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On behalf of the delivery team and co-authors

Butler C, Wilson P, Abrahamson V, Mikelyte R, Gage H, Williams P, et al. Optimum models of hospice at home services for end-of-life care in England: a realist-informed mixed-methods evaluation. *Health Soc Care Deliv Res* 2022;10(24). <https://doi.org/10.3310/MSAY4464>

Optimum 'Hospice at Home' Services for End of Life Care (OPEL): Findings from a mixed methods realist evaluation of family carers' experiences and implications for service delivery and development.

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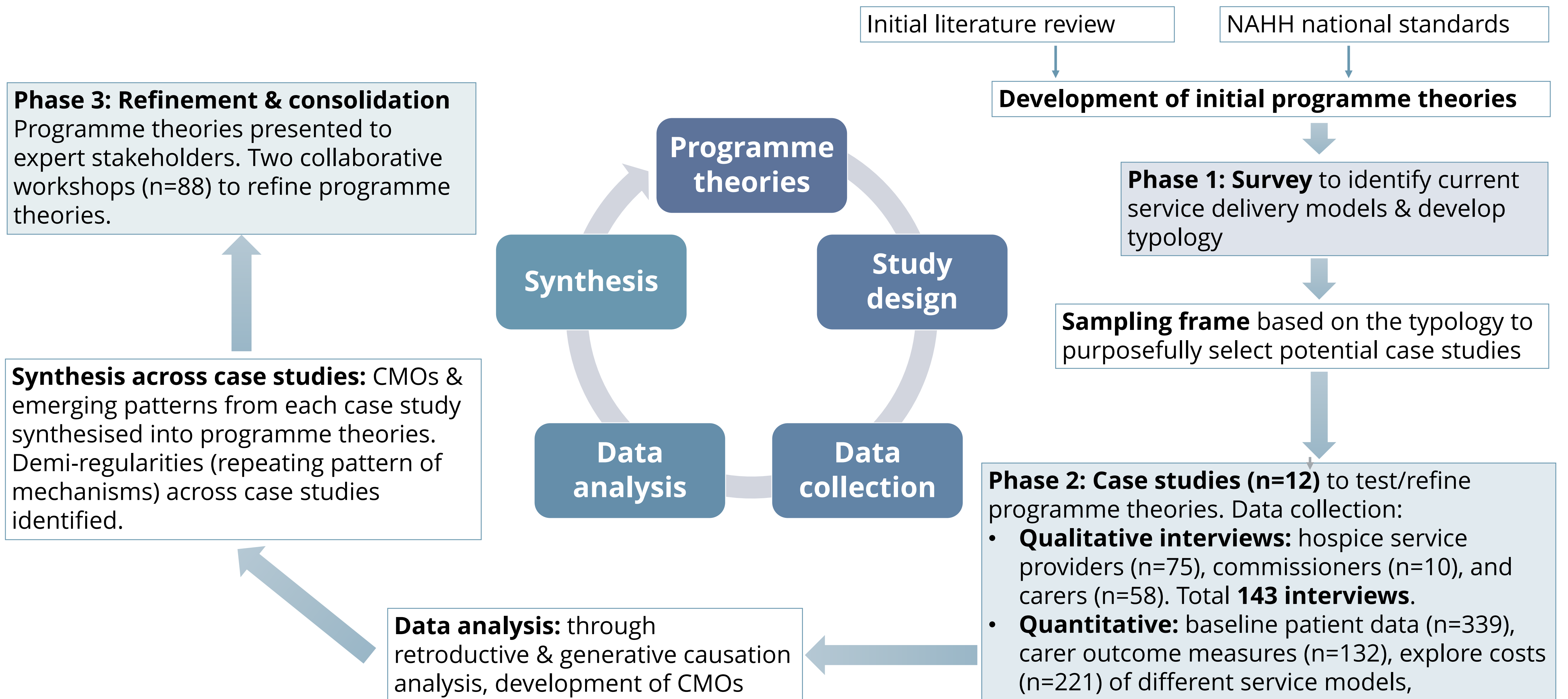


