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# Using participative research methods to explore the experiences of parents and carers of adults with learning disabilities

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# Current Research

- Carers face unique issues-lifelong role
- People now care well into old age
- UK policy states that

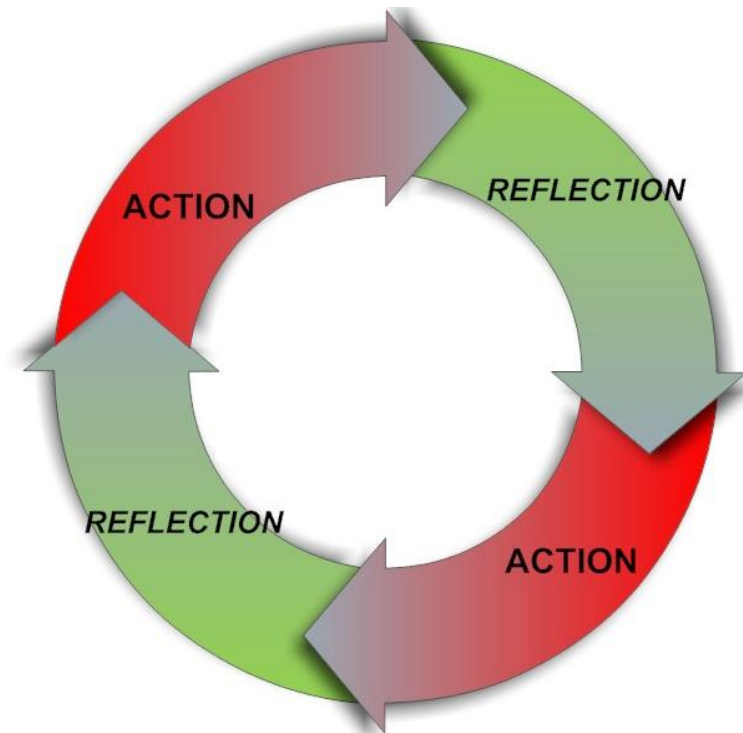
*carers will be respected as expert care partners* (Department of Health 2008)

# Aims

- Can participative research methods enable family carers of people with learning disabilities to collaborate in research?
- Does the current research and policy agenda reflect the needs of family carers?
- How do family carers want to see research about people with learning disabilities and their families prioritised?

# What we did: Participative Action Research

- Participative Action Research (PAR) is research for rather than on participants (Kindon, et al 2007)
- It has a long history of working with and for oppressed groups (Reason and Bradbury 2008)
- Works on a cycle of action and reflection.



# How we did it

## Phase 1

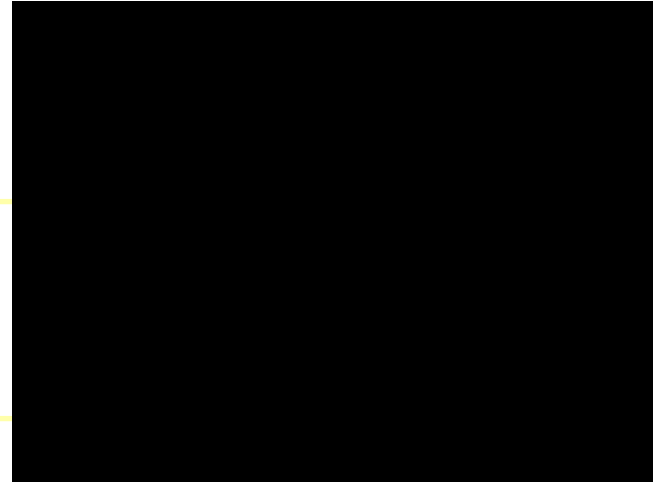
- Informal group discussions
- Recorded and typed up

## Phase 2

- Co-produced research project
- Based on themes from Phase 1
- Dissemination Event (Oct 2017)

