Commission on Dementia and Music

Written evidence submissions

A note on the treatment of evidence

This document includes all submissions for the Commission on Dementia and Music's call for written evidence. Only those submissions where the author(s) explicitly requested that their evidence not be published have been excluded.

Evidence has been treated as qualitative and only spelling and/or grammatical edits have been made. Within whole submissions, no content has been changed in a way that would have altered its meaning, and no content has been removed.

Evidence by: Age UK Trafford

1. **What is the current 'state of play' of dementia and music?**

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

Age UK Trafford provides the following for people with dementia: Music, exercise to music, dancing and karaoke are provided as part of our dementia specific day support programme 5 days per week; We also hold a weekly "disco" as part of an afternoon for people with dementia, people ae encouraged to dance; We also hold a bi-monthly cabaret afternoon which includes a "tribute show" such as Frank Sinatra, Abba, Elvis (costumes are used), people are encouraged to sing along with the singer and then to dance after the formal show.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

It is funded as part of our day support activity which is a combination of CCG funding, spot purchase by local authority and social enterprise. We also provide monthly line dancing but not specifically for people with dementia.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

This provision is specific to Trafford.

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

This is a difficult one – as the impact is often immediate and due to the nature of dementia may not last beyond the short memory of the person involved. However, we should take an assessment during and immediately after the activity, this would demonstrate the immediate effect. Carers should also be approached to find out how they feel the activity affected their cared for, whether that was a short-term effect or could they see a longer benefit, e.g. maybe improving their sleeping pattern that day, or their engagement with carer was better etc.

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

We could work out a unit cost based on the staffing required, premises costs and the time period, however we are not sure how this could be mapped against outcomes. There is no price on watching a service user who is unable to communicate and/or difficult to engage with in normal circumstances come alive when music and dancing are involved.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**
Limited to the premises available – we presently do it only as part of our day support but we could provide it separately for people with dementia as a general activity as well as in day care but we do not have the financial resources to do so.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

I think it's important to remember the age group is changing and that "it's a long way to Tipperary" and other WW1 songs are now no longer appropriate to stimulate memories. Yet you often still hear them in some dementia settings. People now need the likes of Frank Sinatra, Elvis and the later singers such as ABBA etc. to stimulate their memories of going out to dances with their friends and loved ones. It's important to encourage participation through dancing and singing along not just playing the music and hand clapping.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

We need to show the activities and the results. The kind of activities we are engaging in are available on our Facebook page (@ageuktrafford) in video form – we need to show people what can be done and then show them what it achieves.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

We need to build more evidence of the benefits and impact on both the person with dementia and their carers.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

It should be something that is integral to any work with people with dementia. There is little else that stirs a memory as strongly as a piece of music, whether you have dementia or not. Therefore, it is something that is more or less guaranteed to do so in a person with dementia.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

Everyone working with people with dementia.

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

Those with the resources to fund/or provide the provision of music and dance interventions.

2.7 What should our one, clear message be? **[Max. 100 words]**
The most important thing for a person with dementia is to stimulate good memories – the most effective way to do so is often through the medium of music and dance.

2.8 Do you have any final comments? **[Max. 100 words]**

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. 50 words]**

Age UK Trafford has been working in the Borough of Trafford area for 42 years. We have been supporting people with dementia and their carers for 25 years. We have dementia advisers and provide day support for (currently) 67 people with dementia a week. We also provide social activities and information/support meetings for people with dementia and their carers.

Evidence by Alan Caddick

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

From what I know it is thinly spread and differs widely between venues. There is no co-ordinated curriculum or plan of action. Activities are usually from voluntary groups/individuals, varies from simple singing unaccompanied, piano playing /singing, singing duos/groups visits to day centres with communal singing. The leaders of such activities don't seem to have much enthusiasm to engender a spirit of involvement.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

It's mostly voluntary from sparse groups who are minded enough to care. Day centre activities can be council run, Age Concern or charity formed voluntary dementia supporters.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

Given the little publicity and knowledge about this area, there must be many. There is a vast chasm of different views from all and sundry which serves to present a confusing and terrifying picture to anyone unfamiliar with dementia, hence most switch off, and it becomes ignored.

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

Better quality of life. Enabling recognition of surroundings, and interaction with others.

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

Provided it is well co-ordinated with a centrally led and laid down structure disseminated via a well-constructed network it may be possible.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

Money, Money, Money. Also, governments, despite their faux concerns and grand words, seem reluctant to take a lead in setting up a panel of advisers to explore and devise a suitable plan of action. Lack of interest/enthusiasm nationwide.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

Technology; with increasing popularity of the many forms of communication, and so many in all age ranges embracing it, there is tremendous opportunity to enable dementia persons to recognise their existence, and immerse themselves in a world they are/were familiar with.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

This is an ambiguous question. See 1.6 and 2.1

2.3 Where do we still need to build evidence? **[Max. 250 words]**

Evidence of what? The current parlous nature of the NHS is a barrier. It is fragmented to the extent that there is no connection between the once uniform structure, to enable a recognised path of exploration. This is a crucial topic and must be centrally led with impetus from government.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

I would envisage regional centres (4 at most) to manage a co-ordinated plan to facilitate the setting up of an ongoing working group to invite selected professionals for their input. This would enable a diverse group view to achieve a positive input for a conclusive plan of action.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

It would simply be another strand of the NHS with special responsibilities for this area.

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

One person, Dr Max of the Daily Mail (Saturday edition), would be ideally suited for this task. He is a brilliant thinker, with positive views and a well-spoken advocate for those with less mental capability. He pulls no punches and says it like it is; this is what is drastically needed when we cannot see the wood for the trees.

2.7 What should our one, clear message be? **[Max. 100 words]**

Get this started and stop messing about. It is crucial for the future benefit of everyone and, for all affected persons, to act without further delay. I envisaged this therapy twenty or so years ago. It came by visiting someone in a care home. I saw most of the residents plonked in a chair in a communal lounge. Most were asleep. There was no stimulation or interesting activity to keep them alert.

2.8 Do you have any final comments? **[Max. 100 words]**

Music, related to the respective ages of the recipients, can play a vital role to enliven those with memory loss or impairment. When I was a Psychiatric nurse in the late 60’s I used it to entertain Downs residents. The response and interaction was phenomenal. I was their hero and they looked forward to the music sessions.

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. 50 words]**

Male 74 years of age. Left school 15 no Quals. Trained as General Nurse 1961. Physic nurse 1964. Geriatric /General nurse 1965. Bank manager 1970 – 1993.

Evidence by Alzheimer's Scotland

Introduction

Alzheimer Scotland is Scotland's leading dementia voluntary organisation. We work to improve the lives of everyone affected by dementia through our campaigning work nationally and locally, including facilitating the involvement of people living with dementia in getting their views and experiences heard. We provide specialist and personalised services to people living with dementia, their families and carers in over 60 locations and offer information and support through our 24-hour Freephone Dementia Helpline, our website (www.alzscot.org) and our wide range of publications.

Alzheimer Scotland welcomes the opportunity to contribute to this call for evidence.

General Comments

In our work, we take a rights-based approach to supporting people with dementia, their families and carers. A key part of this approach lies in involving people with dementia, their families and carers in our work, to ensure that our priorities are focused on areas in line with their views and experiences of living with dementia.

