

Testing the ASCOT Easy Read with community dwelling older people with cognitive impairment in Australia



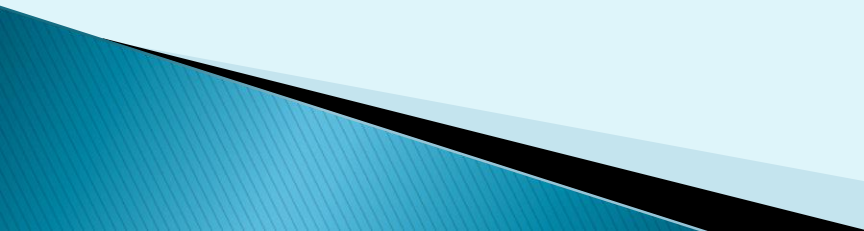
Dr Lyn Phillipson
NHMRC–ARC Dementia Fellow
Australian Health Services Research Institute
University of Wollongong

James Caiels and Ann–Marie Towers
Research Fellow
Personal Social Services Research Unit (PSSRU)
University of Kent



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Agenda

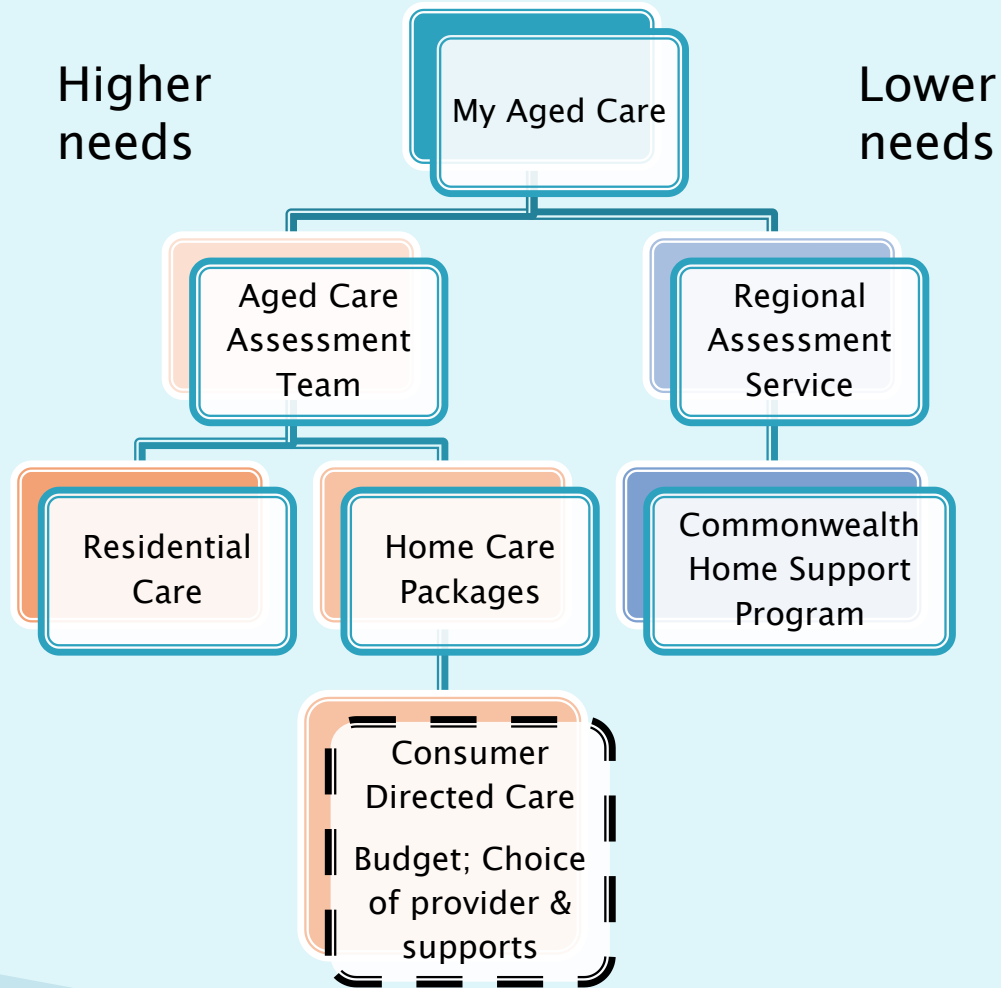
- ▶ Australian context – aged care reform
 - ▶ Need for alternative tool formats to assess SCRQOL in Australia
 - ▶ Testing ASCOT ER suitability for older people with cognitive impairment
 - ▶ Results
 - ▶ What next?
- 

