FULL/LONG TITLE OF THE STUDY

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

SHORT STUDY TITLE / ACRONYM

Improving interprofessional collaboration with self-neglect

PROTOCOL VERSION NUMBER AND DATE

Version Number	Author	Date	Changes from previous version
1.0	DO	31.01.22	Protocol as submitted to pre-sponsorship panel (PSRP)
1.1	DO	09.03.22	Protocol revised to respond to PSRP comments: - minor inconsistencies corrected and clarifications added where requested (p. 10, 29, 43). - discussion of WP5 expanded. NIHR disclaimers added (p. 1) and contact details modified (p. 4).

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SIGNATURE PAGE

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor

I also confirm that I will make the findings of the study publically available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

For and on behalf of the Study Sponsor:

Signature: .... Date: ....../....../......

Name (please print): ....

Position: ....

Chief Investigator:

David Orr .... Date: 03/02/2022

Name: (please print): David Orr

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STUDY SUMMARY

Self-neglect can have serious consequences for individuals' self-care, health and wellbeing, and requires collaboration between many practitioners, from Adult Social Care, Health, Fire & Rescue, Environmental Protection and other organisations. Yet practice reviews highlight repeated failings in working together. Joint working in self-neglect under current policies is sparse and has overwhelmingly focused on social work perspectives. This NIHR-funded study aims to identify what problems arise in interagency and interprofessional practice with self-neglect, and how they can be addressed.

Existing research, Safeguarding Adults Boards' (SABs) multi-agency procedures and Safeguarding Adults Reviews will be reviewed to map evidence on factors influencing collaborative working. Interviews with 75-100 practitioners and managers from relevant agencies and 15-20 people who have experienced self-neglect will gather experiential perspectives. An economic assessment, based on interview and service data, will develop case studies of service costs of multi -agency self-neglect.

Three focus groups will then be held with up to 12 practitioners to co-design service solutions and resources, based on the findings. The uptake, acceptability, utility and initial impact on practice of the group's outputs will be evaluated within participating SABs using an online survey and follow-up interviews with 15 practitioners.

A PPI panel will be recruited from service user groups linked to participating SABs, who will bring local knowledge and experiences relevant to self-neglect. The panel will have a key role in advising on each stage of the study.

Key beneficiaries are SABs, practitioners, and people in self-neglect. Outputs will be tailored to each stakeholder group: findings report for SABs; guidance and learning tools tailored to each of Housing, Community Nursing, etc; online training resources; professional journal articles. The researchers will work with SABs and safeguarding networks to apply the findings to improve the cohesion of assessment and intervention, leading to more seamless support and reduced service gaps.

Planned Study Period: 01/03/22 – 30/06/24

FUNDING AND SUPPORT IN KIND

FUNDER(S)	FINANCIAL AND NON-FINANCIAL SUPPORT GIVEN
The study is funded under the Health Services & Delivery stream of the NIHR. Monitoring Officer: Alan Marshall netscomms@nihr.ac.uk National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre University of Southampton Alpha House, Enterprise Road Southampton SO16 7NS	Financial support of £475,992.84 is provided to fund the study. Advice and support for the study is provided by the CRN.
Five participating Safeguarding Adults Boards (identities withheld to protect anonymity)	The Safeguarding Adults Boards are providing in-kind support with recruitment, data collection and stakeholder input. The costs of Link Officers between the SABs and the research team have been budgeted into the study, but this does not fully cover the practical assistance from the SABs.

ROLE OF STUDY SPONSOR AND FUNDER

The Sponsor is responsible for:

- Taking oversight of the putting and keeping in place of arrangements to initiate, manage and fund the study
- Confirming that everything is ready for the research to begin
- Satisfying itself that the research protocol, research team and research environment have met the appropriate quality assurance standards
- Satisfying itself that the study has ethical approval before relevant activity begins
- Allocating responsibilities for the management, monitoring and reporting of the research
- Ensuring that appropriate arrangements are in place to approve any modifications to the design, obtaining any regulatory authority required, implementing such modifications and making them known
- Satisfying itself that arrangements are kept in place for good practice in conducting the study and for monitoring and reporting.

The funder will monitor and periodically review the progress of the study, with advice from the Study Steering Committee. The funder will receive prior notification of all outputs. Study design, conduct, data analysis and interpretation, manuscript writing, and dissemination of results remain the responsibility of the research team.

ROLES AND RESPONSIBILITIES OF STUDY MANAGEMENT COMMITEES AND GROUPS

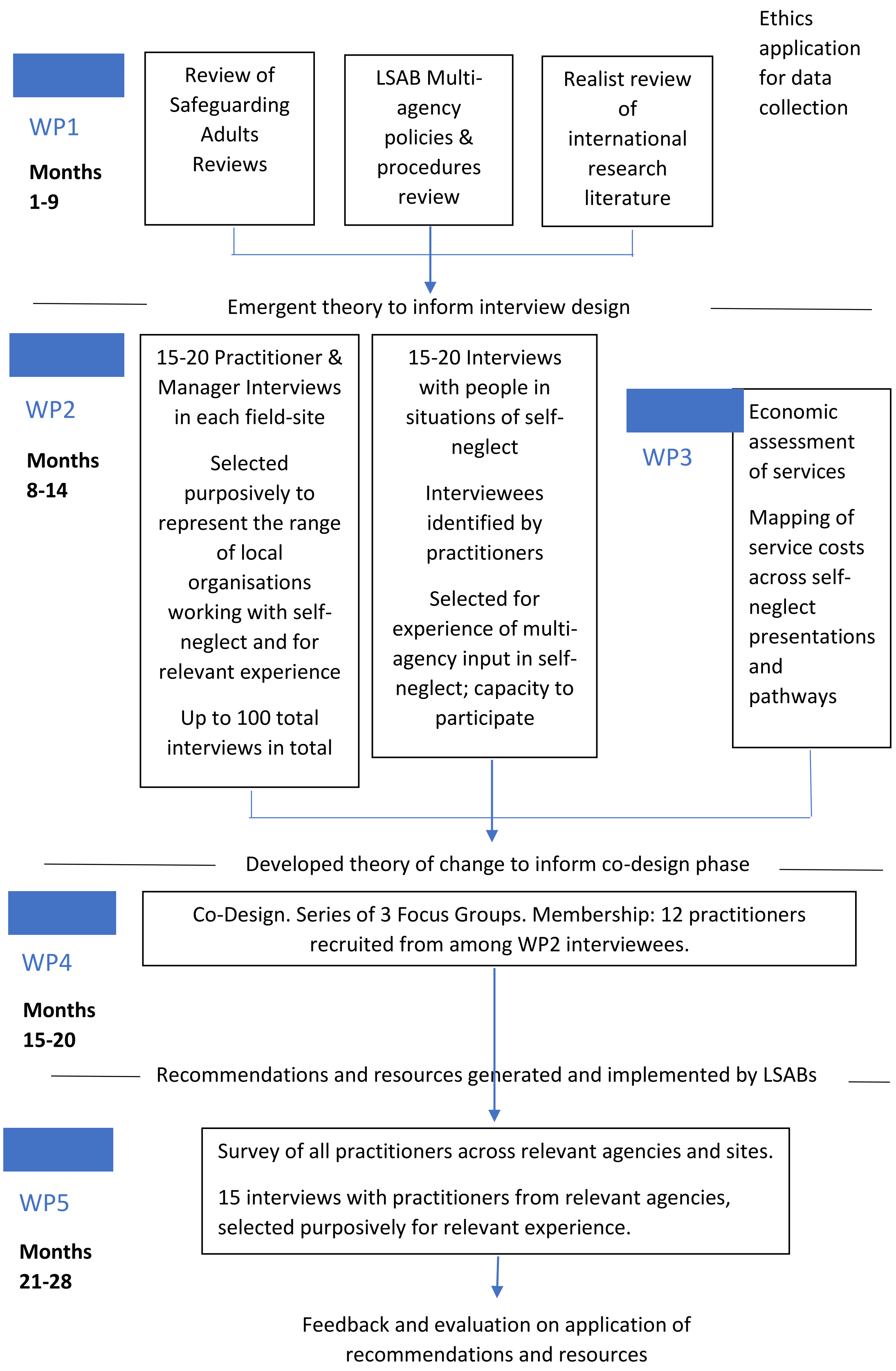
The Study Steering Committee provides independent oversight of the study on behalf of the NIHR as funder. It will meet at least annually, and consider reports from the Chief Investigator.

The Lived Experience Panel is recruited through the participating Safeguarding Adults Boards and by the Chief Investigator. It informs the study with lived experience perspectives and is coordinated and facilitated by the PPI Lead and the two lived experience research team members. It will meet at set points during the Work Packages, specified in the project timeline.

The stakeholder group brings together representatives of the Safeguarding Adults Boards with research team members. It will consider progress as needed.

KEY WORDS: **self-neglect, interprofessional, inter-agency, collaboration, safeguarding**

STUDY FLOW CHART



Ethics application for data collection

WP1

Months 1-9

Review of Safeguarding Adults Reviews

LSAB Multi-agency policies & procedures review

Realist review of international research literature

Emergent theory to inform interview design

WP2

Months 8-14

15-20 Practitioner & Manager Interviews in each field-site

Selected purposively to represent the range of local organisations working with self-neglect and for relevant experience

Up to 100 total interviews in total

15-20 Interviews with people in situations of self-neglect

Interviewees identified by practitioners

Selected for experience of multi-agency input in self-neglect; capacity to participate

WP3

Economic assessment of services

Mapping of service costs across self-neglect presentations and pathways

Developed theory of change to inform co-design phase

WP4

Months 15-20

Co-Design. Series of 3 Focus Groups. Membership: 12 practitioners recruited from among WP2 interviewees.

Recommendations and resources generated and implemented by LSABs

WP5

Months 21-28

Survey of all practitioners across relevant agencies and sites.

15 interviews with practitioners from relevant agencies, selected purposively for relevant experience.

Feedback and evaluation on application of recommendations and resources

STUDY PROTOCOL

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

1 BACKGROUND AND RATIONALE

Self-neglect confronts practitioners with many challenges, but given its complexity and the need for input from multiple agencies, collaborative working is one of the most regularly encountered. Statutory guidance defines self-neglect as covering a range of behaviours and situations where not caring for one's health, safety or surroundings puts the self at risk [1]. The person experiencing self-neglect often does not initially welcome or is ambivalent about service input, yet practitioners have a duty to consider risk [2]. Considerable evidence attests to the harm that can result from self-neglect and the stakes for the person experiencing self-neglect may be high [3]. There is no single 'self-neglect' syndrome [4,5], but rather, diverse forms of self-neglect are unified primarily by the similar challenges they pose to the person, professionals and society. The causes of self-neglect are similarly diverse [6,7] and, while there has been progress in developing standardised assessments of severity for some forms of self-neglect such as hoarding [8], there remains no definitive, objective consensus on the threshold at which self-neglect becomes a concern [9]. This frequently poses a challenge to achieving a shared approach between agencies and professionals [10].

Self-neglect was named as a matter for safeguarding in England in 2014 [1]. Key aims behind this change were to raise the profile of self-neglect and to facilitate interagency working under the banner of safeguarding, recognising that self-neglect typically requires effective, collaborative multi-agency and interprofessional working from several organisations. These can span Adult Social Care, Health, Police, Fire & Rescue, Environmental Protection, Housing and voluntary services, as well as others as needed [3,11]. Self-neglect is now firmly on the agenda for all, yet there is still limited evidence on what arrangements best facilitate multi-agency working and how it can most effectively support individuals. Local Safeguarding Adults Boards (LSABs) were afforded considerable flexibility in developing their own policies and procedures, resulting in variation in pathways and coordinating / consultative forums for practitioners. NHS Digital figures show that Boards vary widely in the annual number of completed safeguarding inquiries they report into self-neglect; the difference is pronounced enough that it is unlikely to result only from differences in population or prevalence, but rather seems to indicate that localities are responding to self-neglect through different pathways, which may or may not formally involve safeguarding processes [12]. This offers the opportunity to learn from varying experiences within differing local configurations and contexts.

