



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

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Hospice 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

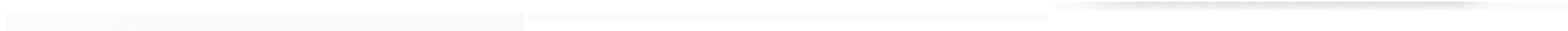
- A local company based in Castletown who developed an app to be beneficial to those with mild/moderate dementia
  - Initial positive feedback

## Memory Lane Games App

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



# The Standard App





# 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



The banner features logos for Scholl Academic Centre, Hospice (care for our community), and Memory Lane Games. The main text reads: "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)". Below the text is a photograph of an elderly woman and a younger woman smiling together. A blue box on the right contains the text: "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." Below this is another photograph of a young man and an elderly man smiling together.

**ARE YOU LIVING WITH DEMENTIA OR CARING FOR SOMEONE WITH DEMENTIA?**

Hospice is looking for people who are living with dementia and are willing to take part in a research study.

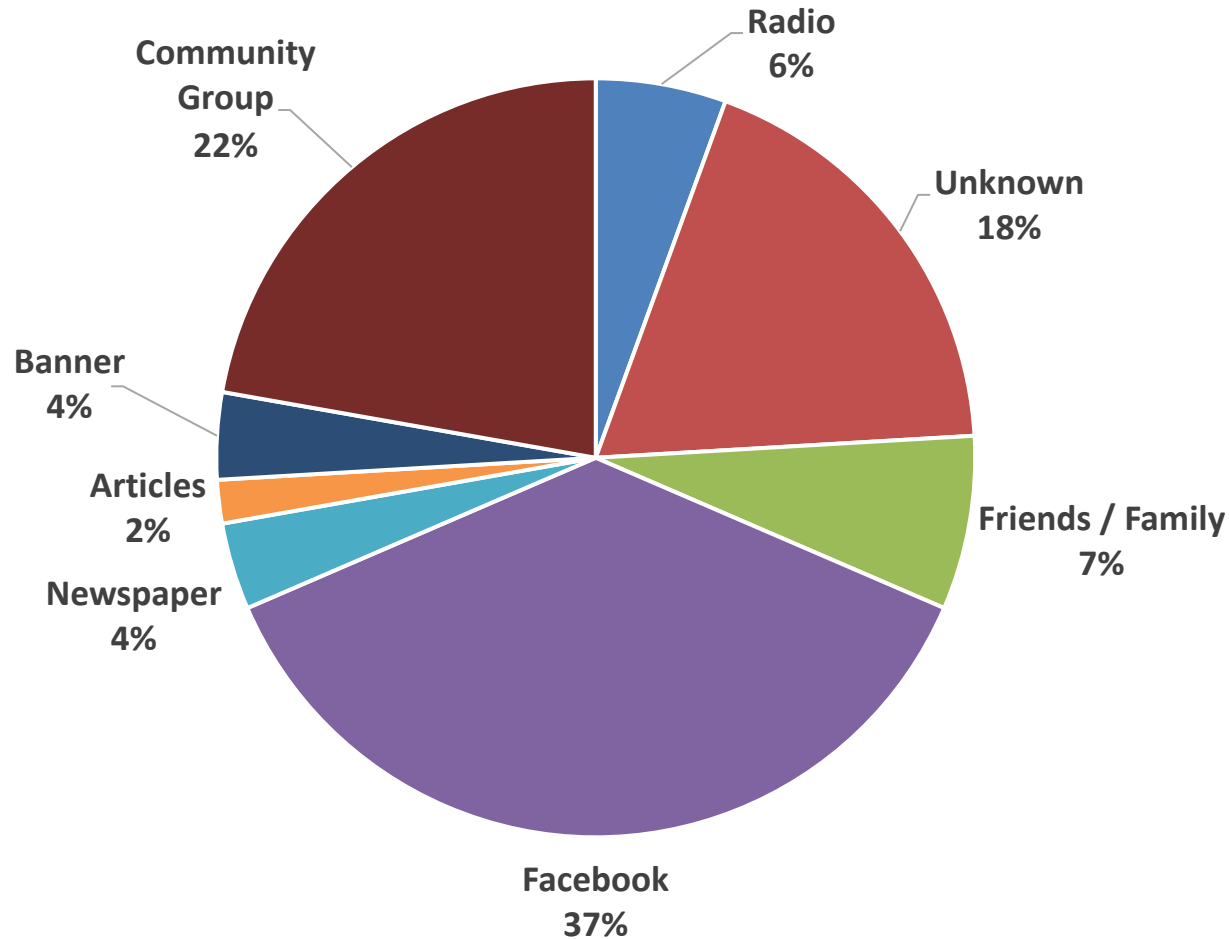
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# How did people get in touch?



