

Evaluating PPI activities within a paediatric palliative care research centre

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Background



- Patient and Public Involvement (PPI) important component of healthcare research
- PPI within paediatric palliative care research requires specific ethical and practical considerations
- PPI a key priority of our Paediatric Palliative Care Research Centre.
- Family advisory board of ~20 parents of children with life-limiting conditions and complex healthcare needs: Our PPI-partners

Study aims



This study aimed to evaluate the Centre's PPI activities. With 3 objectives:

1. To review and map the range of the Centre's PPI activities and their impact on the research processes, outcomes and on the people involved.
2. To gain an understanding of how the Centre's PPI-partners and research staff perceive PPI activities they have engaged with and what could be done better.
3. To determine the areas of success and required improvement in how PPI activities have been conducted and to plan a route forward.

Methodology



Stage 1: Review of PPI activity

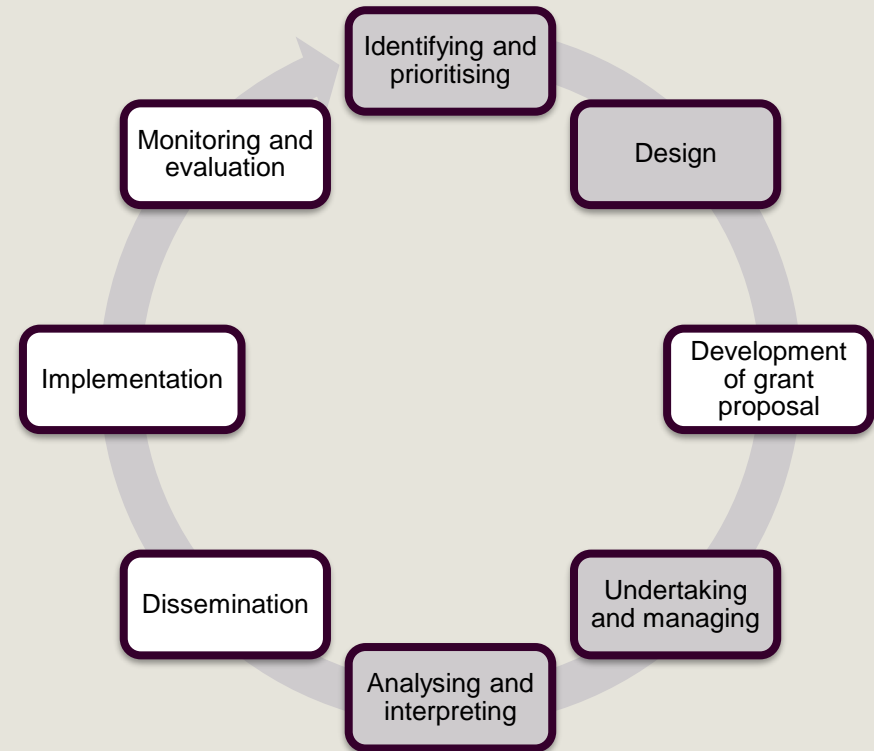
- Extracted data from PPI logs
- Mapped activity to research cycle
- Assessment of effect on research relevance, quality and impact

Stage 2: Qualitative exploration

- PPI-partners invited to complete survey and/or interview
- Online focus group with centre's researchers
- Thematic analysis

Findings from stage 1

- PPI logs from 15 research studies examined and mapped against the stages of research process
- PPI had been concentrated in the 'design', 'undertaking and managing' and 'analysing and interpretation' phases of the research
- Found clear examples of the impact PPI had on research but inconsistent recording made measuring impact difficult
- Highlighted the crucial role of funding in enabling PPI throughout the process.



Examples of PPI Involvement



Stage	PPI Activity	Impact
Identifying and prioritising	Adult social care priorities: Co-production group exists to scope core priorities for research. Worked together to define and identify social care needs.	Designed a programme of research, including scoping review, that explicitly addresses the priority needs identified by the relevant population.
Design	YourTube: PPI group chose study name, changed focus of study and consulted on specific outcome measures.	Study materials were appropriate and more accessible which enhanced engagement with both parents and clinicians.
Development of grant proposal	ENHANCE: PPI partner was co-applicant, writing plain English summary, commenting on grant application and attended ethics committee.	Reassured the research ethics committee that language used was suitable and that social media was an essential channel for study recruitment.
Undertaking and Managing	Early Days: Specific study parent panel. Provided input to interview guides, advised on appropriate language and guided recruitment.	Ensured interviews with bereaved parents are conducted sensitively and appropriately. Improved recruitment and data quality
Analysing and interpreting	ENHANCE: Parent co-applicant was active team member in qualitative analysis, including listening to interviews and team discussions.	Brought their own experience and perspective to data interpretation and to the construction of themes and findings.
Dissemination	CoPPAR: PPI Partners co-presented the project learnings at a conference; informed guidance and facilitated a workshop.	Engaging presentations with the authentic voice of someone with firsthand experience. Generic toolkit tailored for a bespoke group.
Implementation	YourTube: Parent panel partnering with an animation company to produce short videos that capture the study's findings.	Animated videos for use by parents, young people and professionals to discuss and plan different approaches to care.
Monitoring and evaluation	MC 24/7: Specific study parent panel provided continual oversight, as well as representative on Study Steering Committee	Ensured that parents had strategic view and were able to input into issues as they arose.