Successful interventions with self-neglect are characterised by: a person-centred approach that aims to understand the role or meaning of self-neglecting behaviour within the individual's life; understanding of factors influencing self-neglect; flexibility of practitioner input driven by the person's needs over short-term timeframes and tasks; legal literacy; relationship-building that balances compassionate concern with respect; negotiation of agreed ways forward; careful decision-making that weighs the available evidence; and clear coordination with all involved professionals and organisations [11,13]. Effective collaborative working is widely recognised as essential in this. In addition to effective sharing of professional skills and tasks, it leads to timely referrals, enables teams to build on and around practitioners' relationships with the person experiencing self-neglect, and ensures a joined-up experience of safeguarding or other services for them.

However, collaborative working is challenging, particularly with a relatively ill-defined problem like self-neglect. Self-neglect requires input from diverse practitioners working across professional and organisational boundaries in complex systems [14]. Safeguarding Adults Reviews (SARs, previously known as Serious Case Reviews) – inquiries required where there are concerns about the effectiveness of agencies' safeguarding practice – repeatedly identify failings in multi-agency collaboration. For people experiencing self-neglect, these lead to poorly coordinated care, unidentified needs and missed opportunities for person-centred practice. Serious consequences can include health deterioration and even death for some, or unwanted intrusion and surveillance for others [2,15]. To date 56% (n = 180/323) of SARs focusing on self-neglect have called for improved interagency working; several highlighted failings, in following safeguarding pathways and a person-centred approach, that are potentially related to the lapses in collaboration [16]. Qualitative research too has noted difficulties in interdisciplinary collaboration, arising from conflicting values, lack of local protocols, and systemic issues [10]. Not only does this cause difficulties for services and professionals themselves, but it creates confusion for the person experiencing self-neglect and diminishes the possibilities for person-centred care or meaningful strengths-based practice.

This evidence therefore indicates that the inclusion of self-neglect within safeguarding did not fully resolve the known problems with collaborative working. However, it is far from a comprehensive evidence-base. SARs are a vital source of evidence for identifying problems, but at the same time are individual case studies which inherently focus on 'worst case' or 'near-miss' outcomes [2]. As both the most common and most striking form of evidence within the field, SARs dominate the adult safeguarding evidence-base. This creates sampling bias towards cases with negative outcomes, which, if treated uncritically, could favour risk-averse recommendations. Compounding the problem, LSABs' own quality monitoring processes are dominated by audit of individual agencies, with limited focus on the wider system and interactions between those agencies [17]. The practice evidence-base is therefore partial. There may be much to learn from practice about how effective collaborative working is navigated in practice – and SARs do sometimes nod to this in passing – but if so, this is rarely captured systematically.

The research literature is also limited. Most relevant studies predate the Care Act 2014, when self-neglect came under safeguarding auspices, and therefore do not take account of the significant changes in policy and practice that have taken place since then. One early study gathered perspectives on working with self-neglect from a range of professions and reported instances of highly effective interprofessional working [18], but this line of research has not been further developed within the UK. More commonly, studies both pre- and post-Care Act have explored practitioners' views on multi-agency practice with self-neglect, but in doing so have focused on Adult Social Care interviewees almost to the exclusion of other professions. Many people experiencing self-neglect present to primary care and other services [19], yet this is not reflected in the research. Although the predominance of Adult Social Care is understandable to an extent, given its lead role in safeguarding, this can only give a partial picture of the dynamics of collaborative working. For example, in one recent study social workers perceived that other professionals sometimes did not know their responsibilities for self-neglect, that differences in approach and values gave rise to tensions, and that pressures within the other organisations presented barriers [10]; however, without exploration of the perceptions of the other professionals described it is difficult to determine clearly how the difficulties arose or – importantly – how they might be addressed effectively.

The emphasis on Adult Social Care continues into current ongoing research: Woolham et al.'s exploratory study of practice with older people experiencing self-neglect [20] interviews social care practitioners rather than taking a broader view. Cornes et al.'s study of homelessness and self-neglect [21], through its use of case studies following people using services, incorporates a wider range of practitioner perspectives, but its focus on homelessness is specific to a particular client group and may not capture the experiences and pathways of the full range of people experiencing self-neglect.

In summary, although the self-neglect literature consistently evokes effective interagency and interprofessional collaboration as essential, detailed and comprehensive studies of how this works in practice and how it can be improved are rare. There is evidence from SARs and research to indicate that collaborative working with self-neglect often remains sub-optimal and may be hindered by a range of factors [10]. Researchers have largely failed to incorporate perspectives from outside social work, resulting in missed opportunities to learn how to enhance collaborative working for the benefit of people experiencing self-neglect. Research is needed to develop mid-range theory, based on in-depth exploration of post-Care Act collaborative practice in self-neglect, that can inform the planning of safeguarding services, procedures and training to improve the joined-up response received by people experiencing self-neglect.

This study will address this need through the following steps:

- A comprehensive realist literature review of international research, Safeguarding Adults Reviews and Safeguarding Adults Boards' policies and procedures, to map and understand processes of collaborative working in support of people experiencing self-neglect
- Interviews with practitioners and with people who have lived experience of self-neglect about their experience of collaborative working
- Exploratory health economics assessment service collaboration through case studies, to inform analysis with the occurrence and distribution of costs
- Co-production of resources, recommendations, guidance and training, working with practitioner focus groups
- Initial assessment of uptake and utility of resources, recommendations, guidance and training, through survey and interviews with practitioners.

2 WHY IS THIS RESEARCH NEEDED NOW?

Three factors make this particularly timely: (1) Participating LSABs are renewing emphasis on the strengths-based model for self-neglect [22,23]. While a well-established theory in social work, it has arguably not been widely and systematically applied to severe self-neglect. The study will explore experiences of and potential for this approach as a unifying framework for self-neglect across all agencies. (2) The development of Integrated Care Systems and Primary Care Networks aims to improve health services coordination through technology and structural changes [24]. Learning from their impact on self-neglect collaboration offers lessons for maximising compatibility and integration of systems in practice. (3) Because of reduced in-person contact, the COVID-19 pandemic has meant that some aspects of existing best practice may no longer have been realistic and people may be more reluctant to allow practitioners access for fear of infection. Counteracting the distancing effects of restrictions has required innovative approaches to collaboration and to self-neglect work, and creativity in building relationships. Capturing practitioner solutions when faced with this situation will usefully inform future multi-agency practice. Moreover, COVID-19 has left services facing an unprecedented financial strain; research that can help services to work together more efficiently and effectively in providing person-centred support to people experiencing self-neglect is more needed than ever.

SARs continue to raise concerns about self-neglect; it emerged as the most common safeguarding issue giving rise to SARs in a national thematic review [25, p. 17]. In-depth studies taking an interdisciplinary perspective are therefore overdue. The proposed research will identify both systemic and interprofessional factors inhibiting effective multiagency collaboration to inform Local Safeguarding Adults Board (LSAB) oversight of self-neglect work. This will provide evidence on what multiagency models support relevant organisations to work collaboratively with each other and with the person in a situation of self-neglect and develop resources and standards to support the promotion of seamless, person-centred support by services.

Our proposal answers an expressed need among social workers [26] and LSABs, for an improved evidence-base. In a recent ERSC-funded knowledge exchange project led by Orr [27], the 7 participating LSABs named interprofessional working as a top three priority for self-neglect. This was a response to their surveys and practitioner feedback that identified ongoing mismatches in professional expectations of other agencies, notably at the interfaces between Adult Social Care, primary health care, and mental health services. These caused significant professional frustrations, lack of role clarity, service inefficiencies and hindered effective collaboration. LSABs approached to participate in our study have confirmed sustained interest in learning about and acting on its aims, as greater efficiency and more person-centred, strengths-based working will be required to meet ongoing demand. Our consultation for this proposal with University of Sussex Service Users and Carers Network members confirmed that they had often not experienced support with self-neglect as coordinated or integrated.

This proposed study sets out to synthesise different forms of evidence on collaborative practice with self-neglect. Rather than focusing on a specific manifestation of self-neglect within a tightly-defined client group, such as older adults [20] or homeless people [21], it addresses the full complexity and range of presentations which practitioners may encounter, as this best reflects the work of the majority of professionals outside specialist services and the tasks facing LSABs. It brings together analysis of policies, procedures, academic and grey literature, in-depth qualitative research, economic assessment of the interagency interface, and stakeholder co-design focus groups to produce mid-range theory capable of application by LSABs, partner organisations and practitioners to enhance the coordination and coherence of collaborative intervention to support people experiencing self-neglect. Conscious too of criticism that a focus on interprofessional collaboration may potentially strengthen a tendency for professionals to talk *about* the person using services rather than *with* them [28], a key focus will be on the extent to which values and models of self-neglect that put the person at the centre are shared and adopted across organisational and professional boundaries.

The study asks what can be learned from experiences of self-neglect practice about what facilitates or inhibits collaborative working between service organisations, and how this can inform more coordinated, person-centred and effective input.

3 RESEARCH QUESTION / AIMS

The guiding research question for the study is:

> What can be learned from experiences of self-neglect practice about what helps or hinders collaborative working between service organisations, and how can this inform more coordinated, person-centred and effective input?

The key aims of the study are:

- to identify what common problems arise in interagency and interprofessional practice with self-neglect, for whom, and in what circumstances, and to develop mid-range theory exploring how these can be avoided or mitigated ;

- to improve collaborative assessment and care for self-neglect by developing tailored strategies, models and resources informed by the theory generated, to assist LSABs and practitioners to reduce silo working, enhance the person-centredness of their work and support collaborative, strengths-based multi-agency working with self-neglect.

3.1 Objectives

(a) to map how, for whom and in what circumstances, recurrent challenges affecting collaborative working in self-neglect arise, as experienced by those who provide and those who use services;

(b) to synthesise from relevant literature mid-range theory of how contexts and mechanisms for collaborative practice influence outcomes in self-neglect;

(c) to refine this theory in the light of the experiences and perspectives of managers, practitioners and people experiencing self-neglect;

(d) to characterise resources involved in the case management of people experiencing self-neglect by different agencies, and to estimate a range of total costs of case management, in order to inform analysis of the role played by resources within Context-Mechanism-Outcome configurations;

(e) to co-produce from the findings a set of practical and accessible recommendations and resources on collaborative, person-centred, strengths-based multi-agency working for use by SABs, individual organisations and practitioners.

3.2 Outcomes

The project will generate new understanding of the nature of current challenges to collaborative working in self-neglect, a co-designed framework for addressing them, and indicators for success, for use by LSABs to inform their work. Tailored outputs will be produced for the key project beneficiaries to improve training, practice and policy planning. If successful, this should mean increased practitioner confidence, clarity of roles, and smoother integration of practice in responding to self-neglect; at a service level this should mean increased efficiency of multi-agency working. Ultimately, the impact for people experiencing self-neglect should be experience of more cohesive approaches to assessment and intervention, and more seamless support, with reduction in service gaps.

4 THEORETICAL FRAMEWORK

The study is guided by a realist approach, which focuses on what works for whom, under what conditions [29]. The realist paradigm's recognition of the open-system nature of social reality is well-suited to the complexity of practice with self-neglect. Three key aspects contribute to this complexity:

- self-neglect itself is underdetermined; while people experiencing self-neglect may show some similarities in behaviour, the causes, perceptions and effects of their behaviour may have little in common;
- the local systems, resources and organisational relationships available for self-neglect support may vary;
- desirable outcomes for the person experiencing self-neglect are not straightforward to define, but instead may consist of a complex balance between attending to health and/or safety, upholding the person's own desires, and considering how others (e.g. the public, the community) are affected.