## 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



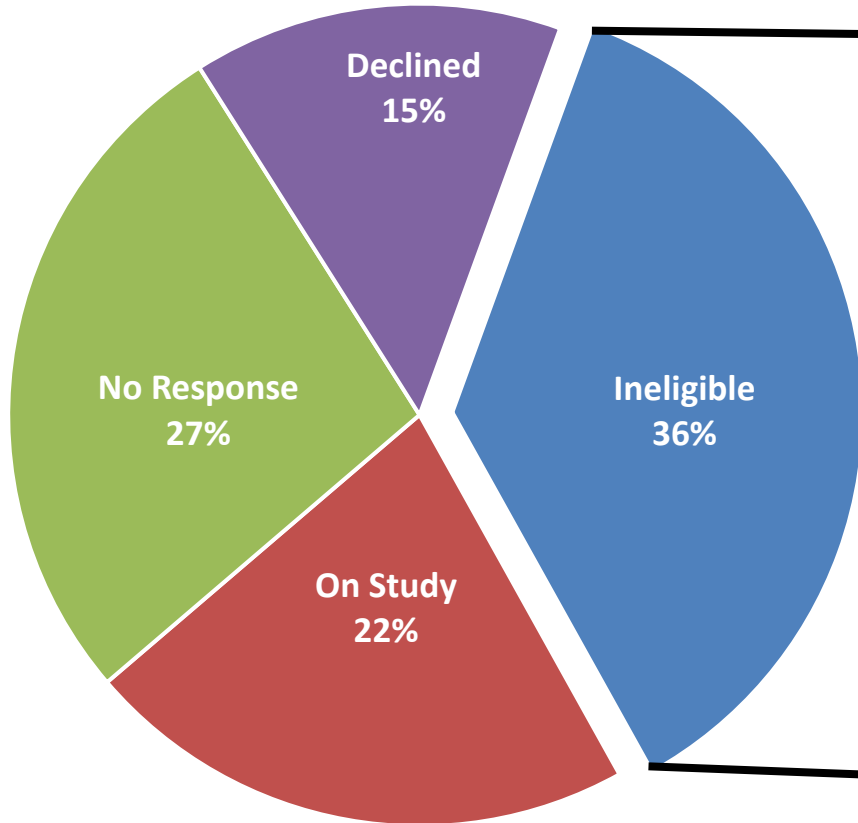
## Recruitment Journey

- Sankey Chart

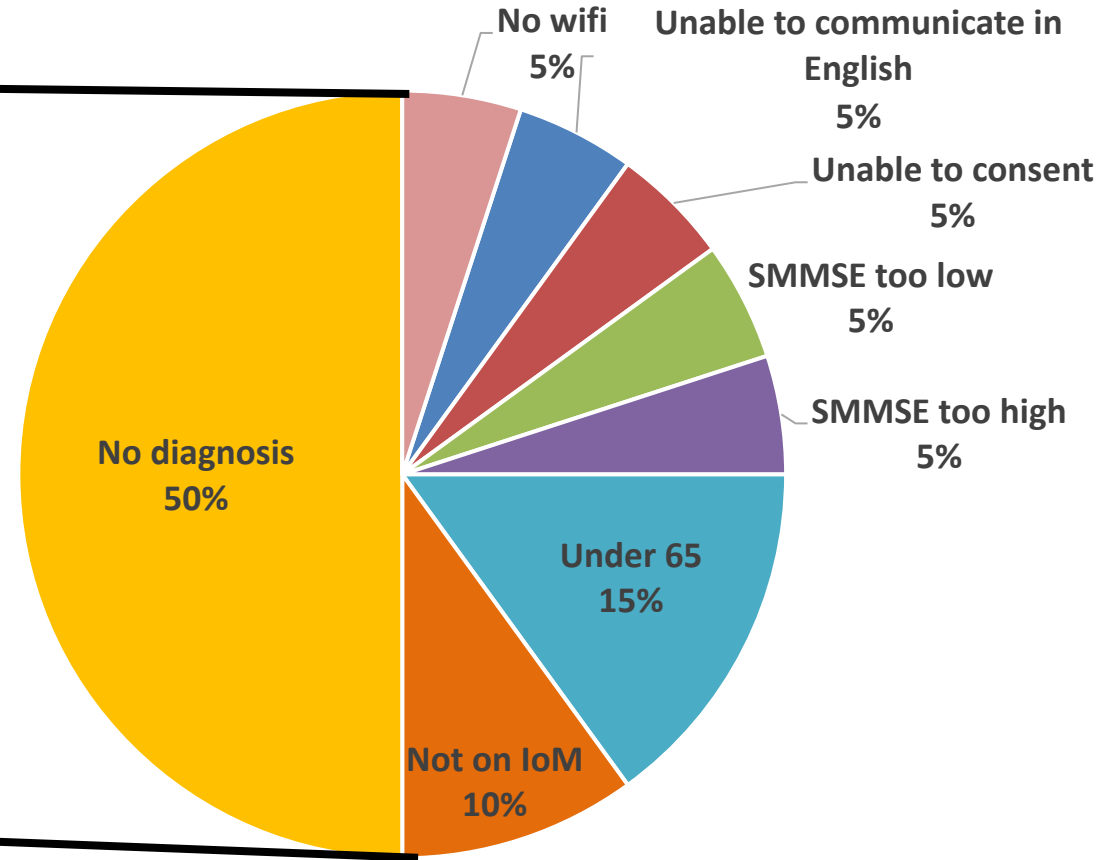


# Recruitment Results - 2

## 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?

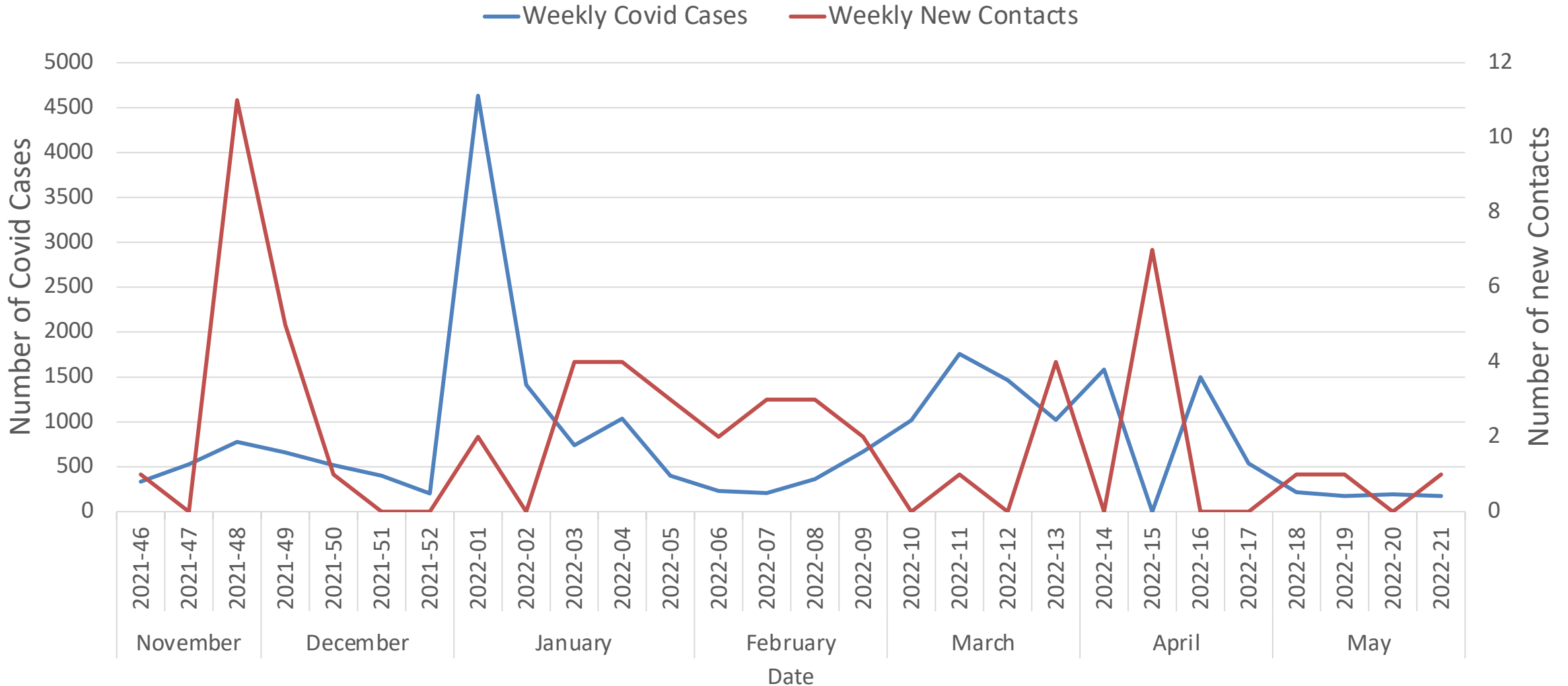


## High no response rates

- 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?







# 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



# 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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