2021 International Conference for

# REALIST RESEARCH, EVALUATION AND SYNTHESIS

16 – 18 February 2021

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

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**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

# 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

**Phase 1: National telephone survey of HAH Services (n=70)**

- 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

**Phase 2: Case studies**

Data collected from 12 case study sites across England:

- 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

**Phase 3: Data refined & disseminated**

- 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

(Butler et al, 2018; Rees-Roberts et al, 2019)

# 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)

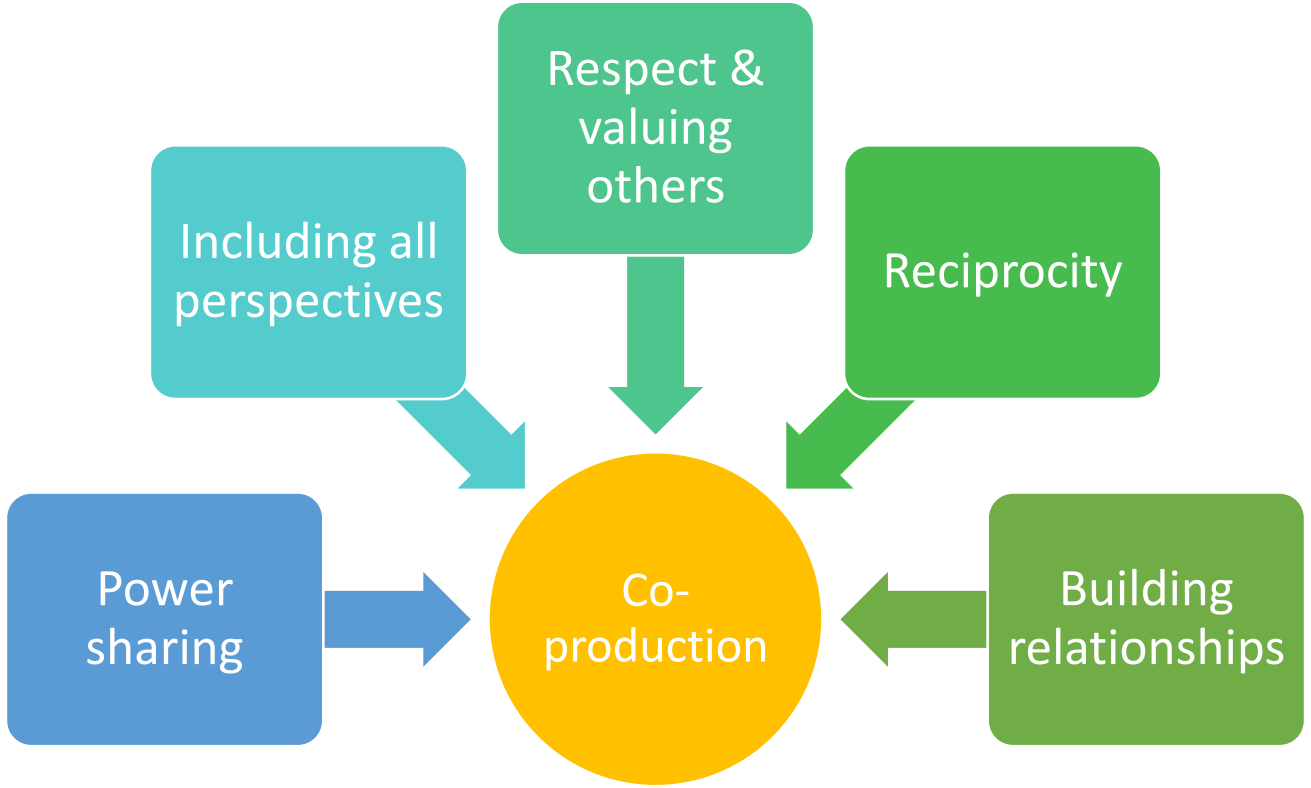
- Stakeholder participation: essential from the outset to **build relationships** so that we became trusted partners.

