Research into practice: using a neighbourhood lens to understand the community-based experiences of people living with dementia

Title

Dr Richard Ward and Dr Martin Quirke

Neighbourhoods
Our People, Our Places

Our Connected Neighbourhoods
A Dementia Enabling Communities Project

BE THE DIFFERENCE

Background: Shrinking worlds

A 'shrinking world' tends to lead to an overall decline in independence as places such as town centres become 'no go' areas, and even shopping locally often becomes dependent on being accompanied by a carer'

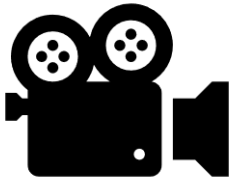
(Duggan et al, 2008)

Project overview
Neighbourhoods: our people, our places

- **Three fieldsites: Central Scotland; Greater Manchester, Östergotland (Sweden)**
- **Three main methods: Interviews repeated after 8-12 months**
- **Participants: 67 carers; 61 people with dementia**

71 walking interviews

107 network maps or sit-down interviews



57 home tours (UK sites only)

Walking interviews

Making places

Viv: There's a tree, its name is the 'knock knock' tree because somebody has painted a white door and has put a tiny little door knocker on it. So you knock on the door to see if the fairies are in, and of course they never are, they've always gone out to see to fairy business.

I: So do they want… every time they [grandchildren] come that's something they want to do?

V: Yes, and the seven year old granddaughter loves going on adventures and so as soon as we're in the valley she'll say, where are we today, grannie, and I have to think. So I've turned it round and say, well where do you think we are, and we have all sorts of adventures. We're in such and such a different land…

(Viv, person with dementia, Manchester)

Ruth: So my library was a bit of a.. I knew there was a problem but I just didn't know what it was and it took ages before it got to a crescendo where suddenly there's a problem. And then when I… my… I just took it upon myself and went up to the girl and said 'look I'm tired of getting these letters. And they're threatening in nature. I've been a member of this library since I was a wee lassie. Why would I now be getting fined?' You know. And then I said you know, 'I've got a diagnosis of dementia'. … I says 'is there not something you could put on the system' you know 'cause I want to use the library, I've always used the library'. Why would I stop using the library!

I: So from the library's point of view, they've…

R: They've come up trumps, now they're very aware

(Ruth, person with dementia, Scotland)

Key messages from the research

- Potential for influencing the social environment was greater than making changes to the material environment
- Participants often found social solutions to challenges presented by the physical environment
- Multiple barriers to neighbourhood accessibility underlined the historical exclusion of people with dementia from design and maintenance of the built environment
- Yet… walking interviews demonstrated the potential to learn from people with dementia about inclusive and supportive design

Research into practice:
Our Connected Neighbourhoods

Arts strand

- Creative approaches to engagement and inclusion

Digital strand

- Promoting digital citizenship through training and introduction to different types of everyday technology

