Doing a good thing well: aiming for quality in patient-oriented research

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Presentation for BC Support Unit Conference
Putting Patients First, Vancouver, 9 November 2017
#PPF17
What is Patient Oriented Research?

Why is it a good thing?

How can we do it well (or better)?
What is Patient Oriented Research?

A concept introduced into public policy to help promote a cluster of values and approaches in health-related research.
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A concept introduced for public benefit... that we should work with in ways that foster social good.
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(which will require critical assessment and discussion of values)
What is patient oriented research?

“Patient-oriented research refers to a spectrum of research that engages patients as partners, focuses on patient-identified priorities and improves patient outcomes. This research... aims to apply the knowledge generated to improve health care systems and practices”

CIHR – SPOR overview factsheet
Patients (+) as potential partners

- People who have particular health conditions
- People who (might) use particular services
- Family members and carers
- People who engage in particular behaviours
- People who live in particular areas
- Members of particular ethnic/cultural groups
- People exposed to particular risk factors
- …
- Representatives of / advocates for …
Forced migrants involved in setting the agenda and designing research to reduce impacts of complex emergencies: combining Swarm with patient and public involvement

Julii Suzanne Brainard\textsuperscript{1*}, Enana Al Assaf\textsuperscript{2}, Judith Omasete\textsuperscript{3}, Steve Leach\textsuperscript{4}, Charlotte C. Hammer\textsuperscript{1} and Paul R. Hunter\textsuperscript{1}
Formation of a type 1 diabetes young adult patient and public involvement panel to develop a health behaviour change intervention: the *D1 Now* study

Mary Clare O'Hara¹,²*, Áine Cunningham³, Cameron Keighron⁴, Gary Allen⁴, Antony Caulfield⁴, Ciara Duffy⁴, Michelle Long⁴, Madeleine Mallon⁴, Monica Mullins⁴, Garret Tonra⁴, Sarah Simkin⁵, Lisa Hynes⁶, Máire O'Donnell², Molly Byrne⁷, Sean F Dinneen²,³ and the D1 Now Type 1 Diabetes Young Adult Study Group
Parents’ perceptions of reasons for excess weight loss in obese children: a peer researcher approach

Fiona Gillison¹, Geraldine Cooney¹, Valerie Woolhouse³, Angie Davies³, Fiona Dickens² and Penny Marno²
“Is all the stuff about neurons necessary?”
The development of lay summaries to disseminate findings from the Newcastle Cognitive Function after Stroke (COGFAST) study

Sarah Barnfield, Alison Clara Pitts, Raj Kalaria, Louise Allan and Ellen Tullo
What is patient oriented research?

Research that:

• Is done in partnership with patients
• Answers questions that matter to patients
• Aims to improve health care

http://bcsupportunit.ca/about/about-us/
What is patient oriented research?

Research that:

• Is done in partnership with patients
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Doesn’t all health research do that?

http://bcsupportunit.ca/about/about-us/
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‘Patient oriented research’: closest concept in UK policy

Patient and public involvement in research

Emphasises ‘doing research with’ not just ‘doing research on’ or ‘for’
From an alien idea (?)…

Illustration used by BMJ for:
... to a supported activity...

- Briefing notes
- Library of examples
- Role description templates
- Budgeting suggestions
- Information about payments and benefits
- Resources for training...

www.invo.org.uk
Principle 4:
Patients, services users and the public are involved in the design, management, conduct and dissemination of research, unless otherwise justified.

www.hra.nhs.uk
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Is more and more direct involvement always better?
What is (and why do) patient oriented research?

Research that:

• Is done in partnership with patients
• Answers questions that matter to patients
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Is that what makes it better?

http://bcsupportunit.ca/about/about-us/
What is (and why do) patient oriented research?

Research that is done in partnership with patients:

• Answers questions that matter to patients
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Does it always?
(And does research without ‘full’ direct partnership never?)
Research that is done in partnership with patients:

- Answers questions that matter to patients
- Aims to improve health care

And are there other reasons for partnership working?
Why involve patients/publics?
Two broad rationales

- **To improve research and its use**
  - Generate better knowledge
  - Do so in better ways
  - Facilitate knowledge translation

- **For other ethical/political reasons**
  - Ensure people who will be affected have a say
  - Support capability development, tackle injustice...
  - Promote openness, accountability, trust...
Why involve patients/publics? Two broad rationales

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Both rationales may be relevant. They can also be in tension.
Why involve patients/publics?
Two broad rationales

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The strength of these rationales can vary
Why involve patients/ publics?

Two broad rationales

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This raises the “what evidence?” question
Evidence of better knowledge generation?

There are examples of:

• Research ‘without’ involvement having shortcomings that were potentially avoidable

• ...

• Involvement leading to positive changes from what researchers would have done otherwise

• ...

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“Can sometimes” does not mean “will always”
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- Research ‘without’ involvement having shortcomings that were potentially avoidable
- ...
- Involvement leading to positive changes from what researchers would have done otherwise
- ...

Are patient partnerships only valuable when they prompt a clear and clearly beneficial change in approach?
Researchers' experiences of patient & public involvement

Overview

In this section you can find out about the experiences of health researchers of involving patients and members of the public in their research, by seeing and hearing people share their stories on film.

Involvement is about research being carried out with or by members of the public, who may play a role in
Why can partnership working improve research? (1)

Our different experiences/ perspectives shape:

- What we see as a problem, and why
- What we see as potentially good solutions
- What we would count as success
- How we formulate research questions
- What would be a good research approach
- How we interpret things
- What harms or downsides we are alert to
- How we’re inclined to prioritise
- …
Why can partnership working improve research? (2)

Access to and consideration of relevant different experiences and perspectives will help ensure we don’t miss important issues and have a better chance of making creative and useful developments.
Why can partnership working improve research? (2)

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Who needs to be involved, at what stages of research, and how, to ensure this?
What could (and should) research teams learn from:

- Previous partnership working / research
- Existing information about peoples’ experiences e.g. →
- Discussion opportunities that don’t make full partnership demands on patients
Patient oriented research: are we doing it well?

What counts as waste in POR and how should we avoid it?

Bearing in mind opportunity costs, what investment is proportionate?

• Public funding resource
• Researcher time and effort on partnership
• Patient partner time and effort on research
• ...

...
Patient oriented research: are we doing it well?

Partnerships vary in quality!
Patient oriented research: are we doing it well?

Is the partnership working in such a way that the expertise, insights and views of all partners are recognised and drawn on appropriately and to good effect, and without wasting public resource or people’s time and effort?

And if not, why not?
How can we do POR well (or better)?

- 27 tools to assess patient and public engagement in health research or health systems decision-making
- Diverse objectives
- Each tool had strengths and weaknesses
- Suitability can depend on evaluation purpose and context
How can we do POR well (or better)?

“Not many tools were developed following a clear definition of patient and public engagement, rarely structuring the tools around a theory of how/what/when patient and public engagement should unfold, nor focusing on (a) particular aspect(s) of this theory of change” (p23)
A summary for now

- Patient oriented research isn’t a simple “it”
- … so be wary of sweeping generalisations!
- There are several good reasons for advocating involvement/partnership in principle
- But there may be tensions between different goals and value concerns
- And more involvement/partnership will not always be unequivocally better
- We need to reflect and share: what matters and how best can we pursue it?

Thanks for listening! Please share your thoughts!