The ILC states that *'as part of this high-level Commission, we are seeking written evidence from a range of experts'* and that the Commission is '*keen to engage with as many perspectives as possible, as the Commission aims to take an inclusive approach to the range of activity in the field*'. However, this call for evidence has not been set out in such a way as to be accessible to people with dementia and the timescale of a month to respond has not allowed for meaningful engagement with people with dementia, their families and carers.

Definition

Alzheimer Scotland believes that there needs to be a clear distinction between social supports and use of music in service settings as part of a range of therapeutic interventions, and music therapy as a highly specialised psychological clinical intervention, delivered by Health and Care Professions Council (HCPC) registered Music Therapists.

Both are important in supporting the wellbeing of the person with dementia, their families and carers. The use of music in different ways and its impact will vary from person to person, with the appropriateness of musical interventions being unique to each individual. However, the specialist skills and knowledge of a HCPC-registered Music Therapist require distinct knowledge, skills and understanding to identify specific outcomes for the person with whom they are working, considering the specific contribution Music Therapy can play as part of holistic, integrated care and support. Part of this includes offering assessments and identifying other interventions or treatments which may benefit the person.

Alzheimer Scotland recognises that Music Therapy and musical interventions have an important role to play as part of a therapeutic intervention offer for people with dementia, their families and carers. However, it is one of many therapeutic interventions that can support this and must be considered alongside other interventions including Art Therapy, Occupational Therapy and Cognitive Stimulation Therapy.

Delivery and Benefits of Music

In community settings across Scotland, it is Alzheimer Scotland's understanding that the majority of initiatives around music and dementia are delivered by the third sector and funded through fundraised income or grant applications to charitable funds. Our own resource centres and services provide specialist therapeutic interventions which support people with dementia to maintain their skills and take part in meaningful activities such musical reminiscence, singing and other music-based interventions; these provide stimulation and social interaction which improve the person's wellbeing and reduce isolation. In addition, there are a number of music-based interventions which are used in both acute care and residential care settings.

As part of the Practitioner Research Project (PRoP) run by the Institute for Research and Innovation in Social Services (IRISS), an Alzheimer Scotland member of staff demonstrated the use of music in people's own homes, even where not used formally as a 'therapeutic intervention', could help improve mood and relax a person with dementia, allowing carers a brief period of rest. Similarly, our experience of working with organisations which delivered home-based musical supports was, anecdotally, very popular with both people with dementia and their carers.

Across Scotland, Alzheimer Scotland supports a number of musical based services and supports providing people living with dementia, their friends and carers the opportunity to take part in a stimulating, meaningful and enjoyable activities, which reduce isolation and provide opportunities for verbal and non-verbal communication. In these groups, people's verbal communication is often brought out; some individuals who previously spoke seldom will, for a short time, begin to speak about the music and experiences attached to the music. These groups run in different ways, with some primarily focused on singing such as the Forget-Me-Notes choir in Edinburgh, which has been involved in a number of projects in Scotland and has attracted interest from some housing associations which support people with dementia. Additionally, we have Music Memories groups in Aberdeenshire which have included attendees from local care homes and cross-generational links being established with the community through involving pupils from local schools who play instruments and sing for the groups. Another example is the, Every Voice Choir in West Dunbartonshire which involves people at different stages of the condition and has performed at different events in the locality, including in the local acute hospital.

These groups work in such a way as to involve as many people as possible (people with dementia, carers, families, friends or anyone with an interest in dementia) to take part, remain connected in their communities and participate in an enjoyable and stimulating meaningful activity. Doing so aims to build confidence in attendees, boosting their social skills but also to break down barriers for people with dementia, challenging stigmatising attitudes and assumptions about what a person with dementia can achieve. During one session in the Aberdeenshire group, an inspector from the social care regulator came along to one of the music groups and praised the involvement of people in sessions and the uplifting atmosphere created by the session.

Another specific project based in our Aberdeen Resource Centre saw a HCPC-registered Music Therapist work with people in both individual and group sessions, allowing them to sing, play instruments and listen to music, depending on their preferences and ability. This allowed the development of the person's skills, confidence and mood over a period of weeks. In this particular case, the service was delivered for both older and younger people with dementia, providing support personalised to each person, including their different tastes in music and preferences for instruments/vocals etc.

Even within group settings it important for those running to the group to understand the individuals within the group; a standardised approach to such sessions is unlikely to provide maximum benefit to participants and may result in individuals taking part becoming agitated or stressed. From their own practice, our colleagues have shared that often small details such as the order songs are placed in, can drastically affect the experience of the person with dementia and the outcomes of such a music-based intervention.

Emerging Opportunities

As the number of people with dementia continues to rise and with an increasing number of people living longer with the condition, it is important to ensure that people are supported in a holistic way which supports them to live as well as possible with the condition. Alzheimer Scotland supports the development and delivery of new ways of working which recognise the importance of therapeutic interventions (including music-based interventions) as a crucial component. As we have noted above, music-based supports are flexible in the way in which they are delivered, being tailored for group or individual sessions. These include:

- A pilot of Enhanced Sensory Day Care for people with advanced dementia, including music as a therapeutic intervention. The pilot was evaluated by the University of the West of Scotland.
- Alzheimer Scotland's 8 Pillars Model of Community Support and Advanced Dementia Practice Model both highlight the importance of therapeutic interventions as a key component of a holistic approach to care and support for a person with dementia. The former was tested as part of the second National Dementia Strategy (2013-16), with the latter due to be tested as part of the third (2017-2020).

Additionally, in Scotland, Self-Directed Support (SDS) legislation was passed in 2013 which aimed to improve the lives of people who use social care services by embedding a human-rights based approach, to give people greater choice and control over the supports and services they access. This includes the option of Direct Payments which, under the provisions of the legislation, allow people to choose how they are supported and on what the money is spent. However, the uptake and implementation of this policy remains low.

These policy areas and models represent just a few of the opportunities which have the potential to radically transform the way in which people are supported, shifting the emphasis away from formal and often institution-based interventions, to social and therapeutic interventions based in the community.

Barriers to Uptake

One of the key barriers in the uptake and delivery of formal Musical Therapy interventions is a shortage of empirical evidence to demonstrate the long-term benefits of music in improving the wellbeing and quality of life of people with dementia. As a result, commissioners and decision-makers are less likely to commission such interventions without evidence of the improved outcomes for individuals. Whilst there is much anecdotal support for musical interventions in the broadest sense and some small-scale work and case studies, the shortage of empirical, peer-reviewed research means its benefit is not always recognised.

In Scotland, the variation in provision of supports and services between the Health Boards and Local Authorities (and more recently Integrated Joint Boards), has created variations in the provision of both health and social care supports and services. Music Therapy is resource intensive and, without the solid evidence base, is rarely funded by statutory organisations. It is beyond the means of many individuals to fund this themselves, meaning generic musical interventions are used as they are easier to deliver and more flexible, based on the time and resource of the context in which it is being delivered (i.e. whether by a local service, community group or by an unpaid carer etc.).

If music-based interventions are to become more widely available and embedded as part of holistic supports and services, a solid evidence base must be built to rigorously evaluate their effectiveness and benefit. Whilst the feedback from people with dementia, their families, carers and professionals is invariably positive, it would be helpful to have a robust evidence base which demonstrates:

- Reduction in stressed/distressed behaviours (including any associated reduction in medication).
- Improved mood and responsiveness in a person with dementia.
- Improved quality of life (possibly using wellbeing scales) for both people with dementia and their carers.