Environment strand

- Supporting activity to change the socio-material environment

Our Connected Neighbourhoods

A Dementia Enabling Communities Project

life changes trust

art link central

Alzheimer Scotland
Action on Dementia

MFN

Macrobert Arts Centre
University of Stirling

NHS Forth Valley

dsdc
Dementia Services Development Centre

Stirling Council

Sve

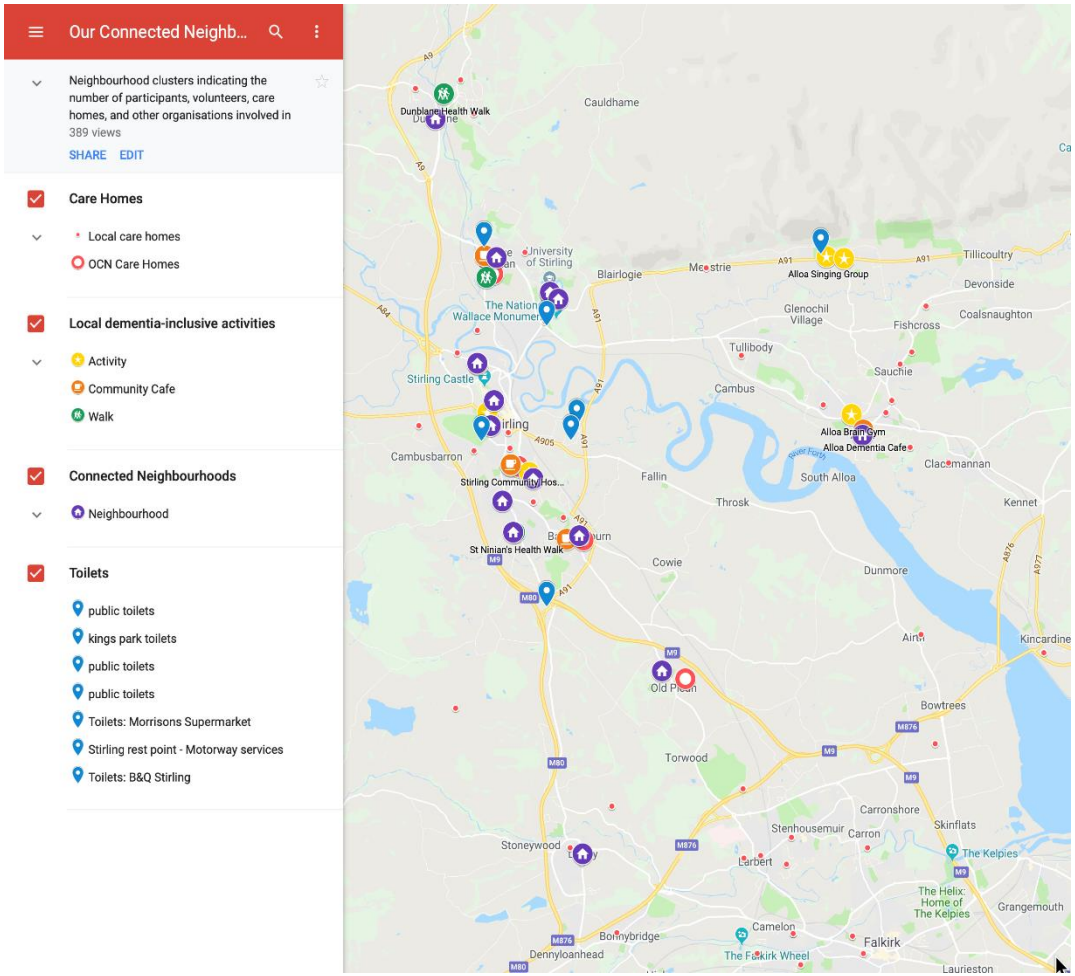
ssafa the Armed Forces charity

Town Break
Dementia Support Services

UNIVERSITY of STIRLING

BE THE DIFFERENCE

Environment Strand Activities: "Experiential Mapping"



PST workshops

- People living with dementia
- Supported by volunteers
- Neighbourhood clusters

Public Environment Assessments e.g:

- Supermarket
- Café
- Public Park

Mapping Local Assets and Barriers

- Co-produced maps
- Digital and analogue

Design Charrettes

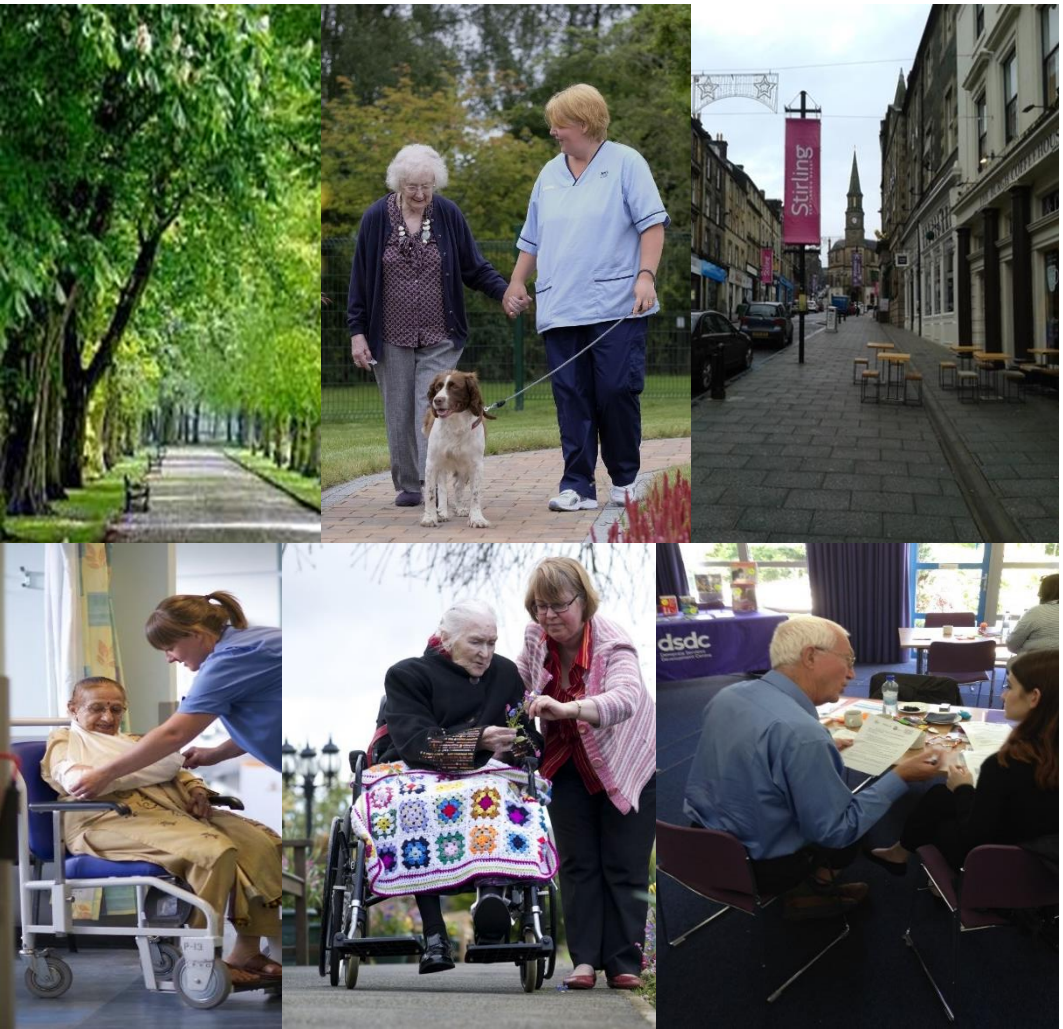
- Stirling City Region Deal
- Local Outcome Improvement Plans

Publicly Available Resources

- Environment/neighbourhood tools
- Lessons learned /case studies

BE THE DIFFERENCE

Place Standard Tool workshops



Identifying Strand Participants

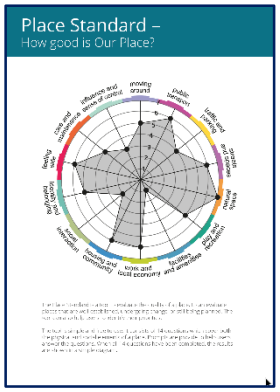
- Partner organisations
- Interviews establish interest
- Neighborhood cluster groups

