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Improving collaborative interagency practice in self-neglect

Submission date	Recruitment status	☒ Prospectively registered
18/11/2022	No longer recruiting	☒ Protocol
Registration date	Overall study status	☐ Statistical analysis plan
07/02/2023	Completed	☒ Results
Last Edited	Condition category	☐ Individual participant data
06/01/2026	Other	

Plain English summary of protocol

Background and study aims
Self-neglect covers a range of behaviours and situations where someone is put at risk by not caring for their health, safety or surroundings. Self-neglect can have serious consequences, from deteriorating health and wellbeing, or even death for some, or unwanted intrusion and surveillance for others. Support to address self-neglect often requires collaboration between many practitioners, from Adult Social Care, Health, Fire & Rescue, Environmental Protection and other organisations. Yet reviews highlight repeated failings in working together. These arise where care and support have not been coordinated, where different organisations have not had a joint understanding of the situation, or where existing systems have not enabled joint working. At the same time, there is much to learn from effective collaborative practice which may go unremarked.
What little research exists on joint working in self-neglect has overwhelmingly focused on social work perspectives. This study aims to engage with a broader range of practitioners to identify what problems arise in inter-agency and interprofessional practice with self-neglect, and how to address them, in order to improve care and support for people experiencing self-neglect.

Who can participate?
1. Practitioners and managers in health, social care, fire & rescue, environmental health, housing, and related fields, who have experience through their roles of supporting people with self-neglect
2. Individuals aged over 18 years, with whom practitioners in the above organisations have worked together due to concerns about self-neglect; carers or family members of these participants

What does the study involve?
The research team will search existing research, multi-agency procedures and published case inquiries for evidence on factors influencing collaborative working. The team will then conduct interviews with 75-100 practitioners and managers from relevant agencies and with 15-20 people who have experienced self-neglect. The interviews will focus on how organisations collaborated to intervene with self-neglect, and what factors helped or hindered.
The research team will then hold three focus groups with up to practitioners to help the research team turn the findings into usable solutions and resources for services. The team will

assess the initial impact of these recommendations using an online practitioner survey and follow-up interviews.

What are the possible benefits and risks of participating?
There will be no immediate benefit to participants. Participants may contribute to the improvement of service support for people experiencing self-neglect, which is potentially of benefit to practitioners working in them and to others who experience self-neglect in the future. The main risk of participating is that some experiences discussed in the interview may be distressing.

Where is the study run from?
The study is run by the University of Sussex and takes place in health, social care and related organisations at five sites across England (UK)

When is the study starting and how long is it expected to run for?
March 2022 to December 2024

Who is funding the study?
The National Institute for Health and Social Care Research (NIHR) Health Services and Delivery Programme (UK)

Who is the main contact?
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Contact information

Type(s)
Scientific

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Integrated Research Application System (IRAS)
310858

Central Portfolio Management System (CPMS)

Study information

Scientific Title
Improving collaborative inter-agency systems and practice in self-neglect: identifying barriers and co-producing solutions

Study objectives
Not applicable. The study is primarily qualitative in nature and does not take a deductive approach.

This NIHR-funded study aims to identify what problems arise in interagency and interprofessional practice with self-neglect, and how they can be addressed.

Ethics approval required
Old ethics approval format

Ethics approval(s)
Approved 15/11/2022, London – Camberwell St Giles Research Ethics Committee (Ground Floor, Temple Quay House, 2 The Square, Bristol, BS1 6PN, UK; +44 (0)207 104 8138, 0207 104 8156; camberwellstgiles.rec@hra.nhs.uk), ref: 22/LO/0595

Study design
Observational; Design type: Qualitative

Primary study design
Observational

Study type(s)
Other

Health condition(s) or problem(s) studied
Health services research

Interventions
The study consists of five Work Packages. Two of these run in parallel, so the overall project consists of four phases. The methods have been selected in recognition of the complex nature of self-neglect; three principal issues contribute to this complexity:

1. Self-neglect is in many ways an umbrella term. It is useful and used in statutory guidance because it describes behaviours and situations that all challenge the person, those around them, and services in similar ways. However, the causes, course, perceptions, thresholds and effects of self-neglect may vary significantly.
2. Because of this diversity, suitable care pathways and support may look quite different for different people experiencing self-neglect, and the organisations involved can vary accordingly. Further variation is introduced by the fact that the systems, resources and organisational configurations in place to address self-neglect differ across localities. This is not only about differences in the services commissioned, as different Safeguarding Adults Boards (SABs) have developed varying guidance on detecting self-neglect or procedures for referral pathways.
3. It is not straightforward to define desirable outcomes in self-neglect. Instead, there is a

complex balance to be struck between attending to health and/or safety, upholding the person's own desires, and considering how others are affected. The legal framework, set primarily by the Care Act 2014 and the Mental Capacity Act 2005, emphasises the role of practitioners in supporting the person experiencing self-neglect to make decisions based on their own values and priorities, though practitioners must also recognise situations when limitations may apply to this (e.g. mental incapacity; high-risk cases where an assessment may take place even if the individual refuses one; situations where the self-neglect is affecting others). Preferred outcomes in one case may be very different from those in another. Because of this considerable diversity in self-neglect itself, service responses and desired outcomes, the need to understand why interprofessional/interagency tensions arise, a lack of consistently reliable data collection on self-neglect cases across services, and the limited existing research evidence-base, mixed-methods with a focus on qualitative data is the approach taken.

