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Discharge from palliative care study

Submission date
14/11/2023

Recruitment status
No longer recruiting

Registration date
29/12/2023

Overall study status
Completed

Last Edited
15/09/2025

Condition category
Other

[X] Prospectively registered
[X] Protocol
[_] Statistical analysis plan
[X] Results
[_] Individual participant data

Plain English summary of protocol

Background and study aims
In the next 20 years, more people are expected to die in community settings, such as their homes. Specialist palliative care is a service often provided by hospices and hospitals that provides support for people with illnesses that cannot be cured and those at the end of their life who are dying, and their close persons. Some people think discharge from specialist palliative care cannot happen - but it does. Around a third of patients are discharged and move to a community setting, as their needs and preferences change. The aim of this study is to understand patients', carers', and general practice professionals' experiences of discharge communications from specialist palliative care. The study will listen to the experiences of these groups to identify how to improve discharge communication in ways that better support patients' and carers' needs.

When someone is discharged, there should be 'discharge communication' with the patient's General Practitioner. 'Discharge communication' can be spoken and/or written. It is well known that good discharge communication is important for patient care and safety. However, it has previously been found that discharge letters from specialist palliative care vary in quality and content. Patients were not always involved in these communications and offered their letters, as they should be. Currently, little is known about how these discharge communications affect patients' and carers' experiences or what their communication needs are at this critical moment in their lives.

Who can participate?
Adult (18+ years old) patients or carers of patients who are discharged to primary care from a participating specialist palliative care facility and primary care healthcare professionals

What does the study involve?
This is a 15-month study starting in January 2024. The study team will speak to a wide range of people who have been recently discharged from hospital or hospice and their carers, as well as staff in General Practice teams to gather their experiences and identify how discharge communications from specialist palliative care can be improved. This will include 30 carers and /or patients with different conditions recruited through hospices and hospitals, in inner city, semi-rural and rural areas. There will also be interviews with 15 healthcare staff. The content of

these interviews will be analysed to understand people's discharge experiences and communication needs. This will help to identify what information is important, and how discharge communication can be made better and easier to understand.

Patient and public involvement:
The need for this project was identified through patient and public involvement in our previous study exploring the content of hospice discharge letters.
The research proposal was developed with three people who have lived experience of palliative care as a patient or carer. They advised on the content and this summary.

Dissemination:
A summary of best principles for discharge communication from specialist palliative care will be co-produced and shared with key specialist palliative care organisations and networks. The findings will be published in academic journals and presented at conferences.

What are the possible benefits and risks of participating?
Participation will not be related to any changes to the medical intervention and care for participants or those they are caring for.

While participants may not experience personal benefits from participating in this research, their views will help us to understand ways of improving discharge communication and processes. Indirect benefits participants may experience include feeling valued as part of a team through being involved in research, and supported, and empowered through speaking to someone and being heard. An anonymised acknowledgement of the contribution of study participants will be provided in all study outputs such as publications as a collective anonymised statement.

Participation in a research study at the end of life – when physical capacity, interpersonal connections and social worth can be experienced as declining – have been experienced as empowering and helped to reaffirm a sense of personhood, self-worth, and dignity. This can occur when participants feel that by taking part in research study they still have something of value to give that could benefit others and society. It can also occur during semi-structured research interviews, which prioritise active listening and are a recording of a person's life and experiences, allow participants to feel seen, heard and valued as a person.

Taking part in this research should not cause participants any direct harm. The topic of this study is palliative and end-of-life care – this means interview discussions may naturally include talking about death and dying. Talking about end-of-life care and dying may make participants feel sad or leave them with questions that the research team cannot answer.

Where is the study run from?
University of Birmingham (UK) and University of Warwick (UK)

When is the study starting and how long is it expected to run for?
October 2023 to March 2025

Who is funding the study?
National Institute for Health and Care Research (NIHR) (UK)

Who is the main contact?
Dr Katharine Weetman, k.e.weetman@bham.ac.uk

Contact information

Type(s)
Public, Scientific, Principal investigator

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Integrated Research Application System (IRAS)
322302

Central Portfolio Management System (CPMS)
54454

Protocol serial number

RG_23-097

Study information

Scientific Title
Improving patients', carers' and primary care healthcare professionals' experiences of discharge communication from specialist palliative care to community settings: a qualitative interview study

Study objectives
Observational study only. The study aim is to understand how discharge communications from specialist palliative care services to primary care are experienced by patients, carers, and healthcare professionals, and how these communications might be improved to support effective patient-centred care.