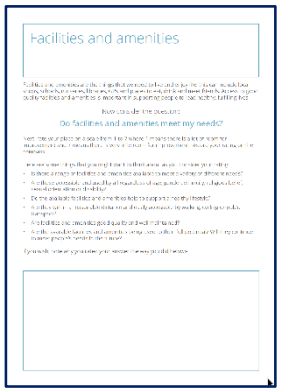
PST workshops

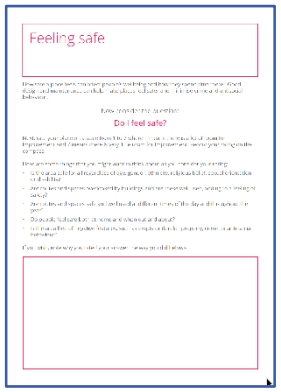
- 22+ People living with dementia
- 3 Neighbourhood clusters (so far)
- Care Homes & Public Venue
- Group workshops (7+ PLWD each)
- 11 Volunteers

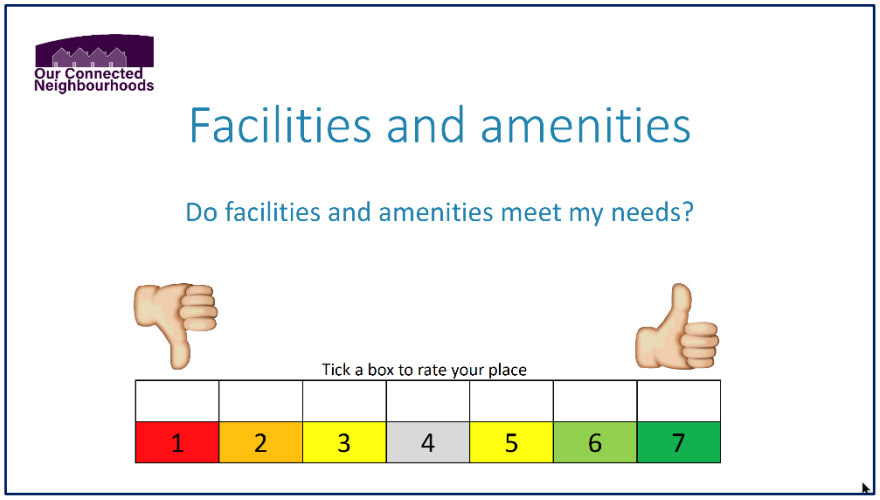
BE THE DIFFERENCE

Dementia Inclusive Considerations for PST workshops









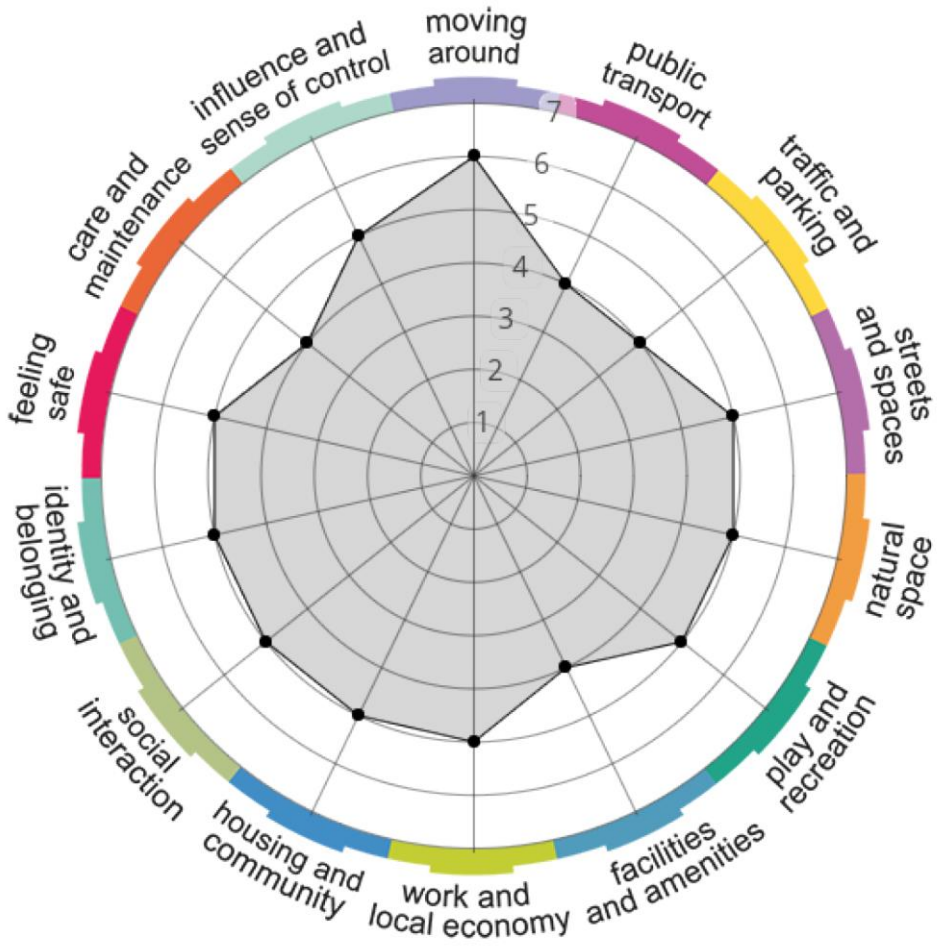
Challenges of Cognitive Impairment

- Difficulty with recall
- Avoid abstract themes
- Supportive communication
- Other impairments (esp. hearing and mobility)
- Minimise excess information
- Adaptive approaches

Other Important Considerations

- Physical and Sensory Setting
- Group Sizes
- Relationship Building
- Organisation and Timing
- Individual communication

