MI DD EL

Music Interventions for Dementia and Depression in Elderly Care



MIDDEL Nottingham Winter, 2022

Bringing music to Nottingham care homes

The MIDDEL (Music for Dementia and Depression in Elderly Care) study reached its target in Autumn, 2022, with the recruitment of the last 4 out of 16 homes.

Twelve of these homes are in Nottingham, so the Nottingham researchers wanted to take this opportunity to thank participating managers, care home personnel, relatives and residents for your contribution to the MIDDEL study. We are not forgetting the all-important music practitioners and volunteers who provide

the intervention in nine homes (the other three are 'controls', where life goes on as normal). You are among a huge number of people without whom the MIDDEL study would not be possible. This number also includes researchers from Nottinghamshire Healthcare Trust and the Clinical Research Network who gather data from home personnel and residents, both in person and over the telephone.



MIDDEL researchers, Ankara, September 2022

MIDDEL International

MIDDEL is an international study involving six countries: Australia, The Netherlands, Norway, Germany, Turkey and the UK.

The Medical Research Council funds the study in the UK where there are two sites, Nottingham and Cambridge. A meeting of the international team was held in Ankara in September. Jodie Bloska, who co-ordinates the Cambridge arm of the UK study, attended in person, together with Smruthi Naripatta, who collects data in Cambridge. Justine Schneider was present online as well as Vigdis

Sveinsdottir, the Chief Investigator, who is based in Norway. They reported that the study has now collected data from more than 900 residents in more than 70 care homes. The target remains 100 homes and 1000 residents. The UK quota has been achieved of 16 homes and at least 160 residents; 12 homes in Nottingham and 4 in Cambridge.



Joanne Ablewhite, University of Nottingham

Why is MIDDEL important?



Kathryn Styles, Research Delivery Manager

Together with our counterparts in Cambridge and in the other participating countries, we expect to be able to measure the impact that frequent participation in music interventions can have on the mood of residents.

The study is designed to compare different approaches to musical activities in different

combinations, which will tell us what a critical 'dosage' might be if effects are found. In due course, the MIDDEL study will answer questions like: what kind of music works best for which residents and at what cost? COVID-19 has led to delays and interruptions to the study, so we now expect the first results to be available in 2024.

Study progress

Thanks to all care home staff and managers who are supporting the MIDDEL study in Nottingham, we have seen great progress.

In less than a year we have recruited 12 homes and about 160 residents in and around Nottingham. The first group of 4 care homes finished receiving the music interventions in summer 2022 and we are planning the final 12-month data collection in

January next year. The second group is about to complete the music interventions and we are in the process of collecting the 6-month follow-up data. The remaining care homes in Nottingham have just joined the study and will be receiving the music interventions, where applicable, before Christmas. The care homes that receive no music intervention are being offered



Kate Hodges

£150 to pay for a musical activity or entertainment as a thank you for taking part. We do encourage the homes not receiving an intervention to accept this gift and to invoice us for the small grant.

Staff survey reminder

Staff surveys have been distributed to all the intervention homes, together with stamped, addressed envelopes so that they can be returned directly to the researchers. We'd like to request care home personnel to complete these surveys if at all possible. They only take a couple of minutes and your responses will be held in complete confidence. The survey information will contribute to our understanding of which interventions are most effective.



Service Support Costs

We acknowledge that the MIDDEL study places quite a burden on homes due to the time and labour involved. We are pleased to authorise some financial reimbursement in recognition of this additional work. All homes taking part, including those that do not receive the music interventions, may claim Service



Support Costs by entering into a contract with the NIHR Clinical Research Network. Carl Sheppard is the contact for these claims (carl.sheppard@nihr.ac.uk) and Carl has been in touch with all the managers.

Enabling Research in Care Homes (ENRICH)

If being part of MIDDEL has inspired you to participate in more research for the benefit of care homes, their staff and residents, you might want to consider joining ENRICH. ENRICH brings together care home staff, residents and their families with researchers. It provides a toolkit of resources to help care homes make the most of research; and researchers to set up and run studies effectively and collaboratively in care homes. Find out what it means to support research in a care home, and what the benefits are for you in participating in research studies.



Visit https://enrich.nihr.ac.uk/care-homestaff/ for more information

Clinical Research Network

With about 160 residents participating, MIDDEL is an intricate and evolving study, requiring compassion and patience to collect data in a way that guarantees the residents' voices are heard and that they feel valued as participants in this project.

