

# The challenges of conducting dementia research on the Isle of Man

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# What is dementia?



## Dementia

- An umbrella term for a range of progressive conditions that result in a decline in memory [1]
- Approx. 46 million people live with dementia worldwide, more than the population of Spain
  - Estimated to increase to 131.5 million by 2050 [2]
  - 1400 diagnosed on the IoM, expected to increase

## Quality of Life affects

- Post diagnosis, a lot of care occurs at home provided by family and friends
- There is a growing need for home support for people with dementia and their carers [3]

1. What Is Dementia?. Alzheimer's Disease and Dementia. 2022. Available from: <https://www.alz.org/alzheimers-dementia/what-is-dementia>
2. Wimo A, Ali G, Guerchet M, Prince M, Prina M, Wu Y. World Alzheimer Report 2015: The global impact of dementia: An analysis of prevalence, incidence, cost and trends. Alzint.org. 2022. Available from: <https://www.alzint.org/resource/world-alzheimer-report-2015/>
3. Chester H, Clarkson P, Davies L, Hughes J, Islam M, Kapur N et al. Cognitive aids for people with early stage dementia versus treatment as usual (Dementia Early Stage Cognitive Aids New Trial (DESCANT)): study protocol for a randomised controlled trial. *Trials*. 2018;19(1).



# The memory game application



## Memory Lane Games

- A local company based in Castletown who developed an app to be beneficial to those with mild/moderate dementia
  - Initial positive feedback

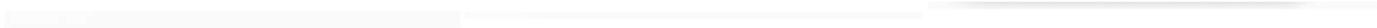
## Memory Lane Games App

- A simple game of identifying pictures
- Can be personalised with own photos and questions



# The Standard App

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# The Personalised App



Creating your own games





# The Memory Game



## Why use a digital tool?

- Tapping into memories may prompt discussion and improve communication with carers and visitors
- Photographs can trigger memories e.g. places, people
  - The generic app has photo-based games but they are not specific to the individual
  - The personalised app allows family photos to be added
- Simple nature of the games
  - No score / repeated tries to get the correct answer / stress-free entertainment



# Study concept and objectives



## Concept

- Examine impact on quality of life (QoL) and communication
- Use any evidence of positive effect and information to design a larger trial

## Primary Question

- Is the use of a personalised app associated with changes in QoL of the person with dementia and/or their carer?

## Secondary Questions

- Any unanticipated effects of using the personalised App?
- Are the study instruments feasible and acceptable?



# Study design - 1



## Subjects

- Single site, randomised, controlled study
- 30 pairs comprising of person with dementia (PWD) and main informal carer
  - Formal dementia diagnosis
  - 65 and over
- 2:1 split of pairs between intervention group and control group

## Intervention group

- Receive an App with generic memory games plus the option to construct games with personalised content

## Control group

- Receive an App with generic memory games only



# Study design - 2



## Timeline

- 26 week study with 3 data collection points
  - Baseline, 13 week, 26 weeks

## Data Collection

- 2 dementia assessments
  - CDR / SMMSE
- 2 QoL assessments
  - Carer QoL / Dementia QoL
- 1 communication assessment
  - HCS

## Other Data

- App usage activity
- Semi-structured interviews



# Recruitment Plan



## Aim

- Recruit people formally diagnosed
- Looking for volunteers
  - They must contact us first
- 30 pairs

## Publicised by

- Social media
  - Facebook and Instagram
- Media
  - Local newspapers, banners, posters and community centres
  - Online news reports (BBC / ITV etc.)
- Radio
- Dementia support groups
- Contacted other NGOs

