

Supplementary material

S.1. Advertisement to recruit PPI team



PATHWAY

Invitation to be a research Programme Adviser

Research title: Improving the effectiveness of psychological interventions for depression and anxiety in the cardiac rehabilitation pathway

What is the research about, who is funding it and what will happen to the findings?

- The PATHWAY research programme aims to improve care for people with heart disease by improving the psychological support they receive to tackle the stress and anxiety that can accompany this condition.
- The PATHWAY research programme is funded by the National Institute of Health Research and is sponsored by the Manchester Mental Health and Social Care Trust.
- The PATHWAY research programme has been reviewed by the Health Research Authority NRES committee North West.
- The results will be used to support cardiac rehabilitation services to deliver interventions aimed at reducing stress and anxiety in people with heart disease.
- Findings will be shared in a variety of ways including events, presentations, groups and meetings. Summaries of findings will be published in newsletters. Articles will be published in academic journals and presented at conferences.

What is a research Programme Adviser and why have I been invited?

- We are looking for approximately 10 lay people (members of the public) to work with us as 'Programme Advisers'. A research programme is a group of research studies that connect together. Programme Advisers will advise the research team on their research approach, documents such as participant information sheets and interview topic guides, the recruitment of participants, findings and how we publicise our results, among other opportunities.
- You do not need to have any previous experience of research to be a Programme Adviser, and you will be fully supported in this role.
- You have been invited to be a Programme Adviser as you are someone who has experience of heart disease, and also of the stress and anxiety that can accompany this condition. You will have personal experience of this or know someone who has been affected by this, such as a family member or friend.

Manchester Mental Health
and Social Care Trust



NHS
National Institute for
Health Research



Invitation to be a Research Programme Adviser

Research title: Improving the effectiveness of psychological interventions for depression and anxiety in the cardiac rehabilitation pathway

Do I have to be a research Programme Adviser?

• **No.** It is entirely up to you to decide whether or not to take part. You can change your mind at any time and a decision to withdraw or a decision not to take part will not be held against you in any way. You are not being asked to be a research participant.

What will be involved if I do decide to take part?

Our first meeting will be on **Wednesday 20th May at 10am**, at the Rawnsley Building, Manchester Royal Infirmary, Hathersage Road, Manchester, M13 9WL.

During the first meeting we will agree upon things such as:

- The exact role of an advisor
- What is expected from you
- How the group will work
- How we can best prepare and support you, including providing any training that you might need
- How we will evaluate public involvement

We will also:

- Seek your views on how we can ensure good involvement principles are upheld by such things as a 'role description' for the role of advisor, ground rules for the group and agreed ways of working.
- Agree on how we can reward your time i.e. Cheque or shopping vouchers.

We anticipate there will be approximately four advisory group meetings each year over 5 years. Most meetings would be approximately 2 hours long. Initially there may be a longer meeting to address any training that you require.

Will there be any recognition for my time and help?

- We have funding to reimburse any expenses incurred when you travel to and from meetings.
- It is likely we can pay up to £75 for each half day's involvement. We recognize that not everyone would want payment or that individual needs may differ.
- *If you are in receipt of state benefits, you are advised to seek advice from your local office as to how payment may affect you should you get involved.*



Invitation to be a research programme adviser
Research title: Improving the effectiveness of psychological interventions for depression and anxiety in the cardiac rehabilitation pathway

What are the possible benefits and drawbacks of taking part?

• Commonly people who take part in studies as an advisory group member experience benefits to their personal development, employment skills and confidence levels. We hope the findings will improve the management of depression and anxiety in people with heart disease. We also think you will have fun!

• There are no expected risks related to taking part. We will need to be careful that any payments we make to recognise your time are unlikely to affect you adversely (e.g. if you receive benefits). It is your responsibility to check how any payments would affect you with your local benefits office or tax office.

• All information which is collected about you during the course of the programme will be kept strictly confidential. We won't let people know of your involvement unless you want us to, for example, by acknowledging you on the final programme report.

What do I do now?

- You do not have to decide if you would like to be a Research Programme Adviser immediately. Take this information away and read it through with others if you wish.
- If you are willing to take part as a Research Programme Adviser, or you have any questions about this, please contact a member of the team using the details below.

Contact details

For further information please contact:

Dr Tracey Williamson

School of Nursing
University of Salford
Mary Seacole Building Room 143
Fredrick Road Campus
M6 6PU

Tel: 0161 295 6424 E: T.Williamson@salford.ac.uk

Thank you for reading this invitation and for considering becoming a Research Programme adviser

UTILISING PATIENT AND PUBLIC INVOLVEMENT IN STATED PREFERENCE RESEARCH IN HEALTH: LEARNING FROM THE EXISTING LITERATURE AND A CASE STUDY

Corresponding author: Gemma Shields (gemma.shields@manchester.ac.uk)

