Research Integrity Framework (RIF) on older persons social isolation and loneliness

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Background

This framework forms part of Re-engages research acceleration programme and sets out our research tenets to ensure the safety and well-being of our older beneficiaries participating in research. The framework recognises that good research should consider the motives, consequence, and context in which loneliness and social isolation occur. This iteration has been developed within a UK context, however, has the potential to form the basis of broader research in other international contexts.

This framework recognises that many of us – academics and organisations focused on service delivery and interventions – engage in collaborative research and evaluation and that all of us have a responsibility to nurture ethical, sound research and to discourage research practice that is unethical or misrepresents itself and or participant experiences. Organisations representing older people who are experiencing social isolation or loneliness, such as Re-engage, have a positive and central role in undertaking and using research to inform ethical and effective policy making and practice. This framework outlines what good research practice related to loneliness and social isolation looks like and, contains the tenets we want researchers, organisations, journals, national and local policy makers, and commissioners to sign up to. There are five pillars within this framework:

1. Transparency, honesty, and accountability
2. Research ethics
3. Equality, human rights, and social justice
4. Engagement
5. Safety, wellbeing, care, and respect

Competent social isolation and loneliness research first and foremost must reflect the fundamental principle that lives differ in significant ways and that these differences matter, *everyone requires a different prescription.* We recognise that an intersectional approach to our research is crucial, and this approach recognises that discriminations based on sex, gender, class, or race, for example, operate together and that individuals may experience different, distinct, or additional discrimination due to a combination of aspects of their social location and identity. To fully understand the lived experience of isolated and lonely older people from diverse backgrounds and identities, research much consider how structural inequality affects their experiences of isolation and loneliness and the appropriateness of the response they receive from society, organisations, and agencies.

In addition, we recognise the importance of research that focuses specifically on groups experiencing intersectional discrimination, and where possible this research should be carried out by researchers from those communities and the organisations that serve them, however this is not a prerequisite to partner with Re-engage on research. Finally, we highlight the importance of meaningful participation, what is often referred to as Public Patient Involvement (PPI), service user involvement or stakeholder engagement. Experiences of people aged 75 and over should be present at the outset of the research endeavour. These perspectives will be given by our research co-production group, where important and early consideration of what is the benefit of the research will be given. It is not ethical to ask for co-production member input if research is poorly designed, methodologically flawed or where the risks to the participant in offering their expertise is not outweighed by the benefits of the proposed research. We also acknowledge that many researchers and service providers may themselves bring perspectives of loneliness and social isolation to the research process.

Rationale

We have developed this framework to promote best practice in relation to older persons social isolation and loneliness research. Building on the contributions of older participants in research more broadly, we think it is important that researchers and practitioners in related fields adhere to and are engaged with research integrity from the outset.

What is research integrity and why is it important to Re-engage?

Research integrity is about doing research that not only leads to results that people can trust and have confidence in but, is carried out in an ethical manner with care and respect for those involved in the process. This framework ensures that all Re-engage research activities will be carried out with a high degree of integrity and therefore other researchers and members of the public can have confidence in our findings, results, and recommendations. At times, the nature of our understanding of conclusions or recommendations may change over the passage of time, however due to our integrity framework, stakeholders and members of the public will still be able to trust the results as they were understood at the time.

T.R.E.E.S – Transparency, honesty, and accountability. Research ethics. Equality, human rights, and social justice. Engagement and Safety, wellbeing, care, and respect.

Our RIF pillars

There are five pillars (T.R.E.E.S.) of our Re-engage research integrity framework. These pillars highlight the key aspects of research in social isolation and loneliness and ageing population studies. By outlining these principles and asking our research partners to adhere to them, our intention is to enable policy makers, commissioners, and other decision makers to better weigh up evidence and increase transparency. These principles also require those who are the end users of research to commit to using our research in ways which are transparent and do not seek to misuse or misquote the findings. We understand that engagement with peers is the foundation of research integrity, and this forms the basis of this framework.

Pillar one: Transparency, honesty, and accountability

Transparency, honesty, and accountability are essential when assessing the values of specific research. This includes being clear about the following information:

1. Who is doing the research? The parties undertaking the research must be clearly outlined whether it is an organisation delivering services, an academic institution or someone else. The type of research project should also be clearly identified including whether it’s undergraduate, taught post-graduate, PHD or a large, funded research project. The experience of the research and research partners, the aims, and the objectives the research is setting out to achieve must be clearly defined from the outset.

