

**Exploring experiences of distress and distress behaviours on NHS inpatient mental health dementia wards**

**Purpose of the study**

The Cambridge Institute for Music Therapy Research at Anglia Ruskin University, in partnership with the Cambridgeshire and Peterborough NHS Foundation Trust, alongside collaborators at the Universities of Cambridge and Hull, are conducting an explorative study to further our understanding of experiences of distress and distress behaviours, including agitation and aggression, and how these are currently managed on National Health Service (NHS) inpatient mental health dementia wards. To achieve this aim, we are conducting focus groups and interviews with people with experience of these wards, including managers, staff members, patients and family members.

This research is part of a larger study, MELODIC (Music therapy Embedded in the Life Of Dementia Inpatient Care), which aims to develop, alongside stakeholders and experts-by-experience, a new music therapy intervention to reduce experiences of distress on these wards. Should you choose to take part, your responses will help inform the design of this intervention. We will then pilot the music therapy intervention on two wards to refine the intervention, see if it is possible to deliver, and see if it has the potential to reduce distress.

**Who are the researchers?**

The lead researcher is Dr Ming-Hung Hsu, who will conduct the research focus groups and interviews with Naomi Thompson, a doctoral researcher at Anglia Ruskin University, and Chris Pointon, a public member of the research team. Other members of the research team are Professor Helen Odell-Miller at Anglia Ruskin University, Dr Ben Underwood at the University of Cambridge and the Cambridgeshire and Peterborough NHS Foundation Trust, and Dr Emma Wolverson at the University of Hull and Dementia UK.

This research is funded by the National Institute for Health Research (Research for Patient Benefit Programme, NIHR204928).

**Why have I been asked to participate?**

You have been asked to participate because you have experience of NHS inpatient mental health dementia wards in a professional or personal capacity in the last 5 years. We will speak to between 28 – 35 people with a range of experience of these wards to help inform our intervention design.

**Do I have to take part?**

You have the right to refuse to take part before or during the focus group or interview and up until data analysis has begun. However, once data analysis has begun it will not be possible to separate your response from that of other participants.

### **Has the study got ethical approval?**

This study has ethical approval from IRAS (IRAS no. 323503), with additional approval provided by Anglia Ruskin University (ARU). All data will be stored in line with the General Data Protection Regulations (GDPR) and ARU research governance guidelines.

### **What will happen to the results of the study?**

The findings will be used to inform the design of the MELODIC music therapy intervention for inpatient mental health dementia wards. This study will form part of the PhD thesis to be submitted by Naomi Thompson. We will also publish the findings in a peer-reviewed journal and present at national and international conferences. It is possible that pseudo-anonymised data will be used in secondary analysis. This means that the information you provide could be shared with other parties for further analysis, but your name will be removed from all data. If this is the case, all participants will be informed via email with the option to opt out of this.

### **Contact for further information**

The research coordinator can be contacted with any queries at: [Naomi.thompson@aru.ac.uk](mailto:Naomi.thompson@aru.ac.uk) Alternatively, you can contact the chief investigator for this research at: [ming-hung.hsu@aru.ac.uk](mailto:ming-hung.hsu@aru.ac.uk)

## **Your Participation in the Research Project**

### **What will I be asked to do?**

If you choose to take part in this study it will involve taking part in a focus group or interview lasting one hour. If you choose to take part in a focus group, you will be in a group with people who have similar experiences and roles to you. For example, staff members on inpatient mental health wards will be in one group, while family members will be in another. If you would prefer, we are offering the option to take part in an interview, either individually or with a trusted person. Focus groups will be led by Dr Ming-Hung Hsu, Naomi Thompson and Chris Pointon. Interviews will be led by Dr Ming-Hung Hsu and Naomi Thompson.

The meetings will take place at the Cambridge Institute for Music Therapy Research or another building at Anglia Ruskin University. At request, focus groups and interviews may take place at an alternative location of preference, such as a ward, as long as a confidential space can be provided. In addition, online participation will be offered where all participants are happy to meet online instead of in-person. All travel expenses related to participation will be reimbursed on presentation of a receipt.

