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Optimum Hospice at Home Services for End-of-Life care (OPEL): realist evaluation and co-production

Co-applicants: Butler C, Wilson P, Abrahamson V, Mikelyte R, Gage H, Williams P, Brigden C, Swash B, Rees-Roberts M, Silsbury G, Goodwin M, Greene K, Wee B & Barclay S.

Funders: NIHR Health Services & Delivery Research (project 14.197.44)

Ethics: IRAS & Health Research Authority, REC:17/LO/0880

The project is led by the University of Kent in collaboration with the University of Cambridge, University of Surrey, Oxford University Hospitals NHS Foundation Trust, Pilgrim's Hospice, Medway Community Healthcare and the National Association for Hospice at Home.

Website: https://www.kent.ac.uk/chss/research/docs/current/2016_11_21_HAH.html



 **PEL H@H**
Optimum 'Hospice at Home' Services for End of Life Care

RESEARCH AT YOUR HOSPICE

You could get involved

What type of hospice at home services work best for patients and carers?

Around the country, hospice at home services are very different. We want to understand what types of services work best for patients and their families/carers so we can share best practice and improve care for all.

If you receive hospice at home services, you may be invited to take part in this National research project.

If you would like further information please contact: *[insert local contact]*  **#OPELSTUDY**

This study has been reviewed by the NREC London - Queen's Square V1.0 12OCT2017



national association
for **hospice at home**



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BACKGROUND

- Hospice at home (HAH) services aim to enable people to have a “good death” at home.
- While this accords with UK policy, statutory services are ill-equipped to meet this demand and there is limited evidence from the perspective of service users, as participants or co-producers, of what aspects are most helpful.
- Our review of the literature and realist synthesis (Hashem et al, 2020) found individual services vary greatly and use many different outcome measures making it difficult to ascertain what works well, for whom and in what context.
- We used a mixed methods realist evaluation to ask:

‘What are the features of hospice at home service models that work, for whom, and under what circumstances?’





STUDY OVERVIEW

<p>Phase 1: National telephone survey of HAH Services (n=70)</p> <ul style="list-style-type: none">• Identified range of service models & characteristics• Developed typology of care models• Consensus event to agree typology• Typology used to select & invite case study sites for Phase 2• Tested initial CMO configurations	<p>Phase 2: Case studies</p> <p>Data collected from 12 case study sites across England:</p> <ul style="list-style-type: none">• Qualitative: realist informed interviews with carers (n=58), providers (n=75, 3 were interviewed twice) & commissioners (n=10).• Quantitative: patient clinic data, outcome measures• Health economics data: service utilisation	<p>Phase 3: Data refined & disseminated</p> <ul style="list-style-type: none">• Two national stakeholder consensus events• Report for NHS England: guidelines for hospices & commissioners to promote contextually informed service development• Dissemination: different formats for carers, providers & commissioners.• Impact activities: funding application
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(Butler et al, 2018; Rees-Roberts et al, 2019)





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CO-PRODUCTION EMBEDDED INTO REALIST DESIGN

- Hospices: **wide range of stakeholders** including service users, carers/family; hospice employees including volunteers; other third sector organisations; health and social care sector; commissioners; and policy makers.
- ‘Each stakeholder group will bring a different cognitive and emotional representation on that issue, shaped by **different experiences and interests**’ (Rycroft-Malone et al, 2016, p222)
- Stakeholder participation: essential from the outset to **build relationships** so that we became trusted partners.
- ‘The ontology of co-production emphasises the importance of engaging and integrating the **multiple perspectives** of stakeholders that can **shape** the **understanding**, and processes of knowledge generation and use.’ (Rycroft-Malone et al, 2016, p223)



