



STUDY PROTOCOL

Staff, caregivers and family members' experiences and perceptions of Intergenerational Programmes inclusive of people living with dementia: A qualitative evidence synthesis protocol

[version 1; peer review: awaiting peer review]

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Abstract

Background

Opportunities for social engagement for people living with dementia are often limited due to a lack of understanding and empathy, as well as stigma associated with dementia. Intergenerational (IG) programmes are formal activities which bring generations together meaningfully. Although benefits of IG programmes have been reported for people living with dementia, more research is needed to understand these programmes and their effects. Specifically, while a recent qualitative evidence synthesis (QES) reported on experiences and perceptions of people living with dementia and young people, of IG programmes (Houghton *et al.*, 2022), there has been limited work synthesising research on the perspectives of healthcare staff, teachers, family members, and informal carers regarding their involvement. Including the range of perspectives from other parties is

essential in understanding the nature and potential benefits of such programmes, as well as in identifying design considerations for future IG programmes in Ireland.

Methods

This is a protocol for a QES of peer-reviewed qualitative papers addressing the experiences and perceptions of healthcare staff, teachers, family members, and informal carers regarding IG programmes inclusive of people living with dementia. A systematic search of 7 databases will be conducted, as well as backward and forward citation checks. Two authors will independently screen texts for inclusion. It is anticipated that thematic synthesis will be used for all included studies. The methodological limitations of studies will be assessed using an adapted CASP tool and confidence in the review findings using GRADE CERQual.

Discussion

IG programmes involve engagement across multiple parties. Developing an understanding of the perspectives of all involved is critical in identifying factors contributing to successful IG programmes, and informing the design and implementation of future IG programmes. This QES will extend the literature and provide key considerations to guide the design and delivery of future IG programmes in Ireland.

Keywords

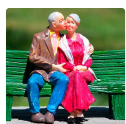
Dementia, intergenerational programmes, qualitative evidence synthesis, social engagement, social exclusion, community-based activities

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Background

The number of people living with dementia is increasing considerably worldwide, with approximately 55 million people living with dementia currently¹. In Ireland, there are approximately 64,000 people living with dementia, with that figure projected to reach 145,000 by 2045². The Model of Care for Dementia in Ireland (2023) report³ highlights *Staying connected* as one of the core strands of post-diagnostic support, recognising the importance of community-based supports and services. Social connection, a sense of belonging and meaningful engagement with others in the community are important components of well-being and quality of life for people living with dementia (Hung *et al.*, 2021; Phinney *et al.*, 2016; Phinney *et al.*, 2007; Wiersma & Denton, 2016). Community-based approaches are also an important potential avenue for addressing stigma associated with dementia, by providing opportunities for greater engagement with people living with dementia (Phinney *et al.*, 2023).

Social exclusion is commonly reported by people living with dementia or by their families (Hung *et al.*, 2020) due to the stigma associated with the condition, as well as a lack of understanding and empathy (Low & Purwaningrum, 2020; Swaffer, 2014). This stigma typically manifests in how people interact with those living with dementia, focusing on deficits associated with the condition, rather than recognising and supporting the individual's abilities and interests. (Wolfe, 2017). As such, the importance of providing avenues and opportunities for social inclusion for people living with dementia is being increasingly recognised.

Intergenerational (IG) programmes are one such avenue for community engagement. IG programmes refer to formal activities which bring different generations together in a meaningful way (Galbraith *et al.*, 2015; Park, 2015; Teater, 2016). The types of activities included as part of IG programmes vary widely. A scoping review by Galbraith *et al.* (2015) included studies of IG programmes which involved art, music, Montessori-based activities, mentorship, storytelling, and recreational activities. Further scoping reviews included IG programmes centred around dancing (O'Reilly *et al.*, 2024), as well as buddy systems and reminiscence activities (Gerritzen *et al.*, 2020). The existing literature has indicated a number of potential benefits of IG programmes, including: reducing loneliness (Pinazo-Hernandis & Carrascosa, 2025); increasing sense of purpose and usefulness (Galbraith *et al.*, 2015); reducing levels of disengagement (Lu *et al.*, 2022); raising awareness about dementia in children engaging in the activities (thus reducing stigma); and maximising the role of the community in social engagement with people living with dementia (Galbraith *et al.*, 2015; Teater, 2016). While much of the research in IG

programmes does not focus exclusively on people living with dementia, the positive effects appear to be consistent across different populations of residents in care homes or other settings, including people living with dementia (Baker *et al.*, 2017; Galbraith *et al.*, 2015; Gerritzen *et al.*, 2020).

