Partnerships between deaf people and hearing dogs: Learning from a randomised controlled trial with a third sector organisation of a complex non-traditional intervention

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The objectives of this presentation

• Describe what hearing dogs do and the charity that provides them
• Provide an overview of PEDRO study
• Present the key challenges we faced when designing the RCT
• Offer our solutions to these challenges
• Outline study progress to date
What are hearing dogs? (And who provides them?)

• Hearing dogs are a specific kind of assistance dog, trained to support people with severe or profound hearing loss.

• Training covers sound and behavioural support
• Funded by charitable donation.
The impact of a hearing dog partnership

1. ‘Sound support’ recognising, discerning and, if appropriate, alerting individual to a range of sounds (both universal and person-specific)

2. Additional benefits
   ✓ improved well-being and quality of life
   ✓ greater participation (work, activities of daily living, social networks)
   ✓ independence
   ✓ ..for those with acquired hearing loss, a sense of regaining their lives.
Rationale for PEDRO

• 800,000 people in the UK have severe or profound hearing loss (HDfDP 2018)
• Existing evaluations of hearing dogs are limited to a handful of poor quality studies.
• A research team at the University of York worked closely with Hearing Dogs for Deaf People to develop an acceptable study design.

People with hearing loss are more likely to experience a number of poorer outcomes than the general population:
- Social isolation
- Dependence
- Unemployment
- Increased risk of accidents
- Mental health difficulties
- Emotional distress
- Increased risk of accidents
- Emotional distress
- Mental health difficulties
- Unemployment
- Dependence
- Social isolation
PEDRO: The study objectives

User experience of applying for a dog

User experience of receiving a dog

Costs

Outcomes (mental wellbeing, impact of hearing loss, health and social care use)
Incorporating a trial into an existing intervention

Apply for HD

Assessment process & creation of applicant profile

Profile visible to trainers who match to puppies

MATCH MADE

Specific training relevant to applicant’s needs

Applicant notified – HD has an overnight home visit

Final training and 5 day residential course

Dog goes home for a weekend with remote supervision

Applicant becomes recipient – ongoing support

Incorporating a trial into an existing intervention
Key Methodological Challenges

1. Designing a robust RCT

- Fulfilling the charity’s maximum wait time commitment
- Incorporating the charity’s scrupulous matching process
Key Methodological Solutions

1. Designing a robust RCT

- Fulfilling the charity’s maximum wait time commitment
  - Participants are randomised to ‘accelerated’ vs ‘usual application timeline’ (UAT) groups

- Incorporating the charity’s scrupulous matching process
  - Used a matched pairs design
NOTE:
Intention to Treat used
Data administration for each pair anchored to Arm B participant receiving dog
Key Methodological Challenges

2. Adhering to protocol timeline and arm allocation

- Outcomes data collection triggered by activity within the charity not visible to research team
- Maintaining adherence to trial arm allocation
Key Methodological **Solutions**

2. Adhering to protocol timeline and arm allocation

**Outcomes data collection triggered by activity within the charity not visible to research team**
- Based at charity headquarters, a Study Support Officer has controlled access to HDfDP’s databases and administers research questionnaires.
- They have no access to the data collected.

**Maintaining adherence to trial arm allocation**
- Ongoing liaison with the charity via the Study Support Officer
- Recognition that some deviation may be necessary, but encouragement that this was minimal
Recruitment to the Study

Approached
N=279

Recruited
N=217 (78%)

Lost before randomisation n=38

Awaiting randomisation n=21

Randomised
N=158

Arm A
n=79

Arm B
n=79

Active Sep 18
n=78

Active Sep 18
n=76

N=2 withdrew application and from PEDRO

N=1 withdrew from PEDRO

Target N T0- 162
Target N T1- 128
### Live retention figures (Sept 2018)

<table>
<thead>
<tr>
<th></th>
<th><strong>T0-1 (point of recruitment)</strong></th>
<th><strong>T0 (point of randomisation)</strong>*</th>
<th><strong>T1 (6 months after Arm B receives dog)</strong></th>
<th><strong>T2 (12 months after Arm B receives dog)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Arm A</td>
<td>78</td>
<td>69/74 (93%)</td>
<td>12/13 (92%)</td>
<td>3/3 (100%)</td>
</tr>
<tr>
<td>Arm B</td>
<td>76</td>
<td>68/73 (93%)*</td>
<td>10/11 (91%)</td>
<td>3/3 (100%)</td>
</tr>
</tbody>
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*T0 only sent if time between T0-1 and T0 > 12 weeks therefore total N lower than T0-1.
Findings and conclusions

✓ The positive working relationship between the researchers and charity has been maintained.
✓ The Study Support Officer role has proved very successful.
✓ Protocol adherence is, to date, extremely good. Only two Arm A participants have had their allocation overruled.
✓ Charities can be keen to collaborate on rigorous evaluations of their services.
✓ Trials can be achieved in these contexts.
The research team

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Lucy Stuttard, Researcher
Jane Maddison, Researcher
Emese Mayhew, Researcher
Philip Boyle, Study Support Officer

Prof. Catherine Hewitt, Trial Design
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