

A Report:

LANCASHIRE

COUNTY OF

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Investigating the Integration of Music Interventions as a Social Prescription for People Living with Dementia

In collaboration with:



Lancashire and South Cumbria Integrated Care Board



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Report Contents

Investigating the Integration of Music Interventions as a Social Prescription for Peop	le
Living with Dementia	0
Report Contents	1
Acknowledgements	2
Introduction	3
Executive Summary	5
The Value of Social Prescribing for People Living With Dementia	5
Why Music as a Socially Prescribed Intervention for PLWD?	6
The Need for Social Prescribing in Dementia across Lancashire and South Cumbria	э.7
Phase 1 - Background	9
Phase 2 - Current	11
A) Exploration of Bid Development	12
B) An Exploration of Qualitative Evidence on Music Intervention to Improve	
Outcomes for People Living with Dementia: A Scoping Review	16
Abstract	
Methodology	
Preliminary Findings	
Conclusion	20
C) Research Project Approach	21
1. Objectives	
2. Research Design and Methodology	
3. Ethical Approval	
4. Research Progress	
5. Preliminary Findings	
i) Accessibility Data	24
ii) Mental Wellbeing Data	26
iii) Qualitative, Open Question Data	28
iv) Quotes from Participants	
Limitations	२२
Conclusions	
Future Recommendations	
Author Reflections - Social Prescribing	
References	
Scoping Review	
Main Document	
Appendices	
Appendix 1: Ethical Approval	
Appendix 2: Questionnaire	

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Introduction

This report is the **continuation** of a **research bid** designed to explore the benefits of the *Power of Music* for *People Living With Dementia* (PLWD).

In early 2024, the Social Prescribing Unit at the University of Central Lancashire) collaborated with NHS Lancashire and South Cumbria (L&SC) Integrated Care Board (ICB) colleagues and community colleagues, to apply for the National Academy of Social Prescribing (NASP) Power of Music Fund to develop L&SC into a Centre of Excellence (Pywell et al., 2024).

The purpose of this Centre of Excellence was to fund research into music on social prescription for PLWD, and to embed this further within the L&SC ICB for the benefit of PLWD and their families, extended families, and carers.

Existing research illustrates this work and supports the significant benefit of music as an intervention in the care of PLWD, especially with music memory commonly being known as one of the last cognitive memories to go in the later progression of dementia (Cuddy et al., 2012). While medications remain important for managing the symptoms of dementia, the integration of non-pharmacological interventions such as singing, song, choir and music can prove essential in providing a balanced and person-centred approach to care. Additionally, as the search for more effective pharmacological treatments continues, non-pharmacological strategies can remain valuable in delivering comprehensive care and enhancing the overall well-being of individuals with dementia (Berg-Weger & Stewart, 2017).

In May 2024, through the UCLan Undergraduate Research Internship Programme (UURIP), a research intern was assigned to continue and develop this work in collaboration with the original partners of the bid.

The original works now formed the foundations of a project to produce a report to support ongoing future research and practice in the L&SC Integrated Care System (ICS).

- The principal aims of this research were to:
- 1) Ensure the **benefits of music for PLWD** are **realised** to **support potential integration** within health and care commissioning as part of a future social prescribing strategy, thereby **strengthen the case for future research** and **practice** in the **L&SC commissioning footprint**.
- 2) Increase **awareness** and **knowledge** of the **benefits of music** to promote **social** and **emotional wellbeing** for **PLWD**.
- 3) Understand how music as a socially prescribed, non-pharmacological intervention, can support PLWD and their carers through a proposed research initiative.

During this 10-week student internship, Iqra Hussain, a second year MPharm student, explored <u>the following areas:</u>

- A) The works of the original bid as well as the <u>potential for future research bids</u> and <u>funding</u>.
- B) A scoping review of the literature, to evidence the effectiveness of music as a social prescribing intervention for PLWD.
- C) Designed and conducted an ethically approved research project to continue this work and <u>collect the perspectives of PLWD and their carers, family, and</u> <u>extended family on music for the brain as a potential social prescribing</u> <u>intervention.</u>
- D) Explored next steps to propel the project and <u>build foundations for future</u> research.
- This will form an invaluable piece of ethically approved research for our colleagues working in this area, and for PLWD who could benefit from the potential embedment of singing, song and choirs as a regular social prescription for PLWD within and across the L&SC ICS.
- For all those involved in the empowerment and care for PLWD, we hope this report will provide <u>more evidence and support for the non-pharmacological</u> <u>intervention</u>; **music on social prescription for PLWD.**



Executive Summary

The Value of Social Prescribing for People Living With Dementia

Social prescribing has emerged as a **valuable** component in the **care** of individuals living with dementia, by addressing their emotional, social, and psychological needs **beyond** traditional medical treatments (Alzheimer's Society, 2024, GOV, 2024; NHS, 2024; Kings Fund, 2020).

As further elaborated upon by Marshall et al. (2024), PLWD often have multifaceted needs that extend beyond medical care, encompassing emotional, social and practical aspects. **Social prescribing addresses** these diverse needs by connecting individuals with non-clinical services and community resources, strengthening community connections which in turn improves overall health, wellbeing and quality of life. This **holistic approach to care for PLWD** ensures that they **can receive comprehensive support**, **enhancing their quality of life** through increased social interaction and engagement via non-pharmacological interventions (Ajiboye et al., 2024; Fletcher et al., 2023; Gould, 2022; Arab et al., 2021).

In addition to this, the NICE (National Institute for Health and Care Excellence, 2018) guidelines for PLWD and their carers state that **psychosocial interventions** should be recommended as **both initial and ongoing management of non-cognitive symptoms** (Ajiboye et al., 2024).

Patel et al. (2018) discusses the wide diversity of non-pharmacological, psychosocial interventions available. Interventions are grouped into sensory (light, multisensory, aromatherapies), activity based (exercise), psychological (reminiscence, cognitive stimulation, and therapy) and creative (art, movement/dance, and music therapy). More significantly, a systematic review conducted by Ueda et al. (2013) concluded that alongside other non-pharmacological interventions, **music was a 'promising' intervention** to treat the behavioural and psychological symptoms of dementia, with results showing **'moderate' impact in relative symptom reduction**.

This holistic and person-centred approach that can be successfully achieved with a social prescribing framework **complements pharmacological treatments**, providing a **comprehensive care strategy** that **supports the diverse needs of individuals with dementia** (Arab et al., 2021).

Why Music as a Socially Prescribed Intervention for PLWD?

There is an growing body of literature supporting the use and effectiveness of music therapy as a non-pharmacological intervention for PLWD, with ongoing research further demonstrating this, which will be discussed in detail later into the report.

Recent findings published in the Lancet by Särkämö (2022) have shown that **recreational choir singing proves beneficial for many PLWD**, at different stages of progression. It is stated that amongst all non-pharmacological practices in dementia care, *music-based interventions* have attracted the most attention with regards to their potential for improving the health and wellbeing of those with dementia. The two most widely used and known music-based interventions are group music therapy (GMT) and **recreational choir singing (RCS)**, and it was notably concluded that in comparison to GMT, **RCS had a greater positive effect on depressive symptoms** (Särkämö, 2022). One reason for this could be the *increased social interaction within a choir environment*, and will be explored further throughout the course of the intern's research project.

Drawing once again upon findings from Ueda et al. (2013), it is notably stated that music intervention through **singing produced 'moderate effects on behaviour and anxiety'** in comparison to music intervention through listening, which alternatively produces effects on depression and anxiety. This is a crucial finding which can suggest that music intervention through singing, and therefore community choirs as such, **can play an integral part in the care of many PLWD.**

As previously mentioned, <u>musical memory often remains intact even as other cognitive</u> <u>functions decline</u> in individuals with dementia, therefore is one of the last memories to go (Cuddy et al., 2012).