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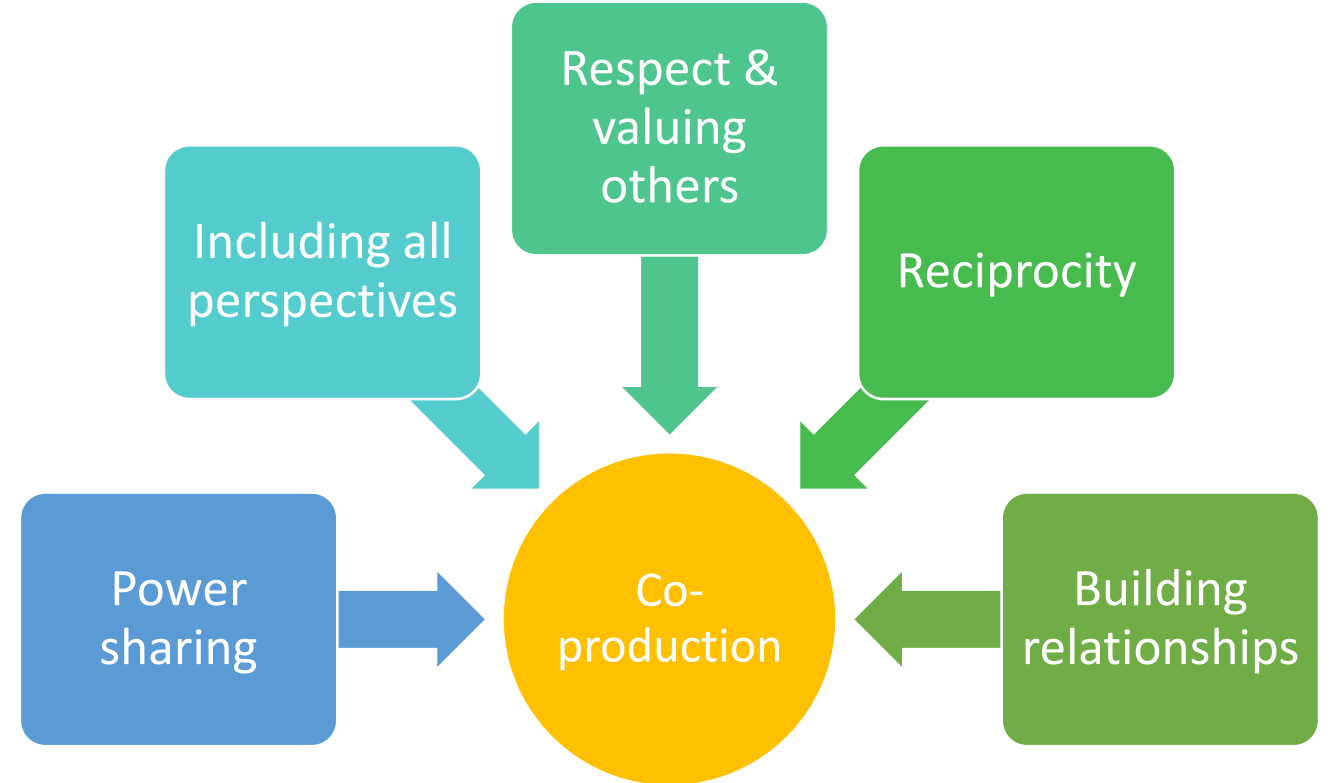
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CO-PRODUCTION PRINCIPLES

‘Co-producing a research project is an approach in which researchers, practitioners and the public **work together, sharing power and responsibility** from the start to the end of the project, including the **generation of knowledge.**’

(Involve, 2018, p4)



NIHR/INVOLVE (2018)





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LIKE MINDS: co-production and the realist endeavour

- **Ontological depth:** belief in ‘what exists’ has depth (real, actual, empirical)
- **Retroduction:** uncovering causal mechanisms; ‘inference to theorise and test hidden mechanisms’
- **Abduction:** ‘the inventive thinking required to imagine the existence of such mechanisms’ (Jagosh, 2020, p2)
- **Different perspectives** widened the range of thinking, creativity and testing of possible underpinning mechanisms



