Appendix II: Review study

What did we do?

We wanted to identify all studies that had examined the following question in adults aged 50 or older who had moved to a retirement community: "What is the experience of moving to a retirement community?". In order to capture experience we only included interview studies in the review.

Retirement communities were specified using the ARCO definition of self-contained homes for sale, ownership or rent where residents have access to 24-hour on-site staff, communal facilities and support if required. These communities could include independent living facilities, continuing care retirement communities, assisted living, or extra care.

We focused primarily on studies where the majority of participants made the move from the community into a retirement community. Studies where participants had made the move from one kind of retirement community to another were not eligible for inclusion.

The following kinds of housing were also excluded from the review:

- Residential care homes
- Naturally occurring retirement communities (NORCs)
- Rooms in private (family) homes

To identify all relevant studies we searched four scientific databases using search terms related to 'retirement communities' and 'qualitative studies'.

After removing duplicates we found 2,868 papers. Papers were independently screened by two investigators to determine whether papers should be included in the review (and disagreements were resolved by consensus). After this screening process 48 studies were identified that met criteria for the review.

**What kinds of papers did we find?**

Of the 48 studies, the majority were conducted in the USA (n=28) or Canada (n=5). The remaining studies were conducted in China (n=1), Australia (n=2), New Zealand (n=2), Korea and the USA (n=1), Finland (n=2) and Israel (a series of 5 studies from one author).

The most common kinds of accommodation examined were assisted living facilities (n=18, and n=2 mixture of assisted living and other). Other kinds of

housing examined included continuing care retirement communities (n=6, plus series of 5 studies from one research group), retirement communities (n=8), supported housing (n=2), senior housing (n=6), and residential aged care (n=1).

After synthesising the results across these different studies we found the following major themes: Decision to move, making the move, adjusting to life in the community, community life and influencing factors (these are also summarised in the thematic map).

Thematic map – systematic review
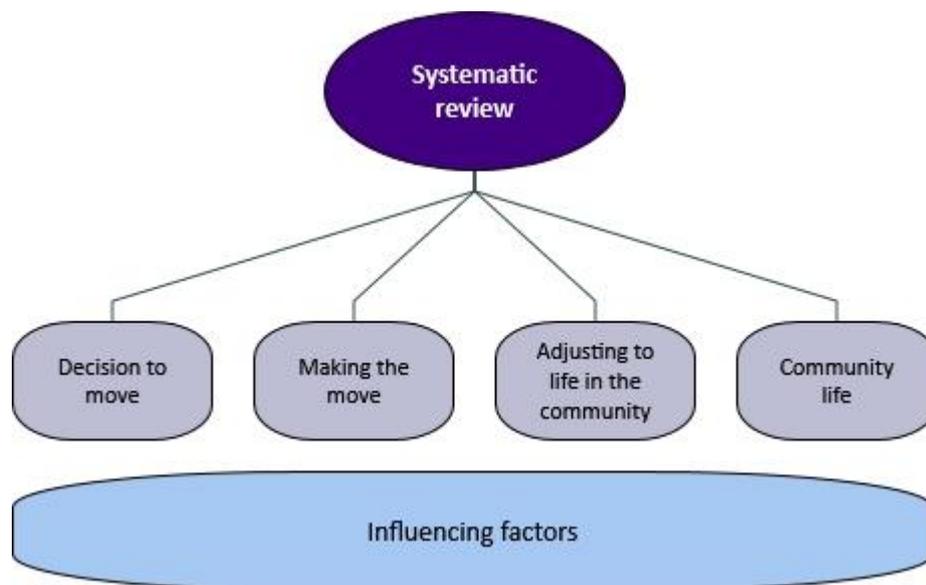
Decision to move

Residents spoke about why they made the decision to move to a retirement community. For different people the decision could be driven by different things:

Decision to move driven by a *critical event*. These were most commonly health events, the death of a spouse or issues related to general decline.

Decision to move seen as an *inevitable decision*. For some residents (particularly in countries where there is a cultural norm of moving to retirement communities), residents spoke of a general awareness that one day they might need to move to a retirement community.

Decision to move driven by different *push* (away from home) *and pull* (towards retirement community) *factors*. Common push factors included not being able to meet self-care needs, issues with home maintenance, health issues of self or

partner, lack of care and support, loneliness, or being alone. Common pull factors included not being alone, being in a safe and secure environment, access to care for current or anticipated needs, greater autonomy from living in a more inclusive environment, not being a burden to family, or being nearer children and family.

The decision to move could be made by different people, so a key sub-theme was **who makes the decision?** The decision is either primarily made by older adult, made in collaboration with trusted others, instigated by others or made by others. Overall, older adults make a smoother transition to a retirement community when the decision to move is instigated by themselves, whereas when the decision is made by another this is often linked with a poorer transition to the community.