Drawing on this aforementioned statement, according to Jacobsen et al. (2015), PLWD can recognize and respond to familiar music *long after* they have lost the ability to recall names or faces. The study conducted showed that patients with Alzheimer's disease *exhibited preserved memory* for music that was familiar to them from their youth, despite significant impairments in other types of memory. Similarly, a study by Cuddy et al. (2012) revealed that individuals with dementia were able to recognise rhythm and sing along to songs they had learned earlier in their lives, demonstrating the <u>remarkable persistence of musical memory</u>. These findings went on to suggest that music can uniquely engage specific neural pathways distinct from those used for other forms of memory, which may explain its persistence even in advanced stages of dementia, providing further evidence for music intervention in the form of community choirs.

As well as improving behavioural and psychological symptoms (BPSD), <u>music can also</u> <u>improve physical activity</u> with regards to the inclination of individuals to move and dance to rhythm. McDermott et al. (2014) showed that PLWD of progression to later stages had been seen to clap along to both familiar and non-familiar music. → With this research project, we intend to understand and expand on the knowledge base for music and, specifically, choirs being used on social prescription for PLWD in Lancashire and South Cumbria.

The Need for Social Prescribing in Dementia across Lancashire and South Cumbria

According to Public Health England (Office for Health Improvement and Disparities, 2020), out of 54,612 dementia diagnoses across the NHS Northwest region, a significant proportion of 15,024 were in the L&SC ICB specifically, which is estimated to rise (NHS L&SC, 2024). The true number of diagnoses may be higher than this and this does not include those with conditions such as Mild Cognitive Impairment (MCI), who may also seek to participate in music interventions through community choirs as such.

Furthermore, upon discussion with Stephen Sandford, the Chief Allied Health Professionals Officer for NHS L&SC, who collaborated on the original Power of Music bid and is also a music therapist, it was highlighted how **music therapy**, whether in the form of personalised music playlists or community choirs, remains **integral to dementia care across the Integrated Care System.**

In addition, with reference to the upcoming publishment of the L&SC ICB 5-year Dementia Strategy, 2024-2029 (NHS L&SC, 2024), this project forms a significant element in improving the lives of PLWD and their carers, which will remain a key priority for both NHS England and the Government. Relevant visions for the strategy include:

- ⇒ Improving care through increased collaboration with the voluntary sector to improve advice and support following diagnoses, creating more accessible support for PLWD in the wider community.
 - This will include partnerships with VCSFE providers, to provide more postdiagnostic support, especially within the community (discussed later).
- Highlighting the importance of giving PLWD and their carers opportunities to stay active, engaged, and maintain a good quality of life within their communities.
- ⇒ Creating higher quality jointly agreed dementia care plans for annual review, accounting for changes in the needs of PLWD,
 - Also ensuring PLWD are involved in research to support the delivery of personalised care.

(NHS L&SC, 2024)

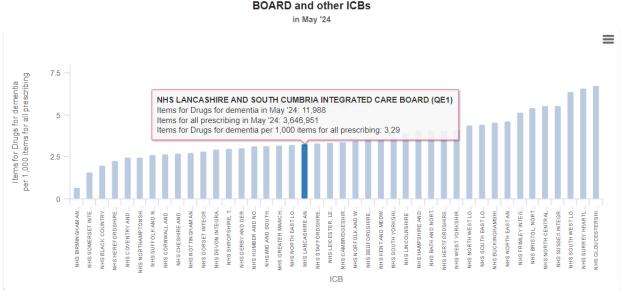
Currently, alongside the implementation of the NHS GP Forward View (2016), social prescribing is set to be a crucial element of improving dementia care. Introduced via the NHS Long Term Plan (2019), social prescribing enables primary care providers to



create referrals to 'link workers', who play an integral role in providing a pathway to non-pharmacological, personalised sources of support, in turn empowering individuals to take control of their own health and so addressing the range of multifaceted needs of PLWD (NHS, 2019; Gould, 2022; Alzheimer's Society, 2024)

In line with NICE guidance (2018), the BNF (Joint Formulary Committee, 2024) adds that PLWD should be offered psychosocial and environmental interventions before antipsychotic therapy, which should only be used in the management of severe symptoms (such as agitation, hallucinations, delusions, risk of harm). This can suggest that if we were to endeavour to integrate socially prescribed interventions, such as the aforementioned recreational group singing, this could potentially result in a measurable outcome of reduced antipsychotic prescriptions in the future. As stated by Rathbone et al. (2024), it is appreciated that social prescribing does not cause any side effects.

Regarding this, a chart is shown below, sourced from the OpenPrescribing database (Bennett Institute for Applied Data Science, 2024).



Items for Drugs for dementia vs all prescribing by NHS LANCASHIRE AND SOUTH CUMBRIA INTEGRATED CARE BOARD and other ICBs

It can be inferred that approximately 0.33% of all items prescribed across the L&SC ICB are <u>items prescribed for Dementia</u> (Bennett Institute for Applied Data Science, 2024). Although this may not seem a significant figure, when mapped in relation and comparison to all ICBs across NHS England, this is somewhat substantial. It can be suggested that the implementation of more social prescriptions for Dementia in the future may have the potential for a more sustainable and personalised approach which will not only enhance quality of life, but also address the complex and multifaceted needs of PLWD (Marshall et al., 2024; NHS, 2023; Gould, 2022)

Phase 1 - Background

In 2023, the National Academy for Social Prescribing (NASP) launched **The Power of Music Fund**, which was aimed at <u>promoting music as a social prescription for PLWD</u> and their carers, and <u>ultimately recognising music as an integral part of dementia care</u> (L&SC ICB, 2024).

The fund was supported by The Utley Foundation and Arts Council England, alongside other investors, and private donors including government bodies and businesses. The fund initially consisted of small grants to support dementia choirs and singing groups, however following this, a large fund was created for a <u>Centre of Excellence</u> to be appointed (NASP, 2024).

In <u>February 2024</u>, the NHS L&SC ICB collaborated with the UCLan Social Prescribing Unit and associated academic colleagues to apply to this CoE fund.

The main aims of achieving the fund for the UCLan SPU to become a CoE with support from the local NHS ICB are summarised below:

- Lead, inspire and ensure the benefits of music for PLWD are realised and integrated fully within health and care commissioning.
- The fund budget would contribute to the following elements:
 - (1) Building sustainable funding at a place-based level embed music within commissioning.
 - (2) Provide free access of music activities through social prescribing to PLWD, particularly those impacted most by health inequalities.
 - **(3)** Reduce barriers faced by PLWD in accessing music on social prescription.
 - (4) Communicate, share, disseminate research and informed best practices.

(L&SC ICB, 2024).

These project aims were planned to be achieved by a mixed variety of methods on the impact of the Power of Music on social prescription for PLWD in L&SC, some of which are listed below:

- Annual report, to include a literature review and grey literature review.
- Scoping existing digital systems within L&SC for social prescribing reporting data and identify requirements for data sharing.
 - This would involve exploration of capabilities & ceilings and highlighting if any impact data is not currently being recorded, as well as building on the existing pilot sites who have used social prescribing data platforms in L&SC.
- Understand perceptions and views of music intervention benefit via contact with PLWD, their family/carers, group choir session leaders, health and social care

professionals involved in care as well as involvement of a local community by community/faith leaders.