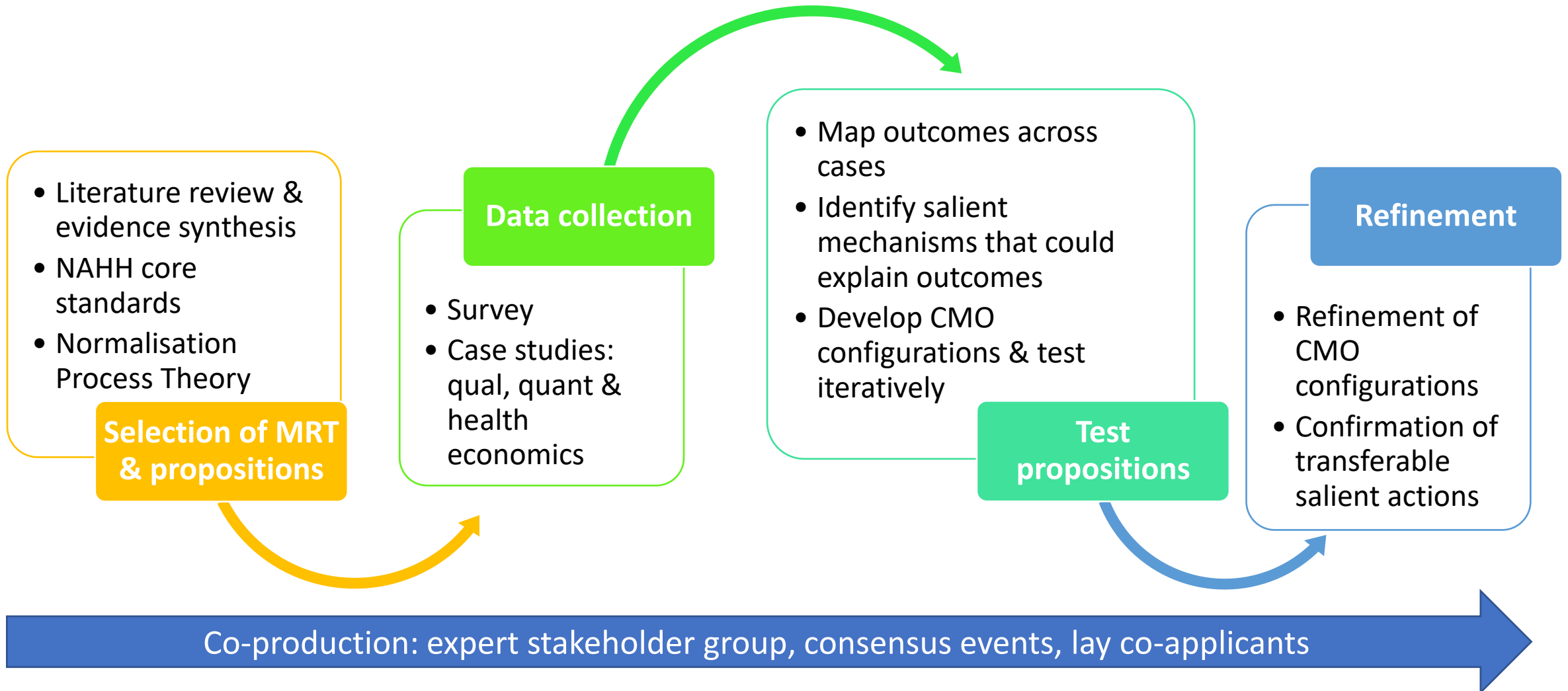
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REALIST EVALUATION DESIGN



GRAHAM AND MARY



Graham Silsbury

Graham has experience of hospice services as a carer and was a PPI representative in a previous study evaluating the HAH service in a local hospice

“At the outset our role was far less hands on but as the project progressed we wanted and felt more confident to be more actively involved. To facilitate this, specific training was arranged. The team too had to be very accommodating to our frequent presence at meetings”

Graham



Mary Goodwin

Mary is a retired registered nurse and paediatric cardiac nurse specialist. She is a member of the CHSS 'Opening Doors to Research' PPI group where she expressed an interest in end-of-life care research





PHASE 2: Case studies

- Graham and Mary requested additional training in realist philosophy and qualitative data analysis
- Regular coding meetings to interpret interview data using Normalisation Process Theory (May, 2009) as a mid-range theory
- Transcripts and audio provided in advance allowed the team to code independently and then discuss together:

“I valued access to audio files along with typed transcripts of interviews. I believe coding of carer interviews in particular were better evaluated when listening to interactions between respondents and researchers, understanding tone and timing” Graham





