Patient involvement in guidelines

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Conflicts of Interest

- No direct financial CoI
- Responsible for the German National Disease Management Guidelines Program
- Chair, Patient and Public Involvement Working Group of the Guidelines International Network
I. Background: Patient and Public Involvement: Rationales and Concepts

II. Core principles of participation – the G-I-N PUBLIC „toolkit“
Why do we think patient involvement is a good thing???
Evidence for PPI

• No evidence that PPI has impact on format, content, wording, dissemination or implementation of a guideline

• Modest evidence from qualitative research that PPI influences guideline processes and attitudes of panel members
Ethical context

Patient and Public Involvement in Clinical Practice Guidelines: A Knowledge Synthesis of Existing Programs

France Légaré, MD, PhD, Antoine Boivin, MD, MSc, Trudy van der Weijden, MD, PhD, Christine Pakenham, B Ed, Jako Burgers, MD, PhD, Jean Légaré, Sylvie St-Jacques, PhD, Susie Gagnon, MA


- Structured analysis of ppi programs;
- Synthesis of methods and underlying goals and rationales;
- Evidence that PPI rather is an issue of credibility and legitimacy.
### Different Rationales for PPI (Knaapen & Lehoux, 2016)

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<thead>
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<th></th>
<th>Consumerist</th>
<th>Democratic</th>
<th>Expertise</th>
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<tbody>
<tr>
<td><strong>Why</strong></td>
<td>Personalized care</td>
<td>More democratic health policy</td>
<td>More useful guideline</td>
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<tr>
<td><strong>Who</strong></td>
<td>Well-informed autonomous consumer</td>
<td>Disinterested citizen</td>
<td>Lay expert</td>
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<tr>
<td><strong>What</strong></td>
<td>Patient preferences</td>
<td>Public values</td>
<td>Experiential knowledge</td>
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ESC CRT Plenary Meeting, Nice. 10/03 2018
Involvement Strategies

• Consultation
  *collection* of information *from* patients/public
  - focusgroups, workshops, survey, literature search, interviews

• Participation
  *exchange* of information *between* CPG developers and public
  - Patient representative(s) in guideline development group

• Communication
  *information to* patients/public for individual clinical decisions
  - patient versions of guidelines, dissemination & implementation, patient decision aids

(Boivin et al. 2010; Rowe & Frewer 2005)
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Agenda

I. Background: Patient and Public Involvement: Rationales and Concepts

II. Core principles of participation – the G-I-N PUBLIC „toolkit“
The G-I-N PUBLIC Toolkit

Issued in 2012, updated in 2015

International experience and best practice examples

1. How to conduct public and targeted consultation (2012)
2. How guidelines can involve people facing barriers to participation (2015)
3. How the chair can facilitate PPI (2012)
5. Patient versions of guidelines (updated 2015)
6. Involving patients in guideline dissemination (2012)
7. How guidelines can support patient involvement in the clinic (2012)

Next update planned in 2019

Freely available!

https://www.g-i-n.net/working-groups/gin-public/toolkit
Keys to success for non-tokenistic PPI

• clarity on what is expected of patient and public members
• effective recruitment processes and Col management
• transparent reporting
• good chairing
• induction, training, support and financial compensation
• evaluation and refinement of processes