Partnering with citizens in research

What’s helpful from our perspective

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Who we are

We are a group of patient advisors each of whom are partnering with a number of different research teams.

We are learning “on the job” with our researchers how to partner effectively. We share our understandings here with you.

We are still in the early stages of experiencing and learning about these partnerships. We welcome insights from you as you go along this road.

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Agenda

1. Understanding the basics
2. Developing a partnership plan
3. Recruiting and on boarding partners
Understanding the basics

1. Context
2. Partnering with us as citizens
3. Key considerations
4. Guiding principles
5. Levels of engagement
6. Productive partnerships
Changes in the landscape of healthcare

Across the Western world there is a growing recognition that

- We as patients should be at the centre of the healthcare system
- We as citizens cannot continue to pay the growing costs for healthcare

Therefore

- New ways to deliver care are required
- And we need to be involved
The shift to engaging citizens in healthcare

There is a general move to have us as patient and family advisors:

- In hospitals
- For health authorities, ministries, arms-length gov’t bodies
- For other healthcare service organizations like LTCs

And we are already involved in research:

- Cochrane
- UK – INVOLVE
- US – PCORI
- On research teams driven by CIHR and other funders
The challenge for researchers

Citizens are ‘in’
Involving us in healthcare is more and more the norm

Criteria for $
Many funders require we be on the research team

New venture
Researchers are not yet experienced with us as partners
Citizen engagement defined

“Citizen engagement is the timely, meaningful and appropriate involvement of citizens in research policy or program development, from agenda setting and planning to decision-making, implementation and review.”

Adapted from the Canadian Institutes of Health Research
Us as partners vs us as subjects

Working together

Studying the subject
Canadian attitudes to health research

- Health and medical research improves healthcare
- Health research benefits the economy
- Not aware of opportunities to participate

http://www.rc-rc.ca/polling/2015-poll
Key considerations in working with us

- Acknowledging our expertise
- Confidentiality goes both ways
- Should we be on all types of projects?
Key considerations in working with us

- Level the playing field – brief us on terms and concepts
- Keep us up-to-date
- Can we help popularize the research?

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Understanding the basics

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Key considerations in working with us

Ethical    Literacy    Practical

• Who wants to partner, why and where are we?
• Resources and funds needed to support us
• Extra time to develop productive relationships with us
Guiding principles for partnership

- Inclusivity
- Co-design
- Mutual respect
What are ways of involving us?

- INFORMATION SHARING
- CONSULTATION
- COLLABORATION
- PARTNERSHIP
Involvement guide

Understanding levels of involvement

- INFORMATION SHARING
- CONSULTATION
- COLLABORATION
- PARTNERSHIP

Provide information to us for understanding

- problems
- opportunities
- solutions

Ex: fact sheets, website, mass media, open house

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Understanding the basics
Involvement guide

Understanding levels of involvement

| INFORMATION SHARING | CONSULTATION | COLLABORATION | PARTNERSHIP |

Getting feedback from us

Ex: fact sheets, website, mass media, open house

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Involvement guide

Understanding levels of involvement

- INFORMATION SHARING
- CONSULTATION
- COLLABORATION
- PARTNERSHIP

Involving us continuously throughout the research process

Ex: mentorship programs, webinars and workshops, conferences

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We are partners in decision-making...

• developing the research concept
• contributing to the design
• supporting knowledge translation

Ex: As partner on the research team itself, as a panelist

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Dealing with our concerns

• Tokenism
• Not being taken seriously
• Time and financial commitments
• Not understanding what is being discussed
• Apathy and discouragement ... nothing changes ...
Recognizing your concerns

• Time to involve and partner with us
• We, as citizens, may not know enough to contribute
• Dealing with our emotions arising from bad experiences as patients
• Lack of clarity of our role
• Lack of clarity for how to involve us
Benefits of partnering with us