Australian Context

- ▶ Major social care policy reform in aged & disability sectors, July 2015
- ▶ Supports for older people delivered through a new 'market driven system that is fair, flexible and sustainable' (DHS, 2017)
- ▶ Aim to support:
 - better access to information;
 - easier access to a range of aged care services;
 - more support for care at home;
 - more choice and control



National Aged Care Programs



What is consumer directed care?

- ▶ Home Care Packages & CDC
- ▶ ‘Model of service delivery designed to give more choice and flexibility to consumers...who delivers care and...types of care and services’.
- ▶ Increased transparency and accountability around costs of care
- ▶ People who can afford to contribute to costs of care should



Dept of Health 2017

Who is making the choices?

- ▶ Aging with cognitive impairment – currently 300K people living with dementia – will increase to 900K by 2050 (Access Economics 2012)
- ▶ Aging with frailty – prevalence of multi-morbidity in older persons ranges from 55 to 98% (Marengoni, Angelman et al 2011)
- ▶ Aging within a multicultural society – 35% of the population >65 years born in another country (ABS 2012)



Assessment of outcomes in community dwelling population?



- ▶ Suitable and feasible methods for home care package clients?
 - Aging at home with complex needs, cognitive impairment (dementia) in a multicultural society
 - Most research with people with dementia done in care homes

Research with people with dementia

- ▶ **Methods and Motivations (Wilkinson)**
 - People with dementia have a right to be included and to have their voice heard
 - People with dementia want to be included
 - Many with dementia can provide consent (+ proxy)
 - Assent should also be assessed
 - As long as benefits outweigh the risks then people with dementia should be included
- ▶ **Home Care Packages Program**
 - Older people with complex needs are ‘consumers’
 - Providing a voice is consistent with principles of CDC
 - Can often show preferences even if cant make the corresponding decision (Miller at al 2016)
 - Insights into lived experience can improve service delivery

Inclusive Methods

- ▶ Methods can be adapted
 - Interviews (Cridland, Phillipson et al 2016)
 - Surveys – e.g. DEMQOL, QAL-AD (early)
 - Principles of ‘Easy Read’ (Jarrett 2005; DRC 2009)
 - Easy words and short sentences
 - Big writing
 - Pictures
 - Sound – so that you can listen to the words*
- ▶ Methods can also be enhanced
 - Doing, creating, stimulus (e.g. pictures), use of aides (e.g. talking mats), observation (Phillipson and Hammond 2017)

ASCOT

- ▶ Adult Social Care Outcomes Tools (ASCOT) (Netton et al)
 - control over daily life; accommodation cleanliness and comfort; personal cleanliness and comfort; safety; social participation; occupation and dignity
 - Multiple formats
 - Self-complete (SC4); Interview (INT 4), Proxy, Carer
 - Easy Read Survey
 - Multi-methods (Care Home 3) – Interview, Proxy Interview, Direct Observation
- ▶ ASCOT in Australia
 - SC4 –adapted and trialled in Home Care Packages (Fine, Eagar et al 2016). Feasible and valid but half the population used ‘proxy’ completion
 - National QI pilot (2015–16) – Pilot of Consumer Experience and Quality of Life Tools in residential aged care

ASCOT Easy Read

- ▶ ‘People who have a disability, impairment or sensory loss should get information in a way they can access and understand.’ (Accessible Information Standard, NHS, 2017)
- ▶ ASCOT-ER (Turpenny, Caiels et al 2016))
 - Aim – create ASCOT survey that is more supportive of completion by people with disability or cognitive impairment
 - Used the principles of Easy Read
 - Development and beta -testing (Younger people with Intellectual Disability & Autism)
 - RQ: Suitable for older people with cognitive impairment?