In Scotland, there are a number of policies for health and social care which have set out ambitious and commendable visions for a rights-based, person-centred system which is delivered seamlessly from the point of view of people using services. Condition specific strategies such as Scotland's National Dementia Strategies, legislation such as the Social Care (Self-Directed Support) (Scotland) Act 2013 and the new National Health and Social Care Standards, all intend to help drive a shift toward improving outcomes for the individual.

However, Alzheimer Scotland's experience of working with people with dementia, their families and carers suggests the policies are not always being realised in practice. It is our experience that transformational system change and service redesign has not taken place across health and social care settings; in some instances, temporary funding has allowed for pilots of new ways of working, however, services often revert back to the status quo once funding ends.

Alzheimer Scotland is aware of this having taken place in relation to funding through Reshaping Care for Older People, the Integrated Care Fund and other programmes of work which did not continue following the initial pilot work. Whilst appreciating that these short-term funding streams are intended as a catalyst for system redesign and trying new ways of working, even where success is demonstrated, mainstream funding can be difficult to secure.

Aligning Interventions with Other Work

If Music Therapy and other musical interventions are to be recognised, valued and embedded as important supports to improve the wellbeing of people with dementia, their families and carers, it will require significant local investment in community-based, social supports and a broader recognition about the improvements in quality of life they bring.

Alzheimer Scotland has supported the development and publication of resources which demonstrate the work of AHPs, including Music Therapists, in supporting and improving the lives of people with dementia, their families and carers in different settings and environments:

- Allied Health Professionals Dementia Champions: Agents of Change - features practice examples provided by some of the AHP Dementia Champions.
- Allied Health Professionals Delivering Integrated Care: Living Well with Community Support – features the vital role of AHPs in delivering of integrated care, support and treatment for people with dementia.

Whilst the Scottish Government's third National Dementia Strategy (2017-2020) does not explicitly mention musical interventions, there are multiple references to the importance of therapeutic interventions for people with dementia, their families and carers. As part of this, there is a commitment to implement the Connecting People, Connecting Support work for Allied Health Professionals as part of the previous dementia strategy. This represents a considerable opportunity to promote and further raise awareness of the way AHPs, including Music Therapists, can support and deliver therapeutic interventions. Alzheimer Scotland supports a National AHP Consultant to deliver this work and work with other organisations such as the British Association of Music Therapists (BAMT).

As part of this work, Alzheimer Scotland has been working in partnership with the Music Therapy profession in Scotland, delivering the Alzheimer Scotland AHP Practice Education Programme. This partnership approach aims to give students the opportunity to experience working with people living with dementia, their families and carers. One element of this work included working with Queen Margaret University in supporting practice placements in Alzheimer Scotland services, including a music therapy intern in one of our services.

Influence and Delivery

Alzheimer Scotland believes no specific organisation should have sole responsibility for delivering musical interventions, with a collaborative effort required between organisations to ensure that robust, evidence-based policy and practice are embedded to utilise music-based interventions and Music Therapy to improve the wellbeing of people with dementia, their families and carers.

Doing so will require further work to build a credible evidence-base which clearly demonstrates the benefits of the intervention to commissioners, policy makers and decision makers. Without this evidence base, it will be difficult to ensure that the benefits of musical interventions are recognised and seen as an important component of supporting people to live well with the condition.

Furthermore, in looking to promote this work and deliver a strong message about the effectiveness of this intervention, the Commission must look to involve people with dementia, their families and carers. People with dementia, their families and carers can more powerfully articulate the benefits of musical interventions and the effect it has on them better than any organisation or professional. As part of its work in this area, the Commission must look to engage with people with dementia, their families and carers to hear their experiences and insights, then develop their report and recommendations to reflect what matters most to them.

Messaging

It is Alzheimer Scotland's experience that social supports and therapeutic interventions are not valued in the same way as more traditional, medical-led clinical interventions. Social supports and therapeutic interventions, including those involving music, singing and sound are absolutely essential to ensure the wellbeing of people with dementia, their families and carers. The value of all forms of musical interventions should be recognised as being beneficial to the people dementia and their carers, with therapeutic interventions having equal importance to more traditional, clinical interventions. It is too often the case that therapeutic interventions and social supports are subject to short-term funding and are the first to be cut where resources and budgets are under pressure.

As part of the Commission's messaging on music and dementia, these points must be made strongly to ensure that policy makers, commissioners and decision makers understand the importance and effectiveness of these forms of support, properly investing and embedding these supports.

Alzheimer Scotland is happy for this submission to made available in the public domain and a copy will be posted on our website.

Evidence by Alzheimer's Society

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

Alzheimer's Society runs Singing for the Brain groups across England, Wales and Northern Ireland. The number and frequency of these varies largely due to the availability of funding.

Singing for the Brain ™ is a structured activity designed for people with dementia that aims to reduce the social isolation, depression and withdrawal often associated with dementia. Research has shown that when communication through speech becomes difficult, people with dementia can still be actively involved in vocal expression through singing – especially through singing well-known and familiar songs. The Singing for the Brain model largely uses familiar songs with regard to musical 'eras' e.g. the forties, the sixties, but also includes new pieces of music so that it not only facilitates recall but also stimulates learning and brings people together. This model emphasises what the person with dementia can still do, rather than what they can't, it is often a very positive experience for all those involved. The sessions themselves offer an opportunity for people with similar experiences to come together regularly and offer each other support – interaction that is considered to be essential by both people with dementia and their carers.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

- Local authorities; NHS; care homes and private funding
- All most all of the Societies Singing for the Brain sessions, are funded through contractual funding mainly as part of a bigger contract delivering a number of dementia services. Overall the income for these services is in the region of £500,000 across, England, Wales and Northern Ireland. This is 60% funded by CCG funding.
- Some sessions are supported by contributions from individuals.
- Volunteers give freely of their time.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

Yes, there are over 300 S4tB groups across England, Wales and Northern Ireland, however their spread is not consistent. Our services are delivered in a number of ways, some with an employed group leader, some with an external musician and some by a contracted leader. There should be variations in each group as these sessions are person centred and deliver music and singing at the request of the individuals and their carers who attend the group. In Wales, there are some Welsh Sessions. We also have a number of sessions delivering services to the Chinese and South Asian Communities.

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

SftB is evaluated against the outcome framework for all Alzheimer's Society services. Outcomes which apply to SftB are:

- I am supported by staff/volunteers
- I have social contact

Staff and volunteers who deliver the service collect data against these outcomes by holding a group discussion with those present at the service who have consented to take part in the evaluation. Using a standardised template as a guide, staff note down the numbers of people with dementia and carers who say yes/no/don't know to the following questions:

1) Do you feel that staff/volunteers at Singing for the Brain are understanding towards you?
2) Do you feel part of a group at Singing for the Brain?
3) Has coming to Singing for the Brain made your life better in any way?

Staff then open up a discussion around each of these questions, and note down verbatim comments from people with dementia and carers separately. Finally, the group is asked

4) How do you think that Singing for the Brain could be different?

This evaluation approach has been developed over several years of service delivery. We strongly recommend the use of a conversational approach to help draw out the most detail possible from service users. Whilst the quantitative scores give an indication of the extent to which outcomes are met, the statistics alone likely to obscure the nuance of people's experiences, and are also subject to bias.

