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Palliative care research funding and the workforce to support it

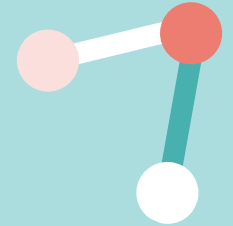
RDS SE, Pilgrims Hospice
and CRN KSS

Research Design Service South East

www.rds-se.nihr.ac.uk



Overview

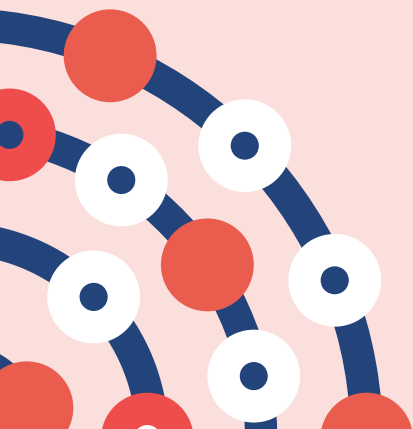


- **NIHR**
- **Research Design Service**
- **Funding**
- **Palliative care research in KSS**
- **Examples of funded studies**
- **Workforce implications**



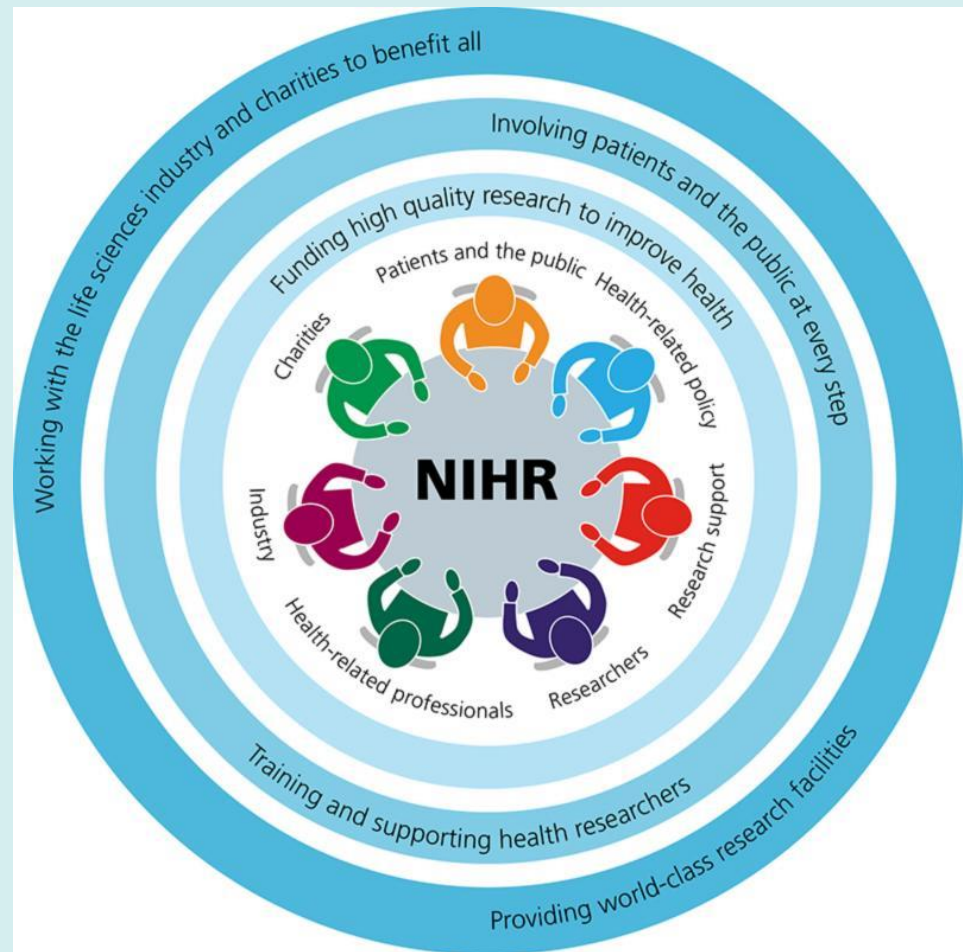


About the RDS SE – how can we help you?