This question is about what you eat and drink. Think about if:

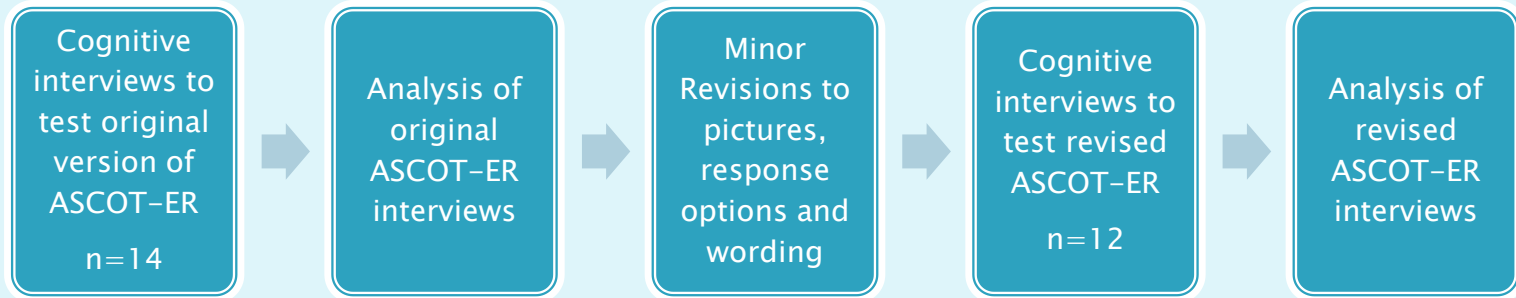
- You can have the food and drinks you like.
- You have enough food and drinks to keep you healthy.
- You can eat and drink as often as you need to.

What do you think about what you eat and drink?

Please tick (✓) 1 box

- | | | |
|--|--------------------------|---|
| I get all the food and drink I like when I want. | <input type="checkbox"/> |  |
| I get enough of the food and drink I like when I want. | <input type="checkbox"/> |  |
| I get some of the food and drink I like when I want, but not enough. | <input type="checkbox"/> |  |
| I do not get any of the food and drink I like so I might get ill. | <input type="checkbox"/> |  |

Method



- Cognitive Interviewing – Staggered reveal method
 - Show picture and describe
 - Show text and discuss
 - Show response options and choose
 - Ask about pictures and text and any need for changes
- Minor changes to words and pictures
- Further trial to assess suitability for self-completion

Results

- ▶ Minor amendments were used to make it more suitable for the older age group
- ▶ Enhancements to text size, picture contrast
- ▶ Minor modifications to response options and pictures to suit the older cohort and the Australian context.



lines from the ends of poems. For as
fewer than 40 lines, only a few have
remained have well over 40 lines, the
On the other hand, a similar process
A similar process
all
page size. This isn't always possible,
longest lines of poetry until the margin
line. This limit will depend partly on
When they consist mostly of lines

**Clear,
readable
content.**

| Demographics | Total, n = 26 | Original ER, n = 16 | Modified ER, n = 10 | P value* |
|--|-------------------------|--------------------------|-------------------------|----------|
| Age (Years), mean (SD) | 63 – 99 82.51 (9.89) | 63 – 99 79.96 (10.98) | 77 – 96 86.59 (6.36) | .063 |
| LOTE, yes n (%) | 2 (7.7%) | 2 (12.5%) | 0 | .508 |
| Gender, Female n (%) | 15 (57.7%) | 11 (68.8%) | 4 (40%) | .228 |
| Education, High school or above, n (%) | 20 (76.9%) | 12 (75.2%) | 8 (80%) | .894 |
| Carer, yes, n (%) | 19 (73.1%) | 9 (56.3%) | 10 (100%) | .023 |
| Co-resident, yes, n (%) | 6 (23.1%) | 3 (18.8%) | 3 (30%) | 1.00 |
| Dementia, yes, n (%) | 9 (34.6%) | 6 (37.5%) | 3 (30%) | 1.00 |
| Mini-cog, mean (SD) | 2.31 (1.62) | 2.19 (1.43) | 2.50 (1.43) | 0.64 |
| HACC, mean (SD) | 9.50 (3.07) | 9.50 (3.18) | 9.50 (3.06) | 1.00 |
| Package Level (1–4), mean (SD) | 2.58 (1.07) | 2.81 (1.22) | 2.20 (0.63) | .107 |

Results – Safety in the home



This question is about how safe you feel in your home.