Sample of evaluation findings

In last year's evaluation of 198 of our SftB services we found the following:

- 98% of people with dementia and 99% of carers felt supported by staff and volunteers
- 96% of people with dementia and 99% of carers agreed that SftB made them feel part of a group
- 95% of people with dementia and 98% of carers felt that SftB made life better in some way

Group discussions tell us more about how these outcomes being met make a difference to individuals and some examples of quotes are below:

"I come on my own to SftB but I don't feel like a loner. People are very accepting and I am not the odd one out" (Person with dementia)

"It gives us something to look forward to every two weeks. In these conditions, your world shrinks - this session stops it shrinking" (Carer)

“It's so uplifting! Signing with others is a lovely way to spend time together. We always leave feeling better for the rest of the day” (Person with dementia)

1.5 Is it possible to establish an average ‘unit’ costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

It is hard to establish exact costs however; the service is run on a term basis with each term lasting between 8 and 12 weeks. The costs depend on venue hire and the individual cost of the Singing for the Brain leader, plus any resources. As such the cost varies. Organisationally we pay a national PRS (Performing Rights Society) license however we are not able to share the exact costs for this. However, it should be noted in any model as paying this is a legal requirement.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

- Transport is cited as a significant barrier for many of our S4tB attendees. The lack of affordable, reliable and appropriate transport particularly in rural areas increases the social and physical isolation that people with dementia experience.
- Social isolation is a big issue for people with dementia as noted already. Some of the Carers that Alzheimer’s Society supports have said that this includes a reluctance by individuals to try something new like S4tB.
- There are examples of individual playlists e.g. Playlist for Life which personalise music and give access to online libraries of a remarkable range of music (sic). However, such arrangements are individually licensed rather than for group settings. The benefits of S4tB rely on social interactions within a group setting as much as the music itself.
- There can be a perception that some music groups are not inclusive for all. Alzheimer’s Society S4tB sessions are open for all, especially for someone who identifies with any of the protected characteristics under the Equalities Act. Based on local demand and where funding can be secured, we run community specific S4tB groups facilitated and led in languages other than English e.g. in Sylheti for the Bangladeshi community in Tower Hamlets, Greater London, funded by the Local Authority.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

- The right to individual music and group music (sic) should be established for every individual with dementia wherever they live, including their own homes, hospitals and care homes. More funding and awareness of such activities is desperately needed to ensure access to them for every person with dementia.
- While specific groups involving music for people with dementia are of great value, as shown by S4tB, all musical groups should be open to people with dementia e.g. choirs, singing groups. By increasing dementia friendliness across Society and communities the isolation felt by people with dementia can be reduced. Alzheimer’s Society believes that

every person with dementia has the right to live their life and not be discriminating against because they happen to have a disease of the brain. Dementia friendly musical activities will help enable this for people with an interest in music or who already participate in music. The values and movement of inclusion and equality for people with disabilities apply equally to people with dementia – that they have the right to play a full and active part in their community, as they chose to do.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

At the moment, the benefits of music on the lives with people with dementia and their carers is not widely known, before more services are developed a broader awareness within the dementia community of the impact of music is required. The current capacity to deliver any music based service at scale is hindered by the desire for current and generational music. Our Singing for the Brain models was developed with resources which are mainly out of PRS licensing. However, a key outcome of the service is to make it person centred so if people want to sing Beatles songs they should be encouraged to do so. However, this can only be achieved with a musician, and any pre-recorded Beatles tunes which often develop reminiscence and conversation could be impacted by the PRS legislation. This area is complex for small organisations and individuals to navigate and the risk of hefty fines are worrying.
Raising public awareness of the impact and benefits of participating in musical activities could be achieved through national television e.g. involving Gareth Malone or the like.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

- Research at a neurological level
- User Involvement
- Awareness of the benefits of musical interventions to People with a Dementia diagnosis and their carers
- More evidence around the benefits of a musical intervention and the impact on communication
- Evidence of the impact on coping strategies between carers and the person with a diagnosis
- Evidence of the cost benefit analysis or social return on investment in relation to musically based interventions
- Evidence of positive mood changes
- Increased mobility after a musical intervention
- Compare different approaches – individual vs group and singing vs listening vs playing, to understand which brings the most benefits and for individuals with less or more progressed symptoms of dementia.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Musical therapies where music and singing are used in a group setting should be aligned to cognitive interventions, the benefits on mood and mental health are similar and these sessions benefit the Carers and the person with a diagnosis. The services are one of the key activities which anecdotally carers enjoy and tell us how wonderful it is to have some positive interactions with the person they care for, in what can be a very difficult and stressful situation for families.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

To ensure that all people who could benefit from these services are able to access them organisations like ours must enable more people, and smaller organisations to deliver these types of intervention. Government, National and Local must help in reducing red tape and complex legislation around musical interventions for people with a diagnosis of dementia. Using community facilities better for this type of intervention and encouraging organisations to showcase the joy that musical services bring could increase the uptake of these types of services and help more people have access to them locally. To deliver at scale we need to enable and empower communities to deliver very local services at scale.

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

- MP’s
- Councillors
- Dementia Friends
- Volunteers
- University Researchers
- Health Providers
- Hospitals
- GP’s
- Funders including trusts and foundations

2.7 What should our one, clear message be? **[Max. 100 words]**

We are all musical. We all have musical memories. Musical memory is deeper and lasts longer than other memories. As dementia physically destroys a brain it strips an individual of other memories. However, music is quite literally a different wavelength, a new highway to connect to an individual’s personal musical memories. Every person with dementia should have the right to their own personal music (sic) both individually and in group settings.

2.8 Do you have any final comments? **[Max. 100 words]**

Thank you for your interest in this vital, overlooked area of research. Music used in a person-centred way stimulates what can simply be called ‘happy’ hormones and is often more effectual than conventional medication – it is cheaper, available 24/7, and has no adverse side effects.

A local carer said:

"Carers can experience a very lonely life, because memory has taken away conversation. Singing with my wife brings me considerable relief to see her smiling, joining in with something and being happy. To attend with my wife is wonderful as I can see a spark in her. It is lonely in the community, but here we can support each other with feelings and experiences. It offers huge comfort."

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. <u>50</u> words]**

Alzheimer's Society is the UK's leading dementia support and research charity, here for anyone affected by any form of dementia in England, Wales and Northern Ireland. We provide information and support, fund research and create lasting change for people affected by dementia.

This response has been collated from our different directorates including Operations, Campaigns & Partnerships and Research. Our frontline workers in Operations that deliver Singing for the Brain activities come with a myriad of life experience and professional experience. This is but one individual example:
I am a Dementia Support Worker for the Alzheimer's Society in Derbyshire. I have worked in this area for 5 years. Before that I have worked as an education officer for Derby City Council. My first degree is in Psychology (BSc) and I have more recently completed an MA in Pastoral Care at Nottingham University.

Evidence by Arts as Wellbeing Trust

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

There are three strands to live music making: One a personal music therapy based approach in care homes and hospitals, the second is small group based work where the musician/s uses multi skilled approaches of singing well known songs, small percussion, creative singing (e.g. Hello and Goodbye songs). Much is improvised and developed in the moment with participants. The third approach is work within the community where carers and their partners come to singing sessions at a local weekly 'choir' session. Some of this leads to performances in the community.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

Mainly delivered by 'community' musicians using acoustic instruments and voice. Some national organisations e.g. Live Music Now and individual Hospital Trust initiatives. Mainly funded by small charities, Hospital friends, care home activity budgets, some participant payment and some by National Lottery (Awards for All and Big Lottery). There are some projects funded by larger charities (e.g. Barings and Paul Hamlyn) where there is an interest in evaluating the musical intervention.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

The sector is led by regional champions for this work. Where they exist then work is developed and likely growing. There are the beginnings of training sessions and courses for musicians working in dementia care home and hospital settings which will spread the provision more widely. Organisations like Arts & Health South West have done much to support and develop this work through conferences and workshops. The Centre for Arts as Wellbeing at the University of Winchester offers a framework and a training course for evaluation of music in dementia settings.