NIHR Mission

“improving the health and wealth of the nation through research”



About us:

NIHR Research Design Service South East

- ❑ **Funded by Department of Health and Social Care** to improve quantity and quality of applications to competitive funding streams in health and social care (not just NIHR)
- ❑ **FREE confidential support** for health and social care researchers across England on all aspects and methods of research design and grant application development
- ❑ **Expert RDS advisers** can help with all aspects of designing a proposal including:

- research design and methods
- funding sources
- refining research question
- outcome measures
- involving patients and the public
- building the right team for your project
- avoiding common pitfalls



About RDS SE

- Part of a national NIHR network of ten Research Design Services funded by the Department of Health and Social Care
- RDS SE operates from three Universities to support applicants across Kent, Surrey and Sussex
- RDS support is tailored to you and your research team's needs. We can work with you face-to-face, by telephone, email or video conferencing – whichever is best for you



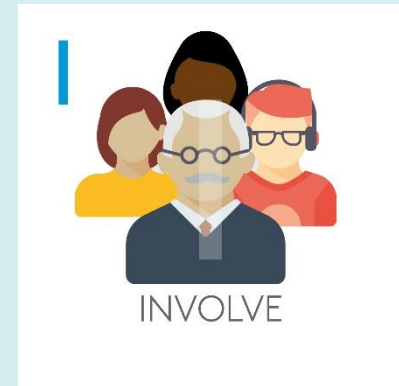
Specialist help

RDS SE Patient & Public Involvement Funds help researchers with the cost of involving patients and the public at all stages of researcher

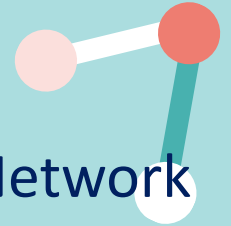
- One payment per study (up to max. £300)
- Apply throughout the year.
- Speak to your RDS adviser before applying.
- More details: <https://www.rds-se.nihr.ac.uk/patient-and-public-involvement/>

RDS SE Pre-Submission Review Panel

- mimics NIHR funding panel – helps increase chance of funding success
- Reviews application before submission to funder – get feedback from expert panel of methodologists/public reviewers and advice on areas to address



NIHR | Clinical Research Network
Kent, Surrey and Sussex

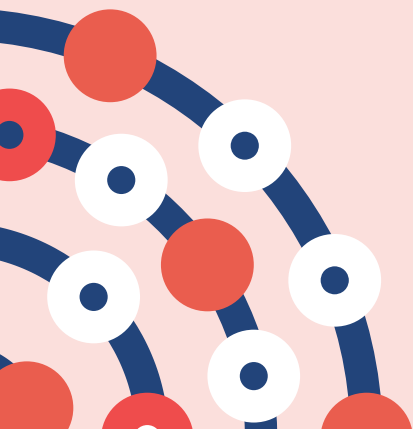


- We work closely with the NIHR Clinical Research Network (CRN) Kent, Surrey, Sussex
- CRN is the clinical research delivery arm of the NHS
- CRN KSS works with hospital Trusts (acute, community and mental health) GP surgeries, pharmacies, and other healthcare providers across Kent, Surrey and Sussex to support the set-up and timely delivery of commercial and non-commercial studies in the NHS in the region
- Provides advice on study feasibility, NHS permissions, cost attribution and effective patient recruitment





