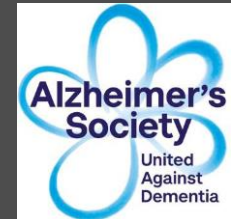


How to conduct meaningful and robust research among people with cognitive impairments

Laura Thomas – Research Director,
Social Research Institute, Ipsos MORI

SRA End of Year Conference 2017

6 December 2017



Overview

Brief

Challenges

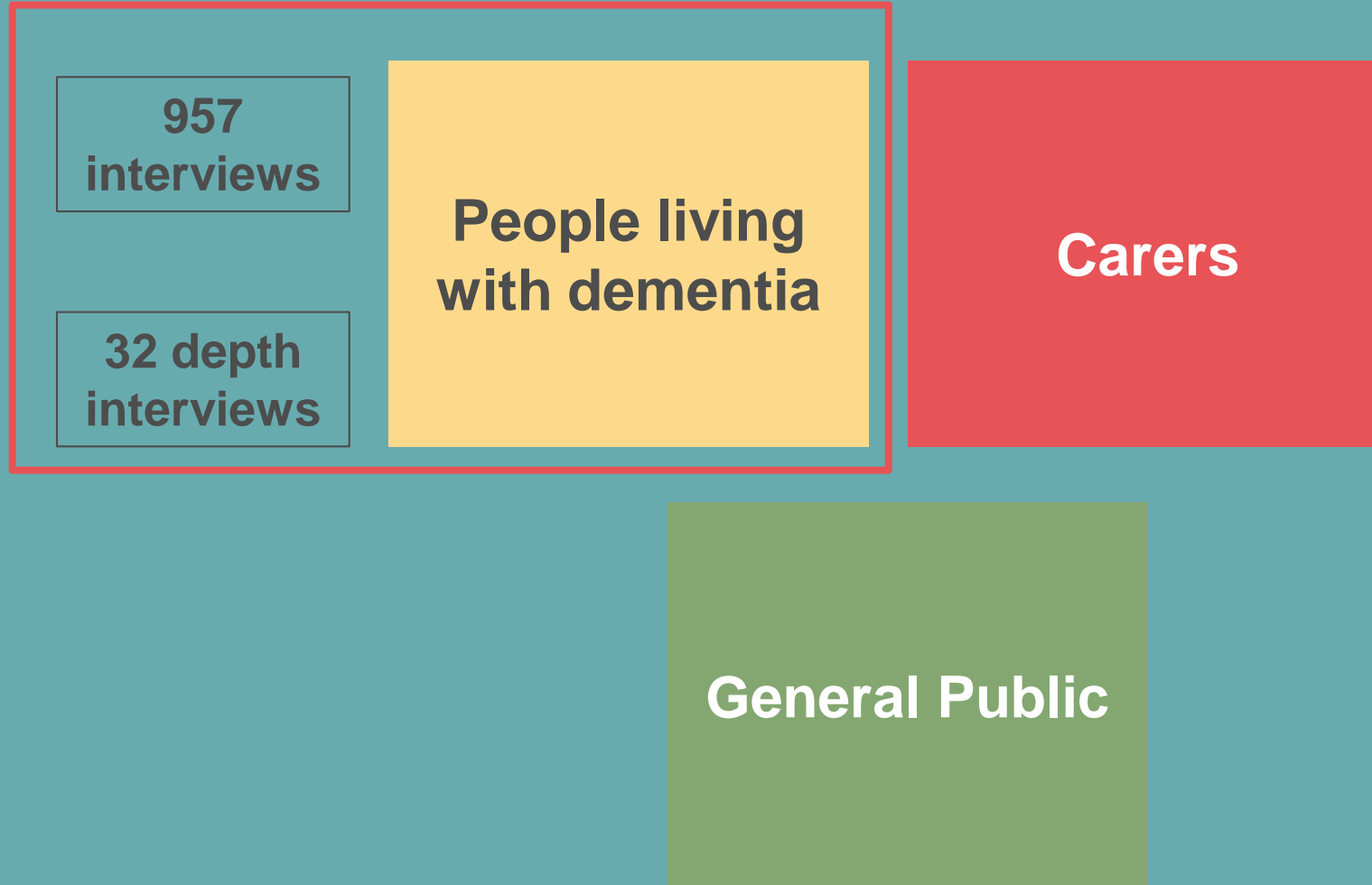
How we
overcame the
obstacles

Implications for
the future

The brief from Alzheimer's Society

- **Inform 5 year strategy (2017-2022)**
 - **Ensure their plans and policies based around people they support**
 - **Voices need to be heard by decision makers**
 - **Challenge research status quo**
- 1 in 3 people will develop dementia
 - 850,000 people in the UK with dementia
 - Dementia is the UK's largest killer

Who did we speak to?



