SUPPLEMENTARY FILE 4: Original quotes

The elders

- Active participation:

On their own:

“I went as far as I could. When I got to where I couldn’t take care of myself the way I wanted to, then it was time to look and seek someplace and to talk and ask questions, and that’s just what I did, and here I am. Somebody knew about this place. They told me about this place, and I didn’t seek anything else. I didn’t ask too many questions. They answered all the questions I wanted to know in the way I liked it. I told my sisters and my doctor where I was going. It’s very much like this all the way. I make my own decisions . . . don’t depend on nobody. Nobody push me back when I’ve made up my mind.” [Groger 1994: Elder] (OQ1)

Keeping control and managing their everyday life:

“But as long as we can make it work, we think it is the best. And if we can’t manage in the house anymore... we can get help with gardening and cleaning and so on. It is better than going away to a place where you might not feel comfortable” [Gabrielsson-Järhult and Nilsen 2016: Elder] (OQ2)

Pre-emptively:

“... see that’s why I want to do it now, a lot of people wait so long that the decision’s taken out of their hands. And then it’s not a voluntary decision.” [Walker and McNamara 2013: Elder] (OQ3)

- Some participation:

The elderly accept decisions made by other people:

“She (daughter) kept telling me, mother, you should be in a continuing care retirement community. I didn’t really want that, to tell you the truth. But, I had no choice.” [Ayalon 2016: Elder] (OQ4A)

“I didn’t want to leave home. They never gave a chance... I was railroaded.” [Iwasiw et al. 1996: Elder] (OQ4B)

The elders are listened to and their opinions are taken into account:

“I asked him: ‘What do you think of this place?’ And he said: ‘It’s all right’” [Ducharme et al. 2012: Family member] (OQ5)
Respecting the elder’s opinion:

“She definitely understood what I said. She shouted ‘no’ over and over with increasing volume and a look in her face expressed ‘over my dead body’, totally terrified. We would have had to move her by force, so we refused. It is a hopeless situation”. [Fjelltun et al. 2009: Family member] (OQ6)

Postponing the decision to relocate:

“Deep down, ideally, he should be in a nursing home, period. That’s where he should be and he should go of his own volition. Ideally, that’s how I see it. There would be people there round the clock, he wouldn’t be alone.” [Ducharme et al. 2012: Family member] (OQ7)

- The elders do not decide:

The decision is taken for them:

“I had no choice. ... They just told me I was coming here and that was it.”; “They [my son and his wife] made the decisions already.” and “I had no choice.” [Johnson and Bibbo 2014: Elder] (OQ8)

The elders are informed of the decision once it is already made:

“I didn’t decide. The hospital, somebody did, I don’t know. [...] When my doctor told me I had to go to a home, I didn’t try to fight it but I cried like a baby. I didn’t know what I was getting into. I still don’t know what I am into. I know I’m in a home, that’s all.” [Groger 1994: Elder] (OQ9)

The elders have been deceived:

“She lied to me like a kid.” “Well, I don’t know anything. I ended up here like a mouse in a trap.” [Johnson and Bibbo 2014: Elder] (OQ10)

Family members:

- Taking into account the elder:

The family members take on a mediator role:

“If she can get the help she requires and she can live the rest of her life where she wants to be and where she’s happy, that means more to me than anything else . . . her husband died in the family home and I think that’s what she wants to do . . . I think if she had a fall and it was her last fall in her own home I think she’d be the happiest woman in the world.” [Heppenstall et al. 2014: Family member] (OQ11)

The family members postpone the relocating decision:

“My sister and I brought her to visit the place. She was willing to go but not right away. It was always later with her . . . she felt she was still too young to go there” [Ducharme et al. 2012: Family member] (OQ12)
The family members lie to the elders:

“We tried to keep it positive. Not say that it’s definite, that he was leaving the house. It’s lying, but it’s lying for a good reason. It’s called a white lie” – [Légaré et al. 2014: Family member] (OQ13)

The family members don’t act against elder’s will:

“She definitely understood what I said. She shouted ‘no’ over and over with increasing volume and a look in her face expressed ‘over my dead body’, totally terrified. We would have had to move her by force, so we refused. It is a hopeless situation” – [Fjelltun et al. 2009: Family member] (OQ14)

- Not taking into account the elder:

Due to the elder’s cognitive impairment:

“Of course, the day that we moved her where she’s now, well, I didn’t go up to her and say: ‘OK, mom, it’s time to go to the nursing home and you’re never coming back,’ of course not. Maybe I should have, but I didn’t see the use of that, I mean, she more or less realized what happened.” – [Ducharme et al. 2012: Family member] (OQ15)

Deciding without the participation of the elders, just informing them once the decision has already been made:

“I had no choice. ... They just told me I was coming here and that was it.” – [Johnson and Bibbo 2014: Elder] (OQ16)

Professionals:

Completely taking on the decision:

“The hospital didn’t want me any more. The hospital decided” – [Heppenstall et al. 2014: Elder] (OQ17)

Other relevant participants:

Validating the decision:

“I had no qualm about putting her here because everything I had heard, and people I had talked to. I have friends that have family members here, a girl that works for me, her father is here. Everyone told me that they get good care.” – [Dellasega and Mastrian 1995: Family member] (OQ18)