NIHR Research Programmes

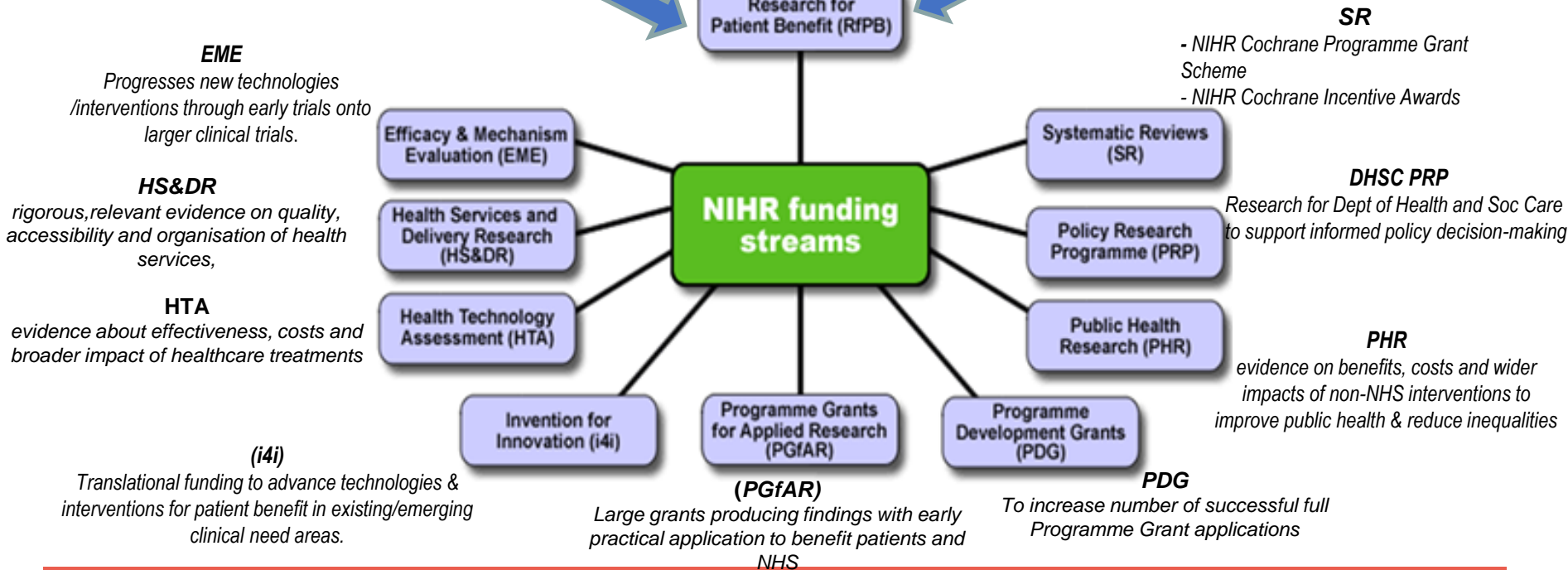


NIHR Funding



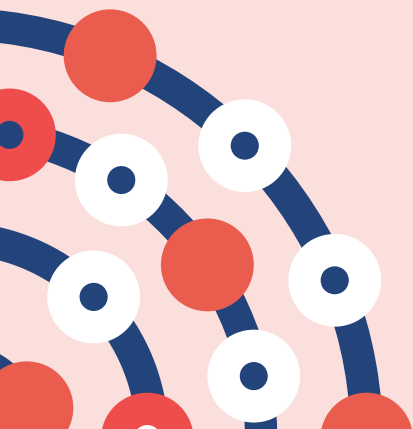
RfPB funds research to improve, expand and strengthen how health and social care is delivered for patients, public and NHS.

RfPB Supports high quality, investigator-led research relevant to the NHS in England (up to £350,000)





Palliative care research



Research Ready & Active Hospice Guide Model

Russell S & Hodgson M 2017, Hospice UK:

Research ready: to be 'ready' for research activity

Research activity: to be research active, engaged, generating or leading



Focus on Palliative Care Research

- The NIHR is a key partner in Consortium for Hospice & community research which was set up in 2017 to support the building of research capacity, competence and activity.

- Since January 2018 the NIHR CRN officially extended their support to health and social care research in non-NHS settings such as hospices

Hospice & Palliative care is a current campaign for the NIHR



Palliative Care Research in KSS



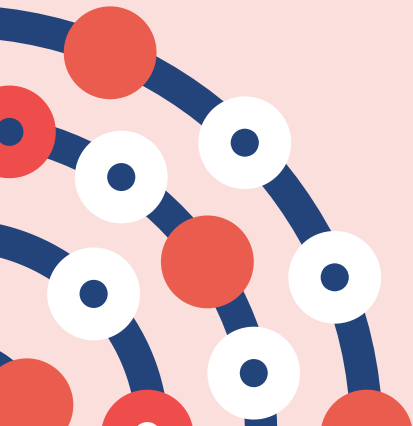
- Kent, Surrey and Sussex has a long history of palliative care research
- Palliative Care research is a particular strength in KSS, & Subspecialty Lead is Mel Waghorn. The portfolio includes both local studies and studies with Chief Investigators outside of KSS, with whom there are established collaborations
- There are two palliative care research groups in the region:
Kent Palliative Care Research Group
 - <https://www.kent.ac.uk/chss/research/groups/palliativecare.html>

Surrey & Sussex collaborative Palliative Care Research group





Example of a funded study



Study Example: Background:

2007-08 Development of Pilgrims hospices
'hospice at home ' (H@H) service – dying at home

2009-12 Evaluation of hospice at home service – Pilgrims Hospice trial
funded by NIHR RFPB

2014 /15 Outstanding questions:

- Have we got the best, most cost effective service to enable patients to die at home in our area?
- National priority for further research (e.g. James Lind Alliance 2015)

New Research developed:

- New hospice at home study initiated at Pilgrims Hospices and led by CHSS at University of Kent + no. of other collaborating partners.