2. Method. We recognise that all methods have bias inherent within them, and that methods should be appropriate to the research questions being asked. Larger research studies are challenging to conduct and expensive and may not be the most appropriate method. Similarly, small in-depth qualitative studies may yield better results but cannot represent the experiences of all cohorts. Therefore, we acknowledge there are limitations with many research approaches and how they can be applied elsewhere. It is important that limitations are transparently recognised to avoid over claiming.

3. Sample characteristics. These should be clearly outlined in the abstract or summary to ensure decision makers or users of the research are able to weigh up the merit of the claims and recommendations being made on the basis of the data available. Abstracts and summaries should include details regarding; the sample size and how representative it is likely to be of all people over the age of 75 and what steps have been taken to consider factors such as ethnicity, locality, and geography.

4. Demographic profiling. It is important to understand whose perspective might not be represented and to understand the nuances of social isolation and loneliness across a variety of groups. Collection of demographic data should be conducted sensitively,

and research participants must have the option not to answer any or all questions if they so choose. Data must be collected on the self-identification of the individual with the characteristic and assumptions should not be made. Disaggregated data related to sex, gender, age, ethnicity, disability, and other relevant factors should be collated as a matter of process.

5. Accessibility. We believe that publications arising from research we are involved in should be widely available to other researchers, as well as the general public. Therefore, all research partners much adhere to and comply with our open access policy. We recognise that there is the potential for misunderstandings and/or misuse of research and therefore recommend the use of executive summaries and press releases as best practice. This enables others to rebut any misinterpretation or misuse of data. Our associated research integrity older persons research checklist (next section) will also help by providing a space for this type of information to be made available outside of the lengthy publication process. Publications must follow our accessibility guidelines, and our research partners should use clear language, avoid jargon where possible to ensure their work is fully accessible. Accessibility must be included in budgets along with other costs.

6. Geographical location. Information about the geographical location of the study is crucial ensuring anonymity remains and needs to be clearly set out. This is important because of the potential role of legal, economic, social, cultural, psychological, and political factors and the ways in which they might differ across geographical settings. When using reference to other research is important to be clear whether that evidence is relevant to the context in which it is being used. For example, using data from rural Wales to comment on the situation in London may be problematic.

7. Partnerships. Collaboration and contribution should be clearly recognised and recorded in all formats. This includes older people who may have advised or been on a project steering group. Researchers should be aware of the burden of any requests being made to individual participants and avoid this where possible. Partnerships also relates to recognising the role of others, ensuring those who are best placed to lead on the research do so. Researchers should adhere to standard authorship guidelines and document decisions regarding authorship within the research process. This should include the roles and responsibilities of authors, including Re-engage.

8. Funders and commissioners. It is important to clearly specify who is funding and commissioning the research/insight study so that the reader is clear about any vested interests. This applies to externally funded and in-house research/evaluations. It is good practice to have this information readily available

Pillar two: Research ethics

Research involving older participants and into the subjects of loneliness and social isolation rase some ethical issues, many of which have been addressed in this framework. All research partners should request independent review of their research plans and protocols prior to conducting any field work. For academic partners, this should be a process whereby checks are undertaken through a review process typically via their own university research ethics committee. For any health-based research this should be through the NRES system in England and Wales and equivalent in other areas. Some service evaluations or insight studies may not at present, be required to undergo ethical review through university processes. However, we believe all research/evaluation should undergo some form of independent ethical review to ensure it adheres to the principles of this framework and adopted in the Research Ethics Committee procedures of most research institutions. All publications must state clearly whether ethic approval was sought and gained including the approving body. In cases where ethical approval is not sought or deemed unnecessary, the reason for this should be clearly outlined, including the steps taken to address any ethical issues or concerns.

Pillar three: Equality, human rights, and social justice

Our third pillar recognises the importance of being aware of and issues linked to equality, human rights, and social justice. This includes some of the principles and ideas laid out in pillar 5.

We recognise the need to acknowledge how injustice and structural inequalities impact and play a role within social isolation and loneliness for people aged 75 and over. International law provides protection from many types of discrimination including discrimination on any ground such as sex, gender, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth, sexual orientation, gender identity, age, state of health, disability, marital status and migrant or refugee status.