The study therefore aims to produce mid-range theory. Mid-range theory is relevant beyond the immediate context but does not seek to achieve a single, universally-applicable account. Rather, it provides a framework through which programme leads, practitioners and researchers can understand how relevant mechanisms interact with contextual conditions and feed into outcomes. They can then incorporate these Context-Mechanism-Outcome configurations (CMOcs) into planning, and refine the understanding through future evaluation. Theory development takes place through a process of iterative development and refinement of preliminary theory.

In this case, the preliminary theory is derived from two established key influences: Network Governance Theory (NGT) and Normalisation Process Theory (NPT), which frame the interagency aspects and interprofessional aspects respectively. The combination of these theoretical approaches complements and enhances the 'whole systems' approach recommended in safeguarding reviews [30] by facilitating the integrated study of organisational environment, team and individual interactions, and wider socio-cultural influences.

NGT is an approach used in the analysis of systems linked by trust rather than hierarchies or markets, in order to manage complex risks and competing imperatives [31]. As such, it applies well to understanding the role and tasks of LSABs, which are flexible networks whose precise composition is determined locally and which are assigned a statutory role, but which must negotiate between interdependent partners – each of which may see the problem through its own frames – in order to achieve these ends. The network's interactions take the form of 'rules' and 'relations', where rules are conceived as the structured arrangements regulating interactions within the network (statutory requirements for agencies and Boards; inter-agency agreements and protocols; resource allocation; monitoring arrangements), and relations as the flexible patterns of discretionary negotiation that take place over, around and within the rules. Developments at this level shape practice and collaboration between professionals, as well as with people experiencing self-neglect, at a more micro-level; at the same time, network interactions respond to the outcomes and feedback from direct practice insofar as these become known (through reporting, audit, surveys, and SARs).

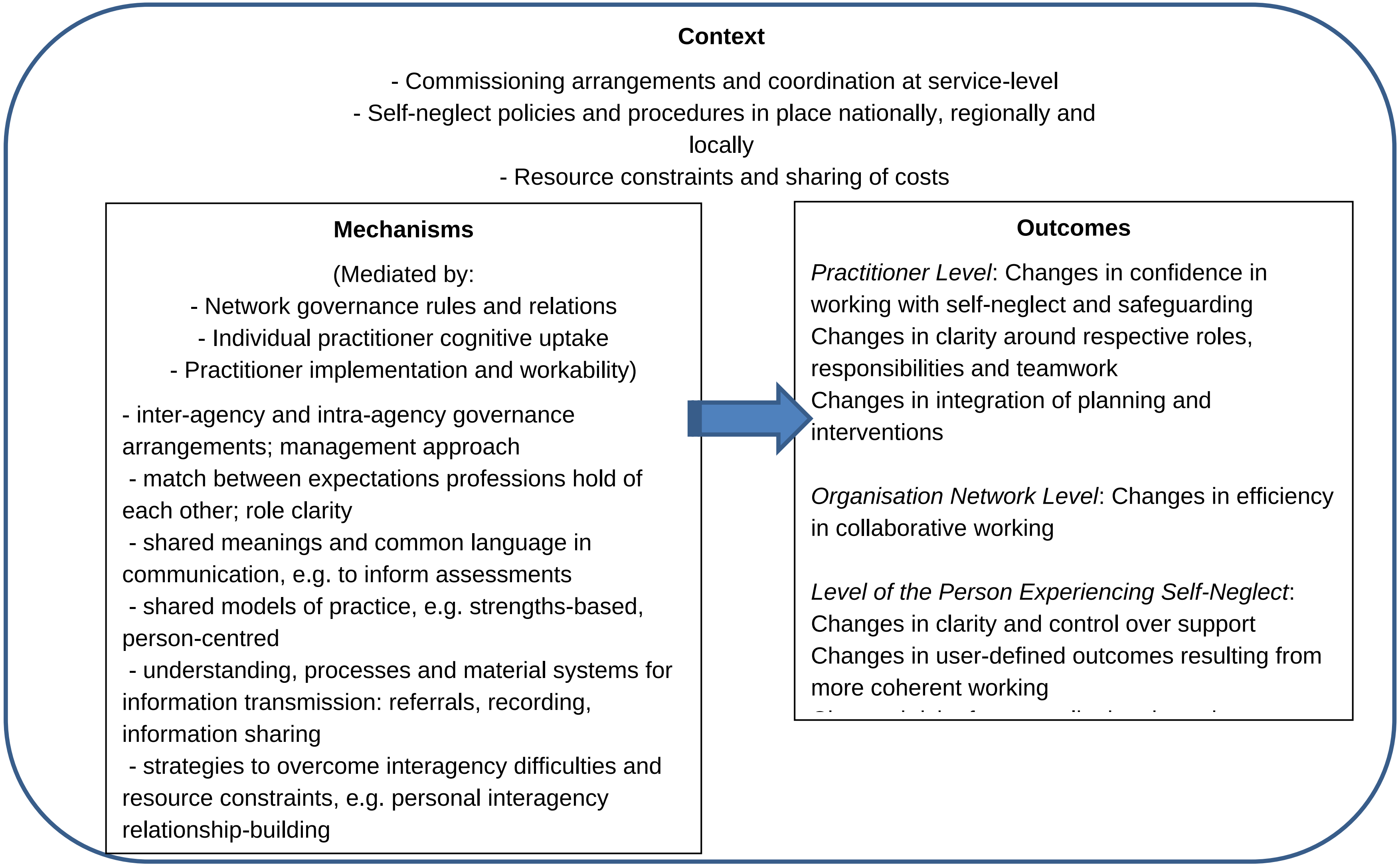
NPT, meanwhile, is a sociological theory designed to understand factors shaping the uptake of new practices or innovations – such as new forms of collaboration or shifting responsibilities for and approaches to self-neglect – within an organisation. It provides an analytic grid under the headings of:

- 'coherence' (extent to which shared meaning of the practice is achieved),
- 'cognitive participation' (buy-in and legitimation),
- 'collective action' (workability in practice, mutual understanding and integration)
- and 'reflexive monitoring' (individual and collective appraisal and, if warranted, reconfiguration). [32,33]

NPT enables structured investigation and the identification of key touchpoints that determine how and whether practice changes.

These two theories provide a framework for understanding how organisational, cognitive and practice change occur. Fig. 1 shows a broad, initial Context – Mechanisms – Outcomes framework which can serve as a foundation for refinement. It is based on the team's existing knowledge of challenges to interprofessional collaboration, derived from a subset of SARs and from our previous knowledge exchange project [27]. Intervention to improve practitioner skillsets in collaborative working and intervention by practitioners to support people experiencing self-neglect should not be conceived separately, as the process of 'reflexive monitoring' means that learning and implementation both loop back into each other.

Fig. 1: Initial Realist Theory of Interorganisational and Interprofessional Practice in Self-Neglect



Context

- Commissioning arrangements and coordination at service-level
- Self-neglect policies and procedures in place nationally, regionally and locally
- Resource constraints and sharing of costs

Mechanisms

(Mediated by:
- Network governance rules and relations
- Individual practitioner cognitive uptake
- Practitioner implementation and workability)

- inter-agency and intra-agency governance arrangements; management approach
- match between expectations professions hold of each other; role clarity
- shared meanings and common language in communication, e.g. to inform assessments
- shared models of practice, e.g. strengths-based, person-centred
- understanding, processes and material systems for information transmission: referrals, recording, information sharing
- strategies to overcome interagency difficulties and resource constraints, e.g. personal interagency relationship-building

Outcomes

Practitioner Level: Changes in confidence in working with self-neglect and safeguarding
Changes in clarity around respective roles, responsibilities and teamwork
Changes in integration of planning and interventions

Organisation Network Level: Changes in efficiency in collaborative working

Level of the Person Experiencing Self-Neglect:
Changes in clarity and control over support
Changes in user-defined outcomes resulting from more coherent working

5 STUDY DESIGN

The study consists of five Work Packages: (1) literature-based realist synthesis; (2) qualitative interviews with stakeholders at five sites; (3) exploratory health economics analysis; (4) co-production of findings and resources; (5) survey- and interview-based assessment of resources, guidance and recommendations.

The literature-based synthesis will bring together Safeguarding Adults Reviews, policies and procedures, and research studies on self-neglect, to consolidate this evidence-base. This provides an informed basis for emergent theory, but – given the limitations noted above – will require supplementing with further data to develop theory that is suitable for full application to self-neglect practice in contemporary England. Therefore we will carry out qualitative research to explore in-depth experiences of self-neglect practice, in addition to the stakeholder engagement strategies that are standard in realist synthesis. Exploratory economic assessment, based on the data gathered from this process about specific cases, will be used to characterise care pathways and resource use. We will explore the feasibility of using INT4, a four-level interview instrument that measures Social Care-Related Quality of Life (SCRQoL) as effectiveness outcome in economic evaluation. The outcome of these stages will be a theory – refined through ongoing consultation with stakeholders – of what hinders or facilitates collaborative working, for whom, under what conditions, which can inform indicators, resources, guidance and recommendations for future use by LSABs and professionals. Throughout all stages, the lived experience panel (described under PPI) will ensure experiential relevance and validity of our approach to people experiencing self-neglect, as our LSAB link officers will do for the Boards.

5.1 WP1: Realist Synthesis

Using RAMESES principles [34], the evidence on multi-agency models in use in England and beyond will be mapped and synthesised to develop an emergent theory to be further refined in WP2-3. In keeping with realist synthesis principles and the reality that much of the knowledge about self-neglect practice in the UK has been generated within practice and policy documents, both academic and grey literature will be reviewed [35, p. 86].

WP1 will be led by Wilkinson, who is experienced in realist synthesis. Support with the review will come from Orr, who is familiar with self-neglect SARs and LSAB policies, and Selwyn and Voyce, who will bring lived experience perspectives to the analysis of a sample of SARs. Analysis will be shared with and informed by the input of the full team and advisory group at regular intervals in its development.

5.1.1 Synthesis Sources

The following strategies will be used to gather relevant material for the synthesis:

(a) All SARs featuring self-neglect and highlighting failings in interagency or interprofessional collaboration (n=180 currently), and related issues such as information sharing, will be reviewed. This set of SARs forms a wide-ranging overview of the forms of self-neglect that occasion serious safeguarding concerns and will identify the key recurring agency interfaces, contributing contextual factors, the nature of problems in collaboration, and the recommendations made for improvement. The research team is uniquely well-placed to undertake this, as the searching stage is already complete: Preston-Shoot has systematically collated all publicly-available SARs in England featuring self-neglect since 2008 and previous analysis of failings reported in SARs already identified which have relevant content [3,36,37,38,39,40]. The remaining task for this synthesis is to revisit these SARs with close analysis of what they have to say about Context, Intervention, Mechanisms and Outcomes in order to inform theory generation and refinement.

(b) LSAB multi-agency procedures for self-neglect will be subjected to documentary analysis, in order to survey the models and approaches adopted across English LSABs. This is important in order to explore the full sampling frame of national practice, without being restricted to those Boards that have commissioned SARs. Comparison of procedures with the recommendations from SARs will permit investigation of SAR learning uptake throughout England, and provide a snapshot of current practice guidance. Orr previously collated all published procedures in 2019; updating the dataset can be done quickly by downloading from LSAB websites or contacting LSABs directly in the few cases where procedures are not published.

(c) The research literature on models, facilitators and barriers for multi-agency working in self-neglect will be reviewed. The databases CINAHL, ETHOS, Grey Literature in Europe, Medline, NHS Evidence, ProQuest Dissertations, Social Care Online and Web of Science will be searched, ensuring that the synthesis is based on a multidisciplinary range of evidence.