## Phase 3

- Structured interviews with the group
- Reflection on process





# The Research Group

- 1 PhD Student (Rachael)
- 3 family carers-2 mothers and one father
- 2 other people started but could not complete the project



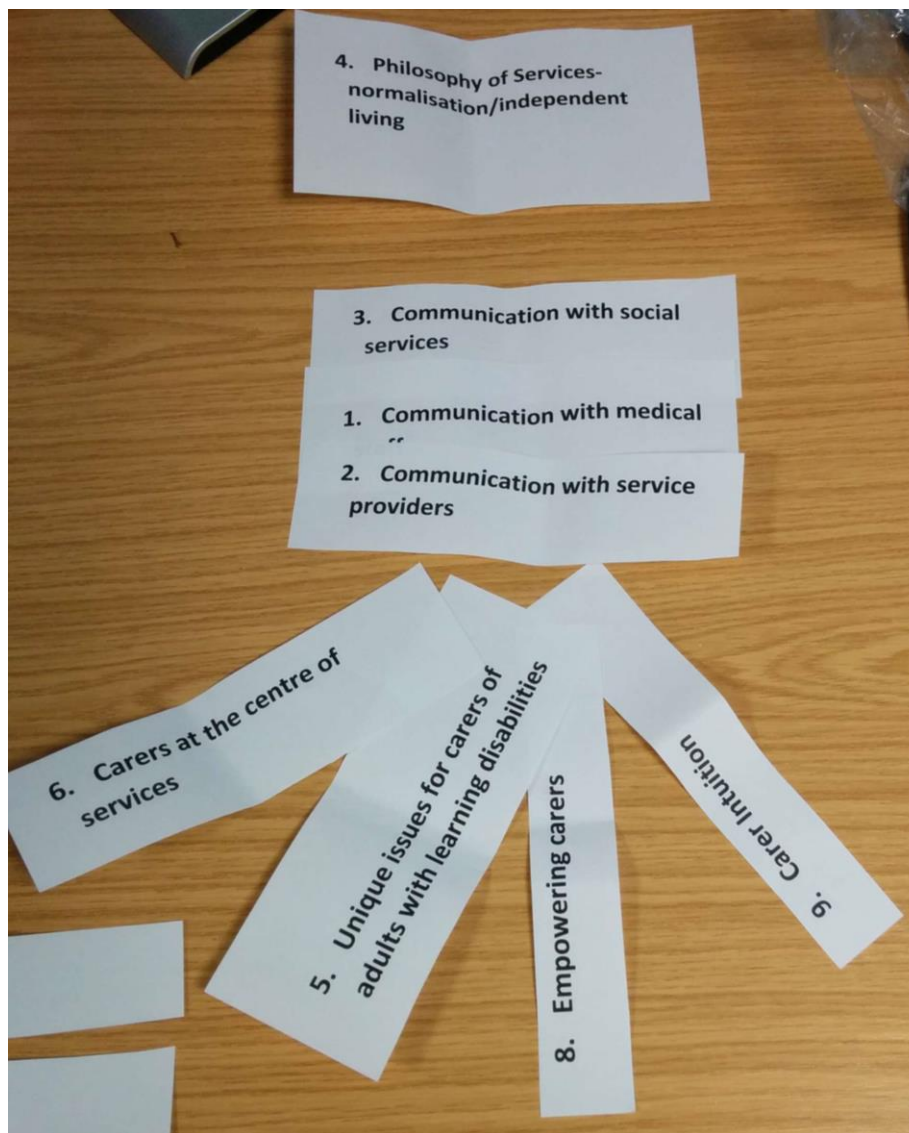


# Phase 1

- Meeting regularly since June 2015
- Unstructured and audio recorded discussions
- Transcribed and thematically analysed
- Themes used to decide Phase 2 research question for Phase 2



# Phase 1





# Phase 1

## Strategies

- Painting a picture
- Saying the right thing
- “Playing the game”

## Feelings

- Like a invasion
- Hidden agenda
  - Pushed out
- Is it just us???