EXAMPLE: Volunteer CMO

CONTEXT	MECHANISM The causal action(s) and responses to those actions which achieve the outcome in the <u>context</u>	OUTCOME
<p>There are national workforce shortages in health and social care so that the paid workforce is in short supply. AND Societal norms re neighbours, community behaviour, families living in <u>close proximity</u> etc. have changed. AND Many people in communities offer their time and skills as volunteers to hospices and other organisations and recruiting, training and managing volunteers takes considerable <u>time</u> AND Some of these people may have relevant health and social care professional skills. THEREFORE The volunteer workforce is attractive to <u>employers</u> but hospices may be concerned about utilising a volunteer workforce, particularly in the clinical setting, feeling that it is not as manageable or reliable as the paid workforce, and having concerns about legal liability, health and safety etc.</p>	<p>If H@H organisations invest in people and systems to recruit and manage volunteers thereby reassuring the hospice organisation about working with a volunteer workforce. If volunteers with existing, relevant skills are identified and they are prepared to use them in the H@H service. AND If volunteers have roles, remit, boundaries and expectations which are <u>clear</u>. If volunteers are well supported by the organisation in their role. OR If the organisation or locality takes a different approach to volunteering (ref compassionate communities), tolerating a different level of “risk” and allowing volunteers to act more like neighbours without a great deal of bureaucracy and procedure.</p>	<p>Then the hospice will feel confident to utilise a volunteer workforce and additional resources will be available to provide care and support to patients and families Volunteers feel confident and clear in their role, volunteer well-being is <u>facilitated</u> and volunteers are retained within the H@H to provide enhanced care for patients and families. Then volunteers will be able to maintain appropriate boundaries that safeguard the patient, their <u>family</u> and the volunteer. More volunteers may be able to get involved with caring and supporting people at home. HOWEVER Volunteers may find the structure and expectations too demanding and inflexible and chose to volunteer elsewhere. Inconsistencies, paradoxes and tensions develop</p>





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BENEFITS OF CO-PRODUCING DATA ANALYSIS

- Graham and Mary directly participated in building and testing CMOs, adding rigor
- Fresh eye and different perspective – particularly useful interpreting:
 - Relationships between carers and professionals
 - Changing relationship/roles between carer and patient over time
 - Professionals expectations of carer role
 - Carer perspective on continuity of care, including post-bereavement support
 - What HAH offered that was different to statutory care

“Initially I was happy to just read the various transcripts and outline the story being told. But as we had the ongoing opportunity to work with the research team on developing and refining the CMOs I became more familiar with them and confident in my ability to use these to do a more detailed analysis. I found it very satisfying to feel I was contributing directly to the actual coding” Mary