Making the move

Residents spoke about the experience if making the move. The experience of making the move was captured by the following experiences and sub-themes:

The experience of **downsizing and letting go of possessions** was seen as a particularly emotional part of the move for many residents (and the part of the move that stayed with them after they had moved to the community). This part of the moving process could be difficult and stressful for some residents, whereas others spoke about the move in a more detached way. Residents frequently spoke of feeling as though giving their possessions a good home with someone else who would treasure them as being something that helped them navigate their distress.

A key part of the process of making the move was **deciding where to move to.** Residents would speak about particular pull factors for their community which included the cultural composition of the community, being with people like them (particularly if they were from a minority group), familiarity with and reputation of the community, joining friends, facilities and lifestyle in the community, social and community factors (such as friendly residents) and location (be that near where they had lived, or near family). Other considerations for residents included the cost of the community, living somewhere with a community feeling, marketing and promotional materials from the community and word of mouth. Deciding where to move to could also be influenced by different factors depending on whether it was the older adult or others guiding the decision.

Making the move to a community was something that some residents reported involved **pre-planning, anticipating the move and waiting to move in**. Some residents reported being on waiting lists, and for others they needed to live in temporary accommodation before a place became available for them.

Adjusting to life in the community

Residents spoke about adjustment in relationship to the initial move and ongoing adjustments and changes in the community. The following were some of the common things that residents spoke about:

The **importance of mealtimes** was discussed by many residents, mostly in those places where meals were provided for the residents. Some residents found having to eat particular food at particular times to be a distressing source of a loss of autonomy, whereas for others they were grateful for regular meals.

The **importance of community activities** was also spoken about by residents, as this was seen as an important way in which they could meet others and develop relationships within the community.

Across different studies there were different **adjustment patterns** expressed by residents. Some residents **struggled** with adjusting to life in the community and spoke about feelings of grief, loss, separation and loneliness from their previous life. Residents generally struggled more when they had to adjust to multiple issues at the same time, had not made the decision to move themselves and were struggling to accept that they were getting older. Some residents **adjusted well**, with a key indicator of a good adjustment across different studies being framed as 'acceptance' and gratitude. Other studies frames being well-adjusted as being open to new possibilities, with some residents speaking about personal growth, increased confidence and tolerance.

Residents also spoke about having to adjust to different aspects of **communal living**. These included navigating their own privacy and personal boundaries, but also learning to respect the privacy and personal boundaries of others. Adjusting to small personal spaces, and the ways in which they made those personal spaces feel like their own. Residents also spoke about having to adjust to living with lots of communal and shared spaces. A further adjustment related to the rules and regulations of living in a communal space, which could be difficult to navigate and seen by some as a loss of independence and autonomy.

As residents adjusted to life in the community they would also speak about the ways in which they **stayed connected** with others outside the community. This was important to most residents, and technology and transportation were mentioned as important ways for the resident to engage with others outside the community. However, some residents spoke of losing friendships and connections from the outside world after they had moved. Where residents were less easily able to leave the community they sometimes spoke of not being satisfied with the amount of contact they had with loved ones who couldn't visit as often as the resident desired. Residents also spoke of staying connected to friends and family who had passed away by actively remembering these people.

An important adjustment to living in a retirement community is the way that the older adult **makes friends and connections** with others. Different residents have different **motivations** for making friends and connections, for some they desire deep and meaningful friendship within the community, for others they desire companionship and neighbourliness. An important modifier is whether a person **self-identifies** as being a 'people person' or whether they are someone who values solitude and time alone. The **process of establishing friendships** is done by making use of common mealtimes, community activities, using communal spaces, taking on voluntary roles and going to welcome events. The first impressions that people had towards one another were important in establishing whether a deeper friendship would be saught. Likewise, **resident characteristics and familiarity** (in terms of similar interests, background and culture) all helped people to establish connections with others. Many **existing residents** also spoke about the ways in which they would welcome new residents to the community, helping new residents feel welcome, signposting them to important things an helping support them through the initial adjustment. There were also some **difficulties** mentioned in terms of establishing connections in terms of infiltrating established groups and cliques, being a source of gossip or bullying, personality clashes, being overwhelmed, or rudeness.

Some residents also mentioned a broader **existential adjustment** they went through on living in a retirement community. This was linked to an increasing awareness of age, ageing and their own death. For some older adults, being older was seen as an honour and privilege, whereas for others it was a source of distress where they would focus on potential future decline. Some residents struggled with thinking of themselves as 'older', and for many this internalised

ageism would be reflected in the way that they spoke about others who had physical or cognitive difficulties.

Community life

After the process of adjusting to life in the community the resident speaks about day-today life in the community.