# Phase 2

- Two co-designed surveys
  - Service Providers
  - Family Carers
- Co-Analysed the data
- Planning a dissemination event (October 2017)

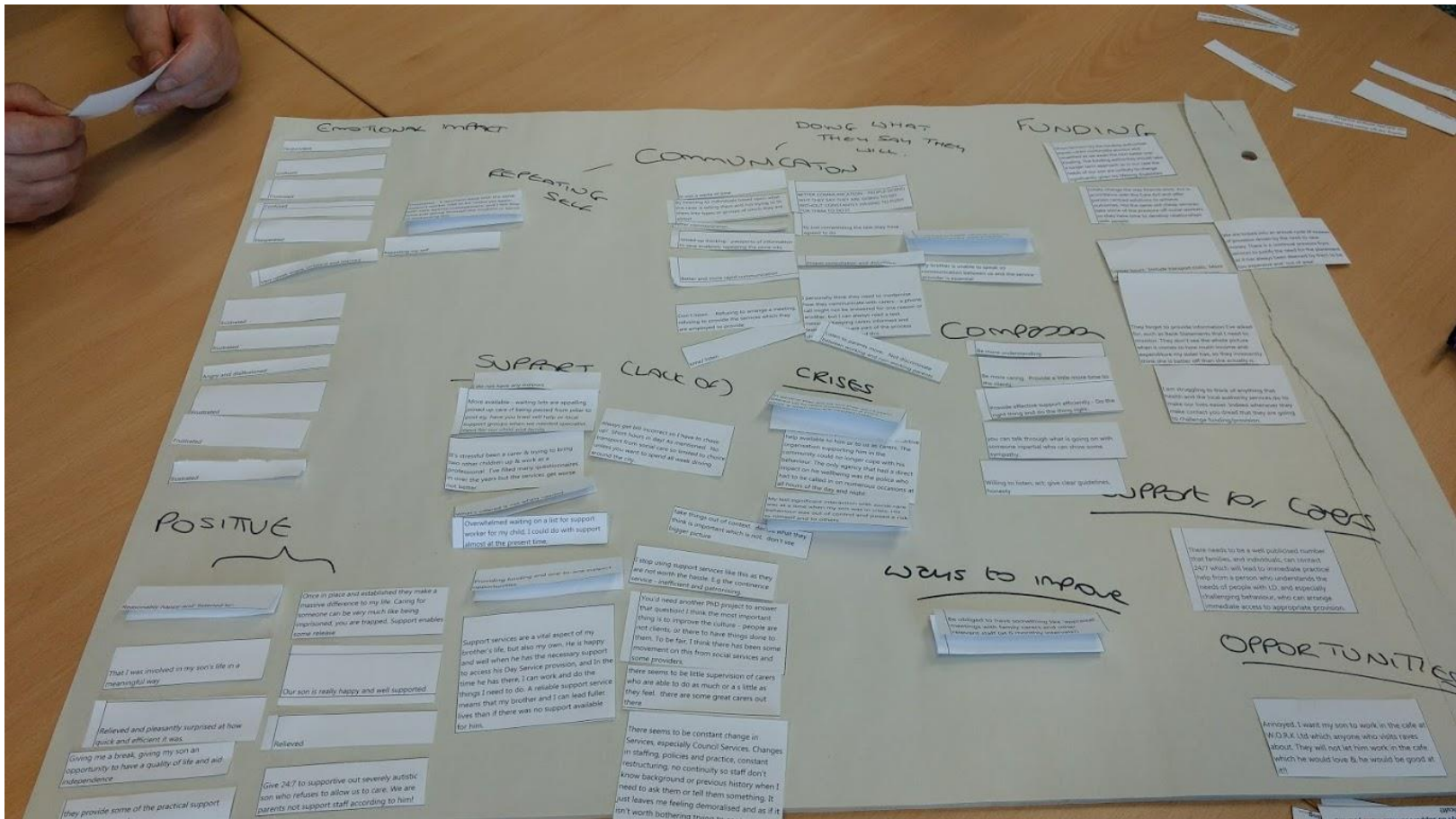


# What we did: Shared the Survey

- Shared with local and national organisations
- Shared by email though paper copies were offered.



