Co-production in the OPEL Hospice at Home Study

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Graham Silsbury, Project PPI co-applicant
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Background

• Development of hospice at home (H@H) services – dying at home

• Evaluations of hospice at home services – Pilgrims Hospice trial.

• Outstanding questions:
  o Have we got the best, most cost effective service to enable patients to die at home in our area?
  o National priority for further research (e.g. James Lind Alliance)

• New Research Question:
  o What are the features of H@H services that work for whom and under what circumstances?
Study overview – using Realist Evaluation

<table>
<thead>
<tr>
<th>PHASE 1</th>
<th>PHASE 2</th>
<th>PHASE 3</th>
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<tbody>
<tr>
<td><strong>National survey of Hospice at Home Services</strong></td>
<td><strong>In depth investigation</strong></td>
<td><strong>Data Analysed, reviewed, refined and disseminated</strong></td>
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<tr>
<td>Analysed to develop a typology of care models</td>
<td>‘What are the features of Hospice at Home services that work, for whom, and under what circumstances?’</td>
<td>1. Stakeholder Consensus events National workshops</td>
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<td>Consensus event to agree typology</td>
<td>Data collected from case study sites (2 per care model) <strong>Qualitative data:</strong> Interviews with service users, providers, commissioners <strong>Quantitative data:</strong> Patient outcomes, Health economics</td>
<td>2. Outputs = guidelines for services and commissioners to help in decision-making and service development</td>
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<tr>
<td>Typology used to select and invite case study sites for phase 2</td>
<td></td>
<td>3. Dissemination Publication, Media, Web, Twitter, Local commissioners, Newsletters, Care providers, Third sector</td>
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<tr>
<td>Test CMO (Context-Mechanism-Outcome) configurations formulated</td>
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**Project output:**
Guidelines for services & commissioners to help in decision-making and service development of Hospice at Home

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**Project PPI Co-applicants**

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<thead>
<tr>
<th>Graham Silsbury</th>
<th>Mary Goodwin</th>
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<tbody>
<tr>
<td>Graham was has experience of hospice services as a carer and was a public and patient involvement ‘representative’ in the previous the RPB study evaluating the H@H service in Pilgrim’s Hospices.</td>
<td>Mary is a retired registered nurse and paediatric cardiac nurse specialist. She is a member of the CHSS ‘Opening Doors’ PPI group where she expressed an interest in end of life care research.</td>
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We also acknowledge the support and feedback provided by Nicola Enright, Anja Schmidtmann and Emily Silcock during the development of the project
Realist evaluation

• Looks to answer the
  • How?
  • Why?
  • For whom?
  • In what circumstances?
• It is explanatory rather than judgemental
• It is theory driven (middle range theory)
  – the phenomenon being evaluated has already been judged as worthwhile, the aim is therefore to understand under what conditions it works best

Realist Evaluation Design

Selection of MRT & propositions

Data collection
  • Literature & evidence review
  • NAHH core standards
  • Normalisation Process Theory
  • Survey
  • Case studies

Test propositions
  • Map outcomes across cases
  • Develop CMO configurations
  • Identify salient actions that could explain outcome patterns

Refinement
  • Consensus on CMO configurations
  • Refinement of programme theories
  • Confirmation of transferable salient actions
Literature & evidence review
- NAHH core standards
- Normalisation Process Theory

Selection of MRT propositions

Co-production example in the project:
- Using NPT as a middle range theory to help us anticipate what context and mechanisms are needed to embed H@H services within EOLC provision

Data collection
- Survey
  - of H@H services

Co-production example:
Selection of phase 2 case study sites from survey results

Map of hospices in the survey

Case study sites selected
- Case study site 1
  - Hospice
  - Region: North West

Case study site 2
- Hospice
- Region: North West

Case study site 3
- Hospice
- Region: London

Case study site 4
- Hospice
- Region: London

Case study site 5
- Hospice
- Region: South East

Case study site 6
- Hospice
- Region: South East

Case study site 7
- Hospice
- Region: Midlands

Case study site 8
- Hospice
- Region: Midlands
What were our results?