- Improve the relevance and translation of research into practice and policy
- Contribute to more effective health services and products
- Contribute to quality of life and a strengthened Canadian health care system
Ingredients for creating productive partnerships

Time
Investing time in our partnership is necessary

Preparation
Good preparation leads to a fruitful partnership

Plan
Planning yields clarity and direction for all partners
Agenda

1. Understanding the basics
2. Developing a partnership plan
3. Recruiting and on boarding partners
Developing a partnership plan

1. Defining the project for the public
2. Approaches to partnership
3. Mapping the research process for partnership roles
4. Defining support
5. Measuring success
6. Impact on the funding application
Defining the project for the public

What is the relevance of the project to us, the public?

Who benefits and how?

Is it sustainable?

What are the research success measures?

“Citizen engagement is meant to ensure that funded research reflects the needs and values of Canadians...

CIHR’s Framework for Citizen Engagement
Approaches to partnership

We can be....

Individual citizens on the team

On a citizen panel

+
Considering a panel of citizens

Why have a panel? What will it do?

How will the panel relate to the team?
Advisory vs decision-making

Practical considerations:
- Support for meeting attendance
- Terms of Reference
- More coordination required
Mapping out the research process

Exploring possibilities for partnership

**Stage 1**
Formative: setting priorities for research

**Stage 2**
Proposal writing, application for funding

**Stage 3**
Implementation

**Stage 4**
Analysis and interpretation of data

**Stage 5**
Dissemination and knowledge translation

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Developing a partnership plan
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# Mapping out the research process

## Stages 1-5

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### Stages 2-5

Developing and implementing a marketing/communications plan
Stage 1: Formative

How can we help contribute to the development of the research plan?

- Determining public relevance
- Setting priorities from our perspective
- Defining outcomes from our perspective
- Defining approach
- Planning for communications and KT
- Identifying partnership approach
- Developing partnership strategy

- And more...
Stages 2-5: Marketing/communications

GOAL: To connect research more directly with the people it serves.

How can we help contribute to the development and implementation of a marketing/communications plan?

• How to enlist the public as an influencer from the start?
• Can social media be used to inform public and other stakeholders?
• What organizations should be aware and track progress?
• Can results be designed for the public audience?
• Can this drive interest by opinion leaders – on TV, print, radio?
Stage 2: Proposal

How can we help contribute to the writing of the application?

- Help develop the partnership approach and strategy
- Review drafts of the application especially the Summary and Patient Engagement sections
- Contribute to the Patient Engagement sections
- Contribute to the timeline and budget decisions
- Contribute to the KT (and marketing) sections
- And more...
Stage 3: Implementation

How can we help contribute to the implementation of the research?

• Help develop patient/caregiver subject communications materials

• And more...
Stage 4: Analysis

How can we help contribute to the analysis and interpretation of data?

• Review the preliminary results of the analysis

• And more…
Stage 5: KT and spreading the word

How can we help contribute to the spread of the research results?

• Coordinate with the marketing/communications plan
• Help develop a public-friendly version of results
• Help develop a social media approach
• Co-publish in non-academic materials
• Co-present findings

• And more...
Our partner roles

Develop a role or “job” description from the review of the stages

Review the partnership approach and assign roles

- Individual partners
- Panel
- Both
Building a partnership timeline and budget

Time factors
- Building the partner plan
- Recruiting, on boarding and orientation
- Coordinating and supporting

Budget factors
- Expenses
- Honoraria
- Extra time and resources to coordinate partners
Planning support for us as partners

Who
• Which team member?
• Peer support?

How
• Admin help
• Expenses
• Access and attendance considerations
• Proactive check ins
• Quick resolution of any issues
• Consistent updates and follow ups
What does partnership success look like?

With the partners,
• Develop key indicators of success
• How to measure
• When to measure
Evaluating the partnership

• How do you know when things are going well?
• How do we know when things are going well?