There are a number of ***positive aspects*** of living in a retirement community that residents speak about. These include the community as a place of ***companionship***, where residents don't have to be alone if they don't want to be. Others positive included neighbourliness, providing care and support, showing empathy and compassion to others, sharing food and shopping feeling accepted and belonging and a broader sense of togetherness within the community. The community would also be spoken about as a place of ***safety and security***, where residents could have peace of mind particularly in terms of any potential future health and care needs.

Some of the ***negative aspects*** of being in the retirement community included feeling as though one has been ***institutionalised*** (particularly in terms of set mealtimes, forced to participate in activities and having to do certain things at certain times. Other issues included gossiping, bullying, physical confrontations and rudeness.

Residents spoke at length about their ***social and community relationships***. Different residents have different ***patterns of interaction*** within the community which is primarily related to the extent to which they have an inside versus outside community social life, and their health and possible disability (i.e., the extent to which a person wants or can get involved with others). Many residents spoke positively about ***volunteering and community roles*** which gave them a purposeful life within the community. Furthermore, across a number of studies having channels whereby residents could engage in ***advocacy*** for themselves and others (e.g., community-staff forum), were important for maintaining staff-resident relations. Some residents mentioned ***inclusivity issues***. These could be related to lack of accessibility of activities led to them not being able to participate (e.g., not being able to hear). Some residents spoke negatively about those who they saw as being frail or having dementia, and there could be a strong sense of 'othering', and at the most extreme those people with disabilities could be actively excluded from activities. However, some residents spoke about others with disability with empathy and showed understanding and

a willingness to make small adjustments to make sure everyone was included. There was also an awareness that different residents had ***different depths of relationships with others in the community***, this could range from strangers, through to describing other residents as family. Inviting people into private space was seen as a marker of deeper friendship. While some people had good relationships there was an awareness that many people within the community could be ***alone and isolated***. People could be both isolated from people within their community, but also people in the outside world. One recurring theme across different studies would be a fear of dying alone.

Influencing factors

Influencing factors were those things that influenced how residents navigated the move to a retirement community.

Life history shapes a person's personality, mindset, and how they navigate changes and their motivations for and ways of making connections with others. For those who have experienced previous major life transitions, any subsequent transition is often framed in relation to previous transitions and how these were navigated. Furthermore, a person's residential history was acknowledged as influencing how they feel about a new environment.

The ***context of a move*** was something that could impact on subsequent adjustment. The motivations and expectations around the broader context of a move (social, financial, health, environmental and whether decision was autonomous) all influence where a resident can move, why they move and how they adapt and adjust.

The amount of ***autonomy, control and independence*** that a person has throughout the experience of the move influences how they adjust. For the resident being able to hold onto control and their sense of self in order to maintain their dignity, independence, health and social connectedness help them to adjust to life in the community. Furthermore, wanting to maintain independence by being in an inclusive environment is a key draw for people to retirement community living. The amount of autonomy that a person has in deciding whether and where they should move to, and the extent to which a decision is forced on them can shape the whole adjustment process to a move. Those people who had a move forced upon them rather than choosing to move generally adjusted less well.

The process of adjustment was framed as ***balancing gains and losses/negotiation*** across a number of studies. At each stage of the move people could weigh up the pros and cons of whether they would move, where they would move to and the broader gains and losses that they got from living in a retirement community.

A key influencing factor was ***familiarity***. This could be in terms of broader life experience, familiarity with the retirement community location, familiarity with communal living or finding common ground/familiar interests and characteristics with other residents. When faced with something unfamiliar (i.e., moving somewhere new), people will naturally be drawn to the familiar as this helps them feel comfortable.

There were also a number of ***individual differences*** that could be observed across different studies which influenced how residents adjusted to life in the community. Where people had less favourable attitudes towards older adults and older age they tended to struggle more with adjusting to life in a retirement community. These negative attitudes could also lead to issues with inclusivity of those who had cognitive and physical difficulties. Those people who adjusted well typically had more positive and open-minded attitudes towards change. Other individual differences that influenced adjustment included whether a person moved into a community as part of a couple of as an individual, their gender, their health, and their mindset and personality.

A person's ***cultural norms and identity*** also influence their adjustment to living in a retirement community. People were often drawn to communities that aligned with their own culture and identity (particularly when from a minority group), and could struggle to adjusting to life in a community when day-to-day life did not meet their own cultural norms. For instance, food was often spoken about as being important for cultural identity and when the food served did not meet what residents were used to this could be a source of notable displeasure.

The ***role of others*** could be seen as helping or hindering adjustment. The most important others were children and family. The role of others could be seen in terms of offering social support (generally helpful), through to seeing social control where older adults has little say or autonomy in what happened to them (generally hindered adjustment).

A persons socioeconomic status has a large influence on how much they can afford to spend when they move and the amount of choice they have.