Further research is, however, needed to better understand the nature of these potential benefits, including key considerations and challenges in designing IG programmes. Research to date has identified some such design and implementation considerations. For example, children and/or their caregivers may be hesitant to interact with people living with dementia (Galbraith *et al.*, 2015). This is consistent with a recent Qualitative Evidence Synthesis (QES) which found that both the people living with dementia and the young people/children participating often feel some trepidation in the early stages of IG interactions and may require reassurance from healthcare staff or teachers (Houghton *et al.*, 2022) to overcome these uncertainties. Similarly, a realist review by Simionato *et al.* (2023) identified the need for pre-programme training and support to reduce any initial uncertainty and/or anxiety, and to provide comfort and confidence as to what can be expected by taking part in an IG programme, both for the people living with dementia and the young people taking part. Other considerations relate to the specific activities chosen for IG interaction. The activities chosen for engagement are important, as the person living with dementia may feel infantilised by certain activities (Bagnasco *et al.*, 2020). In addition to avoiding infantilisation, individual and personal preferences may impact on engagement, and the degree to which activities feel purposeful and meaningful (Houghton *et al.*, 2022). Such findings highlight the need for careful consideration in the design and delivery of IG programmes, with reference to evidence-based design.

A scoping review by De Bellis *et al.* (2023) sought to further investigate what contributes to effective IG programmes. The 14 studies included in the scoping review were primarily from the perspective of residents of aged-care facilities (including people living with dementia), and youths who participated in IG programmes. Only one study included others involved in the activity (teachers, social workers, adult volunteers). This scoping review highlighted choice, comfort, engagement, and reciprocity as key elements of successful participation on the part of the residents. More specifically, studies reviewed by De Bellis *et al.* (2023) suggested that participation should be voluntary, with opportunities for breaks readily available. The duration and timing of IG engagement should also be carefully considered, and morning times may be optimal (Black, 2011). Shared activities should be enjoyable and meaningful for residents (Caspar *et al.*, 2019; Galbraith *et al.*, 2015), and it may also be beneficial to include activities in which the residents feel they can take a more direct role, such as providing mentorship to the young participants. In relation to the youth participants, the choice to participate, reduced academic demands associated with participation, and pre-training were identified as core elements of successful participation (Werner & Linke, 2013). As regards training, multiple studies reviewed highlighted the importance of educating youth about ageing and age-related illnesses as part of their preparation

¹ <https://www.who.int/data/gho/data/themes/global-dementia-observatory-gdo>

² <https://alzheimer.ie/creating-change/awareness-raising/dementia-in-the-media/>

³ <https://www.hse.ie/eng/dementia-pathways/files/model-of-care-for-dementia-in-ireland.pdf>

for participation in IG programmes. (Caspar *et al.*, 2019; Gerritzen *et al.*, 2020; Kim & Lee, 2018; Knight *et al.*, 2017; Werner & Linke, 2013).

Given the complex nature of the design and delivery of IG programmes, it is important that the perspectives of all involved be considered. While a previous QES by some of the current authors (Houghton *et al.*, 2022) extended the evidence base by synthesising qualitative research on the impact of IG programmes on younger participants, as well as the experiences and perceptions of people living with dementia, there remains less focus on the experiences and perceptions of healthcare staff, teachers, family members, and informal carers regarding IG programmes inclusive of people living with dementia. IG programmes typically involve cooperation between some combination of these various parties, and thus developing a more in-depth understanding of their experiences and perceptions is essential in (a) identifying factors which contribute to successful IG programmes and (b) informing the design and implementation of future IG programmes.

Why is it important to do this synthesis?