5.1.2 Synthesis Searches

The search strategy will be refined in consultation with advice from our steering group, including safeguarding practitioners and experts by experience, and through iterative trialling. The starting formulation for development is adapted from systematic reviews into interprofessional education and practice [41], as follows:

> (Self-neglect or Hoarding) AND (interprofessional or multiprofessional or interagency or multiagency or collaborative or “joint working” or partnership)

Further search methods will include: reference snowballing; consultation with specialists; handsearching of key journals (Journal of Adult Protection; Journal of Interprofessional Care; Journal of Elder Abuse & Neglect; Journal of Interprofessional Education & Practice). Provisional inclusion criteria are:

- Academic or grey literature
- Date limits: 2005 – present
- Languages: English, French, Spanish
- Literature which discusses one or more of:
    - Context: state, voluntary or private sector services working in collaboration to support people experiencing self-neglect
    - Interventions: assessment, support and/or intervention delivered through interagency work to people in, or thought to be in, situations of self-neglect
    - Mechanisms: processes through which collaborative support is facilitated or hindered in self-neglect practice
    - Outcomes: practitioner-level outcomes (effects on practice) and individual-level outcomes (quality of support) in self-neglect practice
- Setting is a High-Income Country. This study is primarily concerned with systems and policies falling within the jurisdiction of the Care Act 2014, so literature focusing on England first, then the rest of the UK will be prioritised for their direct transferability of their data. Literature from other High-Income Countries may provide useful findings in relation to collaborative working; for example, inclusion of self-neglect within the remit of Adult Protection Services is much longer established in the USA than in the UK. This literature will therefore be included where it meets the inclusion criteria, with due critical consideration of its transferability to the UK context.

Our familiarity with the literature [4,42] suggests that it will be possible to comprehensively sample the research literature on collaboration in self-neglect practice, but we will adopt theoretical saturation as a criterion if the search reveals substantial new publications that would overwhelm reviewer capacity. A minimum of 10% of references will be double-blind screened by a second reviewer to ensure consistency of decision-making.

5.1.3 Data Extraction and Quality Assessment

SARs are in effect in-depth case studies of what occurred, and valuable as such, but vary in the extent to which they set out the evidence for the recommendations they make in response to failings identified. This will be considered in the synthesis by considering how explicit the reasoning behind the case analysis is and what support is offered for the recommendations derived. Data extraction will include: organisations and/or professionals involved; characteristics of persons experiencing self-neglect; relevant factors and themes reported on contexts, interventions, mechanisms or outcomes relating to interagency and interprofessional intervention and support.

Documentary analysis of LSAB policies. It will extract information on the inter-agency collaboration procedures in place and guidance provided. There will be no quality assessment of policy documents, as there are not yet any tested, commonly-accepted quality criteria which would apply. This is a mapping exercise to explore what current arrangements exist

Following realist synthesis principles, included research studies will be considered first for relevance to the review, i.e. what they contribute to understanding the implementation chains shaping collaborative working. Secondarily, they will be assessed for rigour, i.e. to what extent does the evidence presented support the inferences drawn from it [35, p. 89]?

Data extraction will include: nature of paper; organisations and/or professionals involved in the paper; characteristics of persons experiencing self-neglect; relevant factors and themes reported on contexts, interventions, mechanisms or outcomes relating to interagency and interprofessional intervention and support. Two team members will review each data extraction. Analysis and synthesis will be undertaken iteratively to refine emergent theory of the connections between Context, Interventions, Mechanisms and Outcomes and to identify key gaps in the evidence-base.

5.2 WP2: Interviews with Practitioners and People with Experience of Self-Neglect

Interviews with practitioners, managers and people with lived experience of self-neglect will test the theory emerging from the synthesis against practice experience involving the range of agencies involved, allowing theory refinement. Interviews with practitioners and people with lived experience will be undertaken by the post-doctoral researcher and by Orr. Interviews with managers will be undertaken by the post-doctoral researcher, Orr and Michael Preston-Shoot, whose role as an Independent LSAB Chair gives him relevant experience.

5.2.1 Settings

Five LSABs, with agreement from their partner agencies, have agreed to take part in the study. These sites are located in different parts of England and were selected on the following criteria:

(1) Established LSAB engagement with self-neglect, based on policy development, training activities, and learning through and responsiveness to SARs. This is important both because (a) partnering with LSABs which are demonstrably committed to addressing the challenges of self-neglect increases the likelihood of bringing the study to a successful conclusion, and (b) where there has been focused attention on self-neglect practice, there is more opportunity to learn from organisational experiences than where there has not.

(2) Secondarily, selection aimed for a balanced set of area profiles including both rural and urban authorities, two authorities with high levels of ethnic diversity, and authorities scoring low to medium on the deprivation index rankings. This improves the likelihood that the findings will be relevant to different contexts.

All participants in WPs 2-5 will be recruited from these five sites.

5.2.2 *Sampling, recruitment and consent*

Interviews will take place with (a) practitioners and managers from across the relevant organisations linked to participating LSABs, and (b) individuals who have experienced self-neglect.

(a) Practitioners and managers are the individuals most closely familiar with how the specific contexts in which they work mediate the mechanisms (impact of policy and guidance, models, training) intended to shape collaborative working outcomes, and are therefore well situated to contribute to 'theory gleaning' and iterative refinement [43, p. 349]. Interviewees will be recruited through a general call distributed by LSAB members to their organisations. This will contain information about the study, including the Participant Information Sheet (PIS) for practitioners, giving them time to reflect and to contact the research team with any queries before deciding. Practitioners and managers will therefore be able to self-select into the study. LSAB members may draw individual practitioners' or managers' attention to the call, where they are aware of relevant work the latter have been involved with; however, the decision whether to participate remains with those practitioners / managers, and LSAB members will not have access to information on who has participated.

Inclusion criteria:

- 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 LSAB as having a key role locally in support for self-neglect
- 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).

We will aim to interview 15-20 participants in each area, recruited from across the different organisations working with self-neglect. This is the minimum number we estimate to be necessary in order to gather and triangulate perspectives on the overall organisational system from across the different services involved. We will aim to interview between 1 and 4 participants from each of these partner organisations which has had significant involvement in recent self-neglect cases, ensuring a spread of perspectives within each area. This number has been discussed with the LSABs and, because 4 is the maximum number of interviews with any one organisation, this should not put a disproportionate burden on services at a time when resources have been strained by the Covid-19 pandemic. However, we will maintain ongoing discussions over what is feasible at the time with the LSAB and be guided by their advice. The precise configuration of organisations in the group of interviewees will be closely comparable but may therefore vary slightly between sites; this will depend on the experience with self-neglect of practitioners within the different organisations and on the demands on those organisations at the time.

(b) In parallel with the practitioner interviews, practitioners will identify individuals with experience of self-neglect with whom they have worked who may be willing to participate in interviews. These individuals are an important source of expertise on outcomes and bring insights into some of the mechanisms which may have shaped practices with those particular individuals, groups and networks [29]. Recognising that carers or family members who are closely involved with the person experiencing self-neglect may have important insights, we will include interviews with them where the person experiencing self-neglect explicitly agrees that this can happen.

As self-neglect is not a formal diagnosis, identifying and contacting individuals through services is the most feasible way of recruiting, logistically and ethically [11]. Individuals themselves may not know whether services considered them to be self-neglecting and whether or not any multi-agency involvement they had was in response to this. Because of its nature, self-neglect often requires great persistence and careful relationship-building in order to build trust [2,11,13,15], raising ethical concerns that a direct approach by the researchers might jeopardise engagement between the person and services. Practitioners will therefore be asked to identify potential participants, play a gatekeeping role in assessing risks of invitation to participate, and make initial contact. All previous qualitative research with people who self-neglect known to the researchers – in studies in Israel, Ireland, Scotland, England and the USA [4] – has recruited using practitioner gatekeepers in this way because of the sensitive nature of self-neglect as a safeguarding issue. Once they have identified suitable potential participants, the practitioners would share the study information and query if they are interested in taking part. If so, the practitioners will put the research team in touch with the potential participant, with the latter's explicit consent.

Inclusion criteria:

- Aged over 18
- Has mental capacity to give informed consent to participation in the study
- 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

- In the judgement of the identifying practitioner, invitation to participate in the study would not jeopardise safeguarding or engagement with support services.

The team will aim to carry out 15-20 interviews in total. Previous studies have reported low uptake of research participation by people experiencing self-neglect [5,18]. However, this figure is considered achievable, based on the research team's previous experience in a previous study that was comparable in area and timeline [11]. This figure is expected to be sufficient to inform the realist analysis with the perspectives of those using services on experiences of inter-agency collaboration.

Self-neglect can sometimes be linked to impaired mental capacity. Two people will be able to assess capacity should there be any concerns with interviewees who have lived experience of self-neglect: the accompanying practitioner and the interviewer. The practitioner will have worked with the person and will therefore usually be aware of whether there may be any impairment or disturbance of the mind or brain (the diagnostic test). All practitioners should have received training on mental capacity, as rolling out such training has been a priority for all participating LSABs; given that these practitioners have all had experience of working with the individuals, they should be capable of assessing capacity. The interviewer also must be satisfied that there is no reason to doubt the interviewee's capacity, if the interview is to proceed. This will be either Orr or the post-doctoral researcher. The person's ability to understand, retain and weigh the information relevant to the decision, and to communicate their decision, will be assessed through the use of open questions inviting the person to express how they have understood the implications of what they have read and heard about taking part in the study.

For both sets of interviewees, the interviewer will go through the key information and points of consent at the outset, and monitor consent on an ongoing basis during the interview.

5.2.3 Data Collection

Interviews will be theory-driven, with the purpose of testing and refining developing hypotheses [44]. Interview topic guides will be developed, initially based on the theory developed within Phase 1 and informed by the input of stakeholders on the advisory group. These guides will be targeted on 'gleaning' relevant experiences and perceptions, and eliciting participants' perspectives in 'refining' the developing theory. In keeping with this approach, topic guides will be iteratively shaped throughout Phase 2 to reflect and continue to inform theory development as the interviews progress.

In interviewing practitioners and managers, interviews will aim to gather their views on the contextual factors and mechanisms that determine to what extent interagency working does or does not work effectively, and their accounts of the outcomes achieved. The diversity and complexity of self-neglect mean that to explore mechanisms and context with any validity, it will usually be necessary for practitioners to narratively reconstruct real cases from their practice, so that it can be understood how diverse forms of self-neglect and the agencies involved have shaped the CMO patterns they have observed [29, p. 177]. In-depth reflection on specific cases in this way will afford exploration of how collaborative working was enabled or hindered by mechanisms such as shared or agency-specific assessment tools, language and understandings of self-neglect, agency priorities, communication, joint training, etc. Within the topics are expected to be such factors as: what facilitates or hinders collaborative working in self-neglect (context); attitudes to collaborative working (mechanism); how practitioners navigate collaboration and how they see each other's roles (mechanism); perspectives on how the person in a situation of self-neglect experiences the involvement of different organisations and is enabled to navigate this input (outcome). Organisational studies techniques such as circular questioning (e.g. 'how do you think your organisation is seen by those working in x when it comes to self-neglect?') will map networks and perceptions, as a further way of stimulating practitioner reflection on hypothesised CMOcs. Interviews will be semi-structured, informed by the findings of WP1 and advisory group input, and may be held with individuals, pairs or small groups within a single organisation, depending on the preference and convenience of the participants. Interviews are expected to last up to 60 minutes.

The interviews with people who have lived experience of self-neglect will explore how the involvement of multiple different services, was experienced by the person and how the practitioners involved collaborated (or not) to build respectful relationships. Bringing directly lived knowledge of how some of the mechanisms in operation may have affected their outcomes [29], participants provide another source of data with which to test and refine theory. The interviewer will be accompanied and introduced by a practitioner known to the person. The interviews will be semi-structured, informed by the findings of WP1 and advisory group input. Interviews may last about an hour but will be planned to allow for flexibility to take into account the interviewee's needs.