# What we did: Co-Analysis



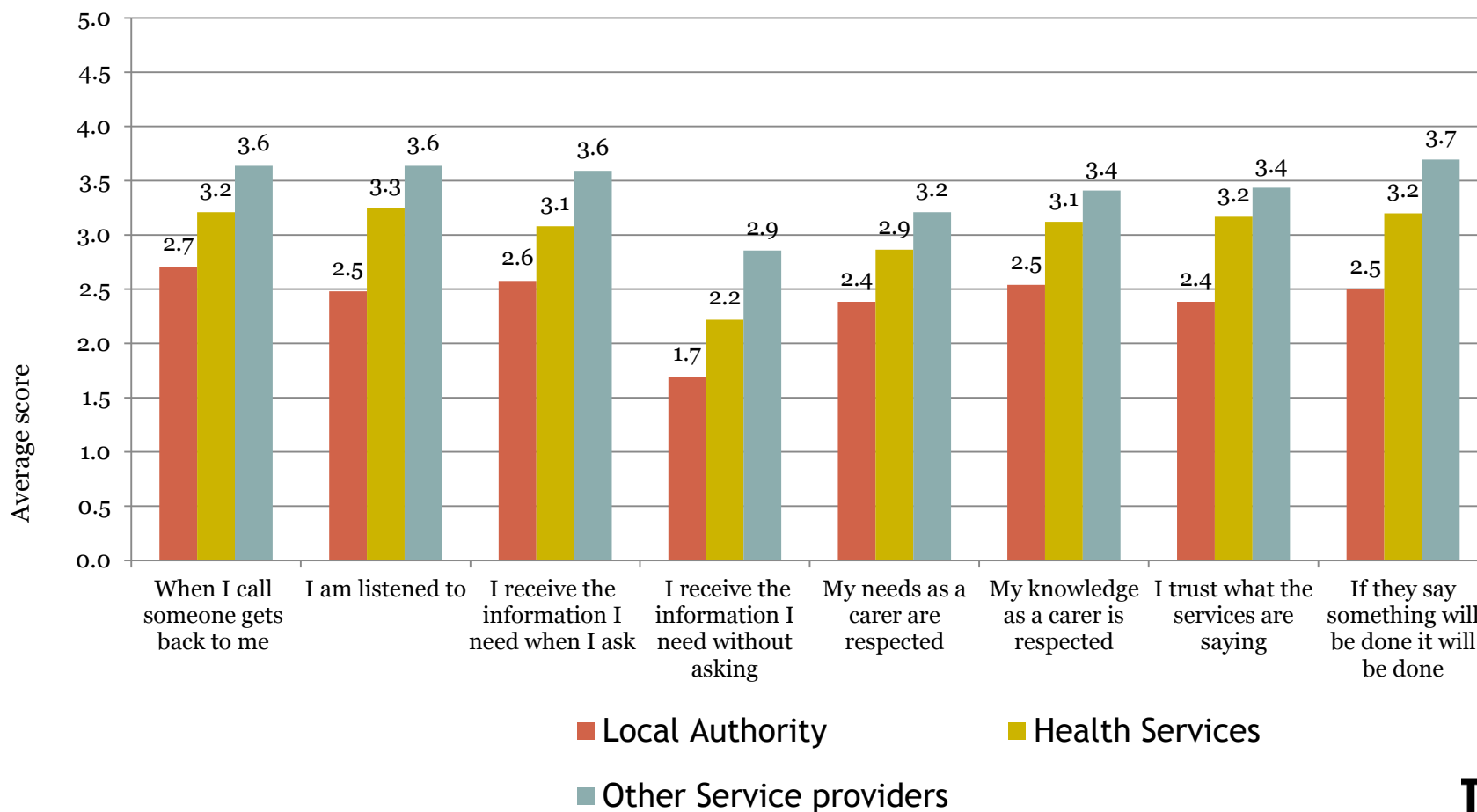


# Findings

- Family Carer Responses: 116
  - **28 from Sheffield**
- Service Provider Responses: 50
  - **25 from Sheffield**