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

Any intervention would be designed within an evaluation framework where the intended outcomes and impacts are thought through in partnership with all stakeholders. A shared understanding of the musical activity and its outcome. The evaluation requires a mixed methods approach using qualitative and quantitative research methodologies. Cost benefit analysis has proven useful to justify sustaining interventions. There have been RCTs in hospital settings that has provided robust evidence (Sarakomo et al, 2015). Outcomes of participatory music or individual music therapy in dementia care will ideally report both person-centred impacts and appropriately selected clinical outcomes that can be evidenced by the data collected and not be overstated. This element of best practice will offer both a creative and credible basis for evidencing music in dementia prevention, diagnosis, treatment, care and end of life care.

1.5 Is it possible to establish an average ‘unit’ costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

It is possible to establish a unit cost for a musical intervention. Weekly sessions with one or more musicians can be costed. There may be regional differences. Live Music Now would have some data on those costs. Mapping those costs against outcome is more difficult. The outcomes are often about the quality of life for people with dementia (PWD) and also for the staff on wards or care homes. Live music in these settings can also change the culture and communication between staff and PWD. The health economics of dementia is likely to be challenging to both measure and interpret but still it is an important part of describing efficacy and effectiveness. The relational nature of the shared music experience means there are quality of life effects for all involved. The skills of participatory musicians and music therapists should not be under-valued nor assumed to be the cheap option; rather the potential of music could be evaluated across the settings where dementia care is delivered and reflect the spectrum of the disease process itself.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

There is a lack of sufficient research and evidence of the effect of live music for PWD and the processes involved. A lack of musicians with the necessary group skills and awareness of the different presentations that occur in different settings for example on an acute ward in a hospital and the lounge of a care home. Skilling care home staff to undertake some singing activities on a daily basis is also needed so that musical activity is not just reliant on the musician coming in once a week. A perception that participatory music may be disruptive for example in an acute care environment. Funding restraints and evidence of cost-effectiveness across settings.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

There are more opportunities for research and evaluation leading to informed training and workshop processes for musicians. There is no one size fits all approach here. The musicians have a need to respond in the moment to the needs of PWD, the staff and the culture and environment of the setting where the work takes place. Sharing of working examples and approaches at seminars. Using the Public Health England Arts and Health Evaluation Framework and developing musical interventions using the Creative and Credible tools. www.creativeandcredible.co.uk.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

Supporting more research and evaluation, working in partnership with the Care Quality Commission, the Dementia Research organisations, NHS trusts and the research infrastructure including the NIHR. There is a need to move from mechanistic, fix it approaches of care for PWD to more relationship based care and live music making can do so much to fuel that change. Demonstrate that music is not merely a token to address quality of life issues for people with dementia but is, in many respects, an integral part of peoples' lives whether they have dementia or not.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

More research is needed to understand what are effective musical approaches. Evidence is needed of the wider effect of music on the culture of the care home and the ward environment. How does a musical intervention affect safeguarding, communication and care for PWD?

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Involvement of all stakeholders (staff, musicians, researchers, managers, activity co-ordinators, PWD and their carers) in the design of a musical intervention would encourage ownership and a wider understanding of what is happening. Having agreed and shared outcomes from the start can avoid confused or failed expectations on all sides.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

Partnerships and collaborations between the NHS and the higher education sector can do much to develop both the agenda and the musicians. A simple statement from the leadership within the NHS and care home sector that live music making has to be included in health care provision for PWD would make explicit the need for planners and commissioners of healthcare developments to consider therapeutic and participatory music in care delivery. Further government could support, for example, a 1% Arts allocation within the costings of new health service developments for PWD.

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

The All Party Parliamentary Group for Arts and Health and the ESRC reports on What Works for Wellbeing have highlighted the benefits of music making. It now requires the Secretary of State for Health to actively support the recommendations in those reports. Care Quality Commission could add live music making to its inspection process.

2.7 What should our one, clear message be? **[Max. <u>100</u> words]**

Living musically with dementia can sustain relationships, support and extend communication and uplift the spirit – a message relevant across the dementia pathway and across all care settings.

2.8 Do you have any final comments? **[Max. 100 words]**

We would advocate the need for quality evidence and the wide dissemination of good practice and process of music making in hospitals, care homes and the community.

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. 50 words]**

Dr David Walters is Director of the Centre for Arts as Wellbeing at the University of Winchester and the Founder Director of the Arts as Wellbeing Trust. Part of the Hampshire Collaboration for Health Research and Education (HCHRE), Professor John Ramage, Deputy Director of Research and Ms Barbara Parry, Collaborative Research Fellow, are collaboration leads for Hampshire Hospitals NHS Foundation Trust.

1. What is the current ‘state of play’ of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

I believe that most people learn about the benefits of music for people living with dementia either via something they’ve read (a blog or article), an activity in their local area (like Alz Soc Singing for the Brain) or stumble upon the benefits, perhaps when a favourite song comes on the radio and the person and those around them start to sing along.

In social care settings, music is most likely to be delivered via playing CD’s, having a piano in-house that staff/residents play, or visiting ‘entertainers’. A minority of people living with dementia may have access to formal music therapy, but this is far from ‘the norm’.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

If the person and their family are actively seeking to introduce more music into the person’s life, then purchasing CD’s, iPods etc, would fall to the person/their family. Organised activities in the local area may be run by charities (like Alz Soc).

In social care, providers would potentially pay to purchase CD players or iPods, instruments like a piano, and to engage visiting entertainers. Music therapists would also have a cost attached that is presumably born by the social care provider, but I have no experience of this.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

I’m sure there are, but I am not able to give evidence of this.

1.4 What should we consider to be ‘best practice’ in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

Quality of life factors are incredibly important. Reduction in medication, improved mood, improved levels of actively and engagement, improved nutrition and hydration, improved sleep.

Also do not lose sight of important factors around supporting the person’s communication (when my dad could no longer hold a conversation, he could still sing a song) and the way music (via singing together etc) can help families to maintain and strengthen bonds in difficult times.

1.5 Is it possible to establish an average ‘unit’ costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

I don’t have expertise in this area.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

Awareness of the benefits of music – the fact that music isn't a 'prescription' like medication is.

Negative attitudes – people who don't believe in the power of music, don't want to open their mind to the possibilities, or feel the benefits are too short lived (remember though, the person may not recall the music activity, but they will remember how it made them feel!).

Access and funding for more organised music activity – for example, engaging music therapists, purchasing technology – like iPods – and skills/abilities to create personalised playlists (or knowledge of initiatives like Playlist for Life) etc.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

As dementia awareness and diagnosis increases, there is a real need for individuals and families to have access to non-pharmacological therapies, of which music is one of the most well-established for people with dementia.