Equity & Diversity

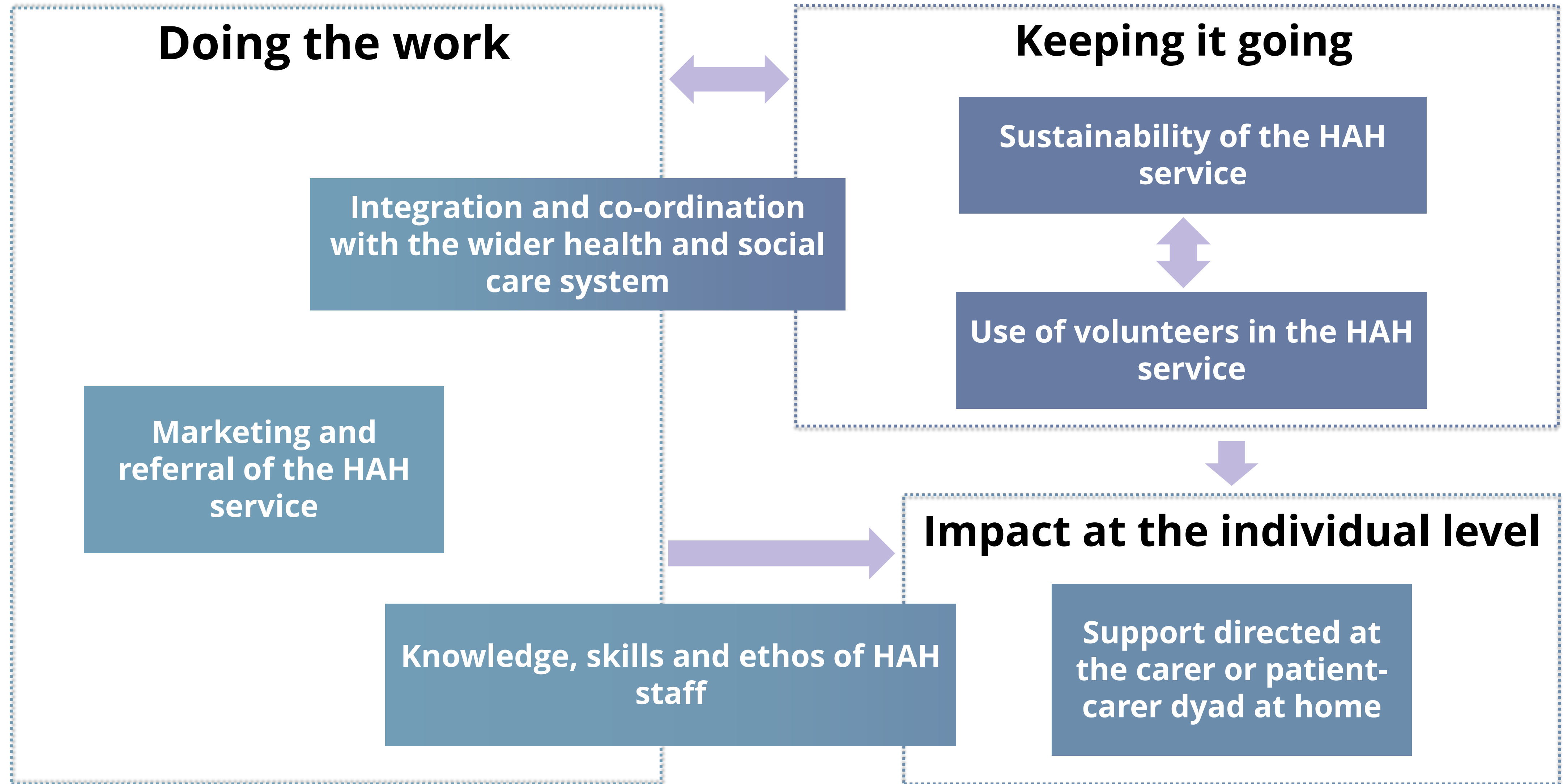
Background

- **Hospice at home** (HAH) services aim to support individuals to receive care and die at home.
- **Service models** in England vary widely, with little evidence of what works best, for whom and in what circumstances.
- We aimed to find out **what is the best service configuration** that would allow more individuals to die where they prefer and have a good quality of death.
- This presentation addresses the following sub-components:
 - What were **family carers' experiences** of HAH care;
 - What did good support look like; and
 - What were the barriers/enablers to this.