Feeling safe means that you are not worried about:

- Being bullied or abused.
- Falling or getting hurt.
- Being attacked or robbed.



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Results – Safety Local Area



This question is about feeling safe when you go out in your local area.

Feeling safe means that you are not worried about:

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- Being attacked or robbed.



This question is about feeling safe when you go out in your local area. Feeling safe means that you are not worried about:

- Being bullied or abused.
- Falling or getting hurt.
- Being attacked or robbed.

Results – Occupation



This question is about how you spend your time.

Think about all the things you do during the day. You could think about:

- Your free time.
- Going to work, college, or volunteering.
- Housework.




This question is about how you spend your time. Think about all the things you do during the day. You could think about:


- Your free time.
- Going to a group activity or volunteering.
- Housework, gardening, reading or watching TV

Results – Visual response scale

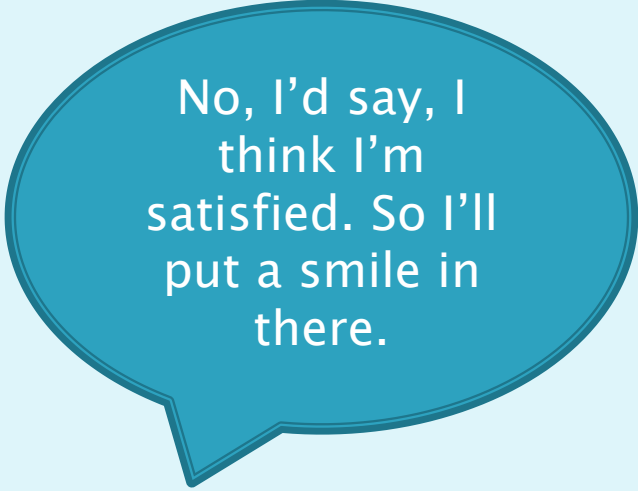
- ▶ There were mixed response with regards to the use of the smiley faces to represent the four text response options.



No I didn't look at any of those smiley things at all.



I don't know.
No good getting around grumpy, is it.
What have we got here.
We've got a smile on our face so that's right.