- Conduct case studies to gain perspectives from PLWD, their carers, referrers in care and care commissioners.
- Use and gather any social prescribing outcome measures where possible in research as well as implementing analytics from existing Social Prescribing data platforms if used (e.g. Elemental pilots have occurred in L&SC).
- Create a plan for comprehensive, sustainable models of resource, funding & research for continuation of the Power of Music in L&SC for PLWD.

(L&SC ICB, 2024)

This bid developed by the L&SC NHS ICB with support from the University of Central Lancashire's Social Prescribing Unit successfully reached **Stage 2** of the NASP Power of Music Fund application process, and scored very highly, meaning it was **shortlisted** (NASP, 2024).

Following this application process, in May 2024, it was announced that the *UK's first Centre of Excellence* for music and dementia would be awarded to Greater Manchester (via Manchester Camerata). Funding totalling just over £1m was awarded by the NASP Power of Music Fund, as well as match funding from the Mayor of Greater Manchester, Andy Burnham, and the NHS Greater Manchester. The Centre of Excellence will enable the continuation and enhancement of the Manchester Camerata and Alzheimer's Society music therapy initiatives, as well as collaboration with NHS Greater Manchester ICB and University of Manchester in undertaking further research into social prescription of music for PLWD (Arts Council England, 2024b; Manchester Camerata, 2024; The University of Manchester, 2024).

→ This demonstrates the bid's potential, and the promising impact of the proposed project aims. This recognition highlights the bid's value and the importance of continuing to develop this initiative to the present day.



Phase 2 - Current

On the 20th May 2024, Iqra Hussain, a UURIP Research Intern began a 10-week internship term to continue and develop this project.

By direct collaboration of the research intern with colleagues who worked on the original bid, the intention and goal is to develop the original aims, which are as follows:

- Continue to expand on the evidence base for socially prescribed music intervention to support PLWD, especially across the Lancashire and South Cumbria region.
- Conduct and disseminate place-based research on open access to advance the project. Explore and highlight around the current gap in research, share findings and raise awareness to advance the understanding and implementation of music interventions - all in an attempt to ultimately enhance the quality of life for individuals with dementia, with recommendations that can be made across the L&SC region but also beyond this.
- Explore potential sustainable funding through alternative providers to provide free access of music activities through social prescribing to PLWD, as well as support future place-based research, including ascertainment of future funding applications.

These aims are intended to be achieved in progress by varied methodology:

- Source and ascertain for alternative funding opportunities and disseminate research findings of the project, to build strong foundations for future work in this area.
- □ Conduct a **scoping review** to *establish* the **current knowledge base** of **music intervention for PLWD**, especially through singing, song and choirs.
- Carry out a live research project within Lancashire and South Cumbria, to comprehensively understand the views of PLWD and their carers on how music intervention provided by community choirs benefits them, as well as understanding barriers faced to be able to work on in the future.

Phase 2 therefore involved:

- A) An **exploration** of potential future delivery & research funding
- B) A scoping review
- C) Ethical approval and implementation of **research** on participants attending choirs for PLWD in L&SC



A) Exploration of Bid Development

The first step in developing the original research bid after Manchester Camerata was announced the NASP Centre of Excellence, was to understand and examine the feedback given.

One area was the requirement for an increased level of match funding with similar levels of in-kind investment. A way that the Greater Manchester Centre of Excellence achieved this was through match funding from the Mayor, Andy Burnham, as well as NHS Greater Manchester (Arts Council England, 2024b; Manchester Camerata, 2024; The University of Manchester, 2024).

Other relevant areas of feedback were positive. NASP were impressed with the range of partners on the project, with optimism of the collaboration process leading to progress in the area. All other areas of the bid were well developed and supplemented with supporting letters and documentation, especially the aim of national delivery impact as well as local, leading to the high score.

Following this feedback, the first step the intern took in developing the bid was in contacting NASP to understand future opportunities that would be offered as part of the Power of Music Fund, with aims to direct the project to alternative opportunities with NASP. NASP stated that although they are working towards securing further investment for a second Centre of Excellence, this is not to be confirmed for a minimum of three months (NASP, 2024). It was also stated that the funding will be aligned to investor outcomes to be more focused in its approach and outcomes to Music and Dementia. From this we can infer that a potential re-application may be possible in facilitation, in the future.

The intern then worked on <u>understanding</u>, <u>sourcing</u>, <u>and exploring other sources of</u> <u>future funding</u> to **enhance** the **original aims** of support for **delivering music interventions**. These are illustrated in an infographic (see Figure 1).

The purpose of applying to further funding opportunities after the original bid achieved stage 2 was to **enhance the delivery of music interventions**, **whether on social prescription or not, across L&SC**.

The intern collaborated with a student medic and volunteer researcher also working on the project, Abhimanyu Dhanakumar, for further exploration of potential delivery and research funds.

 Delivery monies - Funding raised in this area will <u>contribute to existing</u> <u>funding</u> of community choir groups, and related community groups that provide music intervention for PLWD (on social prescription). This would be co-organised with one or more community groups - as all funding is directed to them.



2) Research monies - funding raised in this area would contribute to increased research efforts; researching the effectiveness and importance of socially prescribed music intervention on individuals with dementia.



NIHR ARC NWC Internships.

underrepresenta tion of extensive funding for music intervention for **PLWD**

 Monthly deadlines until February 2025

NIHR NIHR •Funding for • Funding for (Research for Patient Benefit) Research research with a Project clear trajectory Internships to patient involves benefit recruitment of • Criterion met individuals rendering employed by suitable **NIHR** member application: is organisations to relevant to the carry out an priorities and existing needs of the research NHS. progress and Main focus is contribute research to expertise to improve advance work in evidence base the area RfPB (surrounding •Relevance: mental health involves conursing and production with workforce. NIHR patients (SP) Current project and addresses could highlight regional priority. themes for • Annual further relevance in Deadline mental health Monday 13th with regard to January 2025 PLWD Competition 55 - deadline 06/11/24



National Lottery Project Fund

• Organised by the Arts Council England, Supported by the National Lottery •Offers grants of upto £30,000, upon online grantium application/inter

view Criterion met rendering suitable application: intends to make

- a difference to communities in **England with** regards to arts and culture.
- Can apply individually as well as in a colleague group.
- No formal deadline

Figure 1: An illustration of the potential funding applications that could be made in the near future.

(PRS Foundation, 2024; NIHR, 2024a; NIHR, 2024b; Arts Council England, 2024a)

Moreover, the partnership agreement created between the L&SC ICB with the VCFSE (Voluntary, Community, Faith, and Social Enterprise) Alliance in May 2023 also holds value. The agreement states to 'build and work from existing structures' and improve the collaboration between different sectors rooted in co-production (NHS, 2023). This is significant as it could perhaps contribute to the development of a more established social prescribing framework in the future; in which music intervention for PLWD could be implemented.

Other options that were discussed included:

- The National Lottery Community Fund:
 - o Although this is aimed at large non-profit organisations, the Power of Music project could potentially benefit from support aligned with its objectives.
 - o For example, with larger grants, a percentage of the funds are allocated towards evaluating the project's impact, ensuring outcomes are tracked and reported. This can contribute to the long-term scalability of the project.
- Community based funding through interaction with:
 - The Local Council
 - The community itself: 0
 - Online GoFundMe pages
 - Members of the community as match donors:
- \rightarrow The intern also made plans to interact with the Mayor of Preston to present the project and gauge interest and recommendations for the future of the project. Slides delivered to the student volunteer researcher by the intern in developing the work of ascertainment for funding opportunities are provided below for further context.