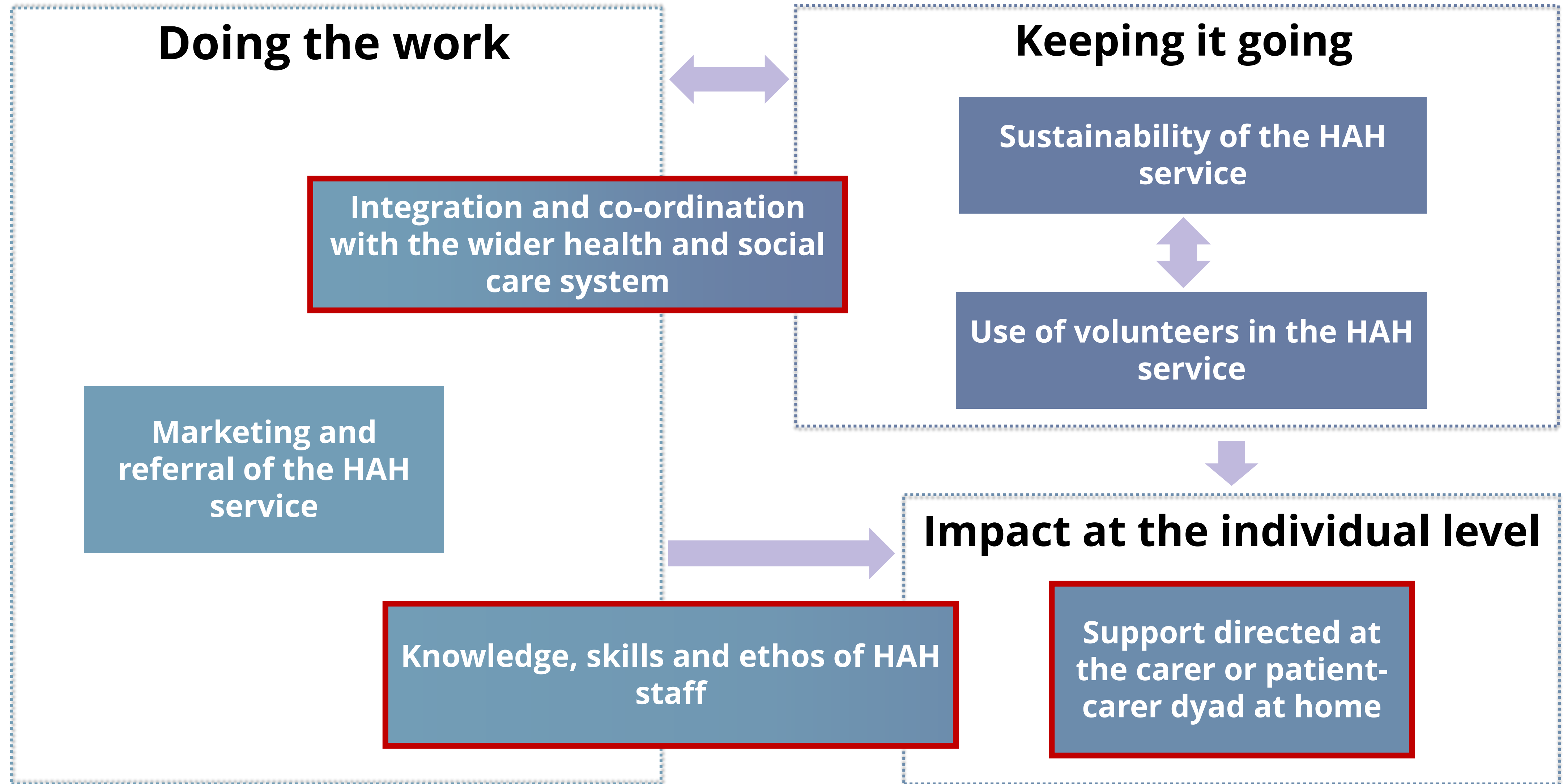
Method: Application of a realist logic of analysis



Findings: Six programme theories



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Knowledge, skills and ethos

Family carers consistently commented on the quality of care

[Hospice] carers were absolutely gold standard excellent, and from agencies it was hugely variable.

PC12 (Spousal Carer)

Hospice-at-home staff were highly skilled and differentiated from others by their ethos

Everyone we met from the hospice throughout those three and a half months... all had that wonderful, wonderful ethos.

DC21 (Filial Carer)

Hospice-at-home staff had time to care, were flexible and client-centred:

They can see that there's no rush. They can see that we want to give quality care... time is so massive. It's priceless isn't it, time.

MSP01 (Hospice-at-Home Sister)

Integration and co-ordination

Organisational level strategies across services to enhance integration and co-ordination

We have a quarterly End of Life Community Nurse Meeting which we all go to, so the CNSs, the Hospice-at-Home Team, the Community Nursing Services...

MSP05 (Community Team Leader for End-of-life Care)

Frontline strategies to build trust and ensure integrated care

Finding the best person to do the job at the time.

XSP04 (Community Matron)

When I first started, I felt like the district nurses were a bit like 'oh, can we trust what this person says?'... once we all got to know each other... they'd gained confidence with us.

WSP005 (Health Care Assistant)

Out-of-hours support/ knowing who to contact & when

The nurse said to me "now you do realise we have a 24 hour helpline at the hospice, if you have any queries... pick up the phone and someone is here"... I burst into tears because it was the first time I felt we were being truly supported to care for mum.

DC21 (filial carer)

Support directed at the carer

Setting expectations of what can or cannot be provided

•I didn't realise that it [HAH] only lasted for so long, something like two weeks.

CC013 (Spousal Carer)

•You don't understand certainly at the beginning what the scale of the task is going to be as a carer...

XC01 (Spousal Carer)

Molding (hands-on) care around the dyad

•I think distinctive was it made me feel like it was personal to us and I felt comfortable, almost like a family...

GC018 (Spousal Carer)

•The [HAH] nurse was... preparing us and saying... his breathings changed again... it was... nice and reassuring.

DC011 (Filial Carer)

Bereavement: a double grief

Very suddenly you are on your own... I was with [husband] from the age of sixteen till now and this is the first time I've ever been on my own.

LC029 (Spousal Carer)

Implications for Hospice at Home services

- Key markers of a good service included staff who:
 - Were experienced in death and dying with time to care and provide hands-on care;
 - Worked closely with other services to respond rapidly and provide the necessary intensity of care;
 - Had the necessary expertise and knowledge, promoted supportive relationships through the process of dying and attended to carers' needs.
- Larger services were able provide earlier interventions and a wider breadth of services.
- Areas of potential improvement included bereavement care.