Document created by Charlotte Brigden, co-applicant within the OPEL H@H study. This project was funded by the National Institute for Health Research Health Services and Delivery Research Programme (project number 17/197/44). The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the HS&DR Programme, NIHR, NHS or the Department of Health.



Feedback from researchers to project Patient & Public Involvement (PPI) representatives

End of Year 1

PPI Activity

PPI Input

How has this made a difference?

March 2017

Project Launch Coapplicant meeting London

- Added to discussions on the importance of role of the carer in terms of support with medications
- Input to group activity of how to interpret the normalisation process theory (NPT)

Graham made some really good points that made us think differently about the NPT constructs

April 2017

Feedback on Phase 2 study information sheets and procedures from:

PPI co-applicants
Pilgrims Hospice
H@H staff
Pilgrims Hospice
patients

- Useful information on content and language of information sheets and documentation.
 When/how to follow up for carer interviews (PPI reps)
- content/language of patient information sheet sheet/study procedures (patients)
- H@H staff helpful to highlight barriers to recruitment.

 Suggested a flyer to give out in advance to make approaching patients easier

Wording on info sheets used verbatim. We should be upfront with carers and approach them postbereavement with 1st info sheet

Felt Graham & Mary's input to phase 2 was key factor in it being approved without amendments by ethics committee

Patients & staff affirmed process/info was appropriate. Introduced flyer as additional document.

July 2017

PPI co-applicant feedback on CMOs from qualitative survey data

- Importance of continuity of care e.g impact of 0 hours contracts or having single point of access (Mary/Graham)

Affirmed configuration of the CMOs in development. Provided helpful insights to consider when building on the CMO evidence by informing the H@H model programme theory v2 July 2017

August 2017

Co-applicant Meeting London

- support on developing final CMOs & model typology from survey results
- input into selection of phase 2 case study site shortlist

Views considered as part of a wider group. Graham keen to support the geographical spread of the sites which was taken on board in final selection

September 2017

PPI co-applicant feedback on project flyer to hand out to participants feedback on design, content and wording of flyer

Affirmed its appropriateness

Useful information on wording used verbatim as suggested by Mary

November 2017

PPI co-applicant feedback on ACHR service use tool and diary

- Detailed feedback received on draft of adapted ACHR telephone script and accompanying diary for the carer to use as an aide memoire.
- Thoughts provided on how useful it is e.g. in identifying best H@H model and providing costing (Mary)

January 2018

Co-applicant Meeting London

- Feedback on site recruitment for one hospice site where access to service was much earlier. e.g. if recruit too far ahead they may not die in study period meaning a lot of missing data (Mary) Recruit everyone and only collect data when change in care (Graham)
- ACHR discussion about researcher follow up after death . Suggested warn beforehand at recruitment that will call. Make sure care by H@H service captured in enough detail (Mary).
- Feedback on carer interview topic guide . e.g. suggest spiritual care etc covered (Mary/Graham)

Overall view from researchers

Subsequent feedback from health economist meant the original validated tool couldn't be changed currently.

All info received was reflected in the final version of the diary. Regarding its usefulness it was fed back that this information will be collected in other ways.

All points considered. Decision on site recruitment considered among a wider group and further discussion with site. Decided to approach all patients. Concluded that it may not be ethical to recruit and then not collect data.

Detailed information will be collected in interviews with regard to detail of H@H service. ACHR only captures service use and cannot be adapted

Spiritual care to be included as prompt on the interview topic guide.

They have found the PPI input to have been very helpful and had influenced the development of the study. Mary & Graham's input considered paramount to creating a project document set that was as good as possible.

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Feedback from researchers to OPEL project Patient & Public Involvement (PPI) co-applicants, Year 2

February 2018 - January 2019

PPI Activity

PPI Input

How has this made a difference?