Factors to Consider upon Application

- Understanding and accurately portraying needs and benefits
 Highlight benefit of music intervention and needs to enhance
- Clearly defined program design and implementation
 Goals, expectations, team collaboration, schedule/timeline
- Comprehend levels of funding
 Eligibility/relevance of local, national, departmental levels
- Differentiate types of funding
 - Government grants, foundations/nonprofits, corporate sponsorships and community fundraising
 - Additionally capacity to apply;
 Gauging interest from internal/external colleagues

Searching for Funding Opportunities: <u>Why and How</u>

- ✓ Make music and choirs more accessible for people with dementia
- ✓ Deliver music on social prescription as a new and rising interventionmusic is integral for PwD as elaborated upon by NHS Chief AHP Officer
- ✓ Build sustainable funding for the intervention at a placebased level (locally across the ICB) on a non-profit basis

Summary of Actions

Work in partnership to:

- Create a plan in finding funding opportunities: criteria, aims
- Consider all factors within this plan

Gauge colleague interest:

- Inform of opportunities and plans to apply to funding

13

B) <u>An Exploration of Qualitative Evidence</u> <u>on Music Intervention to Improve</u> <u>Outcomes for People Living with</u> <u>Dementia: A Scoping Review.</u>

Abstract

This short scoping review aims to explore the qualitative evidence available regarding music intervention in the form of singing, song or choirs for PLWD, focusing on direct therapeutic outcomes for future embedment in a social prescribing framework, and for future place-based research relevant to the L&SC Integrated Care System and beyond.

By reviewing existing qualitative research on how music intervention (in the form of singing, song, or choirs) impacts individuals' cognitive function, overall well-being, behavioural/psychological and other symptoms, a qualitative understanding and awareness can be provided of how music interventions can reduce social isolation, enhance community engagement, and improve overall quality of life. Consequently, the role of social prescribing in integrating music interventions into care for PLWD can be further explored in the future.

While this report includes an overview of the preliminary findings, the full methodology and detailed PRISMA results have been reserved for future journal publication. The complete review is currently being prepared for formal peer review, and further development of the review will be ongoing. The preliminary findings presented here will illustrate the available qualitative evidence on the use of music interventions for dementia,

Methodology

The search strategy aimed to capture a broad range of select studies exploring the effectiveness of music interventions (specifically singing, song and choirs) for PLWD to support the future implementation of social prescribing in integrating these interventions into dementia care.

Following elements of PRISMA guidelines, searches were conducted across four major databases: MEDLINE, PsycINFO, Web of Science, and CINAHL (Page et al., 2021). The search focused on literature published between 2016 and 2024, coinciding with the implementation and recognition of social prescribing with its reference in the NHS GP Forward View Plan in 2016 as well as the NHS Long Term Plan in 2019 (NHS, 2019; NHS England, 2016). The review included only English-language journal articles and academic journals to ensure the inclusion of peer-reviewed and high-quality studies.

After identification of studies, the literature retrieved was screened using the PICO (Population, Intervention, Context, Outcomes) framework.

18 studies of 41 originally identified using the PICO criteria were included. 17 were identified through database searches whilst one was sourced separately via open grey searching and is a recently published protocol for a complex intervention systematic review connecting social prescriptions for PLWD and their carers (Marshall et al. 2024).

This study aimed to map literature around the use of singing, song and choirs for PLWD and what effect this has with regard to qualitative findings such as, but not limited to, thoughts, perceptions and observations. Main themes and findings identified which contribute to the evidence base for music intervention and therapies for PLWD will be briefly discussed.



Preliminary Findings

Improving Management of Dementia

There was a recurrent theme of firsthand effects observed of music intervention in directly reducing agitation, anxiety, depression experienced by individuals in community-based focus groups (Veal et al. 2022; Thompson, Z., et al., 2022).

Moreover, a study conducted within a hospital setting by Thompson, N., et al. (2023) revealed that when music therapy was provided to patients with Dementia, the improvement in mood and agitation was not only temporary but also lasted throughout the day, proving valuable in creating a better environment which positively impacts mood, reducing agitation and distress.

Another qualitative study conducted by Osman et al. (2016) at a Singing for the Brain[™] group found that attending and participating in the choir activities helped in accepting and coping with a dementia diagnosis, due to the facilitation of social support, valuable interactions with other PLWD and their carers.

Enhancing Cognition, Memory and Communication

A range of studies have shown that music interventions and therapies can stimulate musical memory by stimulating reminiscence via familiar songs, which has a mutually beneficial impact on PLWD as well as their carers (Lee et al. 2020; Osman et al., 2016). Mittelman and Papayannopoulou (2018) have elaborated on this suggesting that it may perhaps slow cognitive decline in Dementia.

Besides this, research by Clare et al. (2019) in a residential care setting has demonstrated that PLWD in late stages tend to express themselves non-verbally in relation to music, and that a live music based environment, such as a choir, can facilitate this method of communication. This is further exemplified in a case study of an individual with severe aphasia in late stage Dementia, where it was indicated that even when language functions decline, music functions such as music engagement may still persist (Baird and Thompson, 2018).

Strengthening Relationships: Self, Carer and Social Connections

The environment established in settings of musical settings supports the social interaction of PLWD with other PLWD, fostering feelings of happiness, enjoyment and engagement, boosting self-esteem and in turn strengthening self-connection, which is significantly impacted by dementia even in the early stages (Mittelman and Papayannopoulou, 2018; Lee et al., 2022). In addition, Fälth et al. (2021) demonstrated

in a separate interview-based study that music therapy in the form of choral singing evidently creates a supportive social context for these aforementioned positive effects.

Further findings by Elliott et al. (2020) highlighted that many music interventions and therapies can act as 'catalysts' for self-connection as well as connection of PLWD with their carers. Engaging with music has been likened to an 'anchor' to the present moment, providing a foundation for strengthening this connection. Alongside this, a subsequent study by Jean-Bernard Mabire et al. (2022), showed that over time, relationships with carer shifted from care staff to close singing partners. Stuart-Röhm et al. (2023) explores this, demonstrating the enhanced caregiver abilities, allowing for better comprehension of the needs of PLWD and therefore providing improve person-centred care.

Balancing Treatment Approaches: Effects of Integrating Non-Pharmacological with Pharmacological Interventions

A longitudinal study by Batt-Rawden and Stedje (2020) found that music intervention has the ability to improve sleep, increasing well-being and so reduced the need for medication, especially psychotropic as stated by Hamiduzzaman et al. (2023).

Overall, according to research by Schneible et al. 2023, the integration of music in long term care for PLWD is a personal, meaningful bridge to individual transformation as well as community engagement.

An ongoing research protocol by Polden et al. (2023) will contribute to the evidence base of not only highlighting the impact of music intervention for PLWD and their carers but highlight it as a sustainable element of care. An additional complex intervention systematic review by Marshall et al. (2024) will contribute to the gap in research by understanding the potential increase of positive health outcomes if a social prescribing framework was adopted for PLWD, and how.



Conclusion

This scoping review provides a preliminary exploration of the recent qualitative evidence available for the implementation of music interventions and therapy in PLWD. Preliminary findings have began to highlight the multidimensional benefits of music interventions, particularly singing, song and choirs, and further analysis could emphasise this value of music intervention as valuable for inclusion in a social prescribing framework for PLWD.

A limitation of the review is that it was restricted to qualitative analysis only, due to the short timeframe in which it was conducted. Moreover, future exploration and further critical analysis of the selected literature is needed to support this groundwork for inclusion in a social prescribing framework. The wide range of non-pharmacological treatments by the implementation of music interventions and therapy available can significantly impact the daily lives of PLWD and, by building on current evidence, future research can contribute to this ongoing evidence base to continually develop informed, innovative, and person-centred care for all PLWD.