**Scholl Academic Centre**  
Hospice  
care for our community  
Memory Lane Games  
care for our community

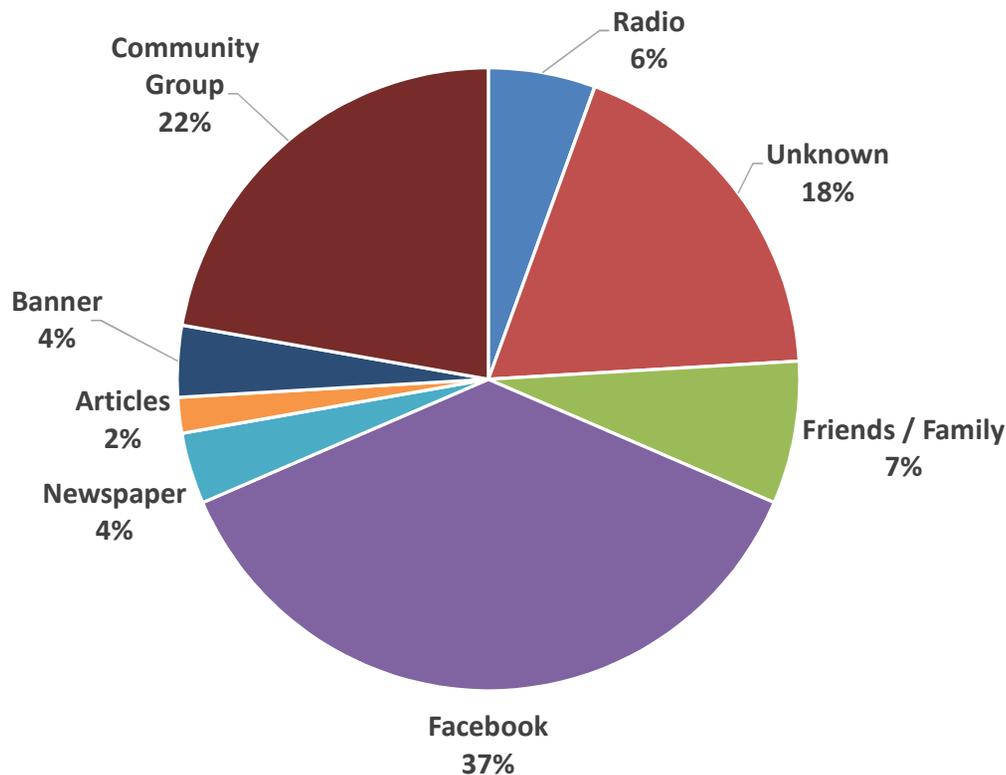
**IMPROVING QUALITY OF LIFE FOR PEOPLE OVER 65 LIVING WITH DEMENTIA:**  
A PILOT STUDY OF AN APP FOR PEOPLE LIVING WITH DEMENTIA AND THEIR CARER(S)

**WHAT IS THE RESEARCH STUDY HOPING TO FIND OUT?**  
We are looking to see if using a memory game app, using content personal to the person with dementia (e.g. photos and pictures), improves their or their carer's overall wellbeing.

# How did people get in touch?



## How each potential participant initially contacted the research team



- Facebook was most successful and had the furthest reach
  - 43,000 ad views
  - 3,000 interactions
- Non-digital marketing reach reduced due to covid lockdowns?
  - E.g. reduced attendance to community groups?
  - We don't have a baseline to compare