We acknowledge that it is rare for research to offer a neutral and bias-free way to understand an issue or to measure outcomes, but good research recognises inequalities that impact research. Our research partners must understand the demographic composition of the population and the power dynamics in society in order to identify groups most likely to be marginalized or excluded from research. Our research partners need to have an awareness of how their own unconscious bias may result in the overlooking of some groups and privileging others, including formation of any research team. All research designed with Re-engage must consider the impact of inequalities on all elements of the work.

People over the age of 75 experiencing social isolation and loneliness, are not a homogenous group and Re-engage do not operate under a ‘one size fits all’ approach. A wide range of individual, social and cultural factors determine how individuals and communities experience and respond to loneliness and social isolation and the intersectional structural inequalities that underpin both loneliness and social isolation and the lives of older people.

The engagement of older people in Re-engage services means we should recognise and value the contribution that our older beneficiaries make to our knowledge in many different ways; designing, implementing, analysing, presenting research, and engaging in community activities to share their experiences and raise awareness on topical issues.

Pillar four: Engagement

Re-engage has developed an extensive monitoring, evaluation and learning framework to measure the impact of our interventions on the loneliness and social isolation of people aged 75 and over. Some of our activities include collaborative research with service providers and engagement with service users (referred to as our older beneficiaries) to inform the research process and methods (often referred to as Public Patient Involvement – PPI). Engagement is a key strength in the work we do but also raises some challenging questions.

Our research partners must ensure there is an appropriate balance among creating a safe space and positive experience for participants, acknowledging their wish to help others, and mitigating the potential harm that unrealistic expectations of what the work will achieve can cause. Researchers must be transparent in their information to potential participants about what they intend to do and ensure they do what they say they will. If commitments are made to feedback to participants, then this needs to be done in an appropriate and timely way, using interim feedback measures if necessary. This applies to service providers too; researchers are required to share interim feedback with service providers to prevent research becoming limited.

Working with lonely and socially isolated older people can be challenging for numerous reasons, therefore researchers must ensure they have their own measures in place for their emotional support needs. Re-engage are not in a position to provide this support.

We are advocates of co-production in socially embedded research. We promote working in a co-produced way with key agencies, organisations, and participants and find this is a helpful way to ensure that the needs of those impacted by loneliness and social isolation are included in the production of knowledge. Co-production can be difficult and the boundaries between co-produced and collaborative research can often become blurred. All research partners must be aware of the aims of the coproduced research, and the roles and responsibilities of each partner must be clearly outlined from the start. Co-produced and/or collaborative research can, if done properly, offer unique benefits to researchers, service providing organisations, and participants. This will include recognising the contribution of individuals and organisations. Research can be designed together to create structures that share power, decision-making and resources and promote leadership.

Re-engage research partners should recognise the risk of power imbalances in research studies and care must be taken to ensure that collaboration is approached in an accessible way which recognises potential these potential imbalances. Re-engage should be costed in funded bids to cover their time, resources, and involvement.

Finally, consideration should be given to ethical dissemination of findings and the role of communications. Project design requires consideration of transparent commitment to how and to whom findings and recommendations will be communicated.

Pillar five: Safety, wellbeing, care, and respect

Our fifth pillar recognises the importance of ensuring participants safety and wellbeing and treating all research participants with care and respect. Researchers must work on the ethical premise of ‘do no harm’ and consider from the outset how their research maintains the safety, both physically and emotionally, of research participants and researchers themselves, with the research process. Details of these considerations must be clearly outlined in the planning and implementation of research studies.

‘Do no harm’ must always be applied in terms of an evaluation of the risks and benefits of conducting research. Some of our older beneficiaries may find their engagement in research triggers unhappy or unwanted memories or emotions and therefore may be somewhat harmful. This needs to be balanced against what participants might gain from their participation in the research and the benefits must be clearly outlined to participants, enabling them to make an informed decision before taking part. An external peer review must be sought to assist in the balance of these risks and harm, peer reviews may be conducted by the Re-engage research co-production group. Re-engage will offer support to research participants throughout the duration of the study and will ensure that the risks of taking part in research are mediated, these costs are included in the Re-engage partner costs model.

Location of research should be safe (physically and emotionally) for both participant and researcher. Participants must be allowed to define what is safe, and arrangements remain flexible and based on their needs. Support must always be considered during the ethical planning of research in this field and researchers need to recognise that safety is context driven. Emergency contact details should be requested and information about how data will be used and stored made clear to the participant, in line with data handling and GDPR policies.