**957
interviews**

**32 depth
interviews**

**People living
with dementia**

Carers

General Public

What were the key challenges?

**Identifying
the target
group**

**Appropriate
stage of the
journey**

**Informed
consent**

**Research
materials &
design**

Budget?

Time?

Planning was key

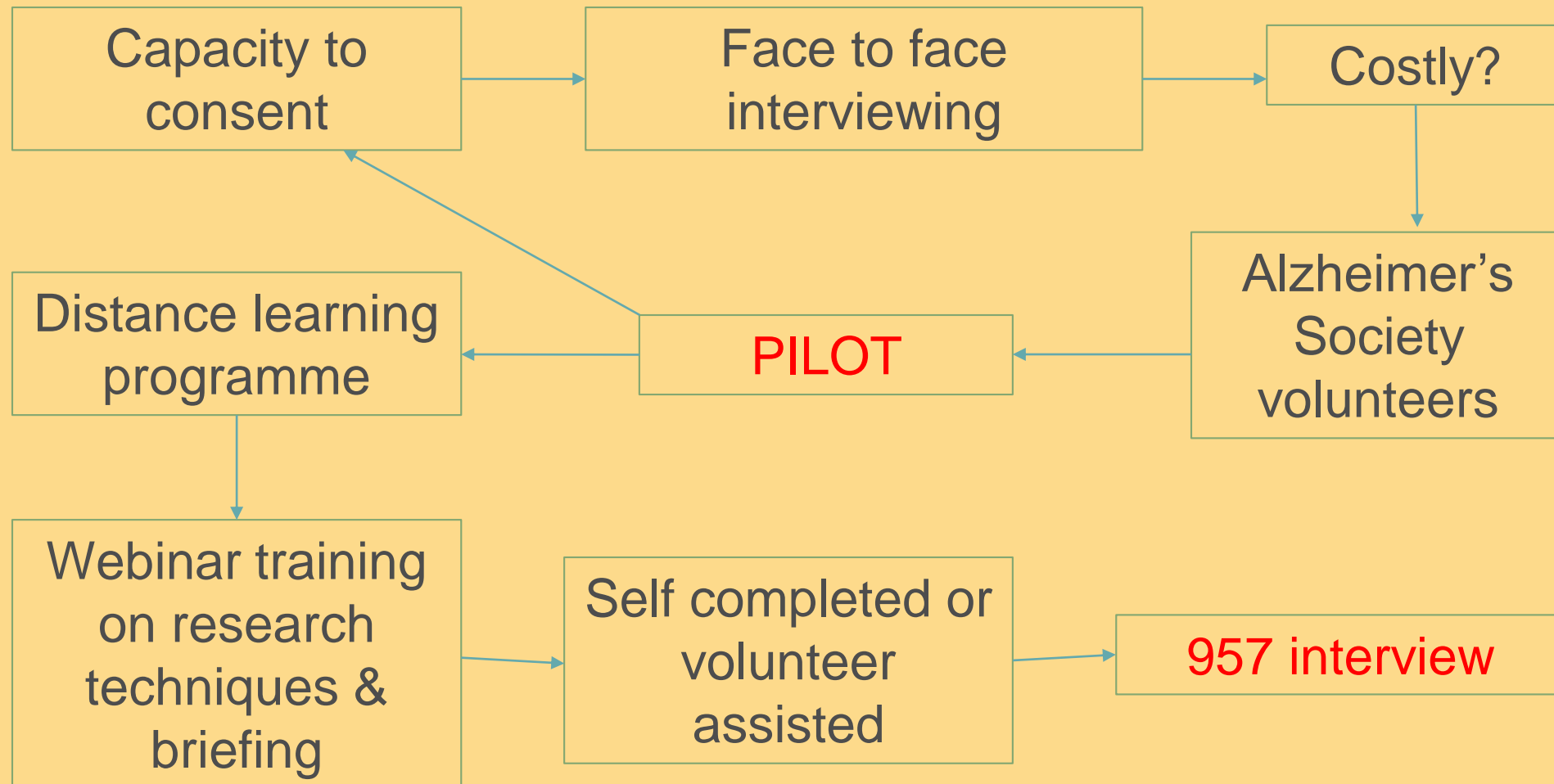
Stage 1 – Scoping stage

- Significant desk research
- Ethical input – informed consent
- Specialist dementia training
 - Different types of dementia
 - Signs and symptoms
 - Practical advice