A PPI panel will be recruited from the areas covered by the five SABs, which will meet formally online at the start, middle and end of each phase. Additionally, each SAB will nominate a link officer to liaise between the research team and the SAB. Both groups will inform the conduct and interpretation of the study with their respective perspectives throughout, enhancing validity and relevance.

The four phases are as follows:

1. Review of current Safeguarding Adults Board policies and procedures, published Safeguarding Adults Reviews (SARs) and international research literature (Months 1-9). Reviewing policies and procedures will produce a comprehensive map of current SAB approaches to interagency working, referral systems and supporting guidance. SARs are inquiries into cases where there are perceived to have been failings in interagency safeguarding practice; reviewing SARs published since the Care Act was passed in 2014 will survey the recurring problems contributing to significant safeguarding failures and the recommendations made by SARs to solve them. Reviewing the research literature will explore theory and evidence surrounding collaborative working in self-neglect.

The approach to review chosen will be realist review, following the RAMESES standards published in BMC Medicine (Wong et al, 2016). This enables the development, using the range of available forms of evidence, of a theory of what works, for whom and in what conditions in facilitating effective collaborative working in self-neglect.

2. Interviews and exploratory health economics assessment (Months 8-14). Interviews will take place with 15-20 practitioners/managers within each of the areas covered by the five participating SABs (a total of 75-100) and with 15-20 people with experience of self-neglect drawn from across all five areas. Practitioners/managers will have experience of working with self-neglect and will be drawn in each area from a range of SAB partner organisations suitable to allow exploration of differing professional perspectives. As is usual for qualitative research, the precise number of interviewees cannot be specified at the outset, but the number of 15-20 was chosen to enable representation from each of the SABs' partner organisations, enabling the study to achieve a balanced overview of the whole system while not imposing significant time burdens on any single organisation at a time of high demand. Interviewees with lived experience of self-neglect will be identified by practitioners who have worked with them and are therefore familiar with their situation. Interviews will explore participants' experiences of collaborative working, what influenced its success or otherwise, and (for people with lived experience) how this affected the experience of support.

Data will be analysed using framework analysis by a team of two academics and two researchers with lived experience. Framework analysis uses an auditable matrix format to identify key themes. Interpretations and key excerpts will also be presented to the lived experience panel and SAB link officers, whose input will provide a further check on the validity of the findings.

Finances have repeatedly been found to influence interagency collaboration, yet little exploration of the implications of self-neglect – other than in hoarding – has taken place. An

exploratory economic assessment will therefore take place, based on case studies of the care pathways of those interviewed. Resource use related to self-neglect assessment will be identified using documentary analysis of SARs and interviews with practitioners/managers. The associated costs will be estimated based on the accounts of interviewees, and may be partially corroborated from agency case records only where explicit permission is given by the person experiencing self-neglect. The feasibility of using the Adults Social Care Outcomes Toolkit (ASCOT) and INT4 interview-based instruments to assess self-neglect-related social care outcomes will be explored, as there is currently a lack of accepted effectiveness outcome measures for self-neglect. Costs and outcomes will be presented in a disaggregated format, as the study is not powered for comparative evaluation and – given the scattered and variable records of self-neglect care – it would not currently be feasible within the scope of this study to scale up the assessment.
3. Co-design focus groups (Months 15-20). 10-12 of the practitioners participating in the interview stage will join a group to help to co-design with the researchers resources, training, recommendations and guidance to improve collaborative working with self-neglect. The groups will meet on three occasions to (1) generate solutions, (2) operationalise selected solutions, and (3) refine solutions, with the input from practitioners ensuring that these research outputs are relevant, relatable, realistic and usable by practitioners and SABs. In the interim the researchers will progress output design, drawing on the input of the groups.
4. Initial evaluation of resources, training and guidance (Months 21-28). The short- to medium-term impact of the resources, training, guidance and recommendations will be assessed in two ways. A survey will be designed to assess broad uptake across the partner organisations belonging to the 5 participating SABs and gather feedback; this will be distributed as part of the SABs' own annual monitoring processes and so will reach the population of relevant practitioners. Interviews with 15 practitioners will follow up their experience of the study outputs in more depth, exploring what was valuable and less useful, and informing any future adaptation or development when sharing with other SABs.

The research questions were shared with a network of people with lived experience, two peer-led mental health voluntary sector organisations and the two expert by experience research team members, who affirmed the potential value of the project. The two research team members have reviewed the proposal and have provided important input. In particular they have: contributed to the planned organisation of the lived experience panel's work within the study; discussed with us the complexity of defining self-neglect and the sometimes different perspectives of people experiencing it (or thought to be experiencing it) and of professionals; and modified the recruitment materials by advising on phrasing, potential concerns of interviewees, and suggesting changes to the order in which information is presented.