Interviewees will be offered the choice of online or in-person interviews, provided that Covid-19 regulations permit the latter. In-person interviews avoid the additional cognitive demands many experience with on-screen interviewing [45] and may facilitate rapport. This may be particularly important when interviewing people experiencing self-neglect. With practitioners / managers, in-person visits also offer understanding of relevant issues such as physical location of different teams relative to each other, which studies have found to influence interdisciplinary collaboration [46,47]. However, it is possible that the new ways of working required by Covid-19 have made this less of a factor, and participants may prefer the convenience of on-line interviews. Some people experiencing self-neglect may find a virtual interview less exposing or demanding. Where online interviews are preferred, MS Teams or equivalent platform used by the service will be employed. If interviewees do not have access to suitable technology, they can make use of agency IT; travel or data costs incurred will be reimbursed.

5.2.4 Data Analysis

Framework analysis will be undertaken, led by Orr and the post-doctoral researcher. This is a qualitative analytic approach that combines a deductive approach, where themes draw from existing theoretical areas of interest which are important to explore, with an inductive approach based on open coding which leaves space for unexpected aspects of interviewees' experience [48]. It therefore corresponds to the realist approach where interviews are shaped deductively by the existing theoretical propositions brought by the interviewer to be tested and refined, while leaving open iterative space for the emergence of unanticipated connections between contexts, mechanisms and outcomes [43]. This allows for the interview data to be systematically compared with and integrated with the theory developed from WP1's realist synthesis, refining it in the process. Its use of a matrix presentation allows for effective comparison across cases (the different organisations within sites, or the same organisations across different sites) and facilitates clarity and consistency between all researchers analysing these data, both 'academic' and 'experts by experience'.

All transcripts based on interviews with people with lived experience of self-neglect, and a sample of those with practitioners, will also be read by Selwyn and Voice, bringing experts by experience input to the interpretation and informing the coding. NVivo will be used to facilitate coding. The developing coding and matrix will be summarised and reported as it develops to the other research team members, lived experience panel and LSAB link members, for their input.

5.3 WP3: Health Economics Assessment

Resources, the distribution of budgets and costs among partner organisations, and how they map on to agency priorities have regularly been found in the interagency collaboration literature to be a key element of context, or – where addressed by the creation of shared budgets through service reconfiguration – a mechanism, which influences outcomes. [49] However, they have rarely been explored in the self-neglect literature, which urges persistence and long-term involvement but – with the partial exception of self-neglect taking the form of hoarding, which has been tentatively estimated [50](Chartered Institute of Environmental Health 2015) – lacks any estimate of the economic implications. Through exploring care pathway costs in a sample of people experiencing self-neglect, Phase 3 enables testing and refinement of aspects of the theory concerning resource demand and its effects on interagency working, strengthening the CMOc analysis. While exploratory, it will also enhance subsequent engagement with theory consolidation by LSAB and manager stakeholders, for whom financial implications are important considerations in the feasibility and outcomes of interventions.

An exploratory economic assessment will be conducted from a multi-agency perspective using the recommended methods for the economic evaluation of health care programmes [51]. We will characterise the main care pathways for a sample of people with different levels of inter-professional support and identify resources involved directly in the management of self-neglect cases. These resources will cover activities associated with assessment, enquiry and advocacy, and include staff time, materials and supportive equipment, household adaptations, transportation and information materials provided to people with self-neglect and their families. Where available, we will also collect data on the use of personal social services (e.g. social workers, community occupational therapists, home care workers, podiatrists), NHS services (e.g. nurse visits, doctor consultations, ambulance call outs, hospitalisations and A&E attendances), social care benefits (e.g. housing benefits, income benefits, disability benefits), and other services including Fire & Rescue and Environmental Health. The data on the use of these services will be collected from the case records where consent is given by service user interviewees and triangulated through the interviews with care providers to check to what extent the data is joined-up. Data on resource use will be costed using the organisations' financial reports and national reference costs [52,53,54]. Currently, there is no accepted effectiveness outcome for self-neglect which can be used in economic evaluation. In this study we will explore the feasibility of using Adults Social Care Outcomes Toolkit (ASCOT) to measure the impact services have on service users' outcomes. We will use INT4, a four-level, individually preference-weighted interview instrument that measures current and expected Social Care-Related Quality of Life (SCRQoL) in community settings [55] and the EQ-5D for the health outcomes [56]. The instrument will be administered in face-to-face interviews with people who have lived experience of self-neglect (WP2). Costs and outcomes of economic analysis will be presented in a disaggregated format given that the study is not powered for comparative evaluation. Given this – and the heterogeneity of self-neglect, which prevents straightforward generalisation – the intention is to map illustrative self-neglect pathways and the corresponding involvement of relevant organisations, as case studies informing CMOc analysis.

5.4 WP4: Co-Design

5.4.1 Recruitment

Having developed mid-range theory to account for facilitators and barriers to effective collaborative working in WP 1-3, we will design indicators, resources, guidance and recommendations to convey the findings to stakeholders and support them in acting upon them. The process of working alongside stakeholders to apply the theory and explore what it allows for in terms of response may itself involve a degree of further 'refinement' and 'consolidation', as practitioners with local knowledge are closely involved to ensure that proposed ways forward are rooted in the realities of practice. However, the primary objective of Phase 4 is to explore, with the participation of practitioners and LSAB members, how the learning from Phases 1-3 might be best communicated to inform improved policy and practice.

Invitations to join the co-design group will be issued to practitioners and managers who participated in interviews (WP2). Inclusion criteria will therefore be the same as for interviews, with the addition that they expressed willingness at the time to be contacted. Up to twelve participants will be recruited, as the largest number generally considered suitable for focus groups before becoming unwieldy. Should more than 12 individuals express interest in participating, selection will be made primarily on the basis of affording as representative a spread as possible across the organisations, recognising the importance of understanding ‘for whom’ proposed solutions work. For professions for whom it is possible, we will see that participation fits with and is recognised as meeting Continuing Professional Development (CPD) requirements for reflective practice to make best use of the time spent. As far as possible, the same practitioners will attend the three groups to support continuity in output development.

5.4.2 Focus Groups

A series of 3 focus groups will be held, each of approximately 1.5 hours. These will be held virtually to enable participants from across the participating LSAB geographical areas to take part in the discussion. The theory developed from the previous stages will be presented and will provide the starting-point for the group’s deliberations. The purpose of the groups will be to (1) Generate solutions, (2) Operationalise selected solutions, and (3) Refine solutions and specify how to meet implementation challenges and evaluation needs. Closely involving practitioners in interactive participatory co-design in this way has been found to maximise the quality and contextual appropriateness of outputs, ensure that project information is packaged to address the priorities and language used by each partner (particularly important given the range of disciplines involved in self-neglect intervention), and improve sustainability and acceptance [57,58,59].

Working with the focus groups and the advisory group, the research team will develop resources, guidance and recommendations to address barriers to collaborative working. These will take account both of needs tailored to specific disciplines and of needs for common understanding across agencies.

5.5 WP5: Assessment of Resources, Guidance and Recommendations

WP4 is expected to produce training, resources, guidance and recommendations to improve collaborative working between practitioners and organisations. Having worked closely with the participating LSABs throughout the project to this point, timely implementation of training and distribution of resources within their agencies should be feasible. Pilot assessment of uptake of these products, in order to enable further refinement, must be undertaken promptly if respondents are to remember details and be able to comment on appropriateness of the approaches and content. The timing of WP5 is therefore intended to allow time for practitioners to have been exposed to training and resources, and to bring it into their practice, but not to leave so long that little useful feedback can be gathered on the outputs themselves.

Some changes, e.g. if there were to be recommendations made about changes to governance and pathway processes, may take considerable time to be adopted, as they may require agreement from many organisations not only within the area covered by the LSAB, but also by regional partners, and some may prefer to link such changes into the timeline of wider reviews of policies and procedures. This is difficult to predict at this stage. Assessment will therefore concentrate on what can be implemented within the lifetime of the study, such as resources and training, but will provide a theoretical framework and guidance on the basis of which LSABs and /or researchers can evaluate future implementation within different contexts.

Uptake of the resources, guidance and recommendations will be assessed within the agencies connected with the participating LSABs. Assessment will be done firstly through an online survey designed by the team to gather data from the wider community of multiagency practitioners on the acceptability, utility and impact on practice. This can be linked in to standard annual LSAB auditing and monitoring activities, to minimise any added burden on services in responding, and can be issued to practitioners throughout the partner organisations of the LSABs. Secondly, 15 follow-up interviews of approximately one hour will be held with practitioners to explore intended and unintended consequences of how the guidance translated into practice within the particular CMO configurations where they work. The invitation to participate in these interviews will be included at the end of the survey; inclusion criteria include:

- Practitioners who have been exposed to the products of the study, and
- Have had opportunity to apply the learning in self-neglect practice.

Both resources will assess changes in confidence, role clarity and integration in practice; the survey will additionally assess uptake. Responses will be analysed using descriptive statistics and framework analysis, and will feed back into the mid-range theory produced by the project.

6 Data Management

The research team members are governed by the *University of Sussex Data Protection Policy*. Primary data generated by the study will include

- interview data from practitioners (WP2, WP5), managers (WP2, WP5) and people with lived experience of self-neglect (WP2)

- exploratory health economics assessment (WP3)
- co-design focus groups (WP4)
- survey data (WP5).

6.1 Data Storage

The digital audio files of interviews and focus groups will be recorded on password-protected recording devices and uploaded to the University of Sussex (UoS) password-protected, cloud-based, GDPR-compliant storage system, Box, as soon as possible. They will be shared only with the professional transcriber, subject to a confidentiality agreement prohibiting any further sharing of the data. Once transcription has taken place and been checked, the audio-recording files will be permanently destroyed.

Where paper files exist, such as signed consent forms from in-person interviews, they will be transported from the interview site within a locked case. They will then be stored in a locked filing cabinet within a locked university office, until such time as they can be scanned and uploaded to the UoS cloud-based storage system. The paper copies will then be destroyed using the university's confidential paperwork shredding service.

Non-audio forms of digital data will be stored in a file within Box. Research data will be stored in folders accessible to the research team members involved in the analysis, while identifiable personal data such as personal contact details for mailing list contacts or electronic consent forms will be stored separately, accessible to the project administrator but not to the research team.

Survey data on the acceptability and utility of the project resources, recommendations, guidance and training will be gathered using the regular monitoring systems of the Local Safeguarding Adults Boards, and the survey results passed to the research team. The use of this data for research purposes will be clearly signalled to respondents on the survey form. Responses will be anonymous, so this material does not constitute personal data.

The anonymised research data and associated materials will be stored for 10 years, in keeping with Sussex policy and recommendations by the Medical Research Council [60].

Analysis of the qualitative data will be carried out using NVivo. Analysis of the health economics assessment will be carried out using Microsoft Excel. Analysis of the survey data will be carried out using SPSS for quantitative data.

6.2 Anonymisation Process

The professional transcriber will remove personal names from the transcripts. The analysts will then check through the transcripts to ensure any details which, despite anonymisation, might plausibly enable reconstruction of the person's identity have been removed.

The letters A, B, C, D and E will be substituted for the name of each Local Safeguarding Adults Board so that the location is kept confidential, while still making clear which interviewees are based in the same area.

6.3 Data Access

Orr and the post-doctoral research fellow will lead the qualitative analysis. Selwyn and Voyce will also undertake review of all interview data from people with experience of self-neglect and a selection of the data from practitioners, to bring perspectives from lived experience. These four analysts will therefore have direct access to the folders containing the anonymised transcripts. Other research team members may advise on the basis of data extracts and the framework analysis grid, but will not be expected to code transcripts directly.

Should the sponsor need access to the anonymised data for audit purposes, this can be provided by granting nominated individuals access to the storage folders.

