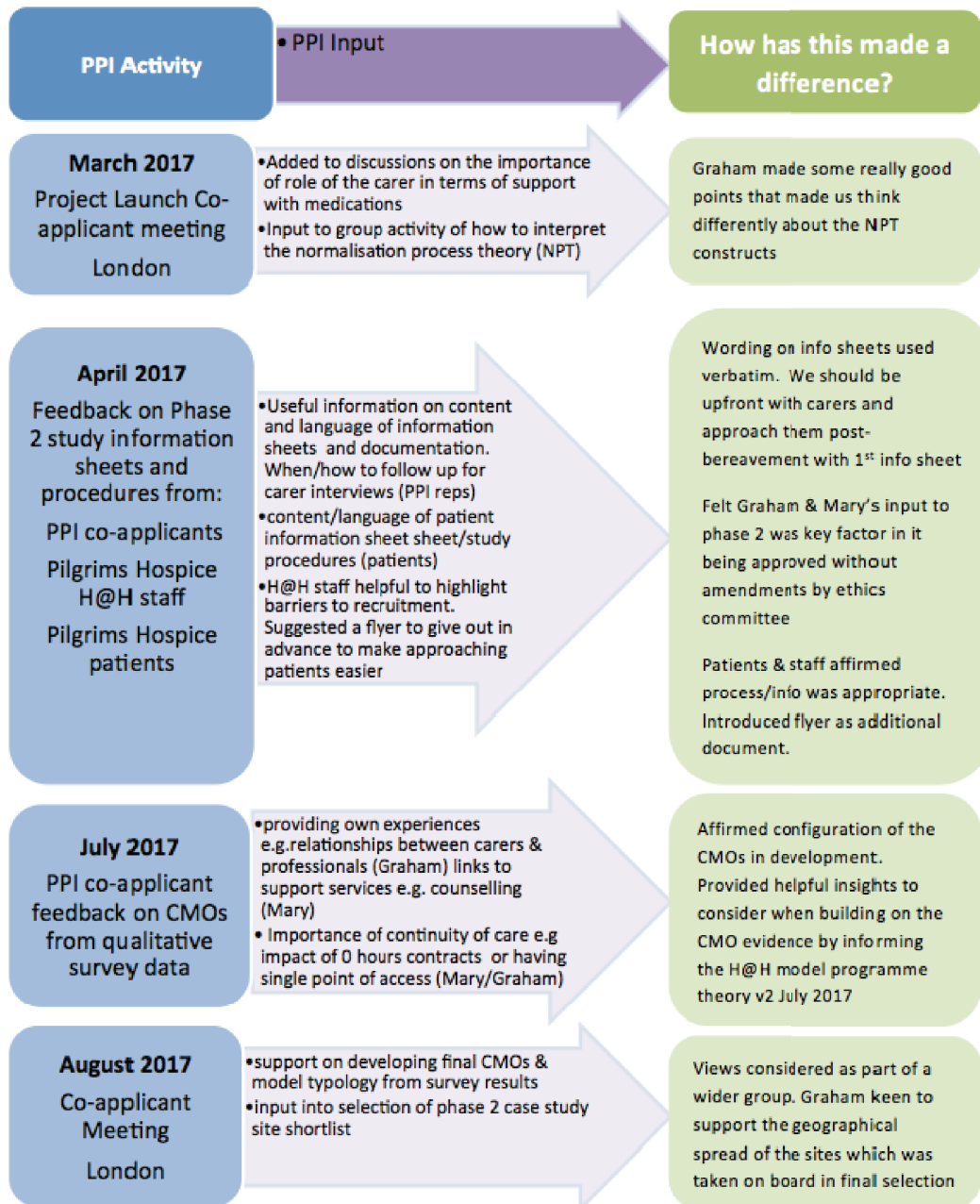


Feedback from researchers to project Patient & Public Involvement (PPI) representatives

End of Year 1



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)

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.

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)

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.