2016 OPEL H@H study funded by NIHR HS&DR programme.
CI is Prof Claire Butler

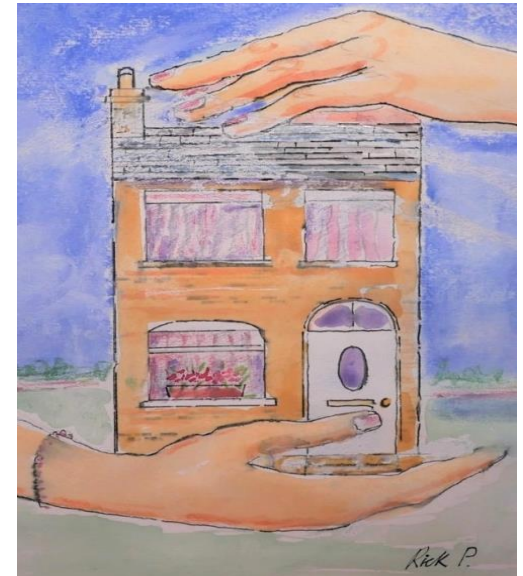


Optimum 'Hospice at Home' Services for End of Life Care

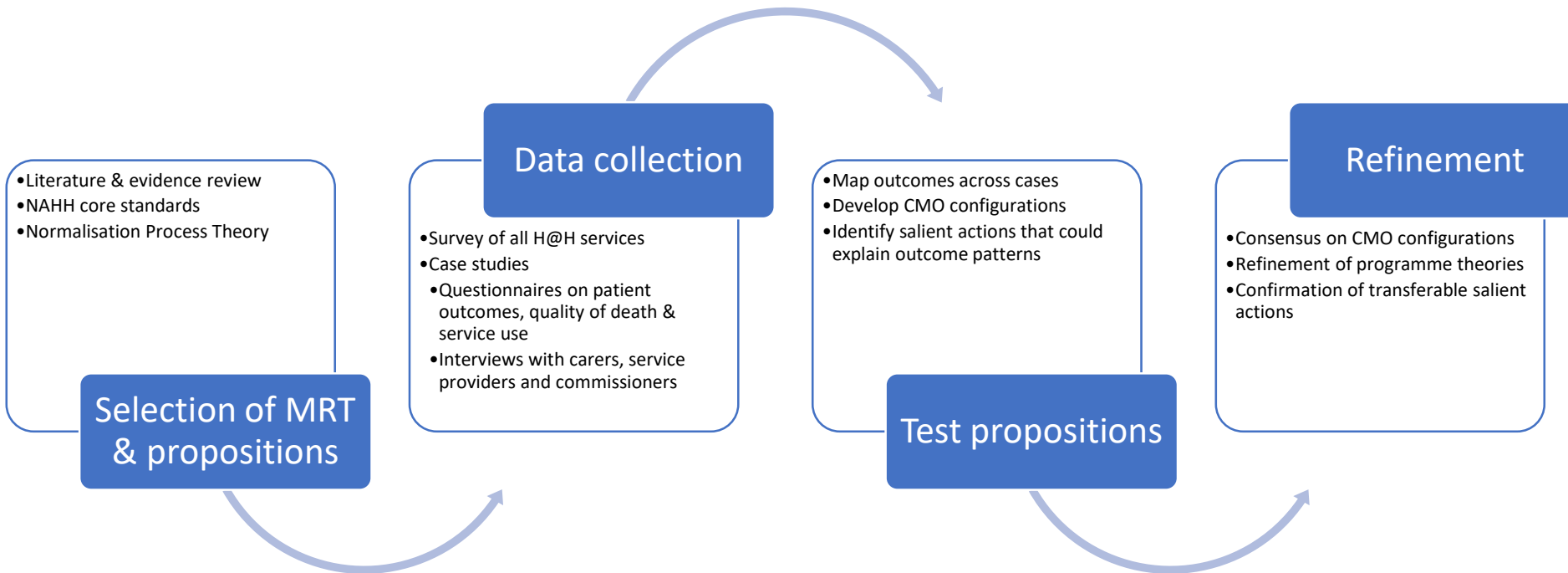


Research Question: What are the features of Hospice at Home models that work, for whom and under what circumstances?