Capitalising on this need is about awareness of the benefits of music and dementia, more availability of therapists, technology and organised local activities, and a clear, coherent case made by those passionate about music for people with dementia to really articulate, in real and practical terms why music is such a great therapy. Give families tips and advice!

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

By creating consistent messages – lots of people are working in this field, but they need to come together under one banner/organisation with clear messages and practical resources. Ensure you involved people with dementia, through organisations like DEEP, every step of the way.

Alongside this, making the case for the benefits of music, the cost savings in terms of people living well for longer (ideally in their own home) with less meds, less costly NHS/Social Care services etc, and the benefits to families and family life. I think there is also something about banishing the traditional British reserve ("I can't sing" – "I don't sing in public") and showing people the fun and joy that can be had.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

On the benefits, how music can help reduce/control upsetting symptoms without the need for meds, and on the cost savings of these benefits.

A strong portfolio of practical evidence, where families have benefitted, where health/social care professionals have connected with a person they care for/support through music etc is also needed.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

There is correlation with art, drama, dance etc – bring professionals in all of these fields on board to see how music can support their work and vice versa. Build an evidence portfolio that has clear links with other therapies to show a holistic picture of support that can benefit many different people with dementia regardless of background, age, hobbies/interests etc.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

People living with dementia and families affected by dementia in collaboration with:
BAMT. Allied Health Professional Organisations. Professional therapists. 3rd sector organisations (charities etc). Social Care Providers. NHS England. Dept of Health.

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

Ideally government ministers/civil servants if you are thinking about national profile and implementation.

But even getting the message about the benefits of music into every Memory Clinic, every GP surgery, every social care provider’s service, would be amazing. Clear messages, practical advice. Nothing weighty that will put families/professionals off. I would also engage through social media etc – think multi-media content, short and concise but very powerful.

2.7 What should our one, clear message be? **[Max. <u>100</u> words]**

Music has the power to change the lives of people with dementia and their families, enabling the person to live well and family members to connect and share magical moments

“When my father could no longer hold a conversation, he could still sing a song”

2.8 Do you have any final comments? **[Max. <u>100</u> words]**

In my consultancy work with social care providers, none of my clients have ever engaged with a music therapist, so in my view this suggests that formal music therapy either isn’t well known about, isn’t affordable, or isn’t considered worthwhile. My father never had access to formal music therapy either. His love of music was nurtured by us, his family, through throwing away his TV, installing a CD player, buying a massive CD collection and printing lyrics (for us to sing with him).

Evidence by Katherine Richards, Music therapist at Kent and Medway, NHS

1. **What is the current ‘state of play’ of dementia and music?**

   1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

Music therapy – group and 1:1 work mainly using singing and improvised music designed to respond, "in the moment" to patients' emotional and psychological needs. This usually takes place in care homes but sometimes in hospitals. Similarly, activities by "Community musicians" – usually involving singing but with a pre-planned structure. In addition, music for entertainment where a group or individual dress up and put on a show for patients, and voluntary music where a volunteer comes to play music for patients.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

NHS, Methodist Care Homes, other care homes, community music organisations such as Sidney de Haan, Sing for your Life, Council for Music in Hospitals.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

I'm sure there are. Even in my own Trust – Kent and Medway Partnership NHS and Social Care Trust – there is music therapy on wards in the East part but not in the West. It has depended on whether or not there has been a manager who has been pro-active in this area.

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

Dementia Care Mapping is a method especially designed to measure well-being and engagement of people with dementia by trained mappers who observe patients over a period of time and document observations using a specially coded system. This has been used to positive effect during music therapy sessions.

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

The BAMT advises an hourly rate for music therapy sessions depending on experience. It would be difficult to predict the outcome in advance.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

Funding for music therapists and other types of music input. In my trust, most people who work on the wards can see the positive ways the patients respond to music therapy, yet continue to fund Occupational Therapy and Psychology rather than music therapy posts. We are Band 7 posts, which is quite expensive. I feel we would be better value for money if we could recruit Band 4 Music Assistants who could work on wards when we are not there using personalised playlists or karaoke which are effective but do not need a Band 7 music therapist to carry out but could be done so under our supervision.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

The value of music in the field of dementia is becoming increasingly well recognised. There are a lot of opportunities around training activities providers and care staff who may not be musicians to use music more in their work, for example using playlists which involve enabling patients to listen to their favourite songs/music in order to engage, relax or stimulate them. Also, reminiscence to music can be used to inspire imagery, and music can be used to inspire dance/movement.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

Train more care staff, fund more music therapists and create music assistant posts to support and carry out additional non-specialist work as described above.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

More music therapy and music research in the use of live and pre-composed music with people with dementia. Books and resources around the area of training staff (I am currently in the process of editing one due to be published in Jan 2019!) and evidence of the value of music interventions by care staff.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Build close working relationships with colleagues from other professions and care staff. Role model using music in the dementia space. Introduce interventions such as playlists which other staff can use.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

Music therapists and music practitioners, managers and commissioners, NHS Trusts, community music organisations, the BAMT, the government, care homes, Dementia organisations such as the Alzheimer's Society.

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

As above.

2.7 What should our one, clear message be? **[Max. <u>100</u> words]**

Music has a crucial part to play in enabling many people to live well with dementia. More funding needs to go into employing music therapists and music practitioners and other staff to support and extend their work.

2.8 Do you have any final comments? **[Max. <u>100</u> words]**

It’s encouraging that this survey is happening and I really hope some of the ideas can be taken forward and used to influence and expand the provision of music therapy and music activities available to people living with dementia.

3.1 Short biography of yourself/your organisations [Max. 50 words]

I am responding both as a former carer to my father, who lived with vascular dementia for 19 years, and my professional role for the past 5 years as a Freelance Campaigner, Consultant, Writer and Blogger.

Evidence by Claire Garabedian, University of Worchester

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

In my view, there are two forms of music being delivered – live and recorded. Live music is provided by musicians of variable capabilities via trained and certified music therapists; music practitioners – a portion of whom have undertaken various forms of training); and well-meaning people who are music hobbyists who generally use voice, guitar, drumming, and pentatonic (5-note) Celtic harps and xylophones. Some people providing recorded music are 'trained' within programs such as 'Playlist for Life', but recorded music is predominantly provided by care staff, family members, and other support personnel, usually in the form of familiar favourite music of the person/persons who are listening.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

Unfortunately, this provision of music for people with dementia is woefully underfunded – despite growing evidence of its benefit for all who are involved. This is particularly true of live music, which although it costs more than recorded music, has been shown to, when provided by appropriately trained and experienced therapists and practitioners, be highly successful at reaching even the most frail people, with the most advanced dementias, and fostering connections between this often isolated population and their families and loved ones.
Funding generally comes through private sources, some care homes provide some funding, and funding also is generated through research grants – although unfortunately, this generally means that music interventions are only offered for a limited length of time as predicated by the design of the funded research project. People with dementia who are living within the community generally rely on charities and private funding in order to have access to music – particularly live music, unless they are fortunate enough to have connects to family/friends who are musicians.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

I believe there is – I am not wholly certain of this, but as Scotland, England, Wales, and Northern Ireland have differing policies in place for dementia care, I would think there are differing amounts of funding being allocated through research grants and care home funding.

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

As a researcher whose entire remit is evaluating the effects of the creative arts with people who have dementia, this issue of 'best practice' for measuring the outcomes and impacts of, in this particular case music, for people who have dementia, remains relatively elusive. The difficulty is the heterogeneity of each person with dementia, and the need for whomever is providing music in any form to be able to respond to the often-nonverbal responses of each person with dementia in the moment. Thus, although there is growing research in this area, it remains predominantly qualitative (i.e. textual rather than numerical), and includes small cohorts of participants.