Despite anonymisation, employees of the organisations involved in the study will have seen the call for participation and will be aware that their colleagues may have taken part in interviews. The study focuses on inter-agency collaboration and it is imperative that participants feel able to speak freely about the effectiveness of working together between organisations; this may be inhibited if the full transcripts are openly available and individuals connected with the sites are free to read into them what they wish. The most ethical course, therefore, is to restrict access to the qualitative data and survey data. The same issues do not arise with the costings data (which assesses resource use and self-rated outcomes), which can be made available as an anonymised dataset. All datasets will be deposited with the University of Sussex’s Figshare repository, but access to the qualitative and survey data will be restricted. Applications by other researchers to view this data will be considered on a case-by-case basis, and a dispute resolution mechanism will be established to settle disagreements over access.

The Chief Investigator, Orr, will be data custodian.

7. Ethical and Regulatory Considerations

Ethical issues arise from exploring experiences of inter-agency practice both with practitioners and with people who have lived experience of self-neglect. These are discussed with reference to each Work Package.

1. *Realist literature review*. While the ethical application is being considered, the team will review research literature, published Safeguarding Adults Reviews, and Safeguarding Adults Board policies and procedures on multi-agency working. This information is all in the public domain and the review does not therefore raise issues requiring ethics committee scrutiny. However, it is important to note that the findings from the review will inform the interview schedules, to ensure that factors demonstrated to affect collaboration are explored in the light of the interviewees' experience.

2a. *Interviews with practitioners and managers*. Practitioners and managers will be recruited through a call issued to practitioners within their organisations, via the Safeguarding Adults Board members. SAB members are usually senior managers, but the recruitment materials they distribute will make plain that participation is entirely voluntary. Participation will be open to all practitioners within these organisations who have experience of working with self-neglect. The main burden of participation in interviews will be the time taken. For this reason the recruitment strategy has been designed to put a minimal burden on any one organisation, by sharing the load across several organisations and across 5 sites. The demand will also be recompensed by the study's products, designed to support good practice, and training workshops offered by the researchers to present on the study's findings. Input based on previous studies by the Braye, the C.I. and Preston-Shoot has been in high demand over a considerable period.

One risk, seldom explicitly considered in research on interagency working, is that open discussion of multiagency difficulties may exacerbate professional tensions when the data is reported by the research team. Studying across 5 sites makes it less likely that practitioners reading the study outputs would identify quotes with any particular individual or team, and the researchers will try to exclude incidental, potentially sensitive information that might identify the interviewee from quotations. The interest of the researchers is in structural and cultural factors that affect collaboration, and the reporting will reflect this rather than individual or team failings.

2b. *Interviews with people who have experience of self-neglect*. These interviewees will be contacted and recruited through the practitioner interviewees, who will act as gatekeepers. Though this means that practitioners will mediate the selection of potential participants, this approach is unavoidable for both practical and ethical reasons:

- Practically, 'self-neglect' as currently used acts more as an indicator of referral pathways used by services than a label with which many service users identify. Self-neglect is not a diagnosis, so recording systems are inconsistent, and no support or activist groups have formed around it. Our engagement with mental health NGOs when preparing the bid showed how challenging it was to find people who explicitly identify as having received service input for self-neglect. Our interest in multi-agency intervention adds another challenge, where many people may be unsure to what extent support they received was either ‘multi-agency’ or focused on the self-neglect itself. Working through practitioners is therefore likely to be more effective in accessing a representative range of the people agencies collaborate to support with self-neglect.

- Ethically, the research, policies and feedback from people with lived experience emphasise the persistence and care needed to build trusting relationships with people experiencing self-neglect. Many are safeguarding cases and can be high-risk. By definition, a feature of self-neglect is often reluctance to accept input from would-be support services. Furthermore, self-neglect can have a range of causes and contributing factors, so interviewers would benefit from guidance from practitioners familiar with the person, who can also advise on appropriate support should that be needed post-interview. In light of this risk of disrupting the relationship with safeguarding services, being guided in recruitment by practitioners is the best way to avoid harm and is the approach adopted by all existing studies of self-neglect identified by the research team which contain a qualitative element.

A limitation of this approach is that it may bias selection of interviewees towards those who have more positive relationships with practitioners. Against this, where people experiencing self-neglect have negative relationships with services they will often be no more open to researchers, and in many cases may not have accepted the sustained collaborative involvement from agencies that is the focus of the research questions. Less filtered views will be gathered by the review of Safeguarding Adults Reviews, which often draw on family members’ perspectives, and may emerge from the lived experience panel.

Interviewees will be given full information ahead of the interview and the interviewer will check understanding, to ensure that consent is informed. Consent will be recorded through a signature, electronic signature, or (if interviews take place online and the interviewee is not confident in supplying an e-signature) audio recording. Support will be provided to promote full participation by interviewees, including interpreting or care assistance if necessary. Where there may be uncertainty about mental capacity, both the accompanying practitioner and interviewer will assess the interviewee’s ability to understand, retain and weigh information relevant to the decision to participate, and to communicate their decision. Interviewees will be reminded that they can withdraw at any time with no repercussions. All interviewers will have a recent DBS check.

Another key ethical issue is the risk of arousing distress through the interview itself. This risk will be minimised through the processes of informed consent, the right to withdraw consent at any time, and efforts by the interviewers to respond appropriately and adjust style and pace to suit the interviewee. If interviewees become distressed, the interviewers will handle such situations with sensitivity, follow a protocol reminding the interviewee of their right to withdraw, and signpost sources of support with advice from the practitioner who introduced them.

The participant information sheet specifies that confidentiality may be limited where there is risk of significant harm, abuse or neglect. If safeguarding concerns arise in the interview, the interviewer would first discuss with the interviewee and seek consent to pass on the information to the care team and/or another appropriate local source of support. However, even if consent is not given, the interviewer may need to alert the care team over significant safeguarding concerns.

While the practitioner will accompany (where interviews take place in person) and introduce the interviewer, they will move out of earshot for the interview itself. Identifying details will be removed at the transcription stage and the analysts will double-check that any identifying information is no longer present.

The C.I., Preston-Shoot and Braye have all undertaken research interviews with both practitioners and people who have experience of self-neglect in previous studies, positioning them well to advise and respond to concerns arising. Experience of conducting interviews on emotionally difficult material will be a requirement for recruitment of the post-doctoral fellow.

Voucher payments will be offered to interviewees with lived experience of self-neglect, as a token of recognition for their time and the sharing of their stories. The amount follows NIHR guidance on payments, so that it should not act as recognition rather than as an undue incentive.

3. *Health Economics Assessment*. Data on resource use related to self-neglect assessment will be estimated using SARs and interview data. Partial corroboration may be obtained from agency case records only if explicit and informed consent is given to the interviewer to view these by the person to whom they relate. Where such consent is given, the interviewer will view records in situ only; no transferral of files will take place and only data directly relevant to resource use will be noted. The data protection measures described in Section 6 will be followed.

4. *Practitioner focus groups*. Willing practitioners from among those interviewed will participate in three focus groups to co-produce useful resources and recommendations based on the study findings. Fully informed consent will be sought. The principal ethical concern here relates to the time burden required of organisations and practitioners. The same mitigating factors are in place as for the interviews: spread across several organisations to minimise burden on any one; support to use focus group participation as reflection in professional registration requirements; contribution of the group outputs to organisation’s mission; and in-kind support in the form of the training provided to the organisations.

5. *Follow-up interviews and survey*. Again, the key issue is the burden placed on services by the time taken for participation. Therefore the survey evaluating practitioners’ experiences of the resources and recommendations produced by the study will be issued through the participating Safeguarding Adults

Boards' communication channels for annual monitoring, and care will be taken to ensure it is no more time-consuming to complete than necessary. It will be clearly explained that the survey results will be used in the research so that respondents are fully aware of what they are consenting to.

Interviews will be sought with 15 practitioners (from across the 5 participating SABs) to obtain qualitative feedback on their experiences of the study resources and recommendations. Informed consent, confidentiality, benefits and risks of harm, and data management remain the same as for the earlier interviews. A further consideration here is that the team members doing this interviewing will also have been involved in developing the resources under discussion, which might conceivably affect their reactions in the interview. However, this same involvement in the earlier stages of the study means they will have a clear grasp of the issues and challenges, which are arguably necessary to inform the interview if key insights are to be elicited and explored, and the interview schedule and preparation will support the interviewer to approach the interview neutrally.

7.2 Research Ethics Committee and other Regulatory Review

Sponsorship will be sought for the study from the University of Sussex. Once confirmed, research ethics committee approval will then be sought from the appropriate NHS or Social Care Research Ethics Committee. WP2 and subsequent WPs will not start until Research Ethics Committee approval is in place.

A study steering committee will have oversight of the study on behalf of the NIHR and will advise the funder on progress and any concerns arising.

7.3 Amendments and Protocol Compliance

Any necessary amendments to the protocol will be submitted to the study sponsor in the first instance and from there to the Research Ethics Committee where warranted. Consultation will also take place with the study steering committee on behalf of the study funder. Unplanned deviations from the protocol will be reported to the sponsor, Research Ethics Committee and study steering committee.

As a multi-phase realist study, it is expected that data collection tools will undergo some evolution as the findings of the realist synthesis (WP1) inform the semi-stuctured interview schedule, the findings of WP1-3 shed light on the problems that the focus groups (WP4) seek to solve, and the nature of the resources, recommendations, guidance and training developed determines the survey and interview questions asked about them (WP5). The research team will update the sponsor as this develops to determine how it is best handled at each point.

7.4 Peer Review

The study has been through two rounds of independent peer review following submission to the NIHR, and a further round of comments following the decision in principle to award. The study steering committee will provide continuing scrutiny over the life of the project.

7.5 Public and Patient Involvement

Engagement with people with experience of self-neglect is central to this study, but meaningful engagement recognises that the term ‘self-neglect’ is often applied primarily by services rather than by service users themselves. While it resonates with many people, others may reject the label, and few actively or collectively mobilise on the basis of ‘lived experience of self-neglect’ in the way they might for a diagnosis or experience of a single service. The PPI strategy takes this into account throughout.

7.5.1 PPI in Design of Research

In preparing Stage 1, the research team consulted virtually with members of the University of Sussex Service Users and Carers Network. This reached a group with diverse experiences without making a priori judgements about whom a 'label' of self-neglect would fit. Members who responded self-identified as having lived experience of self-neglect rooted, for example, in childhood adverse experiences and depression, and of caring for family members who have experienced self-neglect linked to psychosis and dementia. Feedback emphasised how practitioners may define ‘problems’ such as self-care very differently to the person experiencing self-neglect, and the need for all practitioners involved to understand the varied psychological dynamics of self-neglect. Members felt that they had not experienced a clear, coordinated response from different agencies involved that specifically addressed concerns about self-neglect, but that this would have been useful.

When recruiting co-researchers, the research team made contact with two mental health lived experience peer mentoring groups. This did not lead to identification of individuals wishing to represent experiences of self-neglect, but the discussions emphasised that not everyone who is seen by practitioners as self-neglecting would think of themselves as such and the challenges of revisiting those experiences.

Two co-researchers with lived experience of self-neglect, Selwyn and Voyce, are named. They bring complementary lived experiences, peer support skills, and experience of organising and representing service users to the research team.

7.5.2 PPI in Implementation of Research

PPI is integrated at two levels:

1. Stakeholder Panel: All the participating LSABs work with service user groups in their areas, including older adults, mental health, and substance use groups. Among their members are people with experiential insights into self-neglect. We will disseminate an invitation through these groups for

individuals to join a lived experience panel. We will aim to achieve representation of self-neglect from among, at a minimum, older adults, people who hoard, people with mental health difficulties and clients of substance use services. We will also seek to encourage diversity of gender and ethnicity in the panel membership, by explicitly and actively promoting through the user groups our aim to achieve wider representativeness. Provision will be made to assist with translation so that language is not a barrier; the physical venues will be accessible; there will be support with travel and technology access to ensure maximum inclusion. If we cannot recruit 10-12 individuals in this way, we may consult LSAB partners (e.g. local MIND branches) for additional recruitment pathways.