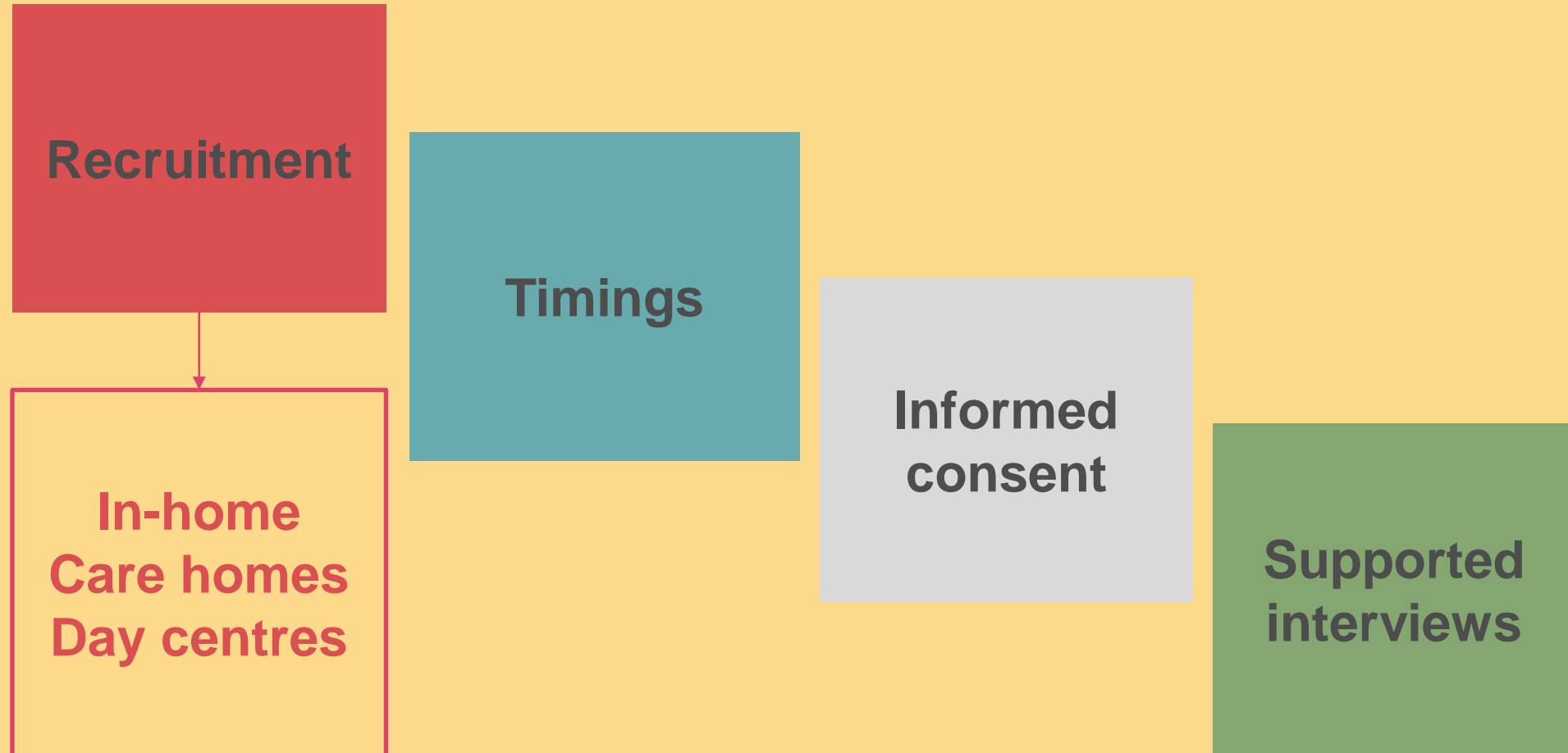
Material design

- Co-creation of research materials
- Cognitive testing and several rounds of piloting
- Streamlined research materials
- Best practice accessibility

How did we approach the quant?



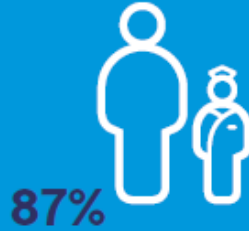
The depth interviews were a little more straight-forward



What did we find?



Almost half (48%) of people living with dementia who were interviewed worry about becoming a burden



87% of people with dementia who were interviewed receive help from family in their day-to-day life but only 14% receive help from a paid carer

'My memory is not what it used to be.... I have got a degree and a postgraduate something or other so once upon a time I was quite clever... It's fairly obvious to people who know me or who knew me, should I say, that I'm not as clever as I used to be. I know I am stupid.'

https://www.alzheimers.org.uk/downloads/file/3545/turning_up_the_volume_unheard_voices_of_people_with_dementia

Conclusion: what does this mean for the future?



Thank you!

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