# Recruitment Results - 1



## Recruitment Journey

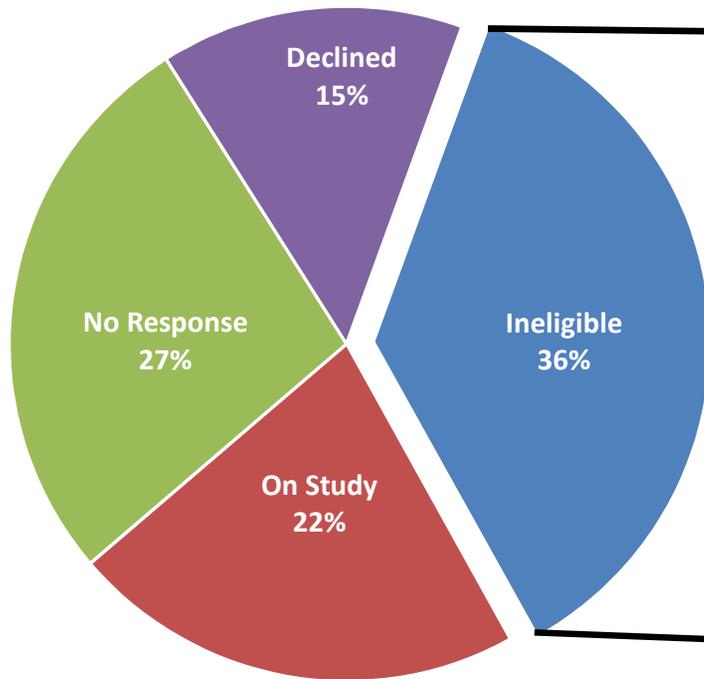
- Sankey Chart



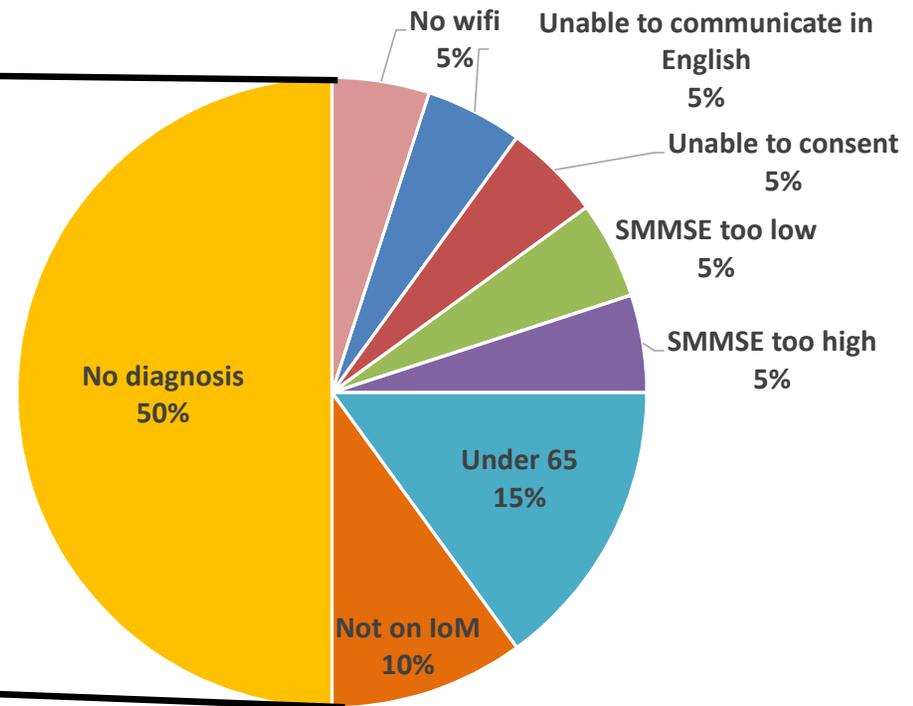


## Recruitment Results - 2

### Overall Recruitment



### Ineligible Participants





# Why were people ineligible?



## High no diagnosis rates

- 50% of ineligible volunteers were not formally diagnosed by the memory clinic
- Covid slowed diagnosis rates down in the UK [4]
  - Could the same thing have happened on the IoM?
- Depending on the stage of dementia, diagnosis in the UK can take from 12 weeks to 12 months [5]
  - We were recruiting mild to moderate

4. Alzheimer's Society comment on how coronavirus is affecting dementia assessment and diagnosis. Alzheimer's Society. 2022. Available from: <https://www.alzheimers.org.uk/news/2020-08-10/coronavirus-affecting-dementia-assessment-diagnosis>

5. Tests and scans used to diagnose dementia. Alzheimer's Society. 2022. Available from: <https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/dementia-diagnosis/dementia-tests?documentID=260>



