A realist synthesis of PROMs feedback to improve the care of individual patients

Dr. Joanne Greenhalgh
Associate Professor
j.greenhalgh@leeds.ac.uk
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<table>
<thead>
<tr>
<th>Name</th>
<th>Expertise</th>
<th>Affiliation</th>
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</thead>
<tbody>
<tr>
<td>Joanne Greenhalgh</td>
<td>Realist synthesis/PROMs</td>
<td>University of Leeds</td>
</tr>
<tr>
<td>Sonia Dalkin</td>
<td>Realist methods</td>
<td>University of Leeds</td>
</tr>
<tr>
<td>Kate Gooding</td>
<td>Realist methods</td>
<td>University of Leeds</td>
</tr>
<tr>
<td>Ray Pawson</td>
<td>Realist methods</td>
<td>University of Leeds</td>
</tr>
<tr>
<td>David Meads</td>
<td>Health Economics</td>
<td>University of Leeds</td>
</tr>
<tr>
<td>Judy Wright</td>
<td>Information Specialist</td>
<td>University of Leeds</td>
</tr>
<tr>
<td>Elizabeth Gibbons</td>
<td>Nurse/PROMs</td>
<td>University of Oxford</td>
</tr>
<tr>
<td>Nick Black</td>
<td>PROMs/policy</td>
<td>London School of Hygiene and Tropical Medicine</td>
</tr>
<tr>
<td>Chema Valderas</td>
<td>GP/PROMs</td>
<td>University of Exeter</td>
</tr>
<tr>
<td>Liz Lingard</td>
<td>Consultant Epidemiologist</td>
<td>NE Quality Observatory System</td>
</tr>
<tr>
<td>Jane Jackson</td>
<td>Nurse</td>
<td>JJ Consulting</td>
</tr>
<tr>
<td>Laurence Wood</td>
<td>PPI representative</td>
<td>Leeds</td>
</tr>
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Overview of presentation

• What is realist synthesis?

• Methodology of the review

• Findings
What is Realist Synthesis

- Review methodology which seeks to explore ‘**what works, for whom, in what circumstances**’ rather than ‘does this intervention work or not’

- Unit of analysis is the **programme theory (ideas and assumptions underlying what the intervention is trying to achieve and how)**, not the intervention itself (what is done)

- Programme theories expressed as hypotheses to be tested— “in this situation, the programme works in this way and produces these outcomes”

- Different forms of evidence (qual/quant) make sense of each other

- The hard slog remains: uncovering, reading and digesting hundreds of primary studies
The Technical Sequence

Realist Synthesis Template (simplified)

Search to provide overview of programme theory (i.e. ‘theory elicitation’)

Question selection to pinpoint key processes for investigation (i.e. ‘theory selection’)

Search for studies best placed to test the chosen theory (i.e. ‘theoretical sampling’)

Quality appraisal of primary studies, not against a hierarchy of evidence, by their ‘theory testing potential’

Data extraction, not to a standard matrix, but to as ‘confrontation of theory with evidence’

Synthesis as ‘theory refinement’

Dissemination as production of abstract ‘middle-range theory’ (i.e. theory re-articulation)
Our review: an overview

Identify theories
- Search to identify programme theories
- Developed a model of how the intervention intended to work
- Selected programme theories to test in collaboration with patients and stakeholders

Search for evidence
- Backwards and forward citation tracking of six key papers and five systematic reviews
- 977 papers, 159 included as title/abstract, 36 included after full text review

Theory testing and refinement
- Tested two main theories with 10 ‘sub theories’
- Data abstracted into evidence tables and used to test and refine theories
- Comparative analysis of across different settings
Programme theory model

Patient completes PROM

- Patient uses PROM information for self-management

Clinician completes PROM with patient through an interview

- Within scope of review

Patient raises concerns with clinician during consultation

- Beyond the scope of this review

Clinician raises patient's concerns in the consultation

Clinician reviews PROMs feedback

Concerns are discussed

- Action is taken to address concerns

Feedback discussed between clinicians

- Clinicians decide on action without patient discussion

Action improves health or QoL outcomes
PROMs as a tool to support patients sharing/raising issues with clinicians