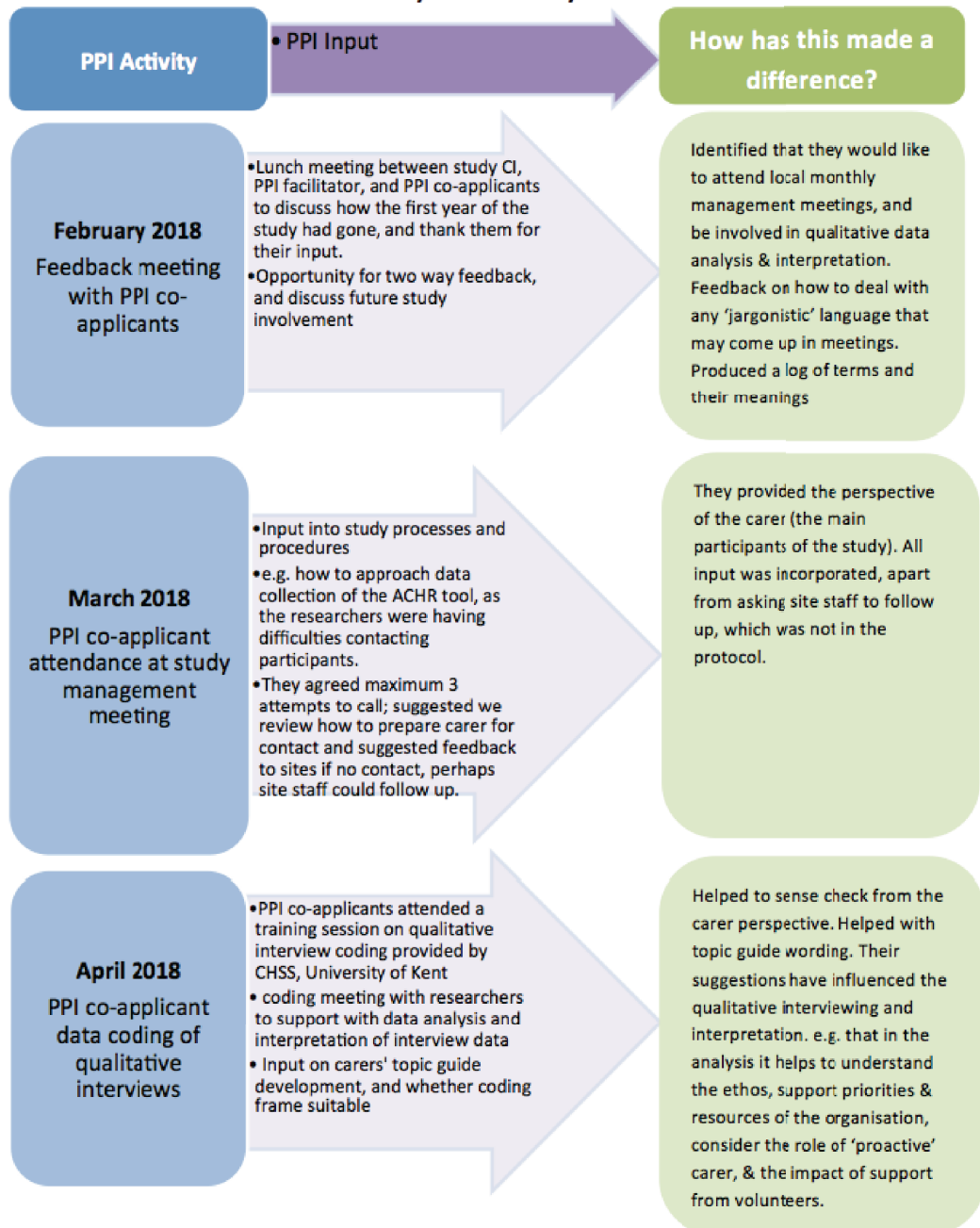
**Thank you for your
help and support**

- Overall view from researchers

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.

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

February 2018 - January 2019



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 co-applicant 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 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 co-production in research at regional conference

- An amendment had been put into ethics to be able to send QODD questionnaire 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/ co-production can work in practice

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.

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

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.

e.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 researchers 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.

e.g. Mary confirmed previous interpretations incorporated in to CMOs, e.g. H@H staff 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 contribute to discussions. Updates and discussions on new sites opening, recruitment and data collection.
- Opportunity to review PPI activity e.g. coding of carer transcripts.