# Why were people ineligible?

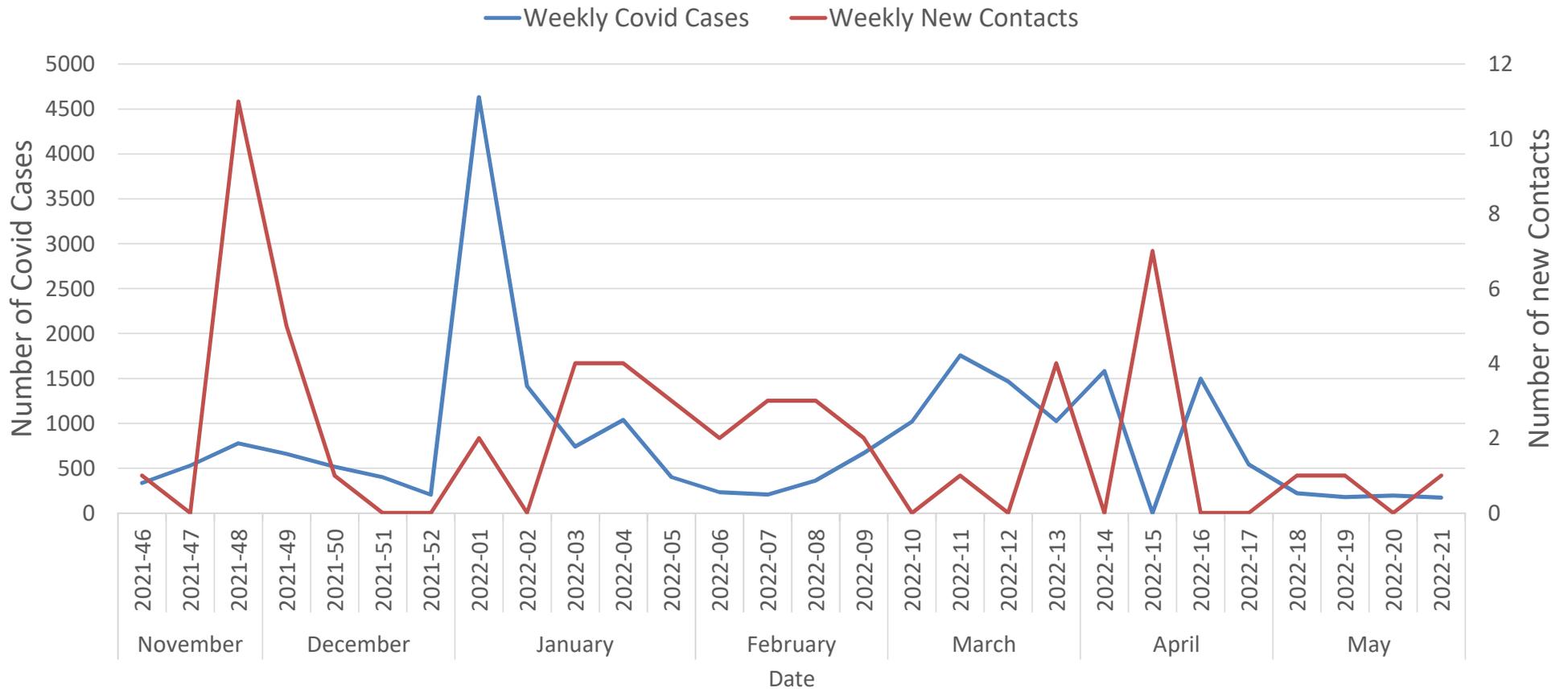


## High no response rates

- 27% of potential participants who initially contacted us we lost to follow up
- Each had four contacts via phone and email before they were classed as 'no response'
- Study wasn't what they thought it was?
- Did covid have an impact?
  - Increased carer stress
  - Lockdowns and isolation rules in vulnerable demographics



# Did covid have an affect on recruitment?



Covid data taken from - <https://ourworldindata.org/coronavirus>



# We have a research naïve population



## ‘I don’t want to be a Guinea Pig’

- A common response when people are offered to take part in clinical trials [6]
  - A result of misunderstanding and lack of awareness surrounding clinical trials
- We lost potential participants to follow up after they had said this exact phrase
- Lack of understanding can lead to miscommunication

6. Wendy Mitchell: I have dementia and I take part in research. Here’s why - The BMJ [Internet]. The BMJ. 2022 . Available from: <https://blogs.bmj.com/bmj/2017/08/08/wendy-mitchell-i-have-dementia-and-i-take-part-in-research-heres-why/>



# Media wording matters



Hospice IOM trialing memory app for dementia **sufferers**

[News Home](#)

[More from Isle of Man News](#)

Manx made dementia app pushes for more participants in clinical trial

[News Home](#)

[More from Isle of Man News](#)

Thursday, December 9th, 2021 4:53pm



The trial hopes to prove the app will improve dementia **sufferers** quality of life



# Research Naïve Population



## Wording Matters

- Using different wording when reporting and during recruitment can have a dramatic effect [6]

Would you like to be involved in research?



Would you like to be involved in changing how dementia looks in the future?



# Why is research important?



## Research

- Healthcare is driven by evidence based research
  - New knowledge and solutions begin with questions and research

## Dementia Research

- The prevalence of dementia is on the rise
  - We should try and understand and help those diagnosed as soon as possible

# How can we improve?



## Changing our research culture

- Increased collaboration with other organisations
  - 7 dementia related organisations contacted – only 2 replied
- Research Registry
  - Sign to be notified about local research
  - Research studies are listed for people to apply
- Research Festivals!
  - We are all important in driving conversations and changing views on research





# Summary



- Main challenges
  - Covid-19
  - Research naïve population
- Our learning
  - Collaboration
  - Difficult to get involved
  - The power of media
- The way forward
  - Make research accessible
  - Raising research awareness





## Questions?



### Get in touch

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