- '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)

# 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)

# 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

# REALIST EVALUATION DESIGN

**Selection of MRT & propositions**

- Literature review & evidence synthesis
- NAHH core standards
- Normalisation Process Theory

**Data collection**

- Survey
- Case studies: qual, quant & health economics

**Test propositions**

- Map outcomes across cases
- Identify salient mechanisms that could explain outcomes
- Develop CMO configurations & test iteratively

**Refinement**

- Refinement of CMO configurations
- Confirmation of transferable salient actions

Co-production: expert stakeholder group, consensus events, lay co-applicants

# 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<br>The causal action(s) and responses to those actions which achieve the outcome in the context | OUTCOME |
|---|---|---|
| There are national workforce shortages in health and social care so that the paid workforce is in short supply.<br>AND<br>Societal norms re neighbours, community behaviour, families living in close proximity etc. have changed.<br>AND<br>Many people in communities offer their time and skills as volunteers to hospices and other organisations and recruiting, training and managing volunteers takes considerable time<br>AND<br>Some of these people may have relevant health and social care professional skills.<br>THEREFORE<br>The volunteer workforce is attractive to employers 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. | 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.<br><br>If volunteers with existing, relevant skills are identified and they are prepared to use them in the H@H service.<br><br>AND<br><br>If volunteers have roles, remit, boundaries and expectations which are clear.<br><br>If volunteers are well supported by the organisation in their role.<br><br>OR<br><br>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. | 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<br><br>Volunteers feel confident and clear in their role, volunteer well-being is facilitated and volunteers are retained within the H@H to provide enhanced care for patients and families.<br><br>Then volunteers will be able to maintain appropriate boundaries that safeguard the patient, their family and the volunteer.<br><br>More volunteers may be able to get involved with caring and supporting people at home.<br><br>HOWEVER<br><br>Volunteers may find the structure and expectations too demanding and inflexible and chose to volunteer elsewhere.<br><br>Inconsistencies, paradoxes and tensions develop |

(CMOs v23 16.4.20)

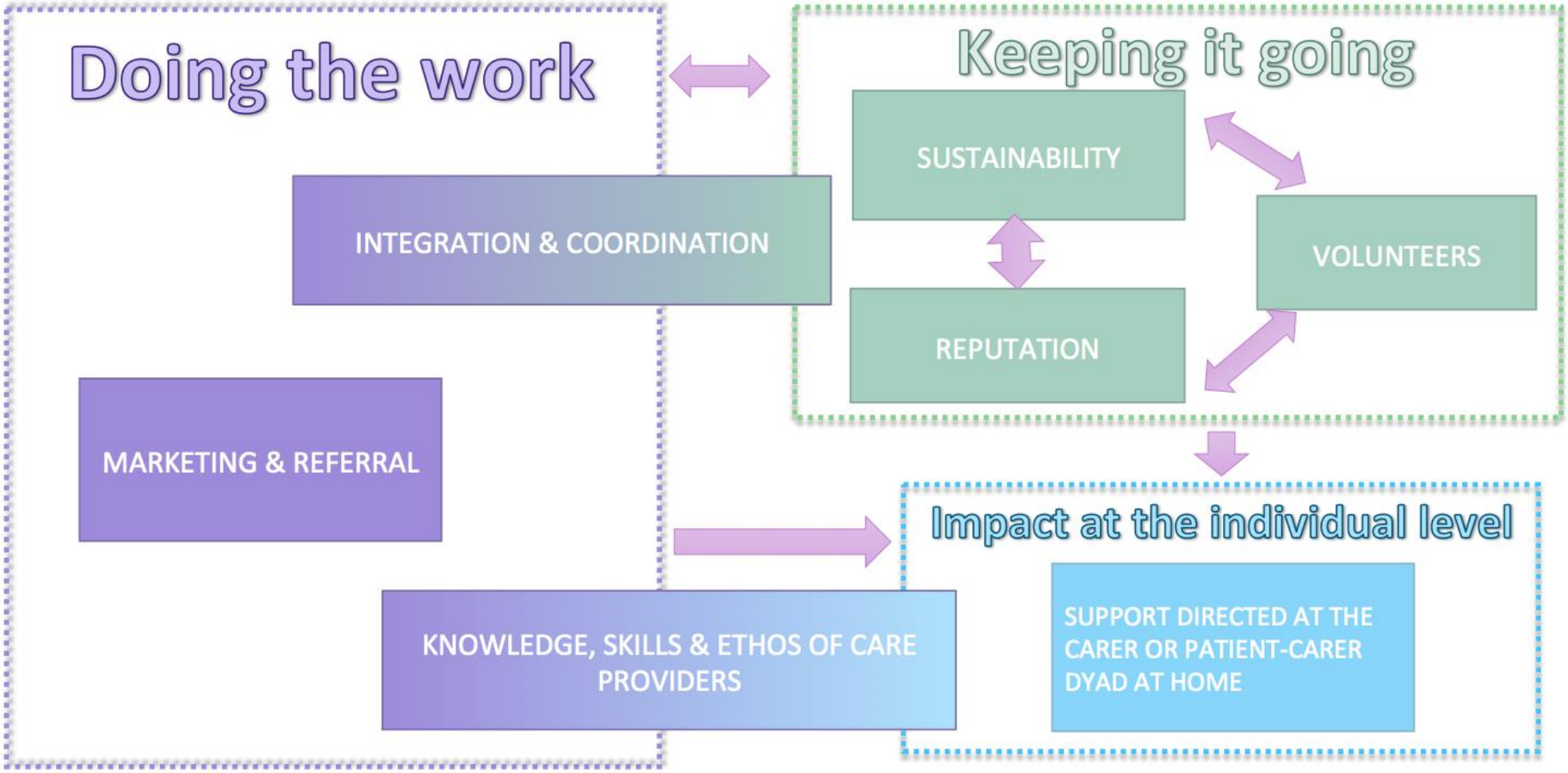
# BENEFITS OF CO-PRODUCING DATA ANALYSIS

