Building a research agenda together: Involving patients and other stakeholders in defining research priorities

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This project is co-funded by the European Union under the Seventh Framework Programme
Grant Agreement No. 306141)
Background

- Healthcare involves a variety of stakeholders
- Important to involve patients and other stakeholders in priority setting in healthcare\(^1\)
- Different perspectives may raise different questions and concerns

\(^1\) Chalmers et al. Lancet 2014;383:156-65
AIM

To develop and test a method for involving patients and other stakeholders in defining priorities, with a focus on social learning.

What do we mean by this?

- Collecting all wishes
- Prioritise wishes

- Developing a shared view on what is relevant and plausible
- Focus on social learning
Methods

Case study: palliative care

- Individual face-to-face interviews with stakeholders
- Invited stakeholders: those who experience the consequences
  - Lay stakeholders
  - Professionals
Scoping is a process to identify key issues of concern at an early stage in planning.

Why?
- Increase the relevance of research
- Identify differences among stakeholders
- Create consensus on what is important
Scoping

The analysis was based on reconstruction of interpretive frames, revealing
  ➢ Problem definitions
  ➢ Judgements of solutions
  ➢ Empirical and ethical background theories
  ➢ Normative preferences
### Box 1: Questions used for scoping exercise: examples

<table>
<thead>
<tr>
<th><strong>Problem</strong></th>
<th>What are key problems experienced or encountered by patients, their families, health care providers or health care managers in the care of patients for whom no curative treatment is available?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Solution</strong></td>
<td>Which measures could be helpful in overcoming these problems, which measures would probably not be helpful, and why not?</td>
</tr>
<tr>
<td><strong>Background theory</strong></td>
<td>What are the main causes of the current situation, notably of ‘system failures’ such as lack of continuity of care?</td>
</tr>
<tr>
<td><strong>Normative preferences</strong></td>
<td>What situation should be pursued, what values should be observed?</td>
</tr>
</tbody>
</table>
Process of the study

1. Identify key questions and concerns of stakeholders with respect to palliative care as part of their interpretive frames

2. Searched for answers by conducting a systematic review of the literature

3. Fed back the results to the participants, soliciting their views of the relevance and validity of the findings
Results

Participants

- Patients
- General practitioners
- Palliative care specialists
- Chaplains
- Nurses
Scoping (step 1)

Key issues and concerns revealed around three main themes
1. Transition from a curative to a palliative approach
2. Continuity of care
3. Meaning of life questions

How can research help patients and their relatives to discover the meaning of life in the presence of an incurable disease
Literature search (step 2)

- Qualitative and quantitative studies
- Multiple interventions

For example
- Life reviews
- Meaning-making interventions
- Music therapy
Feedback stakeholders  (step 3)

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Feedback stakeholders

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  For example
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Conclusions

This study explored, developed and tested a method to define research priorities

- Mismatch between available evidence and stakeholders’ concerns

- Challenging to develop and execute a research agenda that matched the questions and concerns of patients and stakeholders

- Reconstructing stakeholders interpretive frames and sharing the results among them, may be a means of starting a social learning process, resulting in more meaningful priorities of research