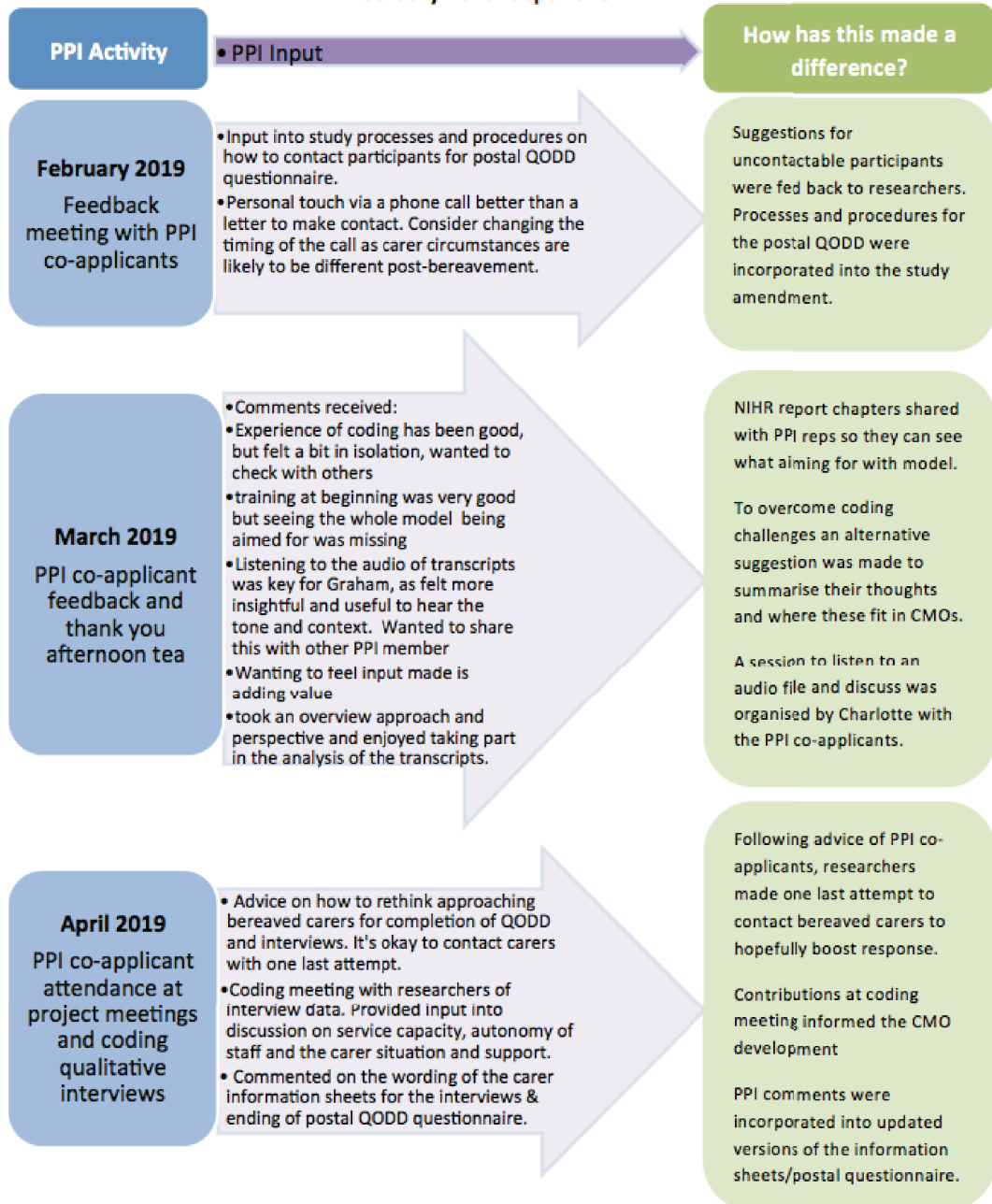
It was highlighted that fully coding each transcript was very time consuming, therefore Mary and Graham will consider the CMOs and how transcripts might affect these and summarise the story of each transcript to minimise time spent.

**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.

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



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.

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.

June- Sept 2019
PPI co-applicant attendance at project and coding meetings

- 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 'cliff-edge 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.

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.

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

- CI 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 feedback 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

- Discussed as a team how 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.
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 co-applicants 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.

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.

Oct-Dec 2019
PPI co-applicant
attendance at
interview coding
meetings

- Discussed interviews at meeting. Some examples of input:-
- 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.

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 CMOs 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

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.

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.

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 counteract reliance on HAH. Post death, there is affirmation of their role of carer.

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.

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.

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.

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.

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.

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 rigour of the analysis 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.