- 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

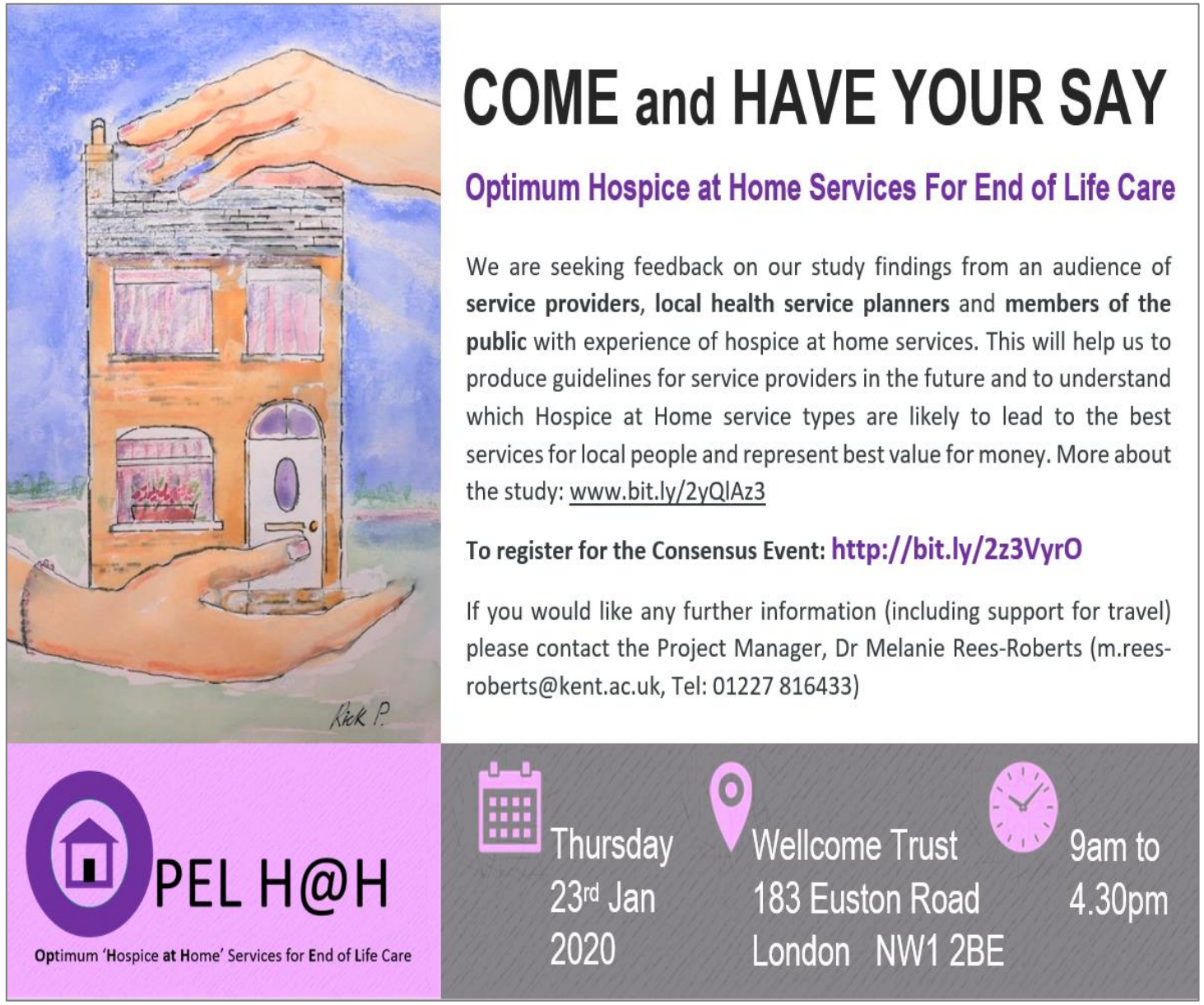
*"Initially I was happy to just read the various transcripts and outline the story being told. But as we had the ongoing opportunity to work with the research team on developing and refining the CMOs I became more familiar with them and confident in my ability to use these to do a more detailed analysis.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