Intervention Type
Other

Primary outcome(s)
The study as a whole seeks to develop theory based primarily on qualitative data and addresses an issue where desired outcomes may vary by individual. The exploratory health economics assessment will consider individual outcomes (albeit at a level that is not powered for comparative evaluation). Currently, there is no accepted effectiveness outcome for self-neglect that can be used in economic evaluation. In this study we will consider two potential outcomes:
1. Social care-related quality of life (SCR-QoL) measured using the Adults Social Care Outcomes Toolkit (ASCOT) instrument INT4 at point of interview only
2. Health-related quality of life (HR-QoL) measured using the EuroQuol instrument EQ-5D-5L at point of interview only

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

Completion date
31/12/2024

Eligibility

Key inclusion criteria
Inclusion criteria for practitioners/managers (interviews, focus groups):
1. Practitioners/managers working in Adult Social Care, Primary Care, Acute Health, Mental Health, the Police Service, Fire and Rescue, Housing, Environmental Health, and voluntary sector or other organisations as may be designated by the local safeguarding adults board (LSAB) as having a key role locally in support for self-neglect
2. Experience of inter-agency practice supporting people experiencing self-neglect (practitioners) or having taken an active role in developing, implementing or overseeing guidance on self-neglect procedures in an inter-agency context (managers).
Beyond these inclusion criteria, purposive sampling will be used to ensure that interviewees represent a spread of organisations/professions.

Inclusion criteria for practitioners (follow-up interviews to evaluate resources, training, guidance produced by the study):
1. As above, plus has exposure to resources, training and/or guidance produced by the study
The evaluation survey will be distributed to all organisations covered by the Safeguarding Adults Boards' monitoring processes.

Inclusion criteria for people experiencing self-neglect (interviews):
1. Aged over 18 years
2. Has the mental capacity to give informed consent to participation in the study
3. Has now, or had in the past, interagency involvement with partner organisations of one of the participating Safeguarding Adults Boards due to concerns about self-neglect
4. In the judgement of the identifying practitioner, invitation to participate in the study would not jeopardise safeguarding or engagement with support services.

Participant type(s)
Mixed

Healthy volunteers allowed
No

Age group
Mixed

Lower age limit
18 years

Upper age limit
100 years

Sex

All

Total final enrolment
96

Key exclusion criteria
Exclusion criteria for practitioners/managers (interviews, focus groups):
1. Does not work within a partner organisation of one of the participating Safeguarding Adults Boards
2. Has little or no direct professional experience of collaborative working with self-neglect

Exclusion criteria for practitioners (interviews to evaluate resources, training, guidance produced by the study):
1. Is not aware of or has not encountered the resources, training and/or guidance produced by the study

Exclusion criteria for people experiencing self-neglect (interviews):
1. Has never had interagency involvement with partner organisations of one of the participating Safeguarding Adults Boards due to concerns about self-neglect
2. Aged under 18 years
3. Lacks mental capacity to give informed consent to participation in the study
4. In the judgement of the practitioner (from any partner organisation), invitation to participate in the study risks jeopardising safeguarding or engagement with support services

Date of first enrolment
10/02/2023

Date of final enrolment
13/12/2024

Locations

Countries of recruitment
United Kingdom

Study participating centre
Publicly listing these sites would potentially compromise the anonymity of study participants because of the details captured in qualitative data, so this information should be withheld.
-
-
England
-

Sponsor information

Organisation

University of Sussex

ROR
https://ror.org/00ayhx656

Funder(s)

Funder type
Government

Funder Name
NIHR Evaluation, Trials and Studies Co-ordinating Centre (NETSCC); Grant Codes: NIHR133885

Results and Publications

Individual participant data (IPD) sharing plan
The datasets generated during and/or analysed during the current study will be stored in a publicly available repository: the University of Sussex Research Data Repository (https://sussex.figshare.com/). The data will become available at least by 2 months following the end of the study, and remain available for a minimum of 10 years on the repository. Consent from participants to these conditions will be obtained.
Interview and focus group transcripts, edited so that they are safely anonymised, will be deposited. Non-sensitive data (documentary review analysis, costings data) will be shared openly; access to the qualitative and survey data will be restricted. This is because the study focuses on inter-agency collaboration and participants must feel able to speak freely about the effectiveness of working together between organisations; even if the data are anonymised, others at the site will know about the call for participation and may draw their own inferences from the transcripts. Applications by other researchers to view this data will be considered on a case-by-case basis; in the event of irresolvable differences over an application to view the data, the ultimate decision will be taken by the University of Sussex Social Science & Arts Research Ethics Committee, taking advice from the data management team at the university.

IPD sharing plan summary
Stored in publicly available repository

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Results article		06/11/2025	06/01/2026	Yes	No
Results article		03/07/2025	06/01/2026	Yes	No
Results article		07/07/2025	06/01/2026	Yes	No
Results article			06/01/2026	Yes	No

Other publications	Mapping and review of self-neglect policies and procedures from safeguarding adults boards in England	04/04/2023	25/03/2024	Yes	No
Protocol file	version 1.2		01/12/2022	No	No
Study website		11/11/2025	11/11/2025	No	Yes