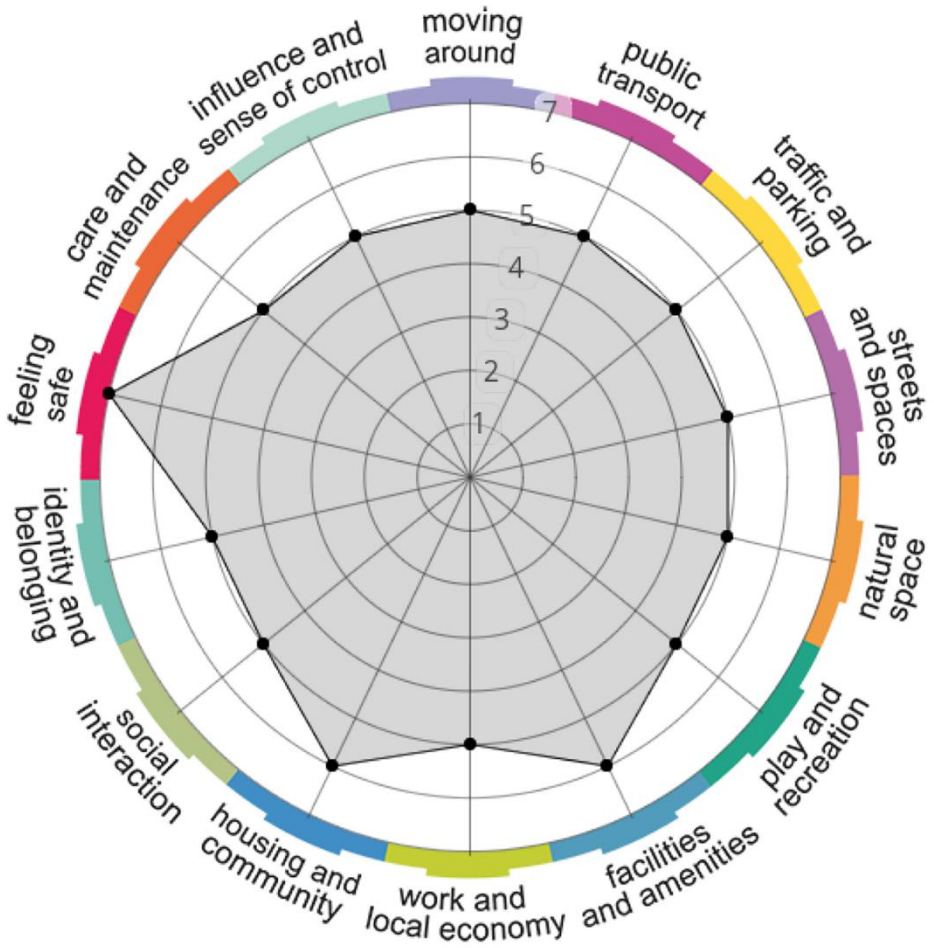
Living in the Community: Town Centre



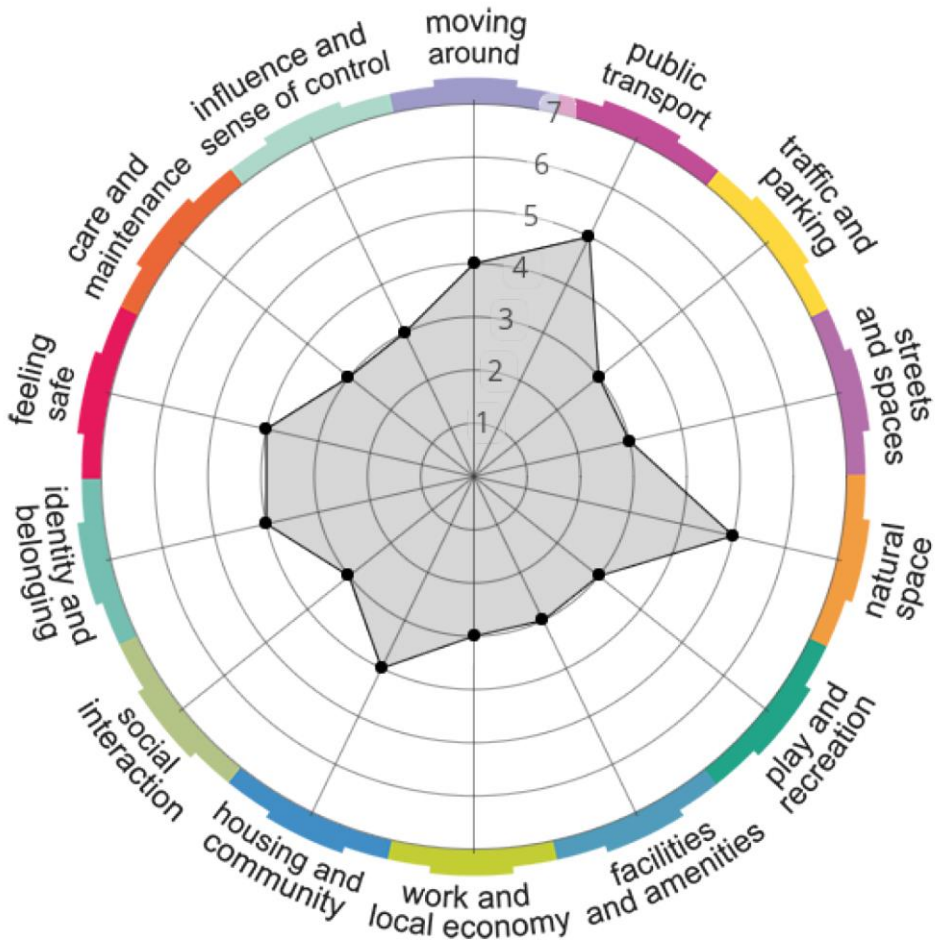
7 people living with dementia
Various physical disabilities
SIMD 10% and 30% most deprived

Challenges:
Public transport
Crossing the street
Opportunities to socialise
Weather
Anti-social behaviour