Identified that they would like

February 2018

Feedback meeting with PPI coapplicants

- Lunch meeting between study CI, PPI facilitator, and PPI co-applicants to discuss how the first year of the study had gone, and thank them for their input.
- Opportunity for two way feedback, and discuss future study involvement

to attend local monthly management meetings, and be involved in qualitative data analysis & interpretation. Feedback on how to deal with any 'jargonistic' language that may come up in meetings. Produced a log of terms and their meanings

March 2018

PPI co-applicant attendance at study management meeting

- Input into study processes and procedures
- e.g. how to approach data collection of the ACHR tool, as the researchers were having difficulties contacting participants.
- They agreed maximum 3 attempts to call; suggested we review how to prepare carer for contact and suggested feedback to sites if no contact, perhaps site staff could follow up.

They provided the perspective of the carer (the main participants of the study). All input was incorporated, apart from asking site staff to follow up, which was not in the protocol.

April 2018

PPI co-applicant data coding of qualitative interviews

- PPI co-applicants attended a training session on qualitative interview coding provided by CHSS, University of Kent
- coding meeting with researchers to support with data analysis and interpretation of interview data
- Input on carers' topic guide development, and whether coding frame suitable

Helped to sense check from the carer perspective. Helped with topic guide wording. Their suggestions have influenced the qualitative interviewing and interpretation. e.g. that in the analysis it helps to understand the ethos, support priorities & resources of the organisation, consider the role of 'proactive' carer, & the impact of support from volunteers.

April 2018

PPI co-applicant attendance at study management meeting & document review

- Input into study processes and procedures
- provided comments on carer interview topic guide.
- Input into how to run
 qualitative data coding session
 Input on timing of the QODD
 data collection post patient
 death. Felt it was acceptable to
 ask carer when they felt it was
 appropriate. 4 months seemed

too long, 6 weeks about right.

These comments were incorporated in the next topic guide draft. Team looking into whether recordings of interviews can be used to help with coding as well as hardcopy transcripts. Advice was taken from the study statistician on impact of different time points of QODD collection. This was agreed & implemented into the study.

June 2018

PPI co-applicant attendance at coapplicant meeting and coding session

- The meeting agenda focused on discussions about site recruitment and participation, data collection.
- Mary commented that some questions in the carer interview schedule may be challenging if the time to death was short.
- coding of a commissioner interview by attendees who provided their transcripts.

Action from the comments on the carer interview guide was for researchers to bear this in mind when conducting the interviews.

Outcomes from the discussion of the coded transcripts were fed to into the further development of the CMO propositions or enforced what was in them already.

July 2018

PPI co-applicant attendance at study management meeting

Presentation on coproduction in research at regional conference

- •An amendment had been put into ethics to be able to send QODD questionaire to participants by post/ email with a cover letter, to try and increase response from carers not responding to phone calls.
- Graham commented it might incentivise carers if they received an update on the study as part of the letter.
- •Graham presented his experiences on the project at the 'Co-producing research: how do we do it?' conference

The cover letter is an ethically approved document and cannot be changed without submitting a protocol amendment. The learning point from this is to ensure documents or ideas are seen by/shared with PPI reps before submission so their suggestions can be incorporated

The conference presentation contributed valuable understanding of how PPI/ coproduction can work in practice

Comments taken on board to persist & different means of contact considered, as carers' lives will have changed & they may have gone away or moved.

Aug 2018

PPI co-applicant attendance at study management meeting QODD data reviewed with further discussion about non-contact of participants by phone. Graham commented that this may be a difficult and busy time for carers so it was worthwhile persisting with trying to contact.

Sept 2018

PPI co-applicant attendance at interview coding meeting

- PPI co-applicants & researchers had coded carer interviews which were discussed as a group to provide a range of perspectives.
- They helped with interpretation of the data to highlight the trajectory/story and the key messages for further refinement of the CMOs.

g.g. Insights from Graham around the importance of single point of access for the carer further developed CMO9. He also felt that listening to the recording gives additional valuable insight that you don't get when just reading the transcript.

Nov 2018

PPI co-applicant attendance at management and co-applicant meetings

- Support with coding of transcripts and discussion at meetings to support the development of the CMOs.
- Discussion about who/when to contact early for QODD data may be influenced by the time reseachers have had to build relationship. Mary agreed that early would be better for carers rather than potentially stirring up memories down the line that were starting to heal.
- Discussion in response to researcher concerns on how to approach the difficult topics in the QODD questionnaire that may be upsetting (e.g carer burden questions). Mary agreed that some of the questions come across as quite harsh and carers should be prepared for this.

g.g. Mary confirmed previous interpretations incorporated in to CMOs, e.g. H@Hstaff offered 'time to care' not 'task orientated', not just the length of time but the 'pace' 'presence in the moment' whilst still doing what is needed and filling the gaps in care.