Participants must only be re-contacted if we have their express permission to do so. Careful consideration must be given to how approaches are made. Online surveys must include information about how data will be used and processed.

Anonymity and confidentiality

Research must ensure the anonymity and confidentiality (excluding safeguarding risks) of participants taking part in research unless they specifically state that they wish to be named. Researchers should be aware of data protection requirements relating to storage of information from participants, a copy of Re-engages' data protection and storage policy will be shared with partners on request. Sensitive or identifiable information must only be requested via online survey, where absolutely necessary and researchers must be aware of data storage agreements/access of on-line survey platforms. We recognise that where possible anonymised qualitative data should be made available. This allows secondary data analysis which makes full use of the time and effort given by participants. However, there will be times when anonymising the data ultimately makes archiving meaningless. Safety concerns should be central to this decision-making process and permission for the future use of anonymised information for research must be sought.

Interpreters

Ideally, researchers should speak the participants language. In instances where interpreters may be required, researchers should ensure that the older person is comfortable and safe with the interpreter and a confidentiality agreement is in place. Re-engage do not currently provide access to interpreters or interpreter services. Only interpreters who are quality-assured and appropriately accredited should be used in research. All interpreter services must undergo a due diligence review by Re-engage.

Research integrity in older person social isolation and loneliness – T.R.E.E.S check list

Our T.R.E.E.S checklist is designed to ensure our research partners commit to the five pillars outlined in our research integrity framework. This will ensure policy makers and commissioners can make decisions about our evidence and recommendations based on a clear understanding of the data being presented to them. Journal articles and some other formats may not have space for detailed information on these issues. Therefore, we ask our partners to complete this information and make it readily available. We also ask that you make clear you are adhering to this framework. We understand that it may not be possible at the start of a research process, particularly where it is co-produced in some way, to answer all these questions and therefore it should be considered a living document.

Transparency, honesty, and accountability

Question	Yes	No	N/A	Partial	Please provide further details
Have you named the funder?					
If not, why not?					
Are the research aims presented clearly?					
Is the population of interest and sampling clear?					
Is bias acknowledged?					
Did you break down the demographic profile of the participants and discuss how representative they are of the population of interest?					
Are perceived or actual conflicts of interest identified and detailed?					

Research ethics

Question	Yes	No	N/A	Partial	Please provide further details
Does your research require formal ethical approval?					
Is this health-based?					
Does it require a review from the university research ethics committee?					
Has it been peer reviewed?					
If independent ethical review has not been undertaken, has this been stated along with steps taken to address any ethical concerns?					
Were internal ethical review processes followed and is this available to end users of the research?					

Equality, human rights, and social justice

Question	Yes	No	N/A	Partial	Please provide further details
Is the context of the research clear? (who, where and why)					
Has consideration been given to either the over or under representation of any groups within the population of interest?					
Have you explained what over. /Under representation means for the research findings.					
If the research focused on a particular demographic, are members of this demographic involved in carrying out the research?					
Does the research examine how structural inequalities could affect the experiences of research participants differently?					

Engagement

Question	Yes	No	N/A	Partial	Please provide further details
Is your research collaborative in some way?					
Have you made it clear where research is collaborative and where it isn’t?					
Who designed the aims and objectives?					
Did service users or providers help decide and/or design the methods?					
Did service users assist in the dissemination process?					
Were people over the age of 75 involved with the research design through the analysis of findings?					

Safety, wellbeing, care, and respect

Question	Yes	No	N/A	Partial	Please provide further details
Are you in contact with people over the age of 75 who are experiencing social isolation and loneliness?					
Have you considered any additional safety issues?					
Have you assessed the risk to individual participants physical and emotional safety and wellbeing?					
Have steps been taken to mitigate any risk of being involved in the research?					
Do participants have access to support?					
Do you have confirmation of safe contact details?					
If required, can you meet research participants safely?					

What safeguards are in place to ensure the safety of researchers and others?					
Have you checked with participants that they feel safe?					
Have you explained the research in detail to the participants, including how you will ensure confidentiality and anonymity?					
Have participants given informed consent to your use of their information?					
If you are using an interpreter, has the interpreter signed a confidentiality agreement?					
Have you checked the participant is happy to use an interpreter?					
If using an on-line survey, does the information make clear where data will be stored? And is this in accordance with Re-engages data storage policy?					
Do you have permission for anonymised data to be used for future research?					