The Nottinghamshire Healthcare Research Delivery Team & the Clinical Research Network have been supporting MIDDEL study data collection throughout 2022. Working with a dynamic and flexible approach, the team conduct a range



Jack Cheshire, Research Delivery Officer

of psychological and cognitive tests in residents of participating care homes. Care home staff have been essential partners in this process, and we remain hugely thankful for their help. Study assessments are expected to be complete by summer 2023. We are committed to delivering such an important study and look forward to continuing our work with residents, their families and the staff at all participating sites. If you spot one of our team visiting your site, please feel free to come and say hello or to ask any questions you have about the study. But, please, do not mention the music interventions! See below.

Angela

Adverse events reporting

As a part of the study, we are required to check that no adverse events have arisen as a result of participating.

Adverse events include things like falls, illnesses and hospital admissions as well as deaths. These events may be unrelated to the study in any way. Still, we need to make a note of them to ensure that we are not putting anyone at risk. When we do our follow up data collection we will ask if any adverse events (AEs) have occurred as a result of taking part in the study and if so complete a form so that we have a record.

"Unblinding"



Abby Campbell, Research Delivery Assistant

It is a key principle of research that the data collector should not know whether a given resident receives an intervention.

It's recognised that such knowledge can influence a researcher's judgement. With 4 different intervention arms in the study, it has sometimes been hard to ensure that the interviewer team stays 'blind' to whether a given

care home receives the music intervention or not. Personnel can help by not referring to the intervention in any way when in conversation with the research interviewer team. Once again Nottinghamshire Healthcare Research Delivery Team & the Clinical Research Network offer sincere thanks for time and support of care home residents and personnel on the MIDDEL study.

Public Participation and Involvement (PPI)

Within the MIDDEL project we work with a group of people with lived experience of caring for family members with dementia in a care home, with musicians who are passionate about music therapy and with staff who work in other care homes.

These varied experiences have provided the MIDDEL team with a rich resource to call upon when needed. The PPI group reviewed our



Elaine Cross, the voice of MIDDEL

publicity materials, and also made a video about the MIDDEL project, working with an animation company to design a brief video that would help explain the project to care homes staff. The PPI group helped make the script clear and easy to understand while Elaine, a group member, recorded the voice-over to the animation. Using her voice for the video instead of one of the animators really brought the script to life.

Music brings people together: a conversation with

Ahmed Pochee

I grew up in South Africa and my father was very strict about music, a very devout Muslim. At home we used to have a radio and listen to music but when my dad was there we used to switch it off. I had ten uncles on my mum's side, they were all very modern. But my two uncles on my father's side, one of them used to like music, he and my dad used to run a shop and my uncle liked to have music all day but then my dad used to switch it off.

My wife Jenny and I used to listen a lot to Terry Wogan, I like classical music too. Then I got involved in the dementia choir and met a lot of very diverse people in the sense that some are outgoing, some very reticent, quiet people. Some of them don't even know where they are, it's amazing if you give them something to sing, they'll be belting it out. One or two of them they're completely different characters when they are singing.



Vicky McClure with Mark DeLisser, conductor of Our Dementia Choir, at Nottingham's Theatre Royal in 2018

Really I just go with the flow. Sometimes it's a bind in a sense, like when we go and sing in places that don't appreciate us. We went to London once and we sang for a business group, and they were running late so they put us into a corridor in this hotel with no air conditioning in the heat. We were all hot and dizzy when we sang, they seemed to have no appreciation. But anyway you take the rough with the smooth.

You seem very laid back – relaxed, about all your public appearances – on stage, on TV and at big events like the Splendour festival.

I had a lot of trepidation at first, of course I used to get anxious, but now I just take it as it comes. I think



Ahmed and Jenny Pochee at Abbey Road recording studios in summer. 2022

the events are all important, but to be honest, with my memory, they all merge into one. After a while, if I think about it, I can remember different ones.

I like music, I like all genres of music, it's uplifting, gets you going. I think it brings people together, it's a common denominator. Several of the original members have passed away now and I miss them. We have recruited a lot of new people now.

Did you ever think you'd have such an active social life?

Sometimes it's too active! We have a very crowded diary.

Our Dementia Choir have released an original song 'What's Your Story?' recorded at London's famous Abbey Road Studios. Founder of the choir, actor Vicky McClure, says "We hope 'What's your story' inspires those living with dementia and those who care for them to know that music is there for them, and that music is a powerful tool they can use to support health and wellbeing."