**DEPENDING ON (context)**
- Structure of PROM
- Nature of patient-clinician relationship
- Other incentives/use of PROMs data

**REASONING**
Patients reflect on their situation and feel like they have ‘permission’ to raise issues

**RESOURCE**
PROMs completion

**OUTCOME**
Patient raises/discusses issues with the clinician
How we tested these theories

Examine different contextual configurations by looking at studies in different settings and using different PROMs:

<table>
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<th>Setting</th>
<th>N studies</th>
<th>Nature of relationship</th>
<th>Structure of PROM</th>
<th>Use of incentives/other use of data</th>
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</thead>
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<tr>
<td>Mental health primary care</td>
<td>4</td>
<td>Usually have existing relationship</td>
<td>Standardised</td>
<td>QOF, indicator of service quality</td>
</tr>
<tr>
<td>Secondary mental health care</td>
<td>4</td>
<td>New but can also be ongoing</td>
<td>Standardised</td>
<td>Indicator of service quality</td>
</tr>
<tr>
<td>Palliative care</td>
<td>9</td>
<td>New</td>
<td>Standardised and individualised</td>
<td>None</td>
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• Patients did feel that PROMs completion helped them to reflect on their situation:

“I think that [completing the questionnaire] helped me in my head as well… I started to think, you know, about why I was getting depressed and that” (Patient, Dowrick et al, 2009)

[it] “felt good because you finally had someone listening to you and trying to help you through what you were going through” (parent, Stasiak et al, 2012)

Patients and clinicians felt patients would only share their concerns in the context of a trusting relationship:

“I think you’d have to have a trust thing built up first to actually share something with that person” (young mental health service user, Stasiak et al (2012))
Clinicians in primary and secondary mental health settings perceived standardised PROMs constrained the relationship/trust building process:

“If you’ve had a very loaded consultation… the HAD scale can appear to trivialise the depth of emotions” (Leydon et al, 2011, primary mental health)

“I like to let them verbalise their concerns rather than handing them a bit of paper and say ‘tick boxes’” (Gamlen and Arber, 2013, palliative care)

They found it hard to fit the PROM into the flow of the consultation:

“Where do you plonk those great big… bombshells in the middle of a normal consultation with somebody” (GP, Leydon et al, 2011)

“They.. Break down in tears and tell you how depressed they’re feeling… and then ‘oh now I’ve got this questionnaire to fill out’ I just think its so inappropriate sometimes” (GP, Mitchell et al, 2011)
Therefore, clinicians either:

- Avoided using them altogether
- Used them at the end of the consultation when they had built up a relationship with the patient
- Adapted how they were used (changed items, how they were administered) – may have affected their validity

When financial incentives were used, clinicians also engaged in ‘gaming’ the data:

“diagnoses of what would be ‘QOF-able’ depression has probably dropped… we realised if we kept labelling people as depressed when they perhaps weren’t, then we weren’t going to see them again and lose the points”. (GP, Mitchell et al, 2011)
Clinicians in palliative care and secondary mental health services perceived individualised PROMs supported the relationship building process.

Therapists felt completion of the SEIQoL helped them to “form a better relationship and trust with the service user” because it enabled them to “get alongside the service user more quickly” (drug and alcohol services, Cheyne et al, 2001).

“I feel that the tool really helps the client to tell their story” (palliative care, Annells and Koch (2001))

- Individualised measures acted as a ‘conversation opener’
- However, less useful as an outcome measure
Conclusions

• Need to think about how PROMs completion and feedback influences not just the ‘information exchange’ and ‘decision making’ functions of the consultation, but also the ‘relationship building function’

• PROMs completion can enable patients to reflect on their situation and makes them feel someone is interested in them

• PROMs completion can serve as a ‘conversation opener’ but require considerable skill to integrate into the consultation

• Not a panacea for improving communication skills of clinicians

• Individualised measures may be better as a ‘conversation opener’ but less useful for tracking outcomes over time