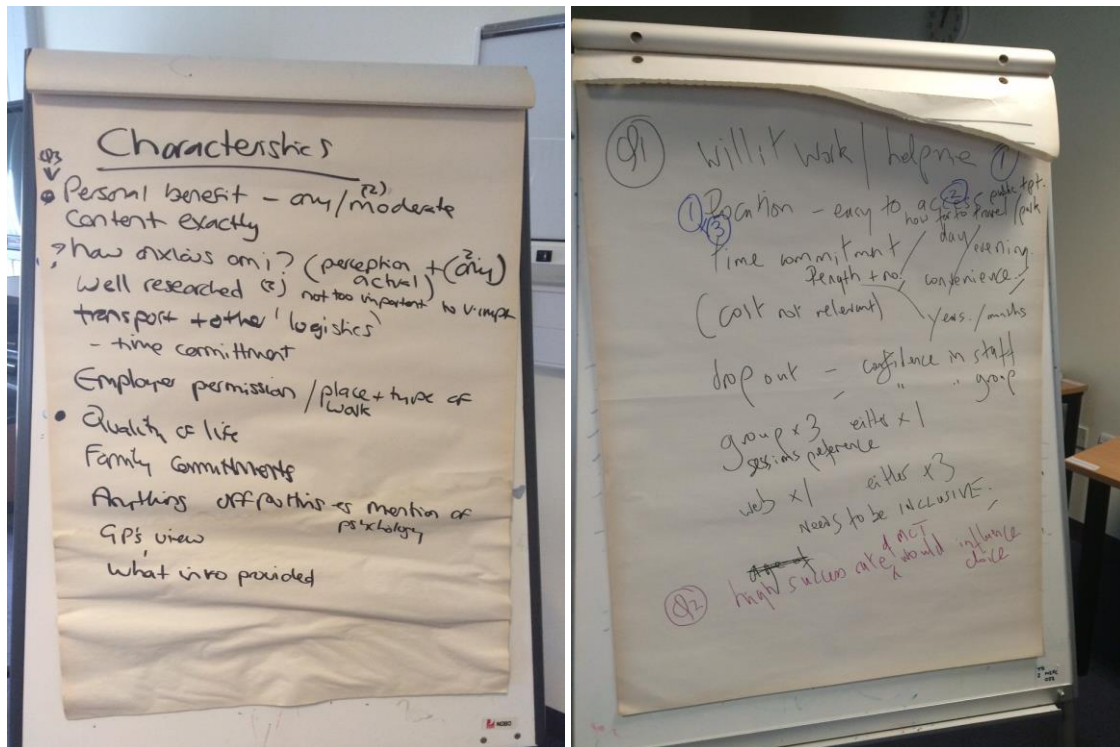
S.2. Overview of current PPI members

Gender	Age at beginning of study	Ethnicity	Marital Status	Qualification	CR service user?	Experience in Research (prior to joining)?	Experience as a PPI member (prior to joining)?
M	-	-	-	-	Y	-	-
F	70	Black African	Divorced	Higher education	N (mental health nurse)	Y	Y
F	53	Black	Divorced	Higher education	Y	Y	Y
M	67	White background	Married	Vocational qualification	Y	Y	N
M	69	British	Married	Vocational qualification	Y	N	Y
M	61	White British	Married	Diploma	Y	N	N
F	65	White British	Married	Higher education	Y	Y	N
F	-	-	-	-	-	-	-
M	63	White British	Married	Higher education	Y	N	N

UTILISING PATIENT AND PUBLIC INVOLVEMENT IN STATED PREFERENCE RESEARCH IN HEALTH: LEARNING FROM THE EXISTING LITERATURE AND A CASE STUDY

Corresponding author: Gemma Shields (gemma.shields@manchester.ac.uk)

S.3. Key feedback on experiment design and participant demographics



- Both groups were happy to discuss what they would consider prior to taking part in a psychological therapy within cardiac rehabilitation.
- Key themes included:
 - Proven **effectiveness** (whether the intervention would work).
 - An understanding of what the therapy would be like and what the participants could expect from therapy. The group discussed that **information** provided prior to therapy would summarise this aspect and could also discuss effectiveness (e.g. trial results).
 - **Accessibility** of the therapy, in particular the **location** (type of setting), availability of public transport links, travelling time and travelling distance, and parking options.
 - Who has **recommended** that you attend therapy, e.g. whether it is a healthcare practitioner that you are familiar with and trust.
 - Who **provides/delivers** the therapy and whether they are experienced with communicating with cardiac rehabilitation patients.
 - **Time** commitment.
- It was challenging for the group to rank the importance of each of the items discussed above though person delivering therapy, information provided before committing to therapy, location and time commitment were thought to be important by the whole group.
- The group also discussed participant characteristics that may influence a decision to partake in psychological therapy in cardiac rehabilitation. The group considered a number of key variables:
 - **Age**, in particular whether the person was over retirement age.
 - Employment, education and family **commitments**.
 - Prior **experience of psychological therapies**.
 - Participant **health**, especially the presence of anxiety/depression symptoms.

UTILISING PATIENT AND PUBLIC INVOLVEMENT IN STATED PREFERENCE RESEARCH IN HEALTH: LEARNING FROM THE EXISTING LITERATURE AND A CASE STUDY

Corresponding author: Gemma Shields (gemma.shields@manchester.ac.uk)

- The group also agreed that in reality, they may start therapy but drop out at a later date if it did not meet their expectations/requirements.