C) <u>Research Project Approach</u>

As part of the continuation of the bid, the research intern set out to conduct a research project in order to support the evidence base for socially prescribed music intervention for PLWD, with a focus on the perspectives of PLWD and their carers within L&SC.

The research project aligns to the UCLan Research Institute of Creativity, Communities and Culture (ICCC), conducted by the Social Prescribing Unit at the university, led by the Intern and support from staff with research time within their existing workload and is titled <u>Investigating</u> the Power of Music in Community Dementia Choirs.

1. Objectives

The research project aims to evaluate the impact that services provided by a community choir have on the attendees who are individuals with Dementia.

The objectives of this study aim to:

- **1)** Assess and understand attendees' **accessibility** to the group. This is with regards to the ease of access in attending the group and if there are any **barriers** that may be faced. These may include:
 - Transportation and location convenience: is the individual able to attend the group with or without the support of a carer?
 - Ease of managing costs: how is this managed, is the individual entitled to PIP to cover relative costs?
 - Is there any additional support that attendees require during sessions? Is this provided?
- **2)** Conduct a thorough exploration of attendees' **views and experiences** of individuals using the service and how they **benefit** from using the service, focusing on the benefits of music intervention for individuals with dementia.
- **<u>3</u>**) Conduct a thorough exploration of **carers views and experiences**, understanding how music intervention provided in the community choirs has impacted:
 - Their **relationship** with the person they care for.
 - Their caregiving experience.

2. Research Design and Methodology

The aims of the research were proposed to be achieved via the use of an online questionnaire, hosted by Microsoft Forms (see appendix 2 for final questionnaire design). The methodology surrounding the distribution of these questionnaires will be detailed.

The Alzheimer's Society runs a number of Singing for the Brain[™] groups both nationally and across Lancashire, which was first established in 2003 (Osman et al., 2016). The aim of the groups, which meet regularly, is to provide music intervention by a range of vocal warm-ups and singing to a variety of both familiar and new songs, all in an environment where PLWD and their carers can socialise with each other (The Alzheimer's Society, 2022).

Via existing contact of Loz Kaye (Director, County of Song) with these groups, the intern was able to offer the opportunity of participating in this research study upon which invitation was successful to one Singing for the Brain[™] group in Lancashire. The predicted sample size was to be around 10-20 participants, from each group as there are two separate groups within that meet weekly.

The methodology in which questionnaire distribution was to take place was a three-step process, as follows:

- (1) Communication to the community group lead (informing them of the study via email. Upon registering interest, a letter of consent to be obtained from the group leaders confirming their interest, permission, and consent to the research study involving their attendees as participants.
- (2) Upon receipt of ethical approval, group leaders verbally explained information to the attendees of the weekly group choir session, informing them of the opportunity to participate, what exactly it involves, and how it will be conducted. The participant information sheet was distributed (see appendix). Group leaders were instructed to gather interest as well as any questions from participants, especially any queries relating to support that may be needed to participate. Group leader took note of attendees who willing and able to participate including their email addresses (avoiding all forms of personal data handled by the research team in compliance with ethics).
- (3) After a 7-day gap with all interest registered, emails containing the invitation to participate, and questionnaire link were forwarded from the intern to the group leader, then to participants. Participants were given a provisional date of questionnaire submission to ensure facilitation of data collection.

3. Ethical Approval

Ethical approval for this research project was successfully granted on the 2nd July 2024 from the University of Central Lancashire (*HEALTH 01130*). Please refer to Appendix B for further information.

4. Research Progress

Post-approval from the ethics committee, the research project was conducted as soon as possible to allow maximal time for data collection.



- Questionnaires were successfully sent out to the group leaders and participants on the 8th July.
- A total of 12 submissions were received by the 22nd July. This marked the official completion of the data collection phase.

Although data analysis exceeded the intern's placement on the project, plans have been put in place to allow for effective analysis to achieve one of the original aims of the project. The data will be analysed using thematic analysis by UCLan staff and coresearchers within the project to evaluate the impact of the service from the perspective of the attendees. The data will be primarily analysed by Iqra (intern) who will continue on the project as a student researcher, who will be working under Samantha Pywell (Intern Supervisor) and we will also collaborate with Stephen Sandford (representative for NHS L&SC ICB) to analyse the responses given by participants on their ease of access to the groups, as well as review data on current social prescribing initiatives.

Other research institutions within UCLan were also contacted with the opportunity to help facilitate the data analysis phase. We intend to apply to publish the findings in a separate journal in the near future.

5. Preliminary Findings

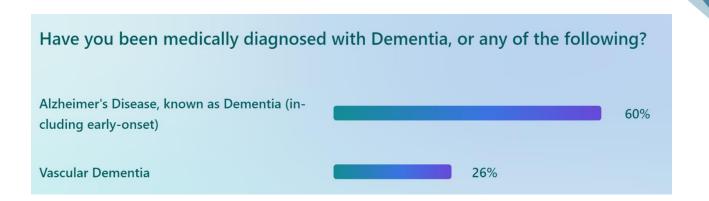
Preliminary findings were taken from the n=12 participants who responded to the questionnaire. All participants stated they were completing the questionnaire in the role of a carer/ family member or friend of the person with dementia.

Although data analysis is pending, select preliminary findings are illustrated below.

Most participants were completing on behalf of a person with Alzheimer's disease or vascular dementia.







24

i) Accessibility Data

Most participants found it between 3 (not difficult nor easy) and 4 (easy) to get to the choir.

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On a scale of 1-5, how easy or difficult is it for you to get to the choir? (1 = very difficult, 3 = nor difficult nor easy, 5 = very easy)