Ethics approval required
Ethics approval required

Ethics approval(s)
Approved 04/12/2023, Coventry and Warwickshire NHS REC (HRA) (2 Redman Place, Stratford, E20 1JQ, United Kingdom; +44 (0)2071048211; coventryandwarwick.rec@hra.nhs.uk), ref: 23/WM/0250

Primary study design
Observational

Study design
15-month observational study design (multi-centre) involving qualitative semi-structured interviews

Study type(s)
Other, Quality of life, Safety

Health condition(s) or problem(s) studied
Palliative care

Interventions
This is a 15-month observational study, (multi-centre) involving qualitative semi-structured interviews. This is a single interview study only with no intervention or follow-up.

This is a qualitative study exploring the lived experiences of those receiving specialist palliative care discharge communications. Qualitative methods are well suited for generating rich data drawing on participants' accounts and allow for the exploration of experiences in relation to contextual settings.

The research team will interview 30 adult patients and/or carers and 15 healthcare professionals (n = 45) and will seek a range of experiences of discharge communication by using a maximum variation approach to sampling, including purposively recruiting people from a range of

demographic backgrounds from 4-6 specialist palliative care services (hospitals and hospices) as well as 5-7 General Practices. Interview data will be analysed using a reflexive thematic approach and will involve input from the research team.

Intervention Type
Other

Primary outcome(s)
Patient, carer, and healthcare professional experiences are measured using qualitative semi-structured interviews conducted over the duration of approximately 1 hour

Key secondary outcome(s)
There are no secondary outcome measures

Completion date
31/03/2025

Eligibility

Key inclusion criteria
Inclusion criteria for patients and carers:
1. Adult (18+ years old) patients or carers for patients discharged to primary care from a participating specialist palliative care facility at a hospital or hospice following an episode of care
2. Discharge event no longer than two weeks ago at the time of participant screening and selection for the study

Inclusion criteria for primary care healthcare professional interviews:
Working in a participating General Practice team (including associated community nursing) and receiving and/or acting upon discharge communications. This may include, but not be limited to, General Practitioners, Nurse Practitioners, and District Nurses.

Participant type(s)
Patient, Health professional, Carer

Healthy volunteers allowed
No

Age group
Mixed

Lower age limit
18 Years

Upper age limit
99 Years

Sex
All

Total final enrolment

Key exclusion criteria
Exclusion criteria (all):
1. Children (those aged <18 years old)
2. Patients who are deemed by their care team or treating clinician as lacking the capacity to provide informed consent to participate in the study (e.g. Alzheimer's) or are otherwise deemed unsuitable for study participation
3. Patients discharged to providers or units other than primary care (e.g. discharge to secondary care)
4. Persons who have expressed a prior wish not to participate in research
5. Bereaved carers (<6 months ago)
6. Healthcare professional who has worked for less than one month in Primary Care

Date of first enrolment
01/02/2024

Date of final enrolment
30/03/2025

Locations

Countries of recruitment
United Kingdom

England

Study participating centre
GP practices, hospices & hospitals in West Midlands
Birmingham Research Park, Vincent Drive
Birmingham
United Kingdom
2SQ

Sponsor information

Organisation
University of Birmingham

ROR
https://ror.org/03angcq70

Funder(s)

Funder type
Government

Funder Name
National Institute for Health and Care Research

Alternative Name(s)
National Institute for Health Research, NIHR Research, NIHRresearch, NIHR - National Institute for Health Research, NIHR (The National Institute for Health and Care Research), NIHR

Funding Body Type
Government organisation

Funding Body Subtype
National government

Location
United Kingdom

Results and Publications

Individual participant data (IPD) sharing plan
The datasets generated during and/or analysed during the current study will be available upon request from Katharine Weetman, k.e.weetman@bham.ac.uk, in accordance with the below. The full datasets will not be made available due to the potentially identifiable nature of the in-depth qualitative data.

Access to patient-identifiable data will be restricted to members of the study co-ordination team who require it for the performance of their role, inclusive of the research team. However, the data and results may be used for secondary analysis for future research and/or research involving modified or different research questions; this may be undertaken by the research team and other researchers. In the latter case, data will only be shared in secure and pseudonymised form with other researchers.

IPD sharing plan summary
Available on request

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Results article		26/07/2025	28/07/2025	Yes	No
Protocol article		20/06/2024	21/06/2024	Yes	No
Plain English results	version 2		15/09/2025	No	Yes
Study website			20/02/2024	No	No
Study website			20/02/2024	No	No
Study website	Study website	11/11/2025	11/11/2025	No	Yes