• Once you have evaluated....
  • How do we all spread the good news?
  • What do we and you do when things go wrong?
Partnership impact on the application

The partnership plan can impact on the following sections:

- Summary
- Detailed description
- Knowledge transfer
- Team roles
- Patient engagement
- Timelines
- Budget
Summary: Developing a Partnership Plan

Roles / stage

Partners (+ panel?)

Support

Measurement
Agenda

1. Understanding the basics
2. Developing a partnership plan
3. Recruiting and on boarding partners
Recruiting and on boarding partners

1. Recruitment process
2. Profiling candidates and our role
3. Attracting and sourcing candidates
4. Selecting partners and panelists
5. On boarding
Recruitment process

This is **not** like recruiting subjects for research. It’s more like a hiring process:

1. Develop a candidate profile and job description
2. Making the need known – the flyer and the method
3. Screening and interviewing candidates
4. Signing up us up as partners and panelists
5. Bringing us on board
Who do you need and what will we do

Assemble the ‘job’ description:

• From the Partnership Plan identify our partner or panelist roles per stage
• Include characteristics of the research project impacting who you are looking for
• Include the team’s commitment to us as partner or panelist

Profile the type of person who makes the best candidate:

• Who can do the ‘job’
• Who ‘fits’ the team
Project elements impacting recruitment

Method
- Quantitative
- Qualitative
- Mixed methods

Location
- Geographic scope
- Sites of care
- Rural - urban

Commitment
- Project length
- Time commitment
Role description

What are the roles outlined in the Partnership Plan?

- Patient partners on the research team > “job” description
- Panel members > Terms of Reference

Include locations and time commitments
Commitment is a 2-way street

The ‘job’ description for the team partner and Terms of Reference for panelists include:

• What we will do for the project
• What you will provide us as support
• How do you keep us in the loop
Profiling a prospective partner

What type of person will add value to your project?

Experiences:
- Patient and/or caregiver
- Time and ability to move beyond our own personal issues
- Real world
- Patient advisor

Soft skills:
- Communication
- Collaborative
- Confidence
Profiling a prospective panelist

What type of panelists? How many?

Experiences:
• Patient and/or caregiver
• Time and ability to move beyond our own personal issues
• Real world
• Diversity

Soft skills:
• Communication
• Collaborative
• Confidence
Attracting and sourcing candidates

Two things are needed to attract and find those of us willing to be candidates:

• An excellent recruitment flyer
• A game plan for where and how to distribute the flyer
Recruitment flyer

This is **not** the same as the subject recruitment flyer.

This is the “sales” flyer – it includes:

- The research story (the hook or sales pitch)
- Target candidate = those of us with interest in the research area
- Commitment required
- Contact info
- Catchy design/look

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The research story – what’s the hook?

Why is the research important to us?

What is the potential societal good of the research?

Why is it important that we be involved?

What is the benefit to us in partnering on this research?
Where and how to distribute the flyer

Physical locations that permit posting flyers

Social media - with attachment or link to online site

Informal networks – emails to those you know
Sources

Where to find those of us who might be interested in research:

- Your network
- PFAs
- Community organizations
- Community centres
- Health centres
- Disease based organizations
- Patient, caregiver groups
- Social media
Selecting partners and panelists

Select at least 2 of us as team partners and at least 2 as extra panelists to handle potential attrition over the duration of the project

- Screen those of us who are candidates by phone
- Interview us with more than one team member to ensure fit – for the team and for us

Schedule on boarding activities
On boarding

Pre-participation materials

Orientation to partnership
  • For patient partners
  • For panelists
  • For researchers and other team members

Introductions and initial team meeting
Summary: Building a Recruitment Plan

Define:

• What we will do
• Who we are
• Where to find us
• How to reach us
• How to bring us on board
Conclusion: Successful partnerships...

1. Include planning, preparation and commitment
2. Can differ from team to team
3. Must be supported with staff time and financial resources
4. Must be measured for improvement
Questions

Thanks for participating!
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