Working through local groups allows us to (a) benefit from their understanding of the service contexts within which we will research, (b) ensure there is a familiar support network for participant s, and (c) enhance the likelihood of research impact by involving people already shaping services. This panel will play a key role in steering the study from the perspective of service users; areas of particular focus will include informing interview planning, approach to recruitment for service user interviews, validation of analysis, and production of resources and guidance. Panel members will be paid for their time.

Due to the geographical spread of panel members, meetings will be virtual, as they have been for these groups during the pandemic lockdown. However, in-person meetings have been scheduled for the start and end of the panels (Covid-19 pandemic permitting) to facilitate group formation and reporting back on the study results, respectively; these will have a live link for those who cannot be physically present. To fit with the iterative nature of the realist framework, panel meetings will take place three times during each of WP1, WP2/3, WP4 and WP5 to support (1) planning the phase, (2) discussing progress, interim findings and sharing developing interpretations, and (3) resuming and interpreting the findings from the phase. Clear, accessible information will be provided ahead of each meeting.

2. Research Team: Two co-researchers with lived experience of self-neglect will ensure that voices of lived experience remain central to the research, taking joint responsibility with others on the research team to ensure Telford’s PPI principles are followed (INVOLVE 2013, p. 16). They will lead stakeholder panel activity and coordinate this geographically dispersed group. In addition they will also jointly contribute directly to interpretation of raw interview data. Between them, Selwyn and Voyce are experienced in facilitating / representing service user groups and in peer support. Orr and Maglajlic will offer all training necessary in the self-neglect and safeguarding policy and research context, and in the project’s research methods.

PPI will be reported following the GRIPP-2 standards. Impact will be captured at three levels through qualitative review: process of involvement, on the research itself and on the research products.

7.6 Indemnity

The University of Sussex will act as sponsor of this research and has insurance in place to cover liabilities arising from the design, management or conduct of the research. Public liability and employers' liability are covered up to a maximum indemnity limit of £50m, and professional negligence in the course of research up to a limit of £10m.

8. Dissemination and Impact

The direct beneficiaries of the study will be LSABs, organisations and practitioners working with people experiencing self-neglect; people experiencing self-neglect should benefit indirectly from the resulting improved understanding and implementation of inter-agency support. Working closely alongside these stakeholders throughout, we will maximise the likelihood of uptake of the outputs and their use in improving the acceptability and effectiveness of multi-agency practice in self-neglect. The dissemination and impact strategy will leverage the team's established profile and influence, built on signposting to Braye et al.'s 2014 study in the Care and Support Statutory Guidance itself, more than 200 practice training workshops that Braye, Orr and Preston-Shoot between them have delivered for LSABs, local authorities, clinical commissioning groups and other professional groupings, and Braye and Preston-Shoot's work on regional and national thematic reviews of SARs. The central involvement in the project of LSABs and lived experience groups from multiple regions further strengthens dissemination capabilities; use of training and resources is built into the project with participating LSABs. The communications and dissemination plan will be iteratively developed and implemented between the research team, LSABs and advisory group through the life of the project.

8.1 Outputs and Dissemination

The study will produce several outputs:

- The protocol and final study report will be freely available through the NIHR website. The report will also be accessible through the University of Sussex and Brighton & Sussex Medical School repositories, and will be circulated to LSABs through networks such as the Independent LSAB Chairs' Network.
- A policy briefing and a practice briefing will be produced for LSABs.
- Further practice guidance and learning tools will be developed, tailored to individual professions (e.g. Community Nursing, GPs, Social Workers, Housing, Fire & Rescue), and disseminated through professional bodies such as the Royal College of Nursing, the Royal College of Physicians and the British Association of Social Workers, to complement dissemination through LSABs.
- A freely available audiovisual resource transmitting key messages will be developed that can be used widely, on LSAB websites and as the basis for workshops at training events.

- Research articles will target the *Journal of Interprofessional Care*, and – in order to enhance impact – key journals which successfully reach both research and practitioner readerships, such as the *Journal of Adult Protection*, the *British Journal of Social Work* and the *British Journal of Nursing*.
- Presentations on the findings will be given at national safeguarding and professional conferences.

The NIHR, as funder, has the right to advance notification of outputs and will be acknowledged in all publications. In accordance with NIHR policy, outputs will be published under a CC-BY licence.

Regular updates on the study progress will be posted on the study website, hosted by the Centre for Social Work Innovation and Research at the University of Sussex. Participants who wish to receive updates on the study findings at the close of each phase will be offered the opportunity to opt in to email updates.

8.2 Authorship

The International Committee of Medical Journal Editors sets out four principles informing assignment of authorship [62]. All authors should (1) have made substantial contributions to conception or design, and/or to acquisition, analysis, or interpretation of data, (2) drafting or critically revising the work for significant intellectual content, (3) have given final approval for the version of publication, and (4) accept accountability for the content of the work. Authorship attribution will be guided by these principles, with journal article authorship reflecting the researchers' involvement in the specific Work Packages those articles are based on. First author credit will normally be given to the individual taking the lead on drafting the publication, The subsequent order will as far as possible reflect the extent of each author's contribution to the output and WP. A statement outlining each author's contribution will be prepared for each output, and will be published where the journal or other outlet allows space for such a statement.

The University of Sussex has an established procedure to address disputes over authorship credit under the *Code of Practice for Research* and, should there be concerns that any candidate for authorship has been treated unfairly, under the *Procedure for the Investigation of Allegations of Misconduct in Research*.

9. Project Management

Lead applicant Orr will project manage the study, with project management support from van Marwijk and Lefevre, and will have overall responsibility for coordinating activities and outputs. There will be monthly meetings of the research team, either virtually or in person, to assess progress and plan.

Alongside this, the interface with the lived experience stakeholder panel and project steering group will require management. Co-applicants Selwyn and Voyce will co-chair the panel and ensure the research team planning and activities are informed by lived experience perspectives. Panel meetings will take place three times during each of WP1, WP2/3, WP4 and WP5, and are described in more detail under PPI. Co-applicant Maglajlic will provide support to Selwyn and Voyce in their roles.

The stakeholder group will include a representative from each of the participating LSABs, Cooper, the PPI Lead, and additional academics with relevant expertise. The group's role will be to monitor progress against milestones, advise on emerging challenges, advise on relevance and suitability of emergent theory, promote the project and advise on dissemination and impact strategies. The group will meet six times over the life of the project and will be kept regularly updated on progress between group meetings through communications produced from each research team meeting.

A study steering committee will be appointed by the NIHR to provide independent oversight. This group will include academics, Safeguarding Adults Board leaders, and people with lived experience. The Chief Investigator will submit reports to this committee, which will meet at least annually to consider progress. The committee will offer an independent view to the funder on any concerns with the research or failure to meet milestones.

9.1 Criteria for Success and Risks

Key criteria for successful delivery of the project include:

Criterion	**Measured by**
1. Timely delivery of findings and outputs	At least monthly progress checks by team and steering group
2. Achieving systemic overview, which represents all key agencies and disciplines	Ongoing scrutiny on recruitment for interviews and co-design groups by team and steering group; reflexive consideration by co-design group
3. Resonance of mid-range theory with key stakeholders	Built into methods through lived experience panel, steering group, SAB involvement and co-design groups
4. Dissemination and uptake of outputs across key stakeholder groups	WP5 evaluation of resource use among participating SABs; tracking dissemination through team networks; monitoring use on SAB websites
5. Indicators, resources, guidance and recommendations to be usable by beneficiaries in practice and policy	WP5 evaluation of resource use among participating SABs; ongoing feedback from indicators where adopted by SABs

6. Impact to be sustained over time	Post-project feedback from SAB training feedback, monitoring and audit, annual surveys

Potential barriers include:

COVID-19 may disrupt possibilities for participation and contact. This risk has been mitigated by putting in place measures to allow virtual interviews and group meetings, taking steps to avoid access to technology becoming a barrier to inclusion. COVID-19 has also placed a resource burden on services which may affect participation rates; this is addressed in the study by working closely with SABs, limiting the demands on any one organisation, tailoring participation so that it can satisfy CPD requirements, and offering in-kind training / resource input for participating SABs.

Attrition of both the lived experience panel and co-design focus group is an inevitable risk. This will be mitigated by timely communication and maintenance of a reserve list of potential participants who could step in if required. If necessary, members of the SAB can advise on further potential replacement members.

There are risks to quality of data if, for example, interviewee permission to access file information on costs or survey response rates are low. These risks will be mitigated by (1) clear explanations of why this is important and (2) close integration into routine SAB data collection so that there is minimal added burden, and timely reminders.

9.2 Team Expertise and Roles

Orr (PI) brings expertise in qualitative research and in systematic and realist reviewing methods. He has been methods lead on mixed-methods systematic reviews funded by the Dept. of Health, DFID and AusAID. He will oversee ethics application, practitioner / service-user interviews (WP2) and follow-up assessment (WP5). He will supervise a post-doctoral researcher in social care (100% FTE). Orr will also review some of the literature for the realist synthesis.

The post-doctoral research fellow will be recruited for the start of Phase 2. The key tasks within the role will include undertaking interviews, co-facilitating focus groups and survey design. Experience in conducting research interviews with potentially vulnerable populations will be an essential requirement for the role.

Wilkinson brings expertise in realist synthesis, with research experience in realist review of diabetes care and realist enquiry through action research. She will lead the realist synthesis (WP1), reviewing some of the literature.

Orr, Braye and Preston-Shoot bring extensive expertise in self-neglect research and its translation into policy and practice. Their studies into workforce development needs, good practice and learning from SARs in self-neglect remain a touchstone in the UK. Braye and Preston-Shoot have worked directly with LSABs to develop research-informed self-neglect policies, authored SARs on self-neglect and recently collaborated to lead a national review of SARs commissioned by the Care and Health Improvement Programme. Preston-Shoot compiled and maintains the specialist database collating SARs that feature self-neglect, an important resource for this project. Preston-Shoot brings deep familiarity with the policy and organisational challenges of self-neglect, having previously been Independent Chair of Luton LSAB and Joint Coordinator of the National Network of Safeguarding Adult Board Chairs; he is currently Independent Chair of Brent and Lewisham LSABs. Preston-Shoot will (a) provide access to the SAR database (WP1) and (b) undertake interviews with managers (WP2). Both Preston-Shoot and Braye will bring their experience of policy development, training and SAR inquiries to advise on resource and recommendation development (WP4), and follow-up assessment (WP5).

Ivashikina has extensive experience of economic evaluations in diverse aspects of health and social care, and has provided methodological advice for Research Design Service London. She will lead WP3 and provide supervision for a post-doctoral researcher in Health Economics (17% FTE, to be recruited in time for Phase 2 of the study), in advising on economic aspects of the realist synthesis (WP1) and undertaking the economic analysis (WP3).

Van Marwijk contributes expertise in co-design, community engagement, collaborative care and the management of people living with long-term health conditions, and has a particular interest in frailty and multimorbidity. As Professor of Primary Health Care and a GP, he brings close understanding of how primary care professionals support people experiencing self-neglect. He will co-lead the co-design phase (WP4) and bring a primary care perspective to planning and analysis in other work packages.

Lefevre is currently P.I. of a £1.9m collaborative ESRC grant researching safeguarding of young people where risks are beyond the family home, and brings experience of realist evaluation with complex safeguarding issues, large-scale research project management. NIHR policy encourages mentoring for lead investigators who, like Orr, are making the step up from leading research grants under £50,000 to one of this size, and Lefevre will fulfil this role as well as bringing the benefits of her experience in realist research.