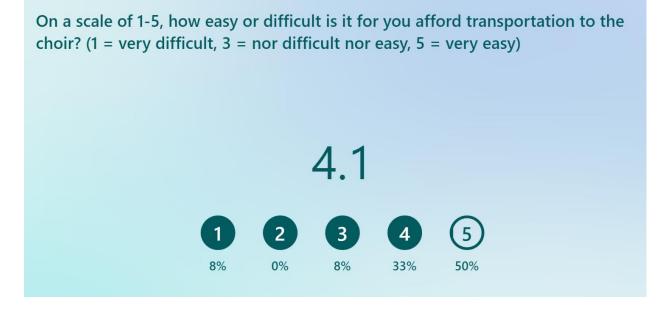
3.6
1 \begin{array}{c} 2 \\ 8\% \end{array} \begin{array}{c} 3 \\ 8\% \end{array} \begin{array}{c} 4 \\ 8\% \end{array} \begin{array}{c} 5 \\ 58\% \end{array} \begin{array}{c} 5 \\ 16\% \end{array}
```

The majority (66%) did not think they were eligible for PIP support to attend/ take part in the choir.

Are you entitled to PIP or another fund to be able to cover the costs of attending community choirs?



Transport was not reported as a barrier to most participants who attended.



50% of participants reported that there are a **few** (choir) groups in my area that can be conveniently accessed.



Additionally, the main barriers & difficulties reported in accessing the groups were parking, waiting list, drive, affordability, and support in attending the group (by carers, family member etc.).

ii) Mental Wellbeing Data

The following questions were designed as SWEMWBS (Short Warwick and Edinburgh Mental Wellbeing Scale Questions to monitor general mental wellbeing of participants (University of Warwick et al., 2008)









iii) Qualitative, Open Question Data

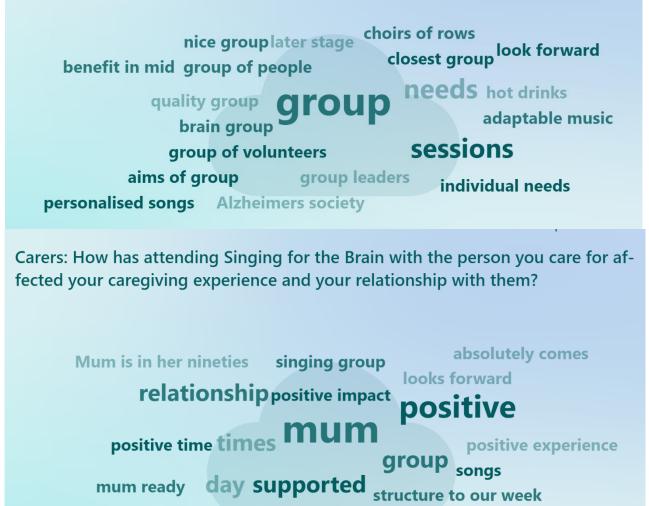
Do you have a favourite aspect of attending the choir sessions, and if so, what i this?

interaction and movements remember clearly community spirit laugh base singing kazoo and whistles drum great fun **Singing** singing with actions mum new friends favourite songs sessions responses activity musical instruments chair base Especially when they have enjoyed



Do you have any other comments or thoughts regarding your experience that you would like to share?

29



love her unconditionally Quality groups dementia but the groups

iv) Quotes from Participants

Q20. How has attending a community choir impacted your health and wellbeing, especially with regards to Dementia?

- "Early & mid stages of Alzheimer's- parent and carer made friends, part of community, meaningful activity, peer support, uplifting, social, volunteer support, feel understood, cared for, get out of house, event to look forward to, express emotions laugh/ cry, memories stimulated. "
- "I have benefited from the **companionship**, the Singing makes me **feel happy**, especially the old songs. The **support has been so good**."
- "It has encouraged conversations with others, as at home, sat in silence. Mood is better, not as agitated. Remembers things still, as has an emotional impact with the groups, and can connect that way. Making a feel good."



- "The singing has certainly helped my mental health the music and songs trigger my memory of the tunes and words and bring back the memories relating to past events. It also to some extent helps with my physical health because of the exercises involved with singing some songs. I have also received thanks from organisers etc for my contribution to the sessions, and this has contributed to my well-being. "
- "The choir has had a **significantly positive impact** on my mum. My mum has felt isolated for a number of years and has rarely participated in social groups. "
- "It is usually a very enjoyable experience for my mum. Occasionally her anxiety is too bad. But it is one of the very few activities that she can take part in and enjoy."
- "It makes me feel as though I belong. It lifts my spirits."
- "I answer this as my wife's carer. I feel it is **good to get out and mix** with other people it sometimes difficult to get my wife motivated to go but once there she generally **enjoys** it."
- "I enjoy the activity"
- "I feel welcomed. I am happy to be able to meet other people and have a laugh. I enjoy singing and remembering the words and songs."
- "It is great to see those with **Dementia joining in the singing despite not being** able to communicate"

Q21. Could you explain how you feel before attending each community choir session?

- "Later stages Alzheimer's- can feel **anxious, upset** especially after morning routine dressing etc. "
- "Excited and nervous "
- "Looks forwards to attending, seeing people, a chance to get out, when isolated at home."
- "Looking forward to it!"
- "Every week my mum remembers its choir day which is very positive and looks forward to going and singing and meeting up with other people in similar situation "
- "There can be **anxiety** before going as mum doesn't really like leaving the house, especially if the weather isn't good."
- "I look forward to it"
- "I as the carer look forward to it. My wife sometimes is a bit reluctant but once there enjoys it "
- "Looking forward to it"



- "I often can't be bothered to leave the house "
- "Excitement "

<u>Q22. Could you briefly describe how you feel after engaging in a choir session?</u>

- "Can be a **mood changer lifts mood**. Smiles at other people, 'talks' to them, admires lovely scarves/ clothes. Had drink. Moves to music. Occasionally can sing along. Feels like party. Can participate with tapping or shakers or dancing".
- "Happy and tired as I put so much effort into the session."
- "Upbeat and happier. "
- "Happy and **energised**."
- "Happy, always has a great time and shares her experience of being at choir with her family. "
- "Mum is usually more cheerful after attending. Even though she probably doesn't remember where she has just been, the sense of enjoyment stays with her for a while."
- "Happier, but tired."
- "Happy "
- "Happy"
- "Happy to have enjoyed meeting people and having a fun afternoon. "
- "Happy"

Q23. Do you have a favourite aspect of attending the choir sessions, and if so, what is this?

- "People and uplifting music"
- "Meeting my friends and new friends. Singing my favourite songs and playing the drum."
- "The singing, but the interaction and movements they do in the group. **A chance to sing and exercise**, as chair base singing with actions. "
- "I started to bring my own musical instruments such as kazoo and whistles to the sessions. I have **great fun** watching the responses when I do this. Especially when they have enjoyed it."
- "Singing songs I remember clearly from my past "
- "Seeing mum **engage** in an activity. "
- "The singing"
- "Not really "



- "Company"
- "Singing and having a laugh "
- "The community spirit."

Q24. Any other comments

- "Frustrating that our closest group closed and <u>40 mins drive</u> to our '<u>local'</u> group now"
- "Encourage anyone to go to choir its soup for the soul"
- "There needs to more of these across the UK. It has changed my life, as I feel I have a life again after giving up driving due to my diagnosis"
- "People take time to talk to me which I like"
- "It's a nice group of people and very supportive as much for the carer as the patient."

→ This data will continue to be analysed by the Social Prescribing Unit team at UCLan with the intention to publish - Thank you to all participants who took part.



Limitations

The primary limitation of this work was due to the 10-week timeframe of the placement. Ethical approval for the research project was obtained during this placement, as was data collection, hence limited time for data analysis.

Although the scoping review has illustrated a set of literature available for the evidence base of music intervention in the form of singing, song and choirs, further qualitative exploration and discussion can be completed in the future. It could also be repeated with a wider net (e.g., more databases given the potential for social prescribing to occur within any database/ journal, more search terms, wider timeframe etc.) As this research was conducted with one researcher (under supervision) it was not possible to conduct a larger scoping/literature review.

Additionally, more research could be conducted with regards to the varying models of social prescription currently implemented in practice, for example the CESP (Community Enhanced Social Prescribing) model (Morris et al. 2020). This will help to further inform future implementation of a social prescribing framework for PLWD.

The 10-week timeframe was not conducive to publishing. The intern author will continue research as a social prescribing and mental health student research volunteer at UCLan to continue this work and grow the future research team. Works within the bid development progress, data analysis of the research project and scoping review article will continue outside of this timeframe with colleagues in an aim to propel the research and apply to future research bids.

With the researcher having no funding, it was not possible to replicate the original research bid submitted to NASP. It is possible future research (including applying for larger research bids) may help grow the research team and work in this area for the benefit of PLWD. This may be possible to achieve soon with more researchers.

Future research can explore larger sample sizes, and exploration of perspectives from people with dementia.

Before and after SWEMWBS data could be used, rather than just after a session to explore longitudinal benefits.

However, further research is required as to the most appropriate outcome measure for this social prescribing intervention and circumstances.



Conclusions

To conclude, this project on "Investigating the Power of Music Intervention through Social Prescribing for PLWD " fulfilled the following aims:

- Explored and ascertained the available funding of both research and delivery monies for application in the future
- Complete a scoping review on the available literature in this area relevant to music intervention to inform future regional social prescribing in the L&SC ICB.