- Phase 1 national survey of H@H services
- Phase 2 In-depth data collection to investigate the impact of different models of H@H on patient and carer outcomes and experiences of end of life care.
- Phase 3 consensus events with stakeholders at the end of data collection to 'sense check' the interpretation of our results



Realist Evaluation Design



CMO= (Context + Mechanism = Outcome)



Phase 1 survey results



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

From the survey data we collected:

- No 2 hospice services were the same as each other - 70 different services



Mixed populations in diverse areas – deprivation, rural/urban



Wide range of staff roles involved, including volunteers

Rapid response
Wide range of care
24/7 care



Funding – only 25% received NHS funding, only 3/70 fully funded by NHS

Wide referral criteria – only 15% of services took patients within last days/weeks of life



H@H services rely heavily on other NHS services e.g. 20% of H@H did not have 24/7 district nursing cover

Local equipment availability

Phase 2 Case Studies

24 hour
services

Sites n = 4

Referrals : > 365 a year

Deprivation = affluent, mixed and deprived

Setting = urban and mixed

Location = south east, London, North east,
east of England

Staff mix = all of HCA>RN, HCA=RN, HCA<RN

Services = D/N 24hr and not

Recruitment: 103 patient/carer pairs

Sites n = 4

Referrals : < 365 a year

Deprivation = 3 x mixed, 1 deprived

Location = South West, London, Midlands

Setting = rural and urban

Staff mix = 3 x HCA>RN, HCA< RN

Services = D/N 24hr and not

Recruitment: 81 patient/carer pairs

Large Provider

Small Provider

Sites n = 1

Referrals: > 365 a year

Deprivation = deprived

Location = north west

Setting = urban

Staff mix = HCA>RN

Services = D/N 24hr

Recruitment: 81 patient/carer pairs

Sites n = 3

Referrals : < 365 a year

Deprivation = deprived and affluent

Location = south coast, south east and
Midlands

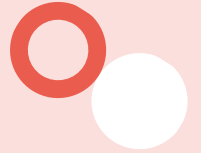
Setting = Rural and urban

Staff mix = HCA=RN, HCA<RN

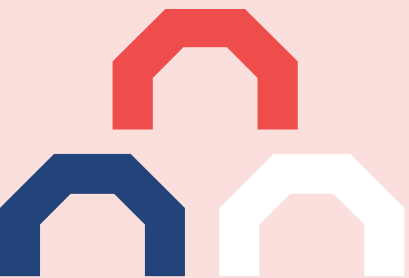
Services = both D/N 24hr and not

Recruitment: 76 patient/carer pairs

Less than 24 h
our services



Workforce Implications



How equipped is the KSS workforce?

- 16 Hospices across KSS, and the number of those taking part in research continues to increase
- Challenge is to ensure sufficient frontline delivery staff to support palliative care studies in the Hospices across KSS
- CRN KSS are finding ways to support this and other important areas of research, including the changing structure to a possible agile workforce



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- CRN KSS are finding ways to support this and other important areas of research, including the changing structure to a possible agile workforce
 - A Palliative Care Strategy was developed in 2018 to support KSS hospices to become research active. New strategy direction is to support research active hospices to become research generating.



Workforce developments in KSS



- Introduction of the NIHR CRN KSS wide Palliative care hub/Research Facilitator to support hospices with research capacity and capability.
 - Some hospices have staff with dedicated posts/time to research e.g.:
 - Research Lead
 - Research Nurse
 - Research Facilitator
 - Research Practitioner
-but not all. Even for those that do, embedding a research culture within a hospice/palliative care workforce is challenging



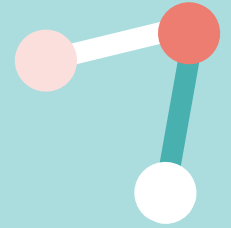


Group exercise



- How can we increase research engagement in the palliative workforce?
- What are the barriers and enablers to achieving this?



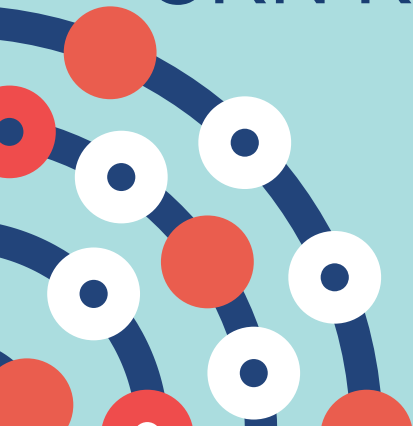


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NIHR

National Institute
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