This synthesis will build on the QES by Houghton *et al.* (2022) which explored the experiences and perceptions of young people and older people living with dementia participating in IG programmes. This current QES will provide further insights from additional perspectives into how IG programmes are viewed, including barriers and facilitators to their implementation. This review will seek to synthesise the perspectives of those involved in supporting IG programmes, including teachers, nurses, and other health care staff. The experiences and perceptions of family members and informal caregivers, for example spouses or children of the person living with dementia; and the parents/guardians of the young people, will also be examined, to provide a more holistic view of IG programmes. QES brings together qualitative insights in a meaningful way that can inform policy and practice (Thomas & Harden, 2008). Integrating these findings with previously published reviews will provide robust evidence regarding key considerations when developing an inclusive IG programme in Ireland, thus providing appropriate and effective avenues for social engagement for people living with dementia and the young people who participate.

Objectives

The aim of this QES is to explore the experiences and perceptions of IG programmes on the part of healthcare staff, teachers, family members, and informal carers. The findings from this synthesis will provide valuable insights for the design and implementation of IG programmes involving people living with dementia in an Irish context.

The specific objectives are to:

- Explore the experiences and perceptions of healthcare staff and teachers regarding IG programmes inclusive of people living with dementia.

- Explore the experiences and perceptions of family members and informal carers regarding IG programmes inclusive of people living with dementia.
- Identify the factors that help or hinder IG programme implementation as perceived by healthcare staff, teachers, family members, and informal carers.

Protocol

The protocol is registered with Prospero (International prospective register of systematic reviews). PROSPERO 2025 CRD420251143155 (Houghton *et al.*, 2025). Available from <https://www.crd.york.ac.uk/PROSPERO/view/CRD420251143155>.

Methods

Criteria for considering studies for this synthesis

Types of studies

This review will explore qualitative primary research, incorporating a number of designs such as phenomenology, ethnography, grounded theory and more contemporary approaches. We will include studies that have used and reported on both qualitative data collection and analysis methods. Data collection methods may include semi-structured interviews, focus groups and observations. Mixed-method and multiple method studies that include qualitative methods of data collection and analysis will also be included if the qualitative component is clearly identifiable and can be extracted. Studies must be peer-reviewed. Studies where the full text is not available will be excluded.

Types of participants

We will include support staff, for example healthcare staff and teachers, who have direct and/or indirect experience of IG programmes inclusive of people living with dementia. We will also include family members and informal carers of people living with dementia who have taken part in an IG programme.

Types of interventions

IG programmes are defined as formal activities that bring different generations together in a meaningful way (Galbraith *et al.*, 2015; Houghton *et al.*, 2022; Park, 2015; Teater, 2016). The activities will range from play, art, education, dance, reminiscence activities, and recreation as identified above. There will be no exclusions based on activity-type, however we will exclude intergenerational experiences among family members. The IG programmes must be inclusive of people living with dementia who are over the age of 65, and young people. Studies focussing on people living with early to late stages of dementia will be included. Young people will be defined as below the age of 18. IG programmes involving pre-school and school aged children will be included. Those including younger adults attending third level education, or aged 18 and over, will not be included. The IG programmes must take place in community care settings, including nursing homes, residential care homes, assisted living facilities, day care centres and rehabilitative

centres. Studies based in hospitals and personal homes will be excluded (Zhang *et al.*, 2024).

Phenomenon of interest

The phenomenon of interest in this study is the experiences and perceptions of staff (healthcare staff and teachers), as well as family members and informal carers of people living with dementia, who have taken part in IG programmes. We will include studies that examine the acceptability, engagement, barriers and facilitators of IG programmes inclusive of people living with dementia provided the perspectives and experiences of the above participant groups are captured.

Search methods for identification of studies

The review will systematically search the literature using electronic databases and also purposively sample papers using citation searching, contacting key authors and following up of references lists as outlined in Booth *et al.* (2016).

Electronic searches

We will search the following electronic databases:

- Medline
- CINAHL
- PsychINFO
- ERIC

- SocINDEX
- Ageline
- Embase

Using guidelines developed by the Cochrane Qualitative and Implementation Methods Group for searching qualitative evidence (Harris *et al.*, 2018), search strategies for each database will be developed in consultation with an expert librarian (MS). We will not apply any limits on language, date or location. The search will be conducted by one author (OH) on all databases in one week. In addition to searching the databases outlined, we will conduct a cited reference search in search engines such as Web of Science and Google Scholar. Finally, we will contact key authors, of included studies, for any relevant unpublished data as well as seeking their expertise about studies that might meet our inclusion criteria as per EPOC guidance (Glenton *et al.*, 2022).