- ✓ Gain ethical approval and collect data from PLWD & carers' perspectives to inform future work within L&SC.
- Produce this **report** on open access. Given the contemporary agenda of music & choirs on social prescription for PLWD, this report has **illustrated new initiatives** which can be used in future projects.

This **scoping review** explored available qualitative evidence on the <u>Power of Music as a</u> <u>socially prescribed intervention</u> from the perspective of a 2nd year MPharm student and research intern working with the Social Prescribing Unit at UCLan. To our knowledge, there exists *very limited* open access forms of research which directly connect social prescribing with dementia.

Therefore, our scoping review <u>contributes to the evidence base and highlights existing</u> <u>research supporting music intervention</u> (specifically choirs, song and singing) for PLWD and their carers. The aim of these findings is to in turn support the **implementation** of **music intervention** in care for PLWD via a **social prescribing framework** in the future.

The **research project** was successfully granted ethical approval and data collection was also able to have been facilitated with thanks to the team at the local Singing for the Brain[™] group. The questionnaire gathered perspectives of people who regularly attend choirs on social prescription in Lancashire. A total of 12 participants took part over a 2-week data collection period, resulting in a valuable set of qualitative (quotes and open ended answers) and SWEMWBS (wellbeing) data.

This **data illustrated the criticality** of being to attend these groups as a **"lifeline"** for PLWD & their carers, for mental as well as "somewhat physical" **health support**, and a **great source** of happiness and enjoyment, especially in **"bringing back memories"**. Notably, **barriers to access** included the lack of convenience of *local* groups, with some being *up to 40* minutes away, as well as *waiting lists* to join groups.

Colleagues at The Social Prescribing Unit will continue to analyse this valuable data and present findings in due course, via methods of dissemination such as presenting and networking at upcoming conferences.

Overall, there is **potential** to **integrate music interventions** (including choir, singing and song) for **PLWD and their carers** across the **Lancashire and South Cumbria Integrated Care System** in much more depth.



At present, this commissioning footprint **lacks** <u>consistent referral pathways</u> known to all those with responsibilities in the social prescribing ecosystems (e.g., social prescribing link workers, GPs, Allied Health Professionals (including pharmacists) and community choir groups), in-depth research and sustainable funding strategies to enable equity of access to this socially prescribed intervention which is evidenced as making a difference specific to health creation.

Future place-based research endeavours, therefore, could benefit from exploring these issues with a solution focused lens, and understanding barriers and facilitators to help better embed social prescribing for PLWD in practice (Hayes et al., 2023).



Future Recommendations

Future recommendations and plans are as follows:

UURIP Internship & Report:

- ★ Report to be shared on open access across L&SC ICS via the ICB, Social Prescribing Unit (UCLan networks, National Academy of Social Prescribing and the Social Prescribing Network
 - o for wider dissemination
- ★ The team will continue data analysis of the research project will continue after the internship term,
 - with collaboration from potential research institutes and student/staff volunteers
- ★ The author & supervisor will explore ways to grow and continue research in this area,
 - primarily through the UCLan student researcher volunteer scheme connected to UCLan CVCL - Centre for Volunteering and Community Leadership
 - and will also explore the aforementioned potential NIHR ARCNWC funding for future research in this area.

Power of Music Project:

- ★ Continue research into how embedding music for PLWD within the L&SC ICS could be done, its efficacy and impact through mixed methods research. Additionally, connect with similar research initiatives to strengthen the case e.g. the 'Together in Sound' project in progress by Anglia Ruskin University (2024), and support more advanced research into the area.
- ★ Call for more research into reducing & ultimately removing barriers to participation in L&SC ICS
- ★ The presence of a sustainable funding model to facilitate music intervention for PLWD is not explicit within the literature → an extensive review of funding mechanisms and potential future funding, particularly through further applications of opportunities, could be done.
- ★ The L&SC ICS Dementia strategy (NHS L&SC, 2024a) will include importance of this intervention for PLWD & their carers
 - Therefore, collectively develop and continue the project aims, to achieve:
- ✓ A strengthened case for future research and practice in the L&SC commissioning footprint.
- Increased awareness and knowledge of the benefits of music to promote social and emotional wellbeing for PLWD.



✓ Greater understanding on how music as a socially prescribed, nonpharmacological intervention, can support PLWD and their carers through further place-based research.

Author Reflections – Social Prescribing

Statement from intern:

"Throughout researching social prescribing of music interventions for individuals with dementia, I have gained a profound understanding of both its benefits and potential impact. Social prescribing, especially as part of the NHS GP Forward View and Long Term Plans of 2016 and 2019, plays a crucial role in addressing the multifaceted needs of patients by integrating non-clinical, or more commonly known, non-pharmacological, services and interventions (NHS England, 2016; NHS, 2019a).

During the course of my internship, I have been able to develop valuable skills in developing this research initiative, such as project management, leadership, and exploring the vast field of scientific research and the role it plays in practice. I am inspired to understand more about social prescribing as well as the role it plays among pharmacy students as future healthcare professionals, emphasising its significance in providing an informed approach to holistic patient care. I intend to explore this further in the future, hone my skills and network both within and external to my field to gather ideas and perspectives on developing this movement. I will be continuing my work on this project, as well as interest in other projects focused around nature-based social prescribing and the social prescribing of yoga after the completion of my internship as a student researcher with existing time within my studies through the Centre for Volunteering and Community Leadership at UCLan.

The involvement of pharmacy professionals in social prescribing has been increasingly recognised as crucial to a pathway for social prescription. Studies have shown that pharmacists, with their accessible position in the community and extensive patient interactions, can effectively contribute to the success of social prescribing initiatives. Howarth et al. (2020) highlighted the potential of pharmacists in identifying suitable patients for social prescribing and supporting their journey through follow-up and engagement.

Furthermore, a study by Brown and Steinke (2018) suggests that incorporating social prescribing into pharmacy practice can enhance patient outcomes and reduce the burden on primary care services, which is currently high.

Moreover, a study by Taylor et al. (2019) found that 85.6% of pharmacists support the role of social prescribing in patient care, although 36.7% were not familiar with the term. It was also identified how the pharmacy team is 'well positioned' within the community to support social prescribing frameworks, however there is a profound lack of knowledge and experience with social prescribing which needs to addressed in order to support this implementation.

As explored and stated by Clews (2020), the number of social prescribing staff, with an example being link workers, has 'more than doubled' in the past year, however the field



of pharmacy has yet to engage with schemes like this that can help patients with their wellbeing. It has been shown to reduce isolation, improve mental health, and provide support for people with long-term conditions.

With the NHS Pharmacy First service launch in January of this year, the social prescribing movement can potentially initiate more profound effect (NHS, 2024b). In a report published jointly by Public Health England, the NHS and the Royal Society for Public Health, it is acknowledged that 'prevention is better than cure' and how social prescribing acts as key component of prevention, but more importantly how all Allied Health Professionals can play a role in improving public health with one way to achieve this being engagement with a social prescribing framework (NHS et al., 2019). With regards to this project and research initiative, perhaps we can achieve a framework whereby interventions such as music can be socially prescribed by a range of allied health professionals, either directly or via a link worker to further personalise care for PLWD.