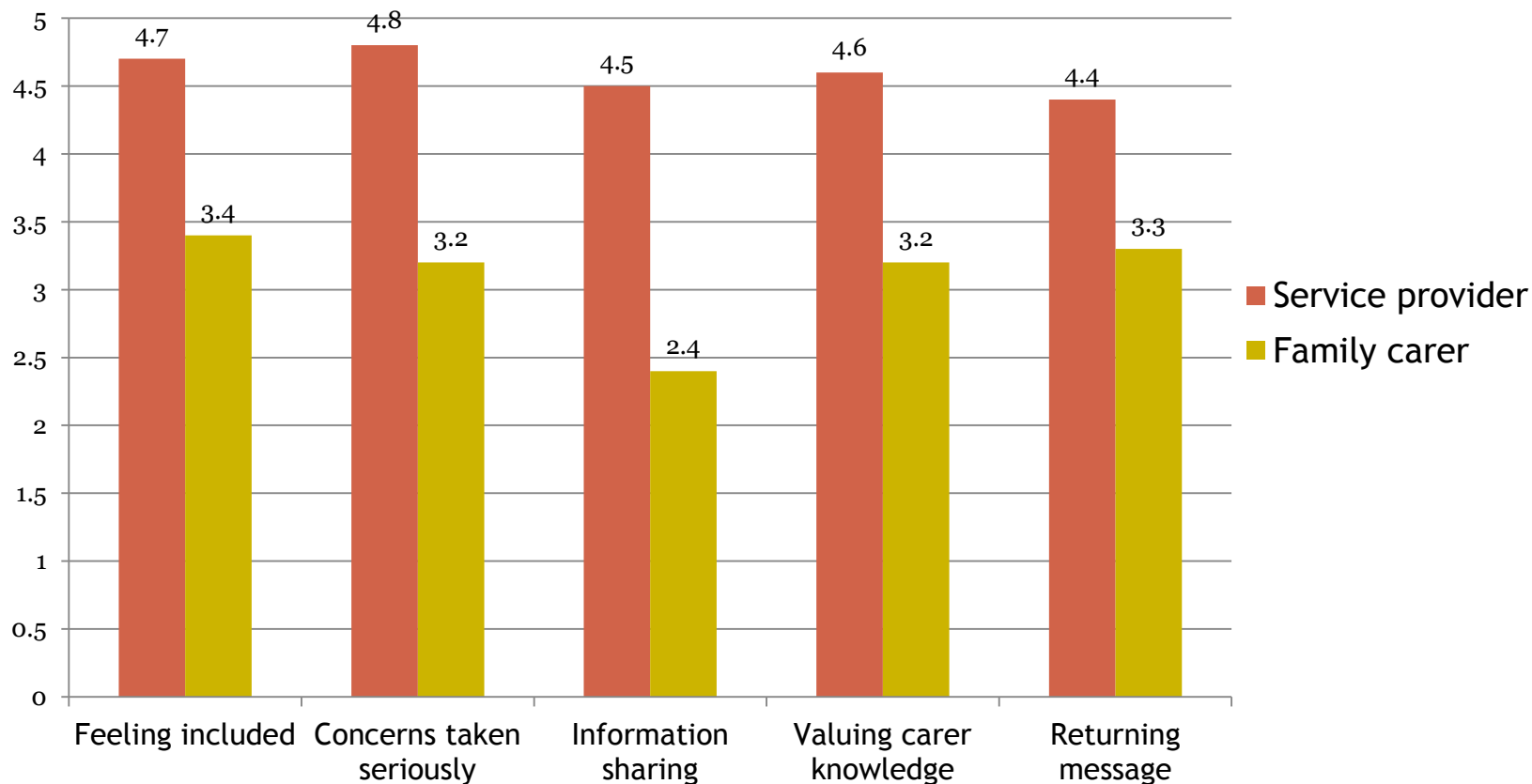
# Findings

## Comparing Average Scores: Carer Responses





## Comparing Service Provider and Carers' responses







# Findings

- There was no significant difference between responses from carers of children and carers of adults
- There was no significant difference between responses from carers from Sheffield and carers from other parts of the UK.



# Findings: Key Themes for Carers

- Emotional Impact on Carers
  - Carers feeling pushed out, judged