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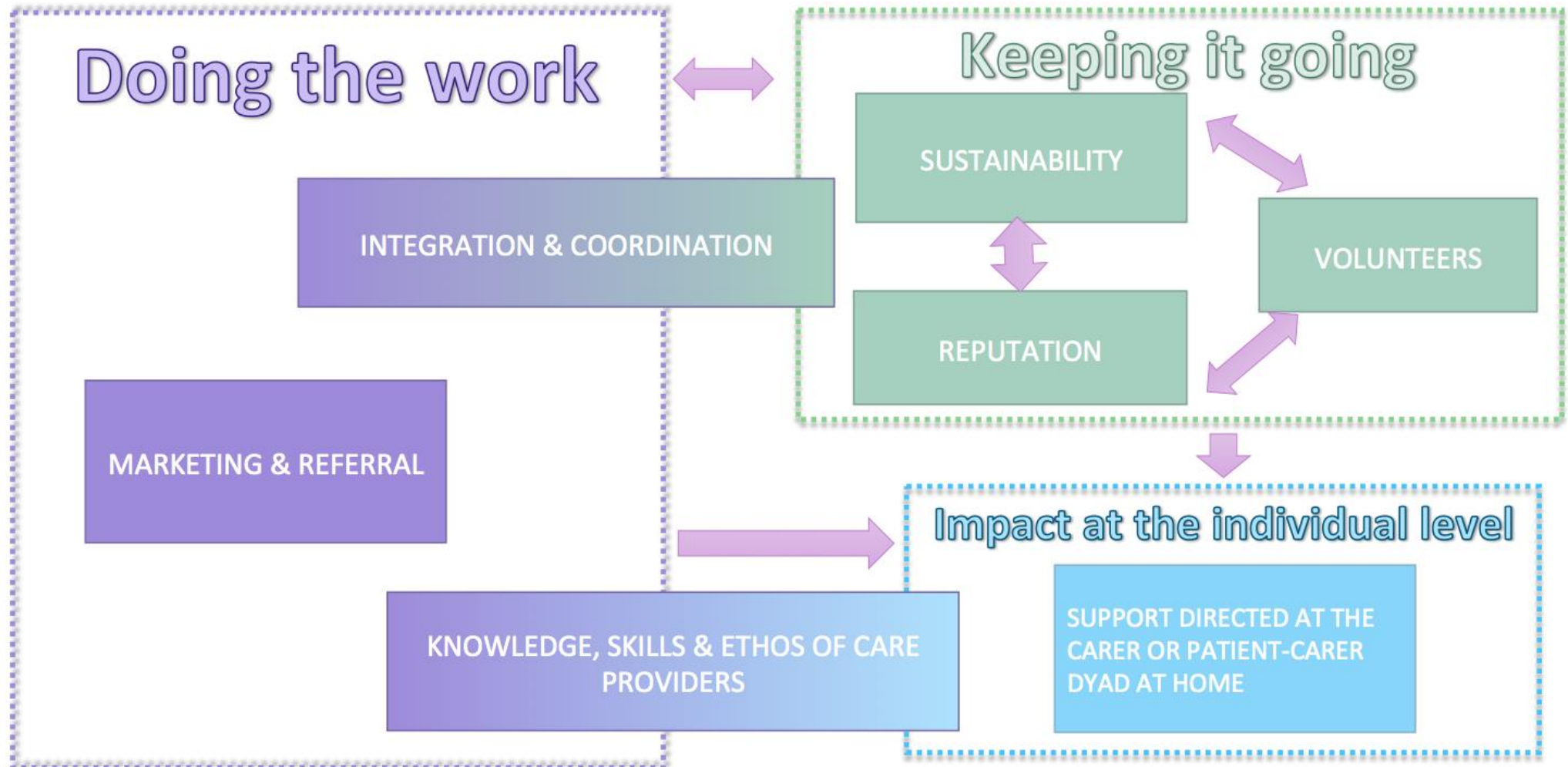


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PHASE 2: CMO development and testing

- Highly iterative process over 18 months
- We all read & discussed nearly every transcript - 143 in total





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PHASE 3: Consensus events and dissemination



COME and HAVE YOUR SAY

Optimum Hospice at Home Services For End of Life Care

We are seeking feedback on our study findings from an audience of **service providers, local health service planners** and **members of the public** with experience of hospice at home services. This will help us to produce guidelines for service providers in the future and to understand which Hospice at Home service types are likely to lead to the best services for local people and represent best value for money. More about the study: www.bit.ly/2yQIAz3

To register for the Consensus Event: <http://bit.ly/2z3VyrO>

If you would like any further information (including support for travel) please contact the Project Manager, Dr Melanie Rees-Roberts (m.rees-roberts@kent.ac.uk, Tel: 01227 816433)



Optimum 'Hospice at Home' Services for End of Life Care



Thursday
23rd Jan
2020



Wellcome Trust
183 Euston Road
London NW1 2BE



9am to
4.30pm



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'VOLUNTEERS' WORKSHOP

How can hospices provide clarity on the role and remit of volunteers?

- a) Obviously for the volunteer and the organisation, but also for the patient/carer
- b) How can the hospice ensure that this clarity protects all involved (volunteers, the hospice, patients and carers) without being unduly inflexible?
- c) What level of risk is 'acceptable'?

"One of our patients used to ask her volunteer to get the shopping and go to the bank for her"

"They can take the patient and carer out in their car, you [volunteer] just have to notify your insurance company"

"This person had dementia and when I went to the toilet he wandered off outside and I had to look for him!"