I think the best numerical/large-scale outcomes can come out of measurements in terms of changes in medication dosages, reductions in hospital admissions, and perhaps falls etc. The remainder of the outputs will need to continue to rely on researcher/carer observations, self-reports from people with dementia when possible, and interviews with persons who have dementia, supporters, carers, and others connected to the music interventions. Which forms to use for 'best practice' are yet to be agreed upon.

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

This again is quite difficult to agree upon as there is such heterogeneity amongst the population regarding personalities, forms and degree of dementias, the extensive changeability of dementia, and the wide variability of music and of those who would be providing music. This is where the importance of funding suitable training for all people who might provide either live or recorded music to a person with dementia is very important; so that there is a guaranteed safeguarding in place regarding each person delivering music will be have a clear working knowledge of nonverbal communication and cues and different forms of dementia.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

Funding and education. Relative to medication, music – even live-music will cost considerably less. The attitudes of funders and staff – from the top down, needs to become more receptive to the value of music – for all involved. This can be achieved through dissemination, training, and active observation on the part of staff. There is also need for greater dissemination of the benefits of music with people who have dementia for medical professionals, care institutions, hospitals, hospices, and the general public.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

There is great need for more appropriately trained musicians to work within this population. There is a lack of knowledge and therefore some trepidation on the part of many musicians regarding dementia, and a lack of an agreed upon method of providing basic training to musicians and the general public. To this end, there is a great need for those organisations that currently provide in-house trainings for musicians/the general public to be called-upon to create one agreed upon and recognised form of training that ensures a basic knowledge of dementia, of nonverbal communication, of working within various institutional settings (care/nursing homes; hospitals; hospices; acute care settings; private homes).

While it is encouraging that the Alzheimer's Society has apportioned some money towards funding PhD studentships focusing on the creative arts and dementia, there could be a lot more attention and funding put into the use of music in particular, and in creating a simple, agreed upon, basic training for ALL who wish to use music for people living with dementia. Training should include overview of the many forms that dementia and how they might exhibit; nonverbal communication; instruction regarding working etiquette within institutional settings such as hospice, hospital, care and nursing homes; ways music can be effectively used for people with dementia; mentoring/shadowing with a musician who is experienced in working within this population; supervised internship; critical reading and discussion of relevant literature; ongoing support and oversight.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

Greater dissemination regarding the benefits (i.e. improvements in engagement, connection, interaction, occupation, identity, evocation of memories, etc.) for people with all types and levels of dementia, as well as its ability to be taken to persons who may have mobility problems. Also highlighting the lack of risks (particularly if each person providing music has been appropriately trained), and the comparative low-cost – particularly as compared with medications etc. It is also imperative that policy makers in government, as well as higher-ups in the medical professions be educated regarding the above, as they will be the gate-keepers – important to also emphasise the benefits for staff/professional carers/family carers regarding connection, mood elevation, and general wellbeing for all who are involved.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

Ongoing research is still needed in all areas connected with the impacts of music for people living with dementia. Research is also needed to measure/understand the beneficial impacts of appropriate training for music practitioners. To this end, it would be very helpful if leading researchers with expertise in this particular field of research be brought together to review present methods of collecting evidence, and to create an agreed upon standardised method of collecting evidence for a protracted period of time towards pooling evidence from necessarily small research projects looking at the impacts of various forms of music interventions on people who are living with dementia.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Yes, we should align music interventions with other areas of work within the dementia space. This can be done through dissemination/education. Also, there is undoubtedly knowledge from research looking at other art forms (e.g. drama, dance, poetry, visual art, etc.), and indeed many other types of activities (e.g. nature, sports, etc.) provided for people with dementia.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

Researchers and practitioners/therapists specialising in the field of music for people with dementia. Also, policy makers, medical professionals, staff, people with dementia and their family and friends who have experienced the benefits of music.

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

Policy makers, medical professionals and staff, institutional managers, people with dementia, supporters of people with dementia. Also, music conservatories and other such institutions regarding the importance of training students for this valuable work, while also enriching their ability to communicate through their music. Also grant funders towards increased collaborative research as discussed previously (see question 2.3).

2.7 What should our one, clear message be? **[Max. 100 words]**

Music of all kinds – particularly live but also recorded can be of invaluable benefit to people living with all forms and levels of dementia, as well as for those who support and care for them. This is because music can reach people for whom verbal communication may have diminished or disappeared entirely. Music can provide occupation, identity, connection, engagement, and interaction for all who are involved – whether in active participatory music-making, or receptive music listening. Music has the ability to transport people into the past and also out of time entirely – 'removing' people from their current realities.

2.8 Do you have any final comments? **[Max. 100 words]**

Thank you for providing a platform for expressing what people like myself – a professional musician and now PhD researcher, dedicated to reaching people who are often especially difficult to reach through standard modes of communication (e.g. people with dementia), and thus are generally isolated and marginalised within society and even within their own smaller communities. The thoughtfulness of these questions makes me hopeful that substantial improved support and thus change is afoot.

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. 50 words]**

Dr Claire Garabedian, a professional cellist and certified music practitioner, is a 'creative arts and dementia' researcher within the Association for Dementia Studies at the University of Worcester. She is currently evaluating several creative arts and dementia projects and is part of the supervisory team for 'TAnDem' Doctoral Training Centre.

Evidence by Department of Health

As noted in the Commission's briefing paper, very large and growing numbers of people are affected by dementia in the UK. The Government remains committed to delivering the Challenge on Dementia 2020, to make England the best place in the world for people with dementia to live.

The March 2016 implementation plan details how the commitments in the Challenge - across four core themes of risk reduction, health and care, awareness and social action, and research - will be met. It identifies the priority actions, and which organisations are responsible for delivery. Working with our partners, we continue to make progress in improving diagnosis rates, ensuring better access to care and support, increasing public awareness and funding dementia research.

Improving post-diagnosis care is a key element of the 2020 challenge and we are encouraging greater personalisation, building support around the individual, and providing people with more choice, control and flexibility in the way they receive care and support. Through the joint declaration on post-diagnostic dementia care and support, we have a strong commitment across Government, health, social care, the third sector and other relevant partners to improve care and support for people with dementia and their carers following diagnosis.

Responsibility for commissioning services to support people with dementia - and their carers - rests at the local level, with clinical commissioning groups and local authorities leading this activity and often playing an important role in encouraging innovation. Social care providers are often themselves innovators and introduce new and creative approaches to meeting the needs of local residents, as do other partners such as voluntary and community sector organisations which offer support to people with dementia. In terms of the potential role of music-based interventions, commissioners and providers are able to draw on existing resources such as the NICE guidance *'Dementia: Supporting people with dementia and their carers in health and social care',* which recommends consideration is given to the therapeutic use of music in certain circumstances.

There is likely to be local variation in the availability of music-based interventions for people with dementia as a result of services being commissioned locally in response to local priorities and the needs of local populations. The outcome of the Commission's work, including its assessment of the evidence of effectiveness, is likely to be of interest particularly to commissioners but also across the health and social care system. Officials in the Department would be very happy to discuss the Commission's findings if that would be of help.