- Services not fit for purpose
  - Inflexible, not joined up
- Poor communication
  - Repeating self, not being listened to



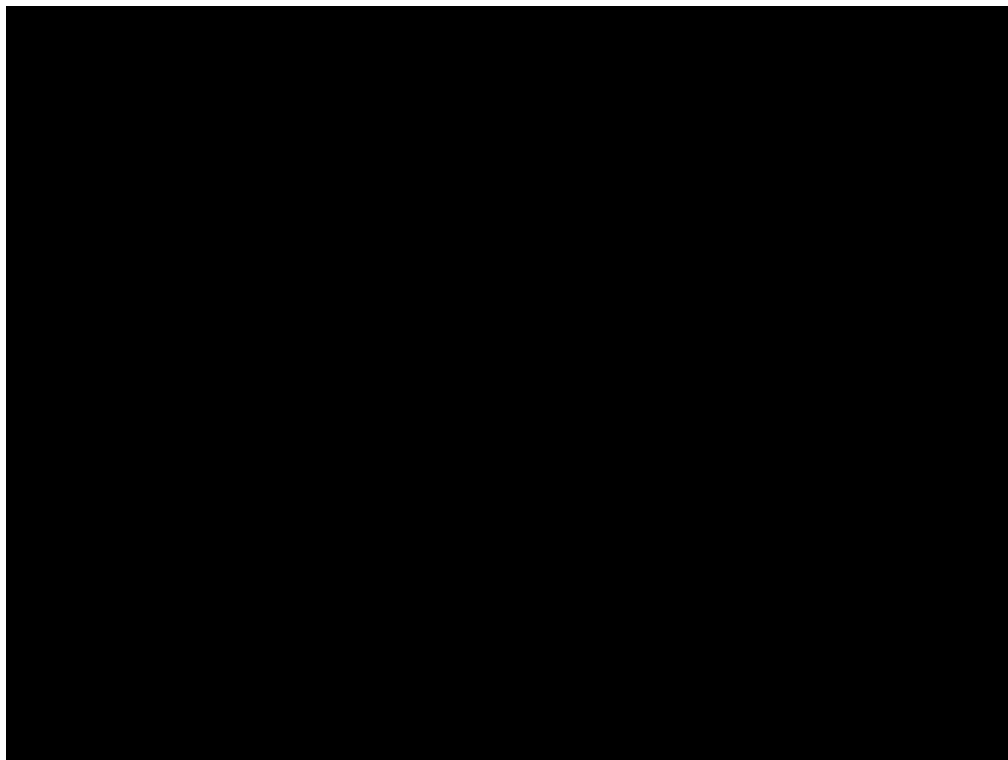
# Findings: Key Themes for Providers

- Carers should be more open and engaged with services
- Understanding the limitations of services
  - “understand we don’t have magic wands”
- Services still need to be more accessible to carers
  - Transport for meetings, more interaction outside office hours