A summary of the electronic search string is presented in Table 1. Certain terms will be truncated, for example teacher* or program* to ensure all spellings are captured. We will adapt our searching of title and abstracts to the individual databases. We will report the results of searching, screening and included studies using the PRISMA flowchart (Moher *et al.*, 2009).

Table 1. Search string (Medline).

#	Searches	Results
1	exp Intergenerational Relations/	4772
2	(intergeneration* adj3 (program* or project* or learning or care or relationship* or activit* or practice* or exchange* or space* or cent*)).tw,kf.	1414
3	1 or 2	5692
4	exp Dementia/	229668
5	(Alzheimer* or dement* or amenti* or lewy* or kliver or benign senescent forgetfulness or frontotemporal lobar degeneration or neurocognitive disorder* or memory complain* or cadasil or pick* disease or Huntington* or CJD or JCD or creutzfeldt jakob).tw,kf.	363864
6	((vascular or senile or semantic) adj3 dement*).tw,kf.	14487
7	((cognit* or memory or cerebr* or mental*) adj3 (declin* or impair* or los* or deteriorat* or degenerat* or complain* or disturb* or disorder*)).tw,kf.	328505
8	Cognition/	142485
9	Cognition Disorders/	67539
10	Nursing Homes/	41423
11	exp Residential Facilities/	61052
12	((residential or long-term) adj6 (care or facility or facilities)).tw,kf.	52547

#	Searches	Results
13	exp Day Care, Medical/	5325
14	exp Long-Term Care/	29715
15	exp Independent Living/	14363
16	(Day adj3 (club or cent* or hosp* or care or unit)).tw,kf.	40023
17	(Nursing home* or retirement home* or community dwelling).tw,kf.	76389
18	((Senior or therapy) adj3 cent*).tw,kf.	8331
19	4 or 5 or 6 or 7 or 8 or 9	750514
20	10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18	213069
21	3 and 19	251
22	3 and 20	323
23	21 or 22	523

Data collection, management, and synthesis

Selection of studies

We will import all references into Endnote 21 and remove duplicates. Five authors (OH, CH, SS, EF, and EQ) will screen titles and abstracts independently to evaluate eligibility against our inclusion/exclusion criteria using Covidence systematic review management system. Where it is not possible to determine eligibility, the full text of the article will be retrieved. Two review authors (OH and CH) will independently review all full-text papers. Disagreements between authors will be solved via discussion, or if required, in consultation with a third team member. As necessary and appropriate, we will contact authors of potential included studies for further information. We will include a table listing the studies excluded from our synthesis at the full text stage and the main reasons for exclusion. We will collate multiple reports of the same study.

Sampling of studies

As QES aims for variation in concepts rather than an exhaustive sample, and because large numbers of studies can affect the quality of the analysis, if the review retrieves more than 40 eligible papers, we will develop a sampling framework to ensure richness and representativeness, as used by [Ames et al. \(2019\)](#). This will involve extracting data from all studies found such as participant characteristics (e.g. nurse/doctor/teacher/son/daughter; study setting (e.g. day centre, residential home); geographical location (including income level); intergenerational activity (art, storytelling, dance, mentoring); data richness (quantity and quality of data provided) and study objectives in order to develop a sampling framework.

Data extraction and management

We will import all full text articles into NVivo Version 2020. Data extraction and the thematic synthesis will be facilitated within NVivo ([Houghton et al., 2017](#)). We will extract three types of data from included studies: contextual information, methodological information, and the findings with author interpretations.