# PHASE 2: CMO development and testing

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



# **PHASE 3**: Consensus events and dissemination



# '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!"

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# '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. | ☐ | |
| Budgets and workforce and organisational structure are managed in an integrated way across provider organisations. | ☐ | |
| A secondment into a different setting (e.g. a healthcare worker into social care) may facilitate integration by the "learning of another language". | ☐ | |
| 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. | ☐ | |
| 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) | ☐ | |
| Clinical records are shared with other organisations. | ☐ | |
| District nurses provide and administer all anticipatory medications (agreed division of labour). | ☐ | |

# 'SUSTAINABILITY' WORKSHOP

## Worked Examples - SUSTAINABILITY

**What is your role?**

☐ service provider ☐ commissioner ☐ member of the public

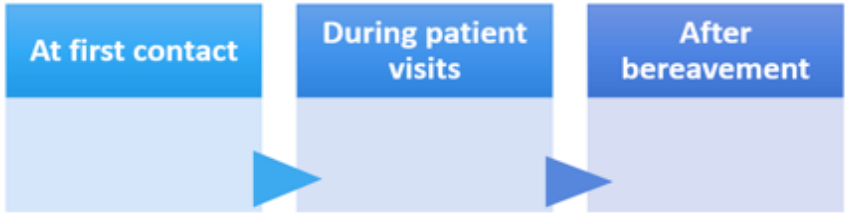
| MECHANISM | DOES IT MAKES SENSE? (tick if 'yes') | DO YOU DO THIS AT YOUR H@H? | COMMENTS |
|---|---|---|---|
| **The H@H service needs to "be on the front foot", i.e. if the H@H service proactively seeks control over the available statutory funding by one or more approaches:** | | | |
| Proposing a business plan and "selling it" to commissioners; | ☐ | ☐ | |
| Providers take the lead and provide services without a great deal of scrutiny, TRUST | ☐ | ☐ | |
| Board of trustees or executive leader develop a reputation for excellence, meaning they are trusted to use funding well | ☐ | ☐ | |
| Taking on a lead provider role and subcontracting with other providers in the area | ☐ | ☐ | |
| Provider partnerships may enable small organisations to maintain their responsiveness and alacrity. | ☐ | ☐ | |
| Accepting a block contract from commissioners to enable predictability to the funding available | ☐ | ☐ | |
| Securing continuing healthcare funding to provide or part-fund services | ☐ | ☐ | |
| 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. | ☐ | ☐ | |
| 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) | ☐ | ☐ | |