Since the amendment to allow early QODD completion a good number have now been completed early having a positive impact on response rate.

Researchers incorporated an appropriate preamble alongside the information sheet on the content of the questions being asked in the QODD when discussing participation in the interview/ before it

Dec 2018/Jan 2019

PPI co-applicant attendance at management meetings

- Enabled PPI representative to be informed of the latest project progress and to contribution to discussions.
 Updates and discussions on new sites opening, recruitment and data collection.
- Opportunity to review PPI activity e.g. coding of carer transcripts.

It was highlighted that fully coding each transcript was very time consuming, therefore Mary and Graham will consider the CMOs and how transcripts might affect these and summarise the story of each transcript to minimise time spent.

Thank you for much for your continued help & support Overall view from the researchers The input from Mary & Graham has been excellent, providing a much rounder view from the carer perspective. This has been invaluable for sense checking data collection & findings.

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Feedback from researchers to OPEL project Patient & Public Involvement (PPI) co-applicants, Year 3 (including extension) February 2019 -Sept 2020

PPI Activity

PPI Input

February 2019 how to contact parti

Feedback meeting with PPI co-applicants

- Input into study processes and procedures on how to contact participants for postal QODD questionnaire.
- Personal touch via a phone call better than a letter to make contact. Consider changing the timing of the call as carer circumstances are likely to be different post-bereavement.

March 2019

PPI co-applicant feedback and thank you afternoon tea

- Comments received:
- Experience of coding has been good, but felt a bit in isolation, wanted to check with others
- training at beginning was very good but seeing the whole model being aimed for was missing
- Listening to the audio of transcripts was key for Graham, as felt more insightful and useful to hear the tone and context. Wanted to share this with other PPI member
- Wanting to feel input made is adding value
- took an overview approach and perspective and enjoyed taking part in the analysis of the transcripts.

April 2019

PPI co-applicant attendance at project meetings and coding qualitative interviews

- Advice on how to rethink approaching bereaved carers for completion of QODD and interviews. It's okay to contact carers with one last attempt.
- Coding meeting with researchers of interview data. Provided input into discussion on service capacity, autonomy of staff and the carer situation and support.
- Commented on the wording of the carer information sheets for the interviews & ending of postal QODD questionnaire.

How has this made a difference?

Suggestions for uncontactable participants were fed back to researchers. Processes and procedures for the postal QODD were incorporated into the study amendment.

NIHR report chapters shared with PPI reps so they can see what aiming for with model.

To overcome coding challenges an alternative suggestion was made to summarise their thoughts and where these fit in CMOs.

A session to listen to an audio file and discuss was organised by Charlotte with the PPI co-applicants.

Following advice of PPI coapplicants, researchers made one last attempt to contact bereaved carers to hopefully boost response.

Contributions at coding meeting informed the CMO development

PPI comments were incorporated into updated versions of the information sheets/postal questionnaire.

June 2019

PPI co-applicants listening to and coding of qualitative interviews Time listening to audio files of selected interviews for discussion at co-applicant meeting. Graham felt this helped to give a clearer picture of the situation and aided interpretation.

- Discussed recruitment, data collection & governance at project management meetings.
- Coding meeting: Questions raised by Graham: Do HAH staff manage time differently to DNs? How do you get best value from the time you have so patients feel they've had good value?
- Co-applicant meeting included discussion of study sites, recruitment & data collection, followed by discussion of qualitative interview transcripts.
- Examples of points fed back from interviews:

Mary: Carer having to repeat things to different staff again & again. Carer didn't value social calls which others have liked— not individualised. Mary:Single most important info

from interview was the potential familial loss that comes from taking on the caring role.

Graham: Admin support, how well defined and controlled is the process, time, logistics, travel Graham: Services to identify 'cliffedge situations' for carers and respond to change, rapid escalation of problems towards death means may slip through the net if RAG rating systems are used.

