



University
of Glasgow

A WORLD
TOP 100
UNIVERSITY

An inclusive approach to patient and public involvement in clinical research

Dr Chris McParland (presenter)

Professor Bridget Johnston

Dr Mark Cooper

WORLD
CHANGING
GLASGOW

THE SUNDAY TIMES
THE SUNDAY TIMES

GOOD
UNIVERSITY
GUIDE
2024

SCOTTISH
UNIVERSITY
OF THE YEAR



Chris McParland – quick CV

- Postdoc research associate at University of Glasgow
- Registered nurse – emergency department and clinical research nursing
- Research interests:
 - Multimorbidity and treatment burden
 - Patient and public involvement in research
 - Nurse-led interventions
 - Mixed-methods research



The EMBARQUE study



- Focused ethnographic study
- People with multimorbidity (2 or more conditions) and palliative conditions, and their carers
- Interviews, observation, participant-led journals
- Exploring concept of treatment burden
- Recruitment from emergency department



Patient and public involvement and engagement

- 11 people with multimorbidity and carers – mainly through Alliance
- Research focus on inclusivity:
 - Deaf and hearing-impaired persons
 - Blind and partially sighted persons
 - People with cognitive impairment
 - People with impaired motor function
- Consultations held May-June 2022
 - Online
 - Telephone
 - Email
 - Option for face-to-face





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Points of friction



RECRUITMENT



DATA COLLECTION



Information sheets

EMBARQUE Study



SHORT TITLE!

EMBARQUE: A focussed ethnography of multimorbidity, treatment burden and burden for carers using reflexive qualitative methods: Participant Information Leaflet for Patients

We are inviting you to take part in a research study. You do not have to take part, it is for you to decide whether you would like to or not. Before you decide, we would like you to understand what the study involves, and why we are doing it. One of the researchers will go through this leaflet with you. You will have time to think about it and to ask the researcher any questions you may have. Feel free to talk to others about the study if you wish. You will be given a copy of this information leaflet to keep.

Please ask if anything is unclear – there are contact details for the research team at the end of this document.

What is the purpose of this study?

We want to speak to people who have two or more long-term health conditions (sometimes referred to as 'chronic' conditions), to hear about the things they do to manage their health conditions.

Lots of adults have a long-term condition, such as asthma, high blood-pressure, chronic pain, arthritis or diabetes. About one-in-five people in Scotland have more than one long-term condition. Because we are living longer than ever before, the number of people who have more than one long-term condition is likely to increase.

Having lots of health conditions can mean you often have to go to the hospital, have to take a lot of medicines, and have to do other things to stay healthy. You might need to get help with some of this, maybe from a family member or a friend. All of this can feel like 'work' for someone with multiple health conditions. This work has been described as 'treatment burden' by other researchers.

People who feel burdened by healthcare may be less likely to do activities to stay healthy, and their health can suffer as a result. We want to speak to people about this 'burden' and the things people do to manage their health conditions. The information you share with us may help improve the way care is provided to others in future.

EMBARQUE Study

IRAS ID: 306289



EMBARQUE study*: Participant Information Leaflet for Patient

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Chris McParland

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LARGE PRINT!

RESEARCHER PHOTO!



Consent process

EMBARQUE Study

IRAS ID: 306289



IRAS ID: 306289

Participant Identification number for this study:

Title of Project: A focussed ethnography of multimorbidity, treatment burden and burden for carers using reflexive qualitative methods (EMBARQUE study)

Name of Researchers: Chris McParland, Prof. Bridget Johnston, Dr Mark Cooper

Consent Form (to be completed by Patient Participant)

Please initial box

- 1. I confirm that I have read and understood the Participant Information Leaflet version 1.4 dated 12th December 2022. I have had the opportunity to think about the information and ask questions and understand the answers I have been given.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my health care or legal rights being affected.
- 3. I confirm that I agree to the way my data will be collected and processed and that personal data will be stored for a minimum of 6 months in accordance with NHS Greater Glasgow and Clyde retention policies. Non-identifiable data will be stored for up to 10 years in University of Glasgow archiving facilities. All data will be handled in accordance with relevant Data Protection policies and regulations.
- 4. I understand that all data and information I provide will be kept confidential and will be seen only by study researchers and regulators whose job it is to check the work of researchers.
- 5. I agree to my interviews being audio-recorded.



IRAS ID: 306289

Participant Identification number for this study:

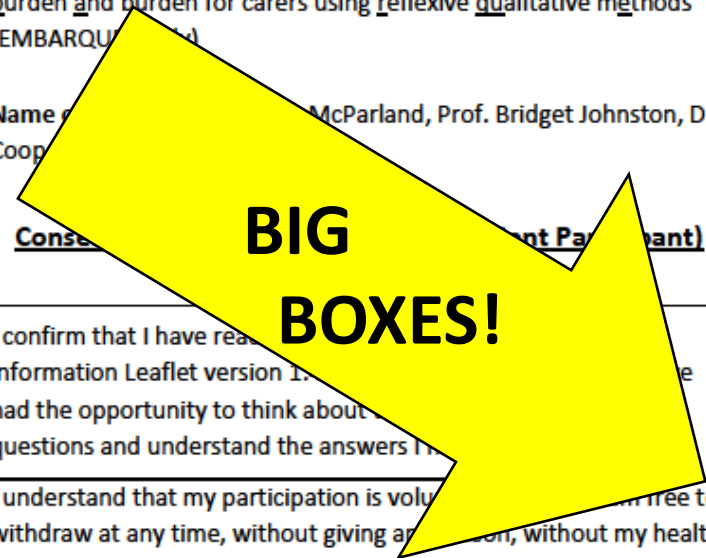
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Data collection

Journalling?



Alternatives

- Digital audio recorders (costed)
- Speech to text technology
- Email



Pitfalls

- Significantly longer to get approval
- Long time to conduct PPIE (groupwork not feasible)
- Not everything worked (WhatsApp)
- Lots of methods unused





Ethics – keep it inclusive



“We can provide reasonable adjustments (such as foam grips or other writing aids) or digital audio recorders (provided by the University of Glasgow) which we would collect at the end of the study. If participants already make use of adaptive technology to communicate, we can provide a secure NHS GGC email address which they can send journal electronic entries to using their preferred method.”



Closing points

- Keep it inclusive at design stage, create options
- Involve early – plan for more time than needed
- Consider communication needs, not just conditions of interest
- Everyone benefits

A graphic consisting of three concentric circles of varying shades of gray, with the text 'The End' written in a white, elegant cursive font across the center.

The End



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Thanks for listening



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Twitter/X: @chrismcpar

#UofGWorldChangers



@UofGlasgow