# 'CARERS' WORKSHOP


## Worked Examples – SUPPORT FOR CARERS

**What is your role?**

☐ service provider ☐ commissioner ☐ member of the public



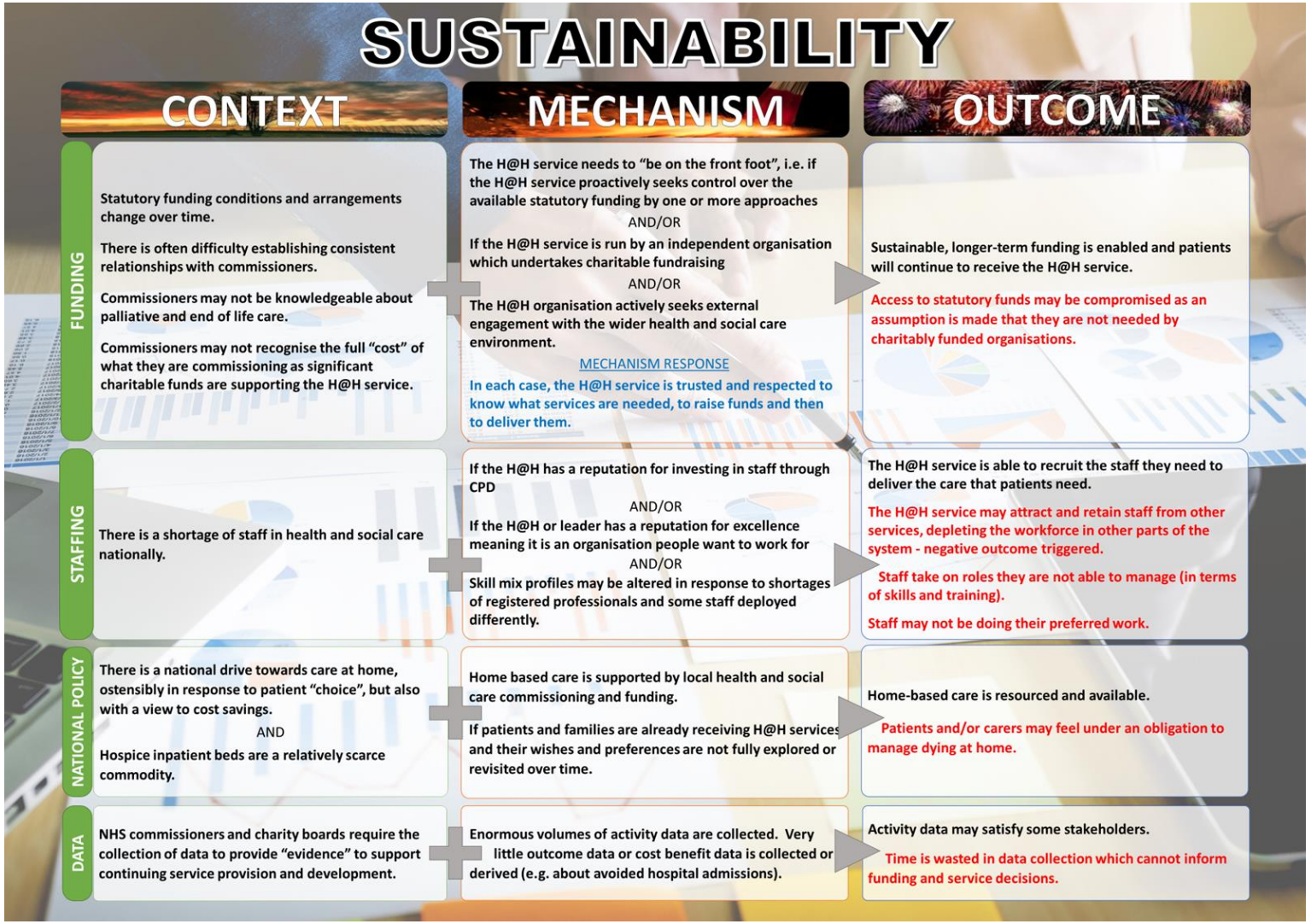

If you were caring for family member / friend at the end of their life, ***how could Hospice at Home support <u>you</u> as a carer***?

## At first contact

# 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*



# 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"*

# ASSESSING IMPACT: On-going dialogue

| Activity | Input | How has this made a difference? |
|---|---|---|
| Sept 2018: Graham & Mary started attending interview coding meetings | • Coding of carer interviews discussed with researchers at coding meetings; facilitated consideration of different perspectives | Insights from Graham re importance of single point of access helped develop CMO9. He also felt that listening to the audio recording provided additional insights |
| Dec 2018: Graham & Mary attended project management meetings | • Enabled co-apps to keep up to date with project progress & contribute to discussions<br>• Opportunity to review their involvement in coding transcripts | It was highlighted that fully coding each transcript was very time consuming. New approach: summarise the narrative of each transcript, providing an overview, & consider alongside CMO configurations. |

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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