'INTEGRATION AND CO-ORDINATION' WORKSHOP

Worked Examples – INTEGRATION & COORDINATION

What is your role?

service provider commissioner member of the public

MECHANISM	WHICH OF THESE APPROACHES ARE YOU TAKING?	TELL US MORE ABOUT HOW YOU DO THIS?
A blended service is provided whereby different services can provide what is needed by the patient without hard boundaries around particular roles; honorary contracts with NHS may facilitate this.	<input type="checkbox"/>	
Budgets and workforce and organisational structure are managed in an integrated way across provider organisations.	<input type="checkbox"/>	
A secondment into a different setting (e.g. a healthcare worker into social care) may facilitate integration by the "learning of another language".	<input type="checkbox"/>	
Other providers trust the H@H to make assessments and will act on their recommendations. N.B. this trust may be based on individuals or on the reputation of the H@H service as a whole.	<input type="checkbox"/>	
An element of flexible workforce is employed (by the H@H service or others) or staff are flexibly deployed from other areas (e.g. inpatient unit)	<input type="checkbox"/>	
Clinical records are shared with other organisations.	<input type="checkbox"/>	
District nurses provide and administer all anticipatory medications (agreed division of labour).	<input type="checkbox"/>	





'SUSTAINABILITY' WORKSHOP

Worked Examples - SUSTAINABILITY

What is your role?

service provider commissioner member of the public

MECHANISM	DOES IT MAKE SENSE? (tick if 'yes')	DO YOU DO THIS AT YOUR H@H?	COMMENTS
The H@H service needs to “be on the front foot”, i.e. if the H@H service proactively seeks control over the available statutory funding by one or more approaches:			
Proposing a business plan and “selling it” to commissioners;	<input type="checkbox"/>	<input type="checkbox"/>	
Providers take the lead and provide services without a great deal of scrutiny, TRUST	<input type="checkbox"/>	<input type="checkbox"/>	
Board of trustees or executive leader develop a reputation for excellence, meaning they are trusted to use funding well	<input type="checkbox"/>	<input type="checkbox"/>	
Taking on a lead provider role and subcontracting with other providers in the area	<input type="checkbox"/>	<input type="checkbox"/>	
Provider partnerships may enable small organisations to maintain their responsiveness and alacrity.	<input type="checkbox"/>	<input type="checkbox"/>	
Accepting a block contract from commissioners to enable predictability to the funding available	<input type="checkbox"/>	<input type="checkbox"/>	
Securing continuing healthcare funding to provide or part-fund services	<input type="checkbox"/>	<input type="checkbox"/>	
Accept NHS funding which will support the HAH service and requires it to deliver other (“non-palliative care”) roles, such as OOH catheter replacement, general rapid response for example.	<input type="checkbox"/>	<input type="checkbox"/>	
Accept funding for elements of service from Personal health budgets (note, often not found suitable in this area where patients and families struggle to manage this)	<input type="checkbox"/>	<input type="checkbox"/>	





‘CARERS’ WORKSHOP

CONTEXT

The carer may require confidence and new skills/support to enable them to provide care up to and including the point of death at home.

MECHANISM

Negotiations take place with the carer about how much they are happy to take on. The carer receives information and training so they are prepared and have appropriate skills that they find acceptable.

OUTCOME

Carers will be able to continue to care, enabling more sustainable patient care at home.

What may help or hinder in trying to provide the right support?

How can Hospice @ Home support you as a carer?

What will be the result of getting the right support?

Worked Examples – SUPPORT FOR CARERS

What is your role?

- service provider commissioner member of the public

If you were caring for family member / friend at the end of their life, *how could Hospice at Home support you as a carer?*