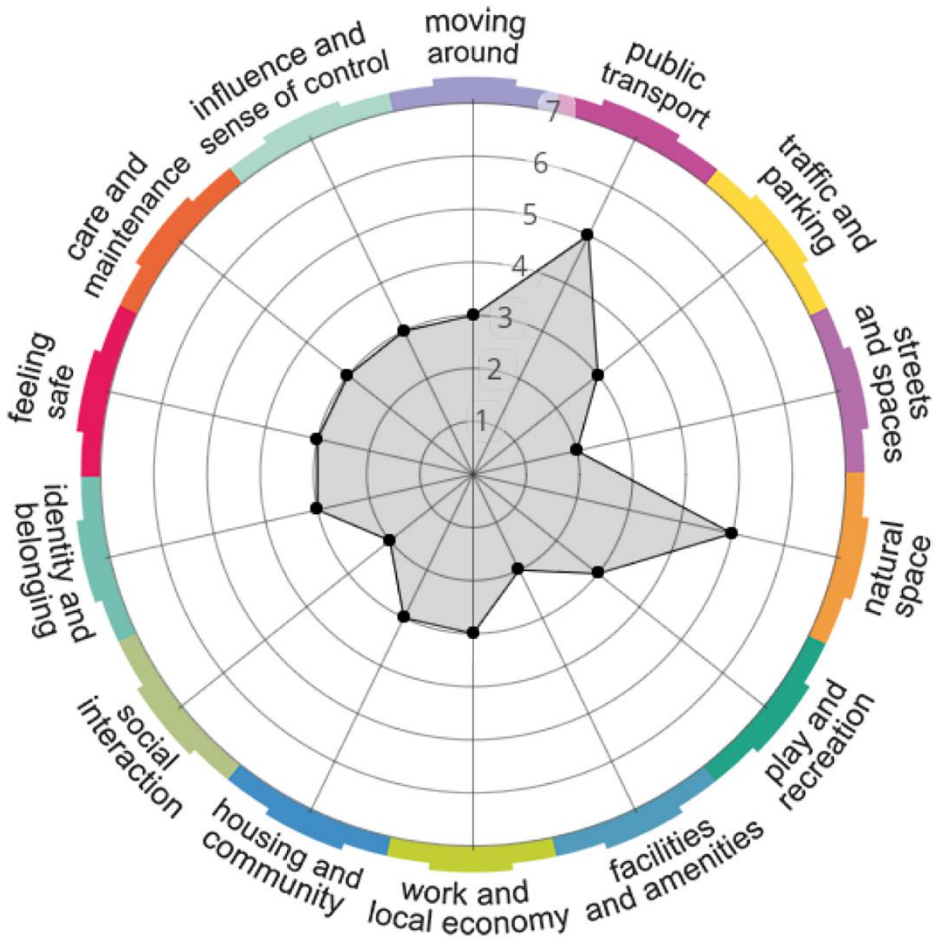
Under resourced Care Home: Wealthy Area



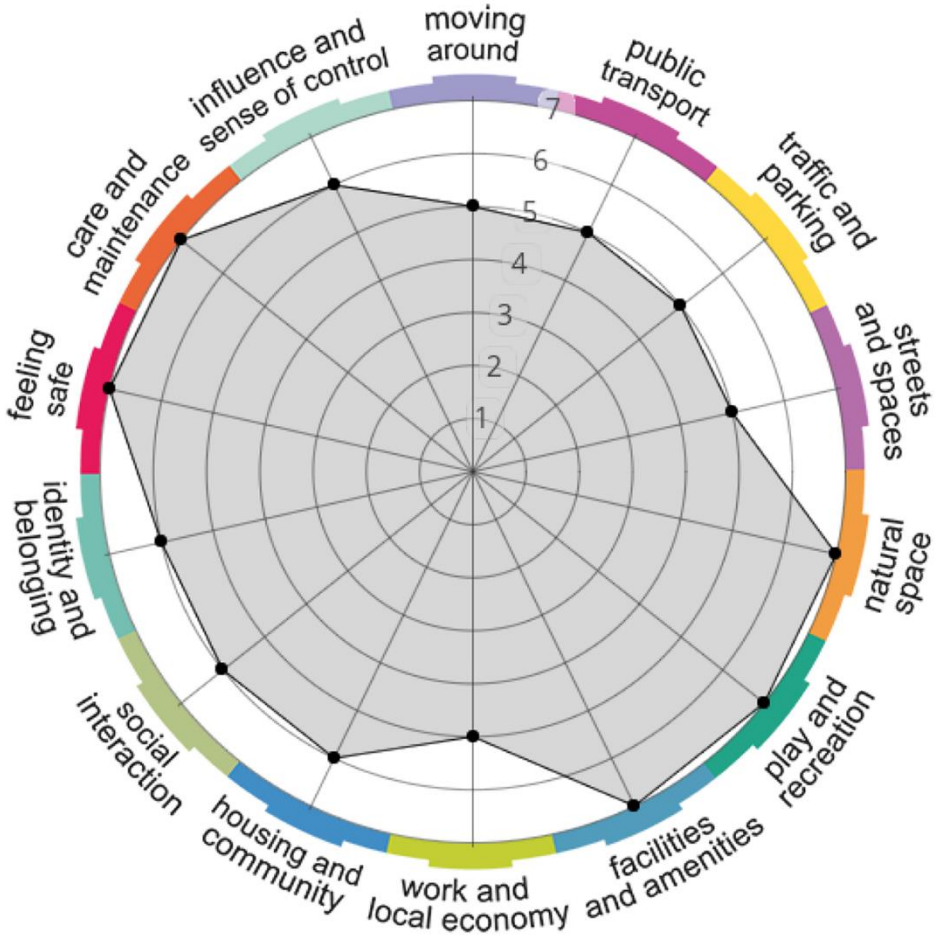
Wider Public: Deprived Area



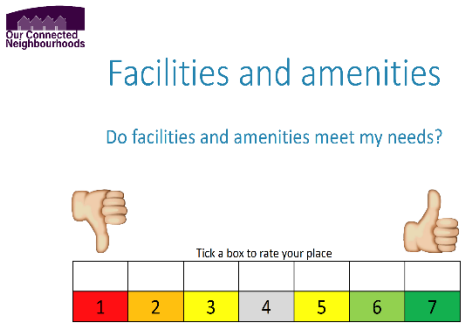
Public Over 55yrs: Deprived Area



Well Resourced Care Home: Deprived Area



Adapting the PST for future



Consider

- Visual theme prompts
- Testing simplified tools
- Neighbourhood walks
- Maps and local photos
- Relationship building (trust)
- Smaller groups & 1:1
- Supported use of digital PST
- Multiple modes of communication (Incl. Talking Mats, flashcards etc).

Upcoming Activities