Data synthesis

The RETREAT framework developed by [Booth et al. \(2018\)](#) will be used to identify the most appropriate synthesis approach. It comprises seven domains: Review question, Epistemology, Timeframe, Resources, Expertise, Audience and purpose, and Type of data. It is anticipated that thematic synthesis, as described by [Thomas and Harden \(2008\)](#), will be used to generate analytical findings as they are useful for policymakers and practitioners ([Booth et al., 2016](#)). The primary data will include direct quotes from participants and the author interpretations of the data. This will be conducted within NVivo with guidance from a previous synthesis on how best to use the coding software ([Houghton et al., 2017](#)) and allows for transparency and clarity in the synthesis process. Two authors (OH and CH) will conduct the thematic synthesis with continuous input from all other authors at each stage. All of the authors will read and make contributions to the final paper.

Subgroup analysis

The potential for subgroup analysis will be determined inductively through the synthesis. Where there are sufficient numbers of studies found, this may include subgroup analysis based on the nature of the intervention (e.g. reminiscence activities vs. art vs. storytelling) the setting in which it is delivered (day centre vs. residential home) or geographical location.

Assessment of methodological limitations in primary studies

Two review authors will independently assess each study for methodological limitations and resolve disagreements through discussion with a third review author if needed. We will use an adapted version of the Critical Skills Appraisal Programme tool ([CASP, 2018](#)), which has been used in multiple Cochrane reviews ([Ames et al., 2019](#); [Houghton et al., 2020](#); [Meskell et al., 2023](#)). Methodological limitations will be assessed based on the following domains: context, sampling strategy, data collection, data analysis, support of individual

study findings in the underlying data, reflexivity, ethical considerations, and other concerns.

Assessment of confidence in the review findings

We will use the Confidence in the Evidence from Reviews of Qualitative research (GRADE-CERQual) approach, developed by Lewin *et al.* (2018) for this purpose. Application of GRADE-CERQual involves assessing the methodological limitations and relevance of studies contributing to a finding combined with the coherence of the finding and adequacy of data (Lewin *et al.*, 2018). GRADE CERQual will be applied to each of the summary findings to assess the confidence in the findings of each statement.

Review author reflexivity

As outlined by Glenton *et al.* (2022), it is important to consider the review team perspectives of the review topic for the purpose of thoughtfulness and transparency. We will develop a reflexivity statement to acknowledge our perspectives, how they may influence the review, and any amendments/modifications to the review process needed to ensure an inclusive representation of multiple perspectives. The Public and Patient Involvement (PPI) co-applicants will be critical to this stage of the review process in providing a broader range of perspectives as interest-holders (Akl *et al.*, 2024).

Dissemination of findings

The findings will be submitted to a peer-reviewed journal for publication. These findings also represent work package one of a wider project which seeks to identify the key components needed to develop a dementia-inclusive IG programme in Ireland that will enhance social connectivity and quality of life for people living with dementia; generate empathy and understanding in young people; and identify the barriers and facilitators to IG programme delivery. The findings of this QES will also be shared with interest holders (Akl *et al.*, 2024), including patient and representative groups via newsletters, social media and professional bodies.

Study status

The study has started. Currently the research team are engaged in screening.

Discussion

While there is evidence to suggest many potential benefits of IG programmes inclusive of people living with dementia,

further research is needed to understand the relationship between IG programmes and these potential benefits, how different parties experience IG programmes, and what are perceived factors that help or hinder IG programme implementation. IG programmes typically involve cooperation between some combination of various roles, including people living with dementia, young people, healthcare workers, teachers, family members, and informal carers. Understanding the experiences and perceptions of each of these parties is important in (a) identifying factors which contribute to successful IG programmes and (b) informing the design and implementation of future IG programmes. The purpose of this protocol is to systematically assess peer-reviewed qualitative research of the perspectives of healthcare workers, teachers, family members, and informal carers in relation to IG programmes inclusive of people living with dementia.

The outcomes of this QES will add to the existing evidence base informing the design of IG programmes, by expanding the synthesized findings to include healthcare staff, teachers, family members, and informal carers. Highlighting and learning from these perspectives will provide robust evidence regarding key considerations when developing an IG programme in Ireland, and thus provide appropriate and effective avenues for social engagement for people living with dementia.

Data availability

Extended data

The data below are available from the Open Science Framework repository, <https://osf.io/q5dmh>.

- Completed PRISMA-P checklist

Data are available under the terms of the Creative Commons Attribution 4.0 International Public License (CC BY 4.0). (Harney *et al.*, 2025)

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