Findings from stage 2

- 4 in-depth interviews with PPI-partners
- 8 anonymous survey responses
- Conducted focus group with 12 researchers
- Analysed data thematically
- Three themes developed



Clarity of process and purpose



Balanced relationships create a safe space



Mutual respect and value for PPI

Clarity of process and purpose



- PPI-partners had a clear understanding of PPI and why they were involved.
- Common awareness their role was to share their “realities”
- Less clarity around the strategy and operation of the Board
- PPI-partners’ needs and circumstances were accommodated

*“I think the one bit that isn’t structured is how you get involved in the kind of additional work that you guys do”
[Partner IV1]*

“Something I would value, and I wonder if it would be useful, is just really laying out the purpose of the group in a really simple way. And that it is purely about research.” [Partner IV3]

Balanced relationships created a safe space



- Continuity and regularity enabled solid relationships to develop between researchers and PPI-partners
- Researchers balanced professionalism with openness
- Partners felt safe and well supported

"We are treated as partners and experts." [Partner IV 4]

"I find it's also, in those bits, it's an opportunity for you to share back little bits of information about you, as well to try and break that power imbalance away." [Researcher]

"It also feels like a time when we can all just come together and talk about stuff." [Partner IV6]

Mutual respect and value for PPI



- PPI-partners and researchers respected and valued each other's involvement
- Both groups felt personal benefits from involvement in PPI
- Consensus that PPI played an important role in grounding, shaping and improving the Centre's research

*"I think it's critical to everything we do."
[Researcher]*

"I honestly couldn't fault the Centre's approach to PPI and how it really, genuinely is at the heart of everything that's done [Partner IV2]

Route to impactful PPI in Paediatric Palliative Care Research

Enabled by investment in time and resources



CLEARLY ARTICULATE PURPOSE AND EXPECTATIONS

- Define the aim of the PPI group
- Agree common understanding of PPI partner and research roles
- Set expectations of commitment



INCLUSIVE AND TRANSPARENT PROCESSES

- Design flexible, accessible meeting formats and timings
- Provide induction training for all
- Build in tracking and assessment of PPI activities



CREATE A SAFE SPACE

- Develop authentic, equal and supportive relationships
- Respect PPI partners' lived experiences
- Encourage peer support

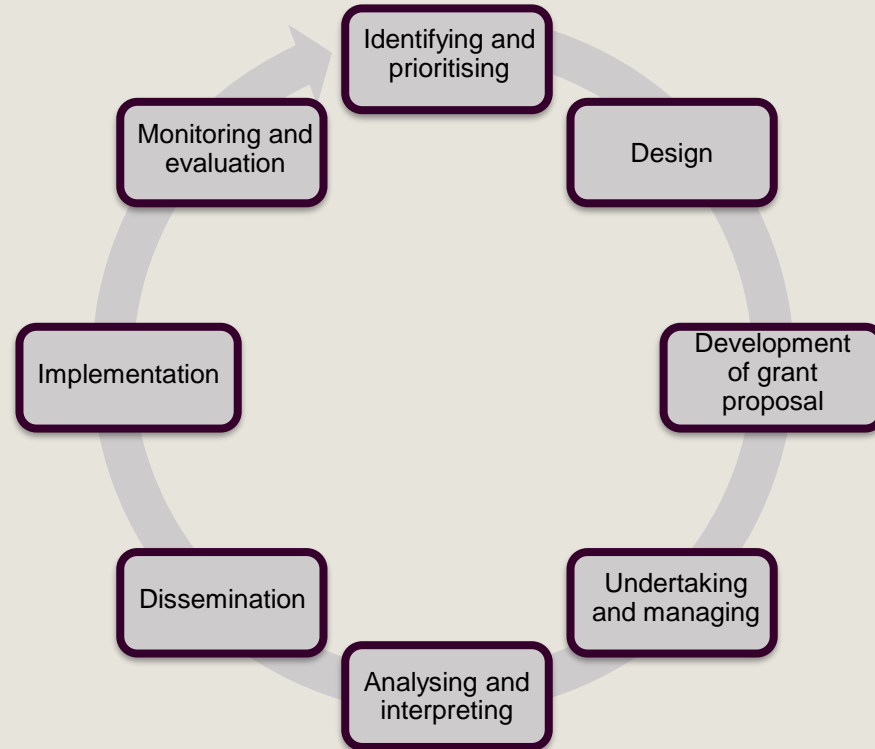


RECOGNISE AND CELEBRATE IMPACT

- Involve PPI partners at all research stages
- Feedback impact to PPI partners
- Acknowledge contributions in research outputs

Underpinned by shared genuine belief in the **VALUE** of PPI

PPI Involvement in this study



Conclusions



- To undertake effective and meaningful PPI in paediatric palliative care research, substantial investments of time and resources are required.
- Roles, processes, and expectations must be explicitly agreed.
- Established relationships ensures a sense of trust and enables authenticity and vulnerability from all involved.
- PPI has positive personal benefits for both researchers and parents, in addition to improving research

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