From the survey data we collected:

• No two hospice services were the same as each other - 70 different services

Mixed populations in diverse areas – deprivation, rural/urban

Wide range of staff roles involved, including volunteers

Rapid response

Wide range of care

24/7 care

Funding – only 25% received NHS funding, only 3/70 fully funded by NHS

Variations in other NHS services e.g. 20% of H@H areas did not have 24/7 district nursing cover

Local equipment availability

Wide range of patient referral criteria accepted by different services

Data collection

• Case Studies
• Quantitative data collection

Co-production example:

Working together to decide on the tools to use in the study.

Input into the processes and procedures for data collection with the carer collected measures: QODD, VOICES and AHRC.

Questionnaire tools used

• QODD – Quality of death and dying, primary outcome measure
• VOICES survey – 2 selected questions used about overall experience of care from carers perspective
• Phase of illness & AKPS – clinical measures
• IPOS – integrated Palliative care outcome scale – measure symptom burden
• AHRC – Ambulatory and home care record – measures service utilisation & care received
**Data collection**

- Case Studies
- Qualitative data collection

**Interviews with:**
Carers, service providers and commissioners
- Using NPT as a tool for qualitative data collection and analysis

**Co-production example:**
- Input into the interview topic guide development
- Working together to interpret interview data, using NPT principles to code data
- Training session for PPI co-applicants

**Pel H@H**
Optimising ‘Hospital at Home’ Services for End of Life Care
Where are we now and where are we going?

Co-production example
We are still at data collection stage, but as a team we have started to develop CMO configurations, from the information we have collected so far from the NAHH standards, the literature and phase 1 survey.

Test propositions
- Map outcomes across cases
- Develop CMO configurations
- Identify salient actions that could explain outcome patterns

Refinement
- Consensus on CMO configurations
- Refinement of programme theories
- Confirmation of transferable salient actions

Thank You
Any Questions?
### Example CMO configuration from the project

**Working title of CMO 3: Service responsiveness and availability**

<table>
<thead>
<tr>
<th>CONTEXT</th>
<th>MECHANISMS</th>
<th>OUTCOMES</th>
<th>Evidenced by</th>
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<tbody>
<tr>
<td>e.g. “If” the service has this …</td>
<td>e.g. “Then” the service will …</td>
<td>e.g. Leading to better patient care</td>
<td>Excerpts of qualitative data from survey, and literature from evidence synthesis</td>
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<tr>
<td>If the H@H service has a flexible workforce (e.g. mix of permanent, flexi staff, zero hours contracts) (C6) If 24h care is provided, including adequate provision overnight (C7)</td>
<td>Then the service is able to respond rapidly to unpredictable and fluctuating workloads in a cost-effective way (M6)</td>
<td>More patients receive the care they need when they need it and where they prefer to be (O6) Less patients have emergency admissions to hospital (O7) More patients have enhanced hospital discharge (O8)</td>
<td>Uncertainty among managers/commissioners about providing 24h DN care (“rapid response teams are being commissioned in place of 24h DN”), range of models and costings (Addington Hall) Patients want contact within a specified period (Addington Hall) Rapid response with capacity to stay not in the system without this service (Butler) Carers trained to administer meds, some found this difficult (Exley) Inability to access OOH care in an emergency left carers feeling abandoned and vulnerable (Exley) Equipment delays were upsetting and frustrating and delayed getting home at times (Exley)</td>
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*Middle range theory (NPT)*  
Sense making Stakeholders may agree that an optimum H@H should be able to respond rapidly  
Buy-in Buy-in and continued support will be enabled if the service is able to respond rapidly to unpredictable fluctuations  
Doing a flexible workforce must include enough people and skill mix to do necessary tasks and to maintain levels of trust in other’s work, also that work is appropriately allocated and supported by the H@H  
Appraisal H@H will be judged on rapidity of response, cost, and the competencies and skills of workforce