By educating future pharmacists and pharmacy students about the value of social prescribing, we can enhance patient care and support the broader health and wellbeing of individuals with dementia. Integrating these concepts into pharmacy education will equip new professionals with the skills and knowledge to implement social prescribing effectively, ultimately fostering a more comprehensive and person-centred healthcare system (NHS et al., 2019; NHS England, 2016)."

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Appendices

Appendix 1: Ethical Approval



University of Central Lancashire Preston PR1 2HE 01772 201201 uclan.ac.uk

2nd July 2024

Samantha Pywell / Iqra Hussain School of Medicine and Dentistry University of Central Lancashire

Dear Samantha & Iqra,

Re: HEALTH Ethics Panel Application Unique Reference Number: HEALTH 01130 Intern FR

The HEALTH Ethics Review Panel has granted approval of your proposal application, 'Evaluating the Power of Music in Practice: music on social prescription for people with dementia'.

Approval is granted up to the end of project date*.

It is your responsibility to ensure that

- the project is carried out in line with the information provided in the forms you have submitted
- you regularly re-consider the ethical issues that may be raised in generating and analysing your data
- any proposed amendments/changes to the project are raised with, and approved, by Committee
- you notify <u>ethicsinfo@uclan.ac.uk</u> if the end date changes or the project does not start
- serious adverse events that occur from the project are reported to Panel
- a closure report is submitted to complete the ethics governance procedures (Existing paperwork can be used for this purpose e.g. funder's end of grant report; abstract for student award or NRES final report. If none of these are available use <u>e-Ethics Closure Report Proforma</u>).

Yours sincerely,

Sodford

Simon Alford Deputy Vice-Chair **HEALTH Ethics Panel**

* for research degree students this will be the final lapse date



Appendix 2: Questionnaire

Inserted below is the questionnaire sent to participants, which gained ethical approval on the 11th June 2024.

Questionaire: Investigating the Power of Music in Community Dementia Choirs (v2 11.06.2024) %

Approval number: HEALTH 01130 Intern FR (see Appendix 1).

This questionnaire is for attendees of a Dementia Singing for the Brain Group.

By completing this questionnaire you are consenting to the anonymised answers being held at UCLan. No identifiable or personal information will be held at UCLan. This information will be used for the purpose of research, an evaluation report and potential future publications (e.g. academic poster, conference).

Before starting this questionnaire, please make sure to read the Participant Information Sheet.

Firstly, you will be asked to complete some questions to obtain your informed **consent**, followed by two sections that form the research based on **accessibility** to the group and an **individual questionnaire** of your experience and views. > Note that there is an *additional section* at the end that is optional and includes one question for <u>carers</u> if they provided help in filling in the questionnaire - this does not have to be completed if not relevant.

Please DO NOT provide any identifiable information - each form is strictly anonymous.

Withdrawal - once this questionnaire is submitted it can not be withdrawn due to anonymity. If you wish to withdraw at any point in the questionnaire, simply close this window <u>before</u> submission of the form and no data will be retained.

If you need to speak with someone after this questionnaire for any concerns or support, please do not hesitate to contact your Community Singing Group Leader.

If you have any additional questions about this study, you can get in touch with the research team via email, at <u>socialprescribing@uclan.ac.uk</u>.

We highly appreciate and value your time in completing this - Thank you! Best wishes, The Social Prescribing Unit at the University of Central Lancashire.

* Required

Section 1 - Consent

Please select the most appropriate option (yes/no) for the following 5 questions to obtain consent. There are 2 additional questions after this - please select the most appropriate option listed.

 I confirm that I have read and have understood the Participant Information Sheet dated 27/06/2024 for the research study, or it has been read to me.
 I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. *

O Yes

O No

- I understand that taking part in the study involves completing this electronic questionnaire hosted on Microsoft Forms by UCLan. *
 - O Yes
 - O No





 <u>Please read the following statements and select the appropriate option:</u> I understand that my participation is voluntary and that I am free to stop taking part and can withdraw from the study at any time before submitting this questionnaire without giving any reason and without my rights being affected. In addition, I understand that I am free to decline to answer any particular question or questions. I understand that the information I provide will be anonymised and therefore once submitted can not be recognised. I understand that following anonymisation I will no longer be able to request access to or withdrawal of the information I provide. *
○ Yes
O No
4. I understand that the information I provide will be held securely and in line with data protection requirements at the University of Central Lancashire. *
Yes
O No
5. Do you give your consent to proceed? *
Yes
O No
6. Are you completing this as the individual with dementia? *
Yes
No - I am a carer/family member/friend completing this on their behalf (with consent)
7. Have you been medically diagnosed with Dementia, or any of the following?
Alzheimer's Disease, known as Dementia (including early-onset)
Vascular Dementia
Dementia with Lewy Bodies
Any other type of dementia (e.g. frontotemporal)
Not dementia - but Mild Cognitive Impairment
None of the above
Unsure

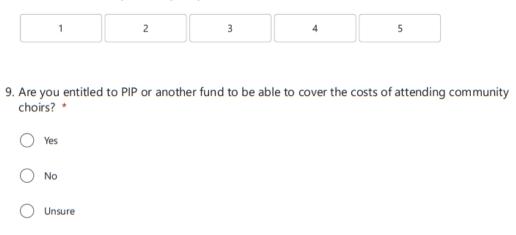




Accessibility

In this section we would like to ask about **how easy it is for you to access the community singing groups**. Please select the most appropriate option for each question, with an open question for your thoughts at the end. Thank you.

8. On a scale of 1-5, how easy or difficult is it for you to get to the choir? (1 = very difficult, 3 = nor difficult nor easy, 5 = very easy)



10. On a scale of 1-5, how easy or difficult is it for you afford transportation to the choir? (1 = very difficult, 3 = nor difficult nor easy, 5 = very easy) *

1 2	3	4	5
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- 11. Which option most accurately describes your views on the accessibility of Community Choirs in your local area? *
 - There are many groups in my area that I can conveniently access
 - There are some groups in my areas that I can conveniently access
 - There are a few groups in my area that I can conveniently access
 - There are no groups in my local area that I can conveniently access
 - Unsure
- 12. If there are any, please could you tell us about any barriers or difficulty you face in being able to attend the community choirs? If you don't feel that there are any then feel free to leave this blank.



Individual Questionnaire

In this section we will explore **how your thoughts, feelings, and feedback have changed since attending the Dementia Singing Groups.** Please feel free to write as much or as little as you like to detail this area in response to the open questions.

- 13. I've been feeling optimistic about the future *
 - O None of the time
 - Rarely
 - Some of the time
 - Often
 - All of the time

14. I've been feeling useful *

- O None of the time
- Rarely
- Some of the time
- Often
- All of the time

15. I've been feeling relaxed *

- O None of the time
- O Rarely
- O Some of the time
- Often
- All of the time

16. I've been dealing with problems well *

- None of the time
- O Rarely
- O Some of the time
- Often
- All of the time





17. l've	been	thinking	clearly	y *
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- O None of the time
- Rarely
- Some of the time
- Often
- All of the time
- 18. I've been feeling close to other people *
 - O None of the time
 - Rarely
 - Some of the time
 - Often
 - All of the time
- 19. I've been able to make up my own mind about things *
 - None of the time
 - Rarely
 - Some of the time
 - Often
 - All of the time
- 20. Could you explain how attending a community choir has impacted your health and wellbeing, especially with regards to Dementia?
- 21. Could you explain how you feel before attending each community choir session?



22. Could you briefly describe how you feel after engaging in a choir session?

23. Do you have a favourite aspect of attending the choir sessions, and if so, what is this?

24. Do you have any other comments or thoughts regarding your experience that you would like to share?

Question for Carers

If you completed this questionnaire **without** the aid of a carer, you may **skip** this section and **progress to submit** the questionnaire.

If you are a carer - please could you kindly answer the question below before submitting the questionnaire. Thank you.

25. <u>Carers</u>: How has **attending** *Singing for the Brain* with the person you care for affected your **caregiving experience** and your **relationship** with them?

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