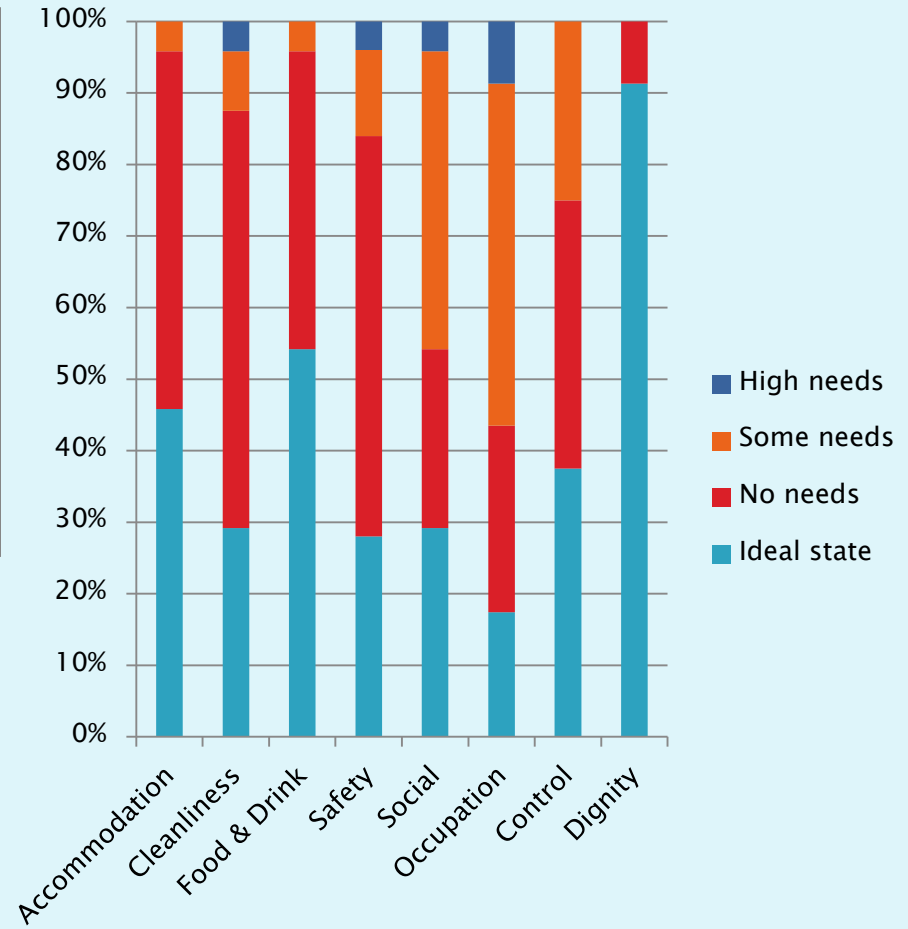
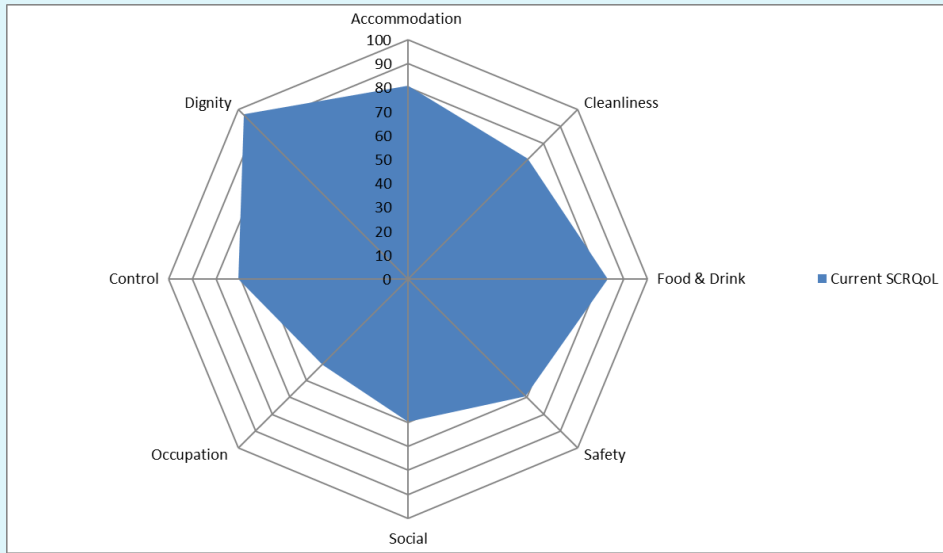


No, I'd say, I think I'm satisfied. So I'll put a smile in there.

Results – Response patterns

- ▶ Only one participant (original version) consistently rated domains as ‘ideal state’.
 - Mini-Cog score of 2 due to inability to recall any of 3 three listed words
 - needed constant re-orienting to the questions and prompting to re-clarify the meaning of each question
- ▶ Other transcripts– some tendency towards relativising QOL in relation to age and disability.
- ▶ Overall, qualitative responses indicated that changes to the wording and pictures of the questionnaire improved the suitability of the survey for the cohort.