You also have the choice on the accompanying consent form to provide feedback on the draft intervention before it is piloted on wards. If you select 'yes' to this, we will send a draft of MELODIC to you via email with some questions and options for open feedback. There is an option to be sent a summary of the findings, both from this explorative research and at the end of the study. Summaries will be sent via email if you select 'yes' here. We are planning a sharing event at the end of the study which you will be automatically invited to via email if you have taken part in the study. You can withdraw from receiving

communications about the study at any point through emailing Naomi and do not need to provide a reason.

### **What information will we ask for?**

We are seeking to learn more about current experiences of distress and distress behaviours for people on inpatient mental health dementia wards, and how these are managed, including any ways that music is used. We are using the term 'distress' and 'distress behaviours' in this study to include any behaviour that is challenging, such as agitation, aggression and apathy, and low mood. We will ask for demographic information and information relating to your experience with NHS inpatient mental health wards prior to the focus group or interview. Topics will cover the following areas:

- The experiences of people with dementia, staff and families;
- How factors, including patient characteristics, staff approach, and ward environment, influence their experiences;
- Current use of music on the wards.

### **What will happen to your data?**

All focus groups and interviews will be audio recorded. It will be possible to join a focus group or have an interview online using Microsoft Teams if preferred. Where this is the case, this data will be video and audio recorded. The audio recordings will be transferred onto a password secured device at the earliest opportunity and deleted from the original recording device. The recordings will be transcribed, with support from otranscribe software, and the transcripts will be kept on a password protected device. All raw data will be held for up to two years.

### **How will we use information about you?**

We will need to use information from you for this research project. ARU will be the sole data controller over the research, with Naomi Thompson and Dr Ming-Hung Hsu responsible for any data you provide.

This information will include your initials, name, contact details, occupation (where relevant), and experience of inpatient mental health dementia wards. People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. Your data will not leave the European Economic Area.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study. It is possible that selected quotes might be used in the PhD thesis, publications and presentations. Although every attempt will be made to ensure the participant cannot be identified this is still a possibility.

### **What are your choices about how your information is used?**

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

### **Where can you find out more about how your information is used?**

You can find out more about how we use your information

- at [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/)
- at <https://www.aru.ac.uk/privacy-and-cookies/research-participants>
- by asking one of the research team
- by sending an email to [naomi.thompson@aru.ac.uk](mailto:naomi.thompson@aru.ac.uk)

### **Are there any possible disadvantages or risks to taking part?**

We do not foresee any significant disadvantages to taking part in this research. We will be asking questions relating to potentially distressing or difficult experiences on inpatient mental health dementia wards. This could cause upset when recalling events. Two of the researchers collecting the data are qualified music therapists who will be able to support participants with processing and expressing any feelings of distress. Participants will be under no obligation to answer any question, and the researchers will ensure participants are comfortable and have time to process any questions throughout the interview or focus group. However, should there be any safeguarding concerns raised this will be reported to the appropriate local authority for the individual.

### **What are the likely benefits of taking part?**

We do not foresee any personal benefits to taking part in the research. The experiences that you share with us will inform the design of the MELODIC music therapy intervention. This intervention may be of benefit to people accessing inpatient mental health dementia wards in the future, and will add to our understanding of support needs in this setting.

### **Can I withdraw at any time, and how do I do this?**

You may withdraw at any point during the study should you wish by contacting Naomi via email, and do not need to provide any reason for withdrawal. However, once data analysis has begun, it will not be possible to separate your data from that of other participants. If you have selected 'Yes' to being contacted to provide further feedback and to receive a summary of findings, you can withdraw from this at anytime through emailing Naomi and do not need to provide any reason.

### **Contact details for complaints**

If you have any complaints about the study please do not hesitate to contact the project coordinator or chief investigator to try and reach an informal solution. However, you may additionally contact [complaints@aru.ac.uk](mailto:complaints@aru.ac.uk) or send any complaints to Office of the Secretary and Clerk, Anglia Ruskin University, Bishop Hall Lane, Chelmsford, Essex, CM1 1SQ