At first contact

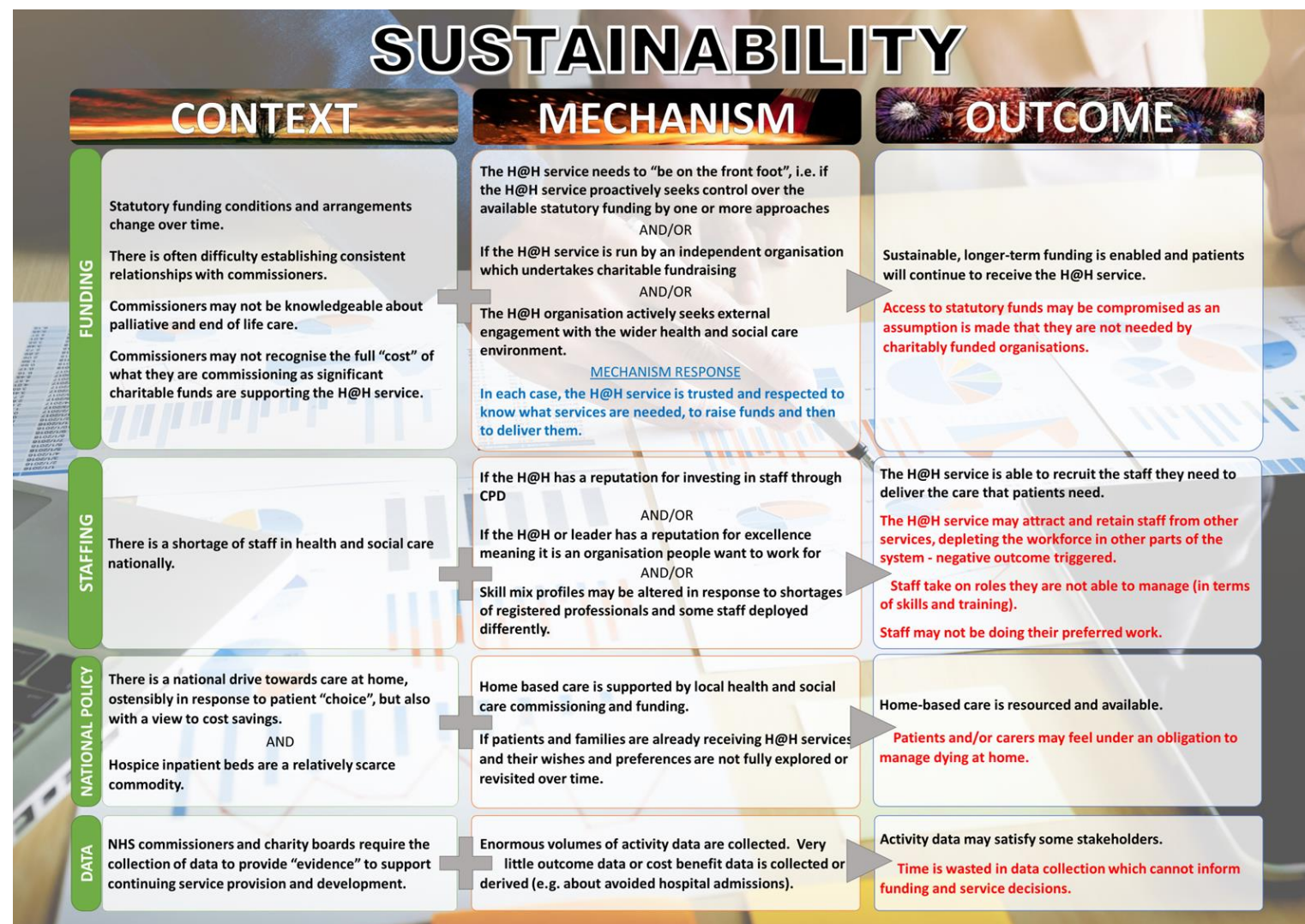
Empty text area for notes or responses.



CMO ‘SPEED DATING’

Move around freely with your post-it notes:

- *Read the CMOs*
- *Talk to colleagues*
- *Talk to the research team*
- *Use your post-it notes to add comments, views, examples, ideas*
- *Put anything you cannot categorise onto the blank CMO sheets*
- *A bell will ring every 15 minutes to help you keep track of the time*





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ENGAGING SERVICE USERS AND CARERS

“My only shortfall comment on the national events would be that there was insufficient representation from the carer/patient group at both workshops despite considerable efforts on our part to correct this. A real challenge for this area of research”

“Had there been strong representation this could have informed the service providers of the challenges experienced by carers/patients in understanding the complexity of the mechanisms at work in providing them the service they received”