- PST Themes for design charrettes
- PST for local asset mapping

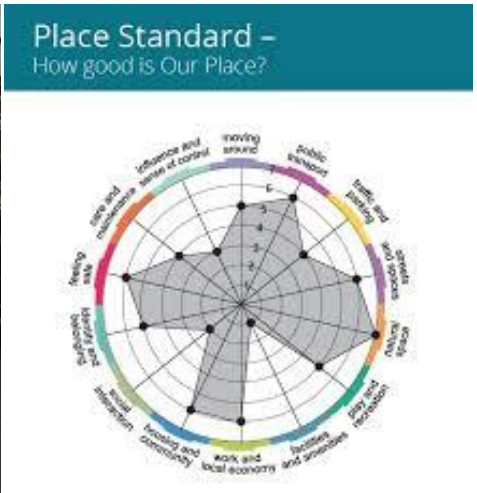
Our Connected Neighbourhoods

A Dementia Enabling Communities Project

Conclusions:

Involving people living with dementia in the PST process:

- Brings unique understanding of the environment and its multiple impacts
- Helps us to identify and challenge normative/ableist design
- Demonstrates the need to ensure minority perspectives are seen, heard and acted upon in the PST process
- **Most importantly – how do we translate PST learning into meaningful change?**



life changes trust

BE THE DIFFERENCE