PPI co-applicants felt listening to the audio file had been a useful exercise but didn't change how they coded interviews. One file was a QODD interview and helped to understand the concerns of doing QODD and then the interview together.

Outcomes from the discussion of the transcripts were fed into the further development of the CMOs or re-enforced what was in them already.

Mary's coding was entered into NVivo software.

Helped provide PPI perspective in the iterative process of analysing and interpreting interviews to further develop CMOs, or confirm what we already had found.

PPI co-applicants were given carer transcripts only, but actually felt they missed out on useful information in service provider/commissioner transcripts which helped to explain the context of the carer interviews. PPI co-applicants were then given these additional transcripts for reference for future coding meetings.

June-Sept 2019

PPI co-applicant attendance at project and coding meetings

Aug 2019

PPI co-applicant comments on site process maps

- Presentation and discussion of process maps for case study sites - Do they provide context for individual services in sufficient detail?
- Mary: Carer support is central as mechanisms in CMOs .Services should be driven by the carer, but somehow this is not translated into the system process. Some of the services identified are not needs driven.

This enabled sense checking of process maps of sites and how they fit with the CMOs, taking PPI perspectives into consideration.

Sept 2019

Watched realist evaluation video and review of CMOs Feedback on consensus event flyers

- •Cl attended realist evaluation course and wanted to show video to whole team to reflect on CMOs and review changes made. Feedback from PPI that language in the video made it difficult to follow.
- Mary fedback on discussion group flyers to advertise project consensus events to public attendees and for PPI discussion groups. Made suggestions on layout, language and wording used.

PPI feedback was that the reviewed CMOs made sense and pleased that there is more emphasis on the patient in CMO9 (and not just the carer).

Learning: A realist evaluation handbook was created for PPI co-applicants at start of phase 2. It may have been helpful to have referred back to this as part of this realist evaluation video exercise.

All suggestions made on the PPI discussion group flyers were incorporated.

Oct-Dec 2019

Planning of
Phase 3 Consensus Events

consensus events will work and roles of the team. Examples of suggestions made:
Graham: take a 'working example approach' to the workshops.
Identify via coloured badges in what capacity delegates are attending i.e are they public, service provider, commissioner) Mary:All 7 CMOs too much to go through in the speed dating session.

Discussed as a team how

Post-it notes with feedback on mechanisms should also be colour coded so that it's clear if member of the public, service provider or commissioner. Planning meeting resulted in detailed discussion from their insight of the data and own experiences, which helped with the planning of the events.

Suggestions for the running of the events from the PPI coapplicants were incorporated into the event plan.

Nov 2019

Volunteer & Carer (PPI) discussion groups

- Graham supported with volunteer and carer discussion groups at Pilgrims Hospice, to sensecheck the results so far and help inform the consensus events.
- Graham helped prepare discussion guides from the CMOs and helped facilitate the groups on 25th November with Charlotte, Research Facilitator.

meeting. Some examples of input:-

Discussed interviews at

- After first insight into commissioner interviews: Mary: If commissioners have piecemeal input they cannot understand the complexity/ nuances of what's being provided by HAH.
- Patient led follow up in HAH: Mary: should be a negotiated partnership based on what is realistic to provide, there may be mismatch.
 Graham: needs to be in context of changes that are coming, needs to be ongoing, continuous feedback, and adjust as you go.
- Reflection of carer experience:
 Graham: A lot of pressure on carer evident. Challenges identified between being a family member and a carer.
 Lack of support available.

Graham's involvement in the planning of the discussion groups. Acting as 'group member', as well as a facilitator, in the carer group was beneficial, as he could draw on his own experiences. Learning: 1. Understanding how the volunteer and carer views/ experiences matched the study findings. 2. How to run similar groups at consensus events.

Outcomes from the discussion of the transcripts were fed into the further development of the CMOs or enforced what was in them already.

Some examples of direct changes to CM Os are:

Graham:

- 'Identify' is a better word than 'drawing in' for CMO2.
- Outcome for CMO9 is enabling carers to continue to care.
- Discussion about the reputation of the organisation when staff are respected suggested this was also marketing and should go in CMO2.