Results – QOL

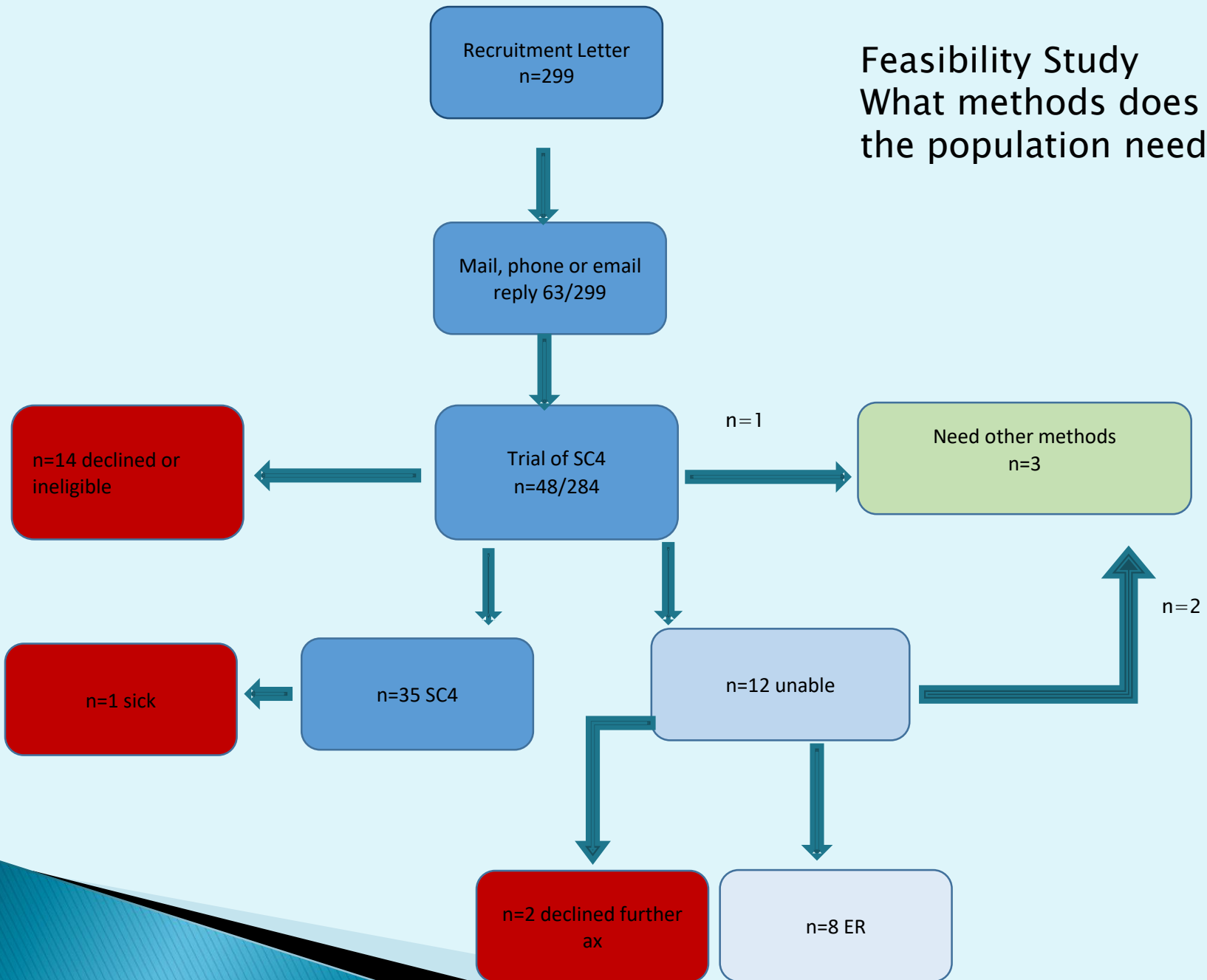


Study 2: Feasibility Study

What proportion of the HCP population will benefit from use of ASCOT-ER?

Feasibility Study

What methods does the population need?



What's next?

- ▶ New recruitment via carer to build trust
- ▶ Adapted Care Home (CH3)
 - Proxy ASCOT
 - Informant Interview (with 'Talking Mat')
 - Direct Care observation – acceptability and usefulness of video?
- RQ: Can CH3 be adapted for use in community settings?
- RQ: Can support in interviews be enhanced with talking mats?
- Intervention (Lifestyle Engagement Activity Program)

Questions?



- ▶ Dr Lyn Phillipson
- ▶ lphillip@uow.edu.au
- ▶ Phone:
+61242214773



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