to partner with in research. In contrast with traditional public and patient involvement, citizens are not only consulted, but they are part of the conception, design, steering, implementation, and management of the research.

## Patients in Publications

Patient advocates need to publish their own research and survey data, and are invited to be co-authors or peer-reviewers. [This open-access course trains patient advocates on how to engage in publications](#)

### Key learning outcomes

1. Assessing the likelihood of publishing research
2. Understanding key stages in the publication process
3. Identifying guidelines on good publication practices



4. Planning a publication, estimating the time required
5. Selecting a suitable journal
6. Authoring a publication, working with publishing professionals
7. Understanding the peer-review process
8. Reviewing and submitting a publication
9. Raising awareness about a publication

## EUPATI Open Classroom

EUPATI is committed to increasing the capacity and capability of patients and patient representatives to understand and meaningfully contribute to medicines research and development (R&D), and to improve the availability of medical information for patients and other stakeholders.

How are we achieving it? EUPATI is providing training for patients and patient representatives from all disease areas on the end-to-end process of medicines research and development – via the [Open Classroom](#) and the online [Toolbox](#).

### Papers and Videos

Richards T, Schroter S, Price A, et al. Better together: patient partnership in medical journals. *BMJ* 2018;3798:k3798. doi:10.1136/bmj.k3798

<http://www.bmj.com/lookup/doi/10.1136/bmj.k3798>

Schroter S, Price A, Flemyng E, et al. Perspectives on involvement in the peer-review process: surveys of patient and public reviewers at two journals. *BMJ Open* 2018;8:e023357. doi:10.1136/BMJOPEN-2018-023357 <https://bmjopen.bmj.com/content/8/9/e023357>

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 <http://bmjopen.bmj.com/lookup/doi/10.1136/bmjopen-2017-020452>

CASP UK: Free critical appraisal checklists and learning tools, easy to train partners to use and will increase research literacy <http://www.casp-uk.net/casp-tools-checklists>

BMJ PATIENT PARTNERSHIP: <http://www.bmj.com/campaign/patient-partnership> AND <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-of-patient-peer-review>

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](https://www.ted.com/talks/sugata_mitra_shows_how_kids_teach_themselves)

Citizen Scientists develop a galaxy [Citizen Science in The Zooniverse - YouTube](#)

McCracken G, Oullier O, Ramsoy T. The Science of Engagement. 2013.

[www.webershandwick.co.uk](http://www.webershandwick.co.uk)

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>