Mary:

 'Unpredictable changes' as new wording for CMO3

Oct-Dec 2019

PPI co-applicant attendance at interview coding meetings

Jan-Mar 2020 Consensus Events

- •Advert/flyer for public attendees to attend the events had been circulated nationally via research networks (e.g. CRN & ARCs), CCGs, Healthwatch, and national charities and groups (e.g. Marie Curie).
- PPI co-applicant involvement in further planning of workshops around the CMOs
- •Graham attended the consensus events in Leeds and London and supported with the facilitation of the 'Supporting Carers' workshop, the speed dating poster session, and the 'So Now You Know' session on how the results should be disseminated for use in practice.
- PPI co-applicants involved in post event discussion.

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Apr-May 2020

Meetings &

Discussion of

final interviews &

refining CMOs

- Graham attended a management meeting and meetings on specific CMOs (on volunteers and carer support).
- Raised the importance of volunteers and the service they provide (and could provide) to carers in H@H, which doesn't stop at death.
- •Insight on being a carer, e.g. there is a decision that is made about being a carer at home. There is a timeline where tasks unfold which you don't know at the beginning. Growth in confidence in skills which can counter act reliance on HAH. Post death, there is affirmation of their role of carer.

Support in particular with planning the carer workshop and plans for how we engage with members of the public/carers/volunteers attending the consensus events.

Twenty-two members of the public attended and contributed to the events (17 in London and 5 in Leeds) which represented a quarter of the overall attendance.

Graham attended the meeting to reflect on the events, inputting to the discussion about the participant feedback on the events & how this informed the CMOs.

Graham helped provide PPI perspective in the iterative process of analysing and interpreting interviews and the refinement of the CMOs.

CMO wording was changed to incorporate comments e.g. before death it is a sense of encouragement. "You can't really say they [carers] ever feel in 'control' so not the right terminology".

Some insights were not incorporated e.g. if already covered, and can only use examples from the evidence. He felt volunteers CMO was biased towards negative outcomes. We were unsure now to change this, and Graham was given opportunity to further expand on this comment.

Aug-Sep 2020

Quantitative & health economic data discussions

- Input into interpretation of the quantitative & health economics findings to include PPI perspective as stakeholders.
- Graham was able to bring in the carer perspective to the discussion of the the data and in what questions to ask of the data in the analysis.

July-Sept 2020:

Feedback on PPI & discussion chapters of the final report

- Overall the PPI co-applicants felt the PPI chapter was a good summary of PPI throughout the project.
- Mary suggested ways the PPI chapter could read better and areas where further emphasis could be put. e.g. importance of the role of research facilitator, and how the role evolved into coproduction.
- Graham participated in meetings about the discussion chapter.

Final work to come:

Final report lay summary and dissemination

- Support with content and language of the lay summary in the final project report.
- Provide insight on best media to disseminate project findings to a public audience. This has already been discussed at previous meetings and at the consensus events.

Graham raised some interesting but subtle issues from the data which are useful points to note for the discussion.

We acknowledge PPI desire to understand how the quantitative & qualitative data will come together in the final report to show overall value of the project. This will come through in the final meeting discussions & data synthesis.

PPI chapter: The points to further emphases were added as quotes. Learning points were also added that PPI doesn't have to be identical & more diversity in PPI and participants should be considered in future projects. Discussion: HAH fills the gaps in care. Analogy given that HAH is mortar in the bricks of the health care system. Reputation of the hospice is important for the carer having a compassionate experience to ease care burden.

PPI input into project outputs is important to ensure the project findings are accessible to the end beneficiaries of the research (i.e. patients and carers) and the wider public. A leaflet of study findings in places where patients and carers visit (e.g. GP surgeries) was suggested.

Thank you so much, Mary & Graham for your dedication throughout the project Overall view from the researchers Graham and Mary really are part of our research team. Their input has been highly valued and an important part of the study in order to make the findings more relevant. The CMOs have been the target and their input has increased the sizeur of the applying and findings.

If you have anything further you would like to tell us about your experience as a PPI co-applicant on the OPEL project you may record it below or in an email. Return this page or email reply to Charlotte Brigden, Research Facilitator: c.brigden@kent.ac.uk.