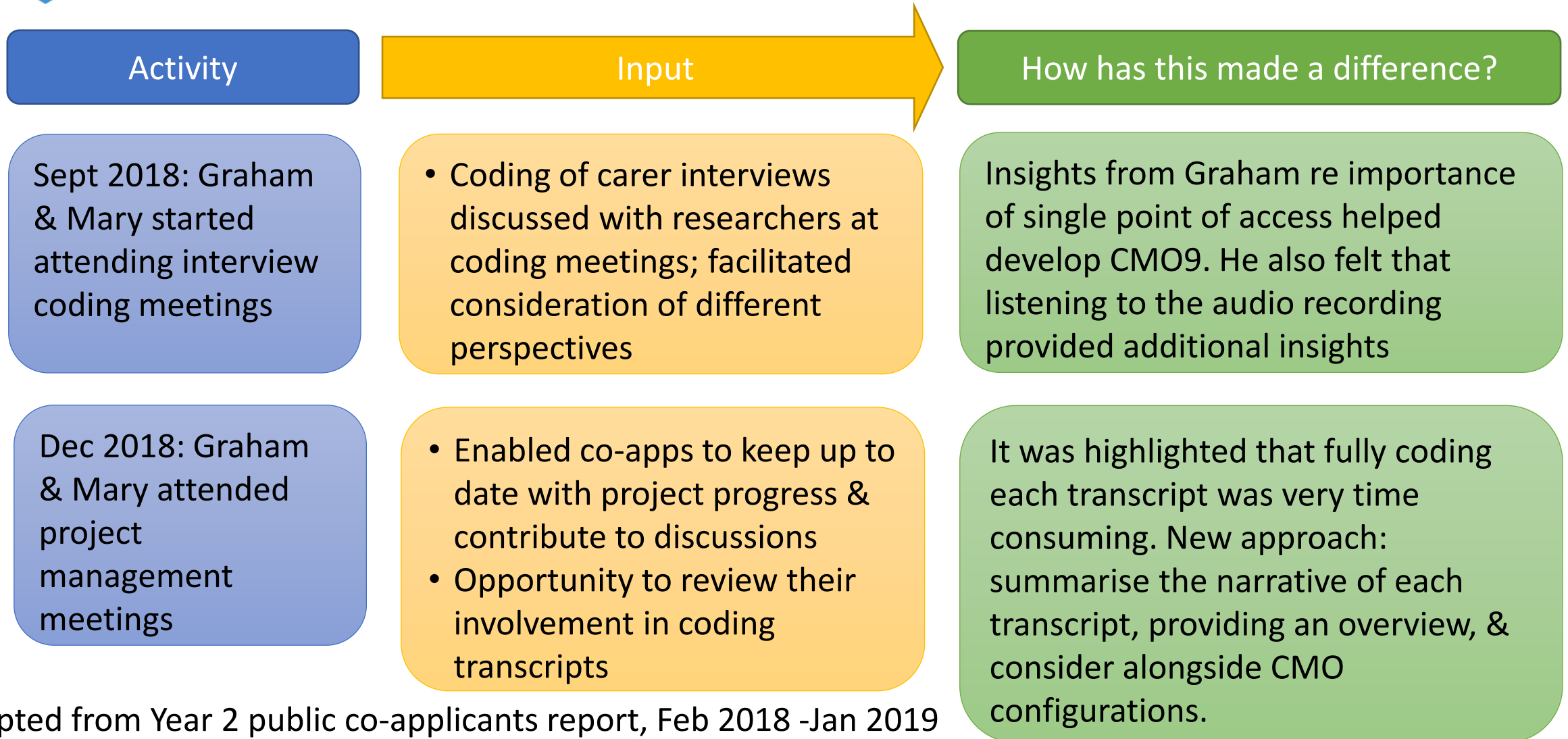
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ASSESSING IMPACT: On-going dialogue



Adapted from Year 2 public co-applicants report, Feb 2018 -Jan 2019





CONCLUSION

- Having two co-applicants with personal experience of end of life care helped embed co-production throughout the project and formalised their role as equal team members.
- Important to have dedicated research facilitator:

“It was vital it was to have access to a dedicated research facilitator who was always available to provide guidance, support and encouragement. I think I might have struggled without Charlotte’s help. Any team using this approach would be wise to have this support role in place” Mary

- Co-production approach greatly enhanced data analysis and added rigour to the process of generating and testing CMOs.
- Realist approach is good fit with co-production in terms of appreciating the complexity of a multi-faceted intervention and representing all stakeholder perspectives.
- We recommend early discussions around expectations and boundaries; build in a generous budget; do not underestimate the time commitment and personal investment.

Sincere thanks to Graham and Mary for all their hard work, humour and invaluable insights





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