# What works well

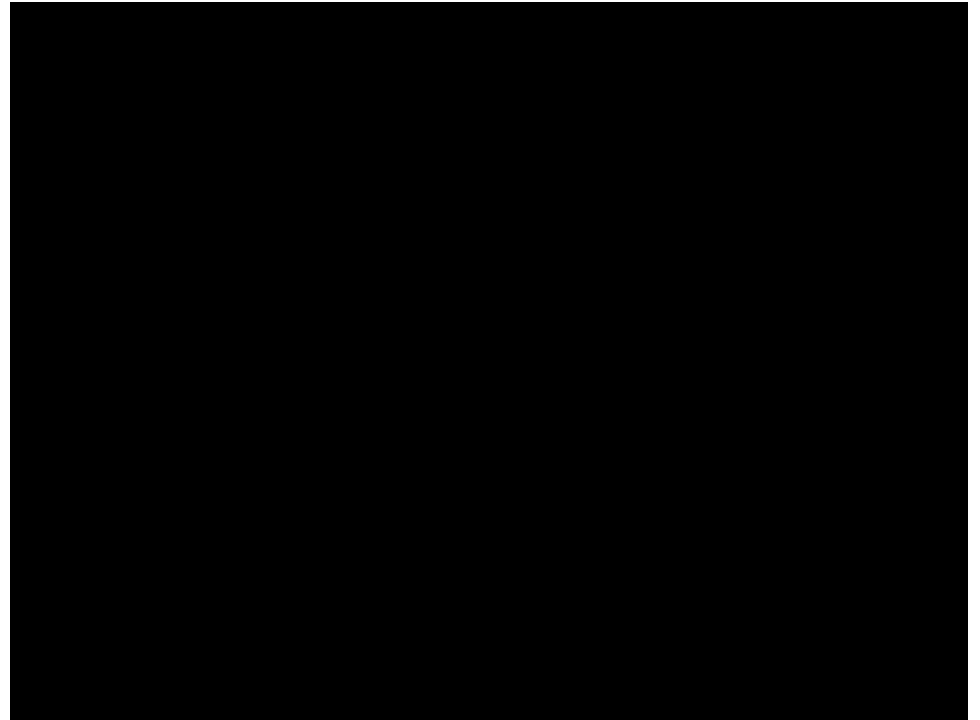
1. Insight
2. Relevance/Quality
3. Impact





# Challenges

1. Time consuming
2. Purpose unclear to potential co-researchers
3. Risky





# What do the carers say?

There is a feeling of joint ownership of not only the project but also the outcomes of the project. A feeling of being really involved and not being used purely to tick a box

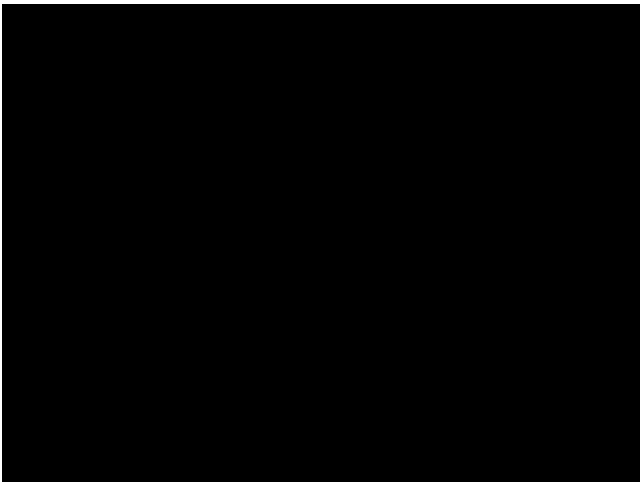
I would say that it feels it's our research as well as yours and not research being "done on us". Also it's about what's important to us and not what someone else has decided is important.

we have been able to construct the research process so that it is not overwhelming



# Impact on practice

1. Involve carers from the beginning
2. Be flexible-are there other ways to get involved
3. Carers shouldn't be 'last to know'
4. Carers want to be involved but not in a 'tick box' exercise





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# Thank you for listening!

## Any questions/ comments?







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Discover  
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Understand.