



Participant Information Sheet

Music in Mind / Power of Music – Research Study

Thank you for your interest in taking part in research linked to the Music in Mind / Power of Music programme, delivered by Manchester Camerata and our local partner charities in the community.

This research aims to better understand how music-based support may benefit people affected by dementia. In particular, it explores whether taking part in musical support sessions is associated with differences in the use of NHS services. The findings will help Manchester Camerata, the NHS and partners understand the potential value of music-based interventions and inform future service planning and commissioning.

What taking part involves

You do not need to attend any appointments, complete questionnaires, or take part in interviews.

If you agree to take part, researchers at the University of Manchester will analyse anonymised NHS health and care data relating to you. This data will be compared with anonymised data from people affected by dementia who have not taken part in Music in Mind / Power of Music sessions.

You will not be contacted by the researchers, and your care or support will not change as a result of taking part in this research. Also, by choosing not to take part in the research, your care and support will not be affected.

Information we need to collect

To carry out this research, Manchester Camerata needs to collect the following personal details:

- Full name
- Date of birth
- Home address (including postcode)

- Group start date *
- Number of sessions attended *

These details are required only so that the NHS can correctly identify and link your health and care records. Manchester Camerata will securely share this information with the NHS. The NHS will remove all identifying information before the data is shared with researchers at the University of Manchester. Researchers will not be able to identify you.



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We will need to know your group start date and number of sessions attended so that we can understand how many sessions you have attended for the research. You do not have to remember this as we will find this information from the normal group records that we keep.

What information will be analysed

The anonymised data may include information about:

- GP practice & NHS community health appointments
- Unplanned hospital admissions
- A&E attendances
- Prescribed medication
- Ambulance call-outs

The research looks at patterns across groups of people and does not examine individual cases.

How your data will be used and protected

All personal data will be handled in line with the UK Data Protection Act 2018 and UK GDPR. Identifiable information will only be used to enable NHS data linkage. Researchers will only access anonymised data. Data will be stored securely and retained for no longer than two years, after which it will be securely deleted.

Consent, capacity and support to decide

We expect that most people attending Music in Mind / Power of Music sessions will be able to decide for themselves whether they want to take part in this research.

We follow the principles of the Mental Capacity Act (2005). This means we assume people have capacity to make their own decisions unless there is clear reason to think otherwise, and we support people to make their own decisions wherever possible.

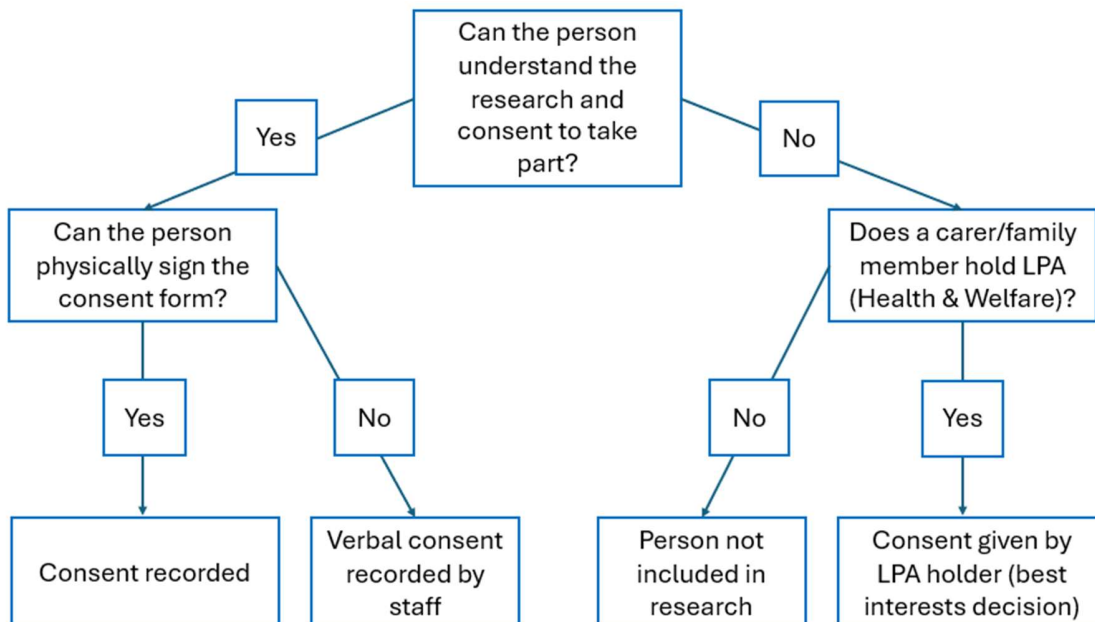
This research does not use implied consent. Attendance at Music in Mind / Power of Music sessions does not automatically mean someone is taking part in the research.

Some people may be able to clearly indicate their agreement but may be unable to physically sign a consent form. In these situations, consent may be given verbally and recorded by a member of staff. This will only happen where the person has demonstrated that they understand the research and wish to take part.



If a person is assessed as not having capacity to decide whether to take part, consent may only be provided by someone who holds legal authority to do so, such as a Lasting Power of Attorney for Health and Welfare. Any such decision must be made in the person's best interests.

Consent decision flow chart (for staff use)



Important: Attendance at music sessions does not equal consent to research participation.



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Consent Form

Participant full name:

Date of birth:

Home address (including postcode):

Option 1 – Written consent

- I have read or had read to me the Participant Information Sheet.
- I understand the purpose of the research and what taking part involves.
- I give my explicit consent for Manchester Camerata to collect my name, date of birth and address and share this information with the NHS solely to enable secure data linkage.
- I understand that identifiable information will be removed before researchers access the data.
- I understand that I can withdraw at any time before my data is anonymised.
- I understand that my data is processed for research in the public interest and that consent is sought for participation and data linkage.

Participant signature:

Date:



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Option 2 – Verbal consent (capacity present, unable to sign)

- The participant demonstrated understanding of the research.
- The participant verbally confirmed that they wish to take part.
- The participant was unable to physically sign but has capacity to consent.

Staff name:

Role:

Signature:

Date:

Record: Verbal consent given and recorded in line with Mental Capacity Act principles.

Option 3 – Consent provided by carer with LPA (Health & Welfare)

- The participant has been assessed as lacking capacity to consent.
- I confirm that I hold Lasting Power of Attorney (Health & Welfare).
- This decision has been made in the best interests of the person with dementia.
- I consent on behalf of the participant for Manchester Camerata to collect and share identifying information with the NHS solely for secure data linkage.

Name of person giving consent:

Relationship to participant:

Type of legal authority:

Signature:

Date:

Staff check: Legal authority seen and recorded.