Selwyn and Voyce bring highly complementary lived experiences of self-neglect, peer support skills, and experience of organising and representing service users to the research team. Selwyn will act as PPI Lead. Both will jointly co-ordinate and lead the lived experience panel, ensure that voices of lived experience remain central and ensure that Telford's [61] PPI principles are followed throughout and contribute directly to interpretation of raw interview data (WP2). Maglajlic brings extensive international experience of participatory research and co-production with mental health survivors. She will provide support and research training to the PPI lead and other PPI representatives over the life of the project.

Cooper brings invaluable experience with service improvement in Adult Social Care. She has been Strategic Director of Adult Social Services (Sutton) and Adult Safeguarding Lead for the Association of Directors of Adult Social Services, and is now Care and Health Improvement Advisor for London for the Local Government Association. She is thus able to inform the study with extensive knowledge of the challenges of safeguarding leadership and will advise on how to achieve implementation and impact.

10. References

1. Department of Health & Social Care. Care and Support Statutory Guidance. London: DHSC. 2018.
2. Braye S, Orr D, Preston-Shoot M. Autonomy and protection in self-neglect work: the ethical complexity of decision-making. Ethics and Social Welfare. 2017; 11(4): 320-335.
3. Preston-Shoot M. Safeguarding adult reviews: informing and enriching policy and practice on self-neglect. Journal of Adult Protection. 2020; 22(4): 199-215.
4. Braye S, Orr D, Preston-Shoot M. Self-neglect and Adult Safeguarding: Lessons from Research. London: Social Care Institute for Excellence. 2011.
5. Day MR, Leahy-Warren P, McCarthy G. Perceptions and views of self-neglect: a client-centred perspective. Journal of Elder Abuse & Neglect. 2013; 33(2): 145-156.
6. Iris M, Ridings JW, Conrad, KJ. The Development of a Conceptual Model for Understanding Elder Self-neglect. The Gerontologist. 2010; 50(3): 303-315.
7. Dahl N, Ross A, Ong P. Self-neglect in older populations: a description and analysis of current approaches. Journal of Aging and Social Policy. 2018; 32(6): 537-558.
8. Frost RO, Steketee G, Tolin DF, Renaud S. Development and validation of the Clutter Image Rating. Journal of Psychopathology and Behavioral Assessment. 2008; 30: 193-203.
9. Yu M, Gu L, Shi Y, Wang W. A systematic review of self-neglect and its risk factors among community-dwelling older adults. Aging & Mental Health. 2020; advance access. doi.org/10.1080/13607863.2020.1821168
10. Mason K, Evans T. Social work, interdisciplinary collaboration and self-neglect: exploring logics of appropriateness. British Journal of Social Work. 2020; 50(3): 664-681.
11. Braye S, Orr D, Preston-Shoot M. Self-neglect policy and practice: building an evidence-base. London: Social Care Institute for Excellence; 2014.
12. NHS Digital. Safeguarding Adults, England, 2019-20. Available at https://digital.nhs.uk/data-and-information/publications/statistical/safeguarding-adults
13. Day MR, McCarthy G, Fitzpatrick JJ (eds.) Self-Neglect in Older Adults: A Global, Evidence-Based Resource for Nurses and other Healthcare Providers. Dordrecht: Springer. 2018.
14. Waring J, Marshall F, Bishop S. Understanding the occupational and organizational boundaries to safe hospital discharge. Journal of Health Services Research & Policy. 2015; 20(1): S35-44.
15. Braye S, Orr D, Preston-Shoot M. Learning Lessons about Self-neglect: An Analysis of Serious Case Reviews. Journal of Adult Protection 2015; 17(1): 3-18.
16. Preston-Shoot M. On (not) learning from Safeguarding adult reviews. Journal of Adult Protection. In press.
17. Preston-Shoot M. Making any difference? Conceptualising the impact of safeguarding adults boards. Journal of Adult Protection. 2020; 22(1): 21-34.
18. Lauder W, Anderson I, Barclay A. Housing and self-neglect: the responses of health, social care and environmental health agencies. Journal of Interprofessional Care. 2005; 19(4): 317-325.

19. Lauder W, Roxburgh M. Self-neglect consultation rates and comorbidities in primary care. International Journal of Nursing Practice. 2012; 18(5): 454-461.
20. Woolham J, Manthorpe J, Martineau S, Steils N, Stevens M, Egan K, Tinelli M. Social care responses to self-neglect and hoarding among older people: what works in practice? London: NIHR. https://www.sscr.nihr.ac.uk/projects/p156
21. Cornes M, Tinelli M, Fuller J, Harris J, Manthorpe, Martineau S. Opening the “too difficult box": strengthening adult safeguarding responses to homelessness and self-neglect. London: NIHR. https://www.sscr.nihr.ac.uk/projects/p141/
22. Department of Health. Strengths-based social work practice with adults. 2017. Available at https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/652773/Strengths-based_social_work_practice_with_adults.pdf
23. Morgan S. A strengths-based approach and safeguarding adults – are they compatible? Journal of Adult Protection. 2020; 22(2): 87-92.
24. Department of Health. Integrating care: Next steps to building strong and effective integrated care systems across England. 2020. Available at https://www.england.nhs.uk/wp-content/uploads/2020/11/261120-item-5-integrating-care-next-steps-for-integrated-care-systems.pdf
25. Preston-Shoot M, Braye S, Preston O, Allen K, Spreadbury K. 2020. Analysis of Safeguarding Adults Reviews, April 2017-March 2019: Findings for Sector-led Improvement. London: Local Government Association.
26. James Lind Alliance. Priority Setting Partnership: Adult Social Work. 2018. Available at https://www.jla.nihr.ac.uk/priority-setting-partnerships/adult-social-work/
27. Orr D. Implementing and embedding research-based organisational change for better outcomes in self-neglect: a co-production approach. Unpublished Report. 2018.
28. Fox A, Reeves S. Interprofessional collaborative patient-centred care: a critical exploration of two related discourses. Journal of Interprofessional Care. 2015; 29(2): 113-118.
29. Pawson R, Tilley N. Realistic Evaluation. London: Sage. 1997.
30. Fish S, Munro E, Bairstow S. Learning together to safeguard children: developing a multi-agency systems approach for case reviews London: Social Care Institute for Excellence. 2008.
31. Klijn EH, Koppenjan J. Governance Network Theory: Past, Present and Future. Policy & Politics. 2012; 40(4): 587-606.
32. May C, Finch T. Implementing, Embedding and Integrating Practices: An Outline of Normalization Process Theory. Sociology. 2009; 43(3): 535-554.
33. Murray E, Burns J, May C, Finch T, O’Donnell C, Wallace P, Mair F. Why is it difficult to implement e-health initiatives? A qualitative study. Implementation Science. 2011; 6: 6.
34. Wong G, Westhorp R, Manzano A, Greenhalgh J, Jagosh J, Greenhalgh T. RAMESES II Reporting Standards for Realist Evaluations. BMC Medicine. 2016; 22(3): 286-303.
35. Pawson, R. Evidence-based Policy: A Realist Perspective. London: Sage. 2006.
36. Braye S, Orr D, Preston-Shoot M. Serious case review findings on the challenges of self-neglect: indicators for good practice, Journal of Adult Protection. 2015; 17(2): 75-87.
37. Preston-Shoot M. Towards explanations for the findings of serious case reviews: understanding what happens in self-neglect work. Journal of Adult Protection. 2016; 18(3): 131-148.
38. Preston-Shoot M. On self-neglect and safeguarding adult reviews: diminishing returns or adding value? Journal of Adult Protection. 2017; 19(2): 53-66.
39. Preston-Shoot M. Learning from safeguarding adult reviews on self-neglect: addressing the challenge of change. Journal of Adult Protection. 2018; 20(2): 78-92.
40. Preston-Shoot, M. Self-neglect and safeguarding adult reviews: towards a model of understanding facilitators and barriers to best practice. Journal of Adult Protection. 2019; 21(4): 219-234.

41. Taylor I, Sharland E, Jones L, Orr D, Whiting R. Interprofessional Education for Qualifying Social Work. London: Social Care Institute for Excellence. 2006.
42. Braye S, Orr D, Preston-Shoot M. Self-neglect: Lessons from research. London: Community Care Inform; 2019. Available at https://adults.ccinform.co.uk/research/research-review-self-neglect/
43. Manzano A. The craft of interviewing in realist evaluation. Evaluation. 2016; 22(3): 342-360.
44. Pawson R. Theorizing the interview. British Journal of Sociology. 1996; 47(2): 295-314.
45. Fauville G, Luo M, Queiroz A, BailensonJ, Hancock J. Nonverbal Mechanisms Predict Zoom Fatigue and Explain Why Women Experience Higher Levels than Men. Available at http://dx.doi.org/10.2139/ssrn.3820035
46. Wener P, Woodgate RL. Collaborating in the context of co-location: a grounded theory study. BMC Family Practice. 2016; 17: 30. https://doi.org/10.1186/s12875-016-0427-x
47. Memon A, Kinder T. Co-Location as a Catalyst for Service Innovation: A study of Scottish Health and Social Care. Public Management Review. 2017; 19(4): 381-405.
48. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Medical Research Methodology. 2013; 13: 117.
49. Glasby J, Dickinson H. Partnership Working in Health and Social Care. 2nd Edn. Bristol: Policy Press; 2014.
50. Chartered Institute of Environmental Health. Hoarding and how to approach it. Available at https://www.cieh.org/media/1248/hoarding-and-how-to-approach-it-guidance-for-environmental-health-officers-and-others.pdf
51. Drummond MF, Sculpher MJ, Claxton K, Stoddart GL, Torrance GW. Methods for the Economic Evaluation of Health Care Programmes. 4th ed. Oxford: Oxford University Press; 2015.
52. Personal Social Services Research Unit. Unit Costs of Health and Social Care 2019. Available at https://www.pssru.ac.uk/project-pages/unit-costs/unit-costs-2019/
53. NHS Digital. NHS reference costs 2018 to 2019. Available at https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/reference-costs
54. Gov UK. Benefits calculator. Available at https://www.gov.uk/benefits-calculators
55. PSSRU, Personal social Services Research Unit. INT4, four-level interview tool. Available at: https://www.pssru.ac.uk/ascot Accessed 15 May 2021.
56. EuroQol. EQ-5D. Available at https://euroqol.org/eq-5d-instruments/ Accessed 20 Sept 2021.
57. Hinchcliff R, Greenfield D, Braithwaite, J. Is it worth engaging in multi-stakeholder health services research collaborations? Reflections on key benefits, challenges and enabling mechanisms. International Journal for Quality in Health Care. 2014; 26(2): 124-128.
58. Jagosh J, MacAulay AC, Pluye P, Salsberg J, Bush PL, Henderson J, Sirett E, Wong G, Cargo M, Herbert CP, Seifer SD, Green LW, Greenhalgh T. Uncovering the benefits of participatory research: implications of a realist review for health research and practice. Milbank Quarterly. 2012; 90(2): 311-346.
59. Greenhalgh T, Jackson C, Shaw S, Janamian T. Achieving research impact through co-creation in community-based health services: literature review and case study. Milbank Quarterly. 2016; 94(2): 392-429.
60. Medical Research Council. MRC Regulatory Support Centre: Retention framework for research data and records. Available at: https://mrc.ukri.org/documents/pdf/retention-framework-for-research-data-and-records/. Accessed 2 January 2022.
61. Telford R, Boote JD, Cooper CL. What does it mean to involve consumers successfully in NHS research? A consensus study. Health Expectations. 2004; 7: 209-220

62. International Committee of Medical Journal Editors. Defining the Role of Authors and Contributors. Available at: http://www.icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-role-of-authors-and-contributors.html. Accessed 26 January 2022.