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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?
“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 research:

- 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/](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
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)

**EME**
Progresses new technologies /interventions through early trials onto larger clinical trials.

**HS&DR**
Rigorous, relevant evidence on quality, accessibility and organisation of health services.

**HTA**
evidence about effectiveness, costs and broader impact of healthcare treatments

**(i4i)**
Translational funding to advance technologies & interventions for patient benefit in existing/emerging clinical need areas.

**PGfAR**
Large grants producing findings with early practical application to benefit patients and NHS

**PDG**
To increase number of successful full Programme Grant applications

**NIHR funding streams**

**Research for Patient Benefit (RfPB)**

**Efficacy & Mechanism Evaluation (EME)**

**Health Services and Delivery Research (HS&DR)**

**Health Technology Assessment (HTA)**

**Invention for Innovation (i4i)**

**Programme Grants for Applied Research (PGfAR)**

**Systematic Reviews (SR)**

**Policy Research Programme (PRP)**

**Public Health Research (PHR)**

**Programme Development Grants (PDG)**

**SR**
- NIHR Cochrane Programme Grant Scheme
- NIHR Cochrane Incentive Awards

**DHSC PRP**
Research for Dept of Health and Soc Care to support informed policy decision-making

**PHR**
evidence on benefits, costs and wider impacts of non-NHS interventions to improve public health & reduce inequalities

**NIHR**
National Institute for Health Research

**NIHR Cochrane Programme Grant Scheme**

**NIHR Cochrane Incentive Awards**

**To increase number of successful full Programme Grant applications**
Palliative care research
Research Ready & Active Hospice Guide Model
Russell S & Hodgson M 2017, Hospice UK:

Research ready: to be ‘ready’ for research activity
- Staff and hospice is a critical consumer of research
- Visible evidenced based care

Research activity: to be research active, engaged, generating or leading
- Staff and hospice engage or contribute to research done by others
- Supports development of research evidence

Research Active (all hospices)
- Staff and hospice lead the generation and development of research
- Leads research evidence and policy

Research Engaged (many hospices)
- Staff and hospice actively undertake and generate research
- Generates research evidence

Research Generating (some hospices)
- Staff and hospice lead the generation and development of research
- Leads research evidence and policy

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

New Research developed:
   o  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
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

Selection of MRT & propositions
- Literature & evidence review
- NAHH core standards
- Normalisation Process Theory

Data collection
- Survey of all H@H services
- Case studies
- Questionnaires on patient outcomes, quality of death & service use
- Interviews with carers, service providers and commissioners

Test propositions
- Map outcomes across cases
- Develop CMO configurations
- Identify salient actions that could explain outcome patterns

Refinement
- Consensus on CMO configurations
- Refinement of programme theories
- Confirmation of transferable salient actions

CMO = (Context + Mechanism = Outcome)
Phase 1 survey results

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
- 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
- Wide referral criteria – only 15% of services took patients within last days/weeks of life
Phase 2 Case Studies

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

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
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.
How equipped is the KSS workforce?

- 17 adult 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.
  - 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.:
  o Research Lead
  o Research Nurse
  o Research Facilitator
  o 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?

Payne S et al 2013, Research Framework for Hospices
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