Evidence by Diana Kerr, Sheila Hardie, Mary Marshall,

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

Music Therapy by Music therapists.

Playlists by relatives and staff in homes.

Singing groups by paid workers E.g. Alzheimer Society employees, care home staff and volunteers.

These activities have a different focus, often for different groups /individuals. Music therapy is clearly for people requiring some type of therapeutic intervention. Most people with dementia, just like the population without dementia, need to be able to experience and engage with music in a natural and familiar way. They need to simply enjoy the music, they do not need therapy. It is critical, if music is going to be of benefit to the many people living with dementia, that the focus of our activity is not through therapists but through people who have the energy, enthusiasm and skill to engage with people with dementia using music.

For the purposes of this response I will concentrate on singing groups set up and run, mostly, by volunteers. This response is based on 20 years' experience of using music with people with dementia and 7 years of being involved in running groups for people with dementia and their carers.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

Voluntary singing groups based on the model we use are funded by fundraising activities carried out by volunteers, by application for grants and by donations. Also, in the case of our group, from royalties from the sale of the book 'Singing Groups for people with Dementia: A guide to setting up and running groups I community and residential settings' (2015) by Diana Kerr, we intended to send a copy of the book but we can find no address to send it to. We would urge you to get the book as it answers many of the questions you ask and is referred to for evidence in our answers to later questions in this questionnaire.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

Yes. There are differences between urban and rural settings. Consider the different challenges posed by setting up a group in the highlands and islands of Scotland with a sparse and often isolated population and a London borough.

There are also, of course, differences between providers of care and support for people with dementia. Some residential and nursing homes provide excellent musical experiences some provide poor experience or none. Such variations will be within regions as well as between regions. To focus on regional differences may allow the real areas of difference to go unchallenged.

1.4 What should we consider to be ‘best practice’ in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

People should be having fun. They should feel a sense of belonging, of joy and achievement. It is worth noting here that sometimes people’s experience of using playlists is one of abandonment as staff and carers are not necessarily present. Also of course we all like different music at different times and there is a danger that people get given one playlist ‘for life’. This is no way is to deny the very positive aspects of the good use of playlists but highlights the need to be cautious about how and for whom activities are provided.

Singing in groups provides a social activity, engagement with others, something often lacking in the lives of people with dementia and their carers. Singing plays to people’s strengths. Given the nature of dementia and its inherent losses it is critical that people’s strengths are emphasised and music and singing are with people until the end of their lives.

Research shows that music improves recall, improves mood, improves communication, reduces challenging behaviour, and reduces agitation and distress (see references pp106/107 and chapter two of the book cited above).

Our experience of involving family and other carers in the groups has shown how beneficial it is to the carers who also relax, and experience the joy of singing, this has an obvious positive knock on effect for the person with dementia (see chapter 2 of the book and the case study ‘Mary’ on page 24 of the book).

1.5 Is it possible to establish an average ‘unit’ costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

No. The cost will vary as there are so many variables. Where the group is held, how much a venue might cost (sometimes it is free), how much for heating, (an issue in the community settings maybe but not in a residential home), is it run by volunteers or paid staff (as in a residential setting). How many people would attend. Our experience is of great variation between 60 and 10. Considerable variation can be within one group depending on weather, time of year, illnesses and transport.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

In residential settings, there are issues about staffing levels although this should not be an issue as staff engaged in singing groups are attending to the needs of a number of people at once.
In residential care and in the community people often think they are not musical enough (see the Book ‘Singing Groups for People with Dementia’ where this issue is dealt with).

In the community, there is a need to find volunteers, train them, find funding and find people who are willing to manage the group. Our experience is that this happens once two or three people get together but they need support and knowledge.

People who are interested in what we are doing come to our group to find out how we do it and get advice. The book, however, has meant many people who cannot visit have been able to set up groups. The book has been described by people who have set up groups as ‘The bible to setting up and running singing groups. This has been the case as far afield as India and Australia. The main barrier seems to be getting the right support and advice.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

With a hugely talented and enthusiastic cohort of retired people there is enormous opportunity to tap into their energy, enthusiasm and skill.

There needs of course to be a varied response to meet varied preferences and needs. No one response is a panacea.

Our view is, however, that the running of singing groups meets the needs of the widest group possible.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

There needs to be more publicity about the benefits.

Staff in residential homes need to be given opportunity to find out how groups work. This could be done by providing workshops throughout the country and inviting managers, activity co coordinators and other interested staff to attend.

The workshops would provide opportunities to learn about the benefits of groups and how to run them (again much of this is in the book, perhaps send the book to every home !!!)
The bodies charged with inspection of care homes should have the use of music as a specific requirement. Music and singing, in particular, are shown (see research cited already) to be one of the most beneficial activities for people with dementia, why is it not always provided?

In the community, there needs to publicity and support. This could be provided by regional or more local bodies. It is important, however, to note that this is not to suggest that there is a single body whose approach is seen as the best. There needs to be flexibility as to how the groups are run and the focus. Gender, ethnicity, age, history all need to be taken into account, this means that groups need to develop their own culture.

Groups need to reflect ethnic differences (The group I am involved with in India has mostly men and few women attending which is the reverse of here. This is because traditionally the men joined things outside the home and women didn't).

Groups for people with younger onset dementia also need to be different in a number of ways.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

You don't it is all out there.

Carers regularly report on the positive effect on both the person with dementia and the carers themselves. This can last for several days following a session.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Please, please start by not using terms like' dementia space' If you are wanting to get music out there then use terms that everyone uses. What does dementia space mean?
If you mean how can the use of music be integrated into the lives of people with dementia then make it happen in day centres, lunch clubs, activity programmes, churches etc.
It needs to be seen for what it is which is something that we all engage with and that we are hard wired to respond to it.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

It would be useful if there was a government central body that had expertise in this area and could provide publicity, support, advice and direction. It would not be helpful to have an organisation that has a 'one fits all' approach.
Smaller local groups should be set up to develop local initiatives.

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

The various groups responsible for inspection and quality control within the residential, nursing homes and NHS organisations.
Community groups, churches etc

2.7 What should our one, clear message be? **[Max. <u>100</u> words]**

Music exists and is central to every culture. We are hard wired to respond to music. This does not change when we develop dementia. In fact, it remains with us until we die. It is the one thing that people with dementia retain when all else is going, so play to their strengths and abilities not their losses and weaknesses. Singing together brings joy, a sense of belonging, a sense of achievement and cuts through the fear of the present.

Singing is a normal activity so do whatever you need to do to enable every person with dementia, who wants, to get out there and sing.

2.8 Do you have any final comments? **[Max. <u>100</u> words]**

The evidence and research around the positive effect of music on people with dementia has been out there for over twenty years, lets now stop endlessly researching and start to put the money into getting music to everyone who wants and needs it.

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. <u>50</u> words]**

Diana Kerr was Course Director of MSc in Dementia Studies at University of Stirling, Research Fellow at University of Edinburgh, Associate Consultant to HammondCare Australia. Diana has over 35 years' experience as a practitioner, researcher, educator and advisor in the field of dementia. Diana has a lifelong interest in music and has been advocating the use of music for people with dementia for many years. She is now involved in helping to run and set up groups.
Sheila Hardy retired social worker/practice teacher with special interest in working with people with dementia and their families. A founder member/organiser/volunteer of group for people with dementia and their carers in Edinburgh and further afield.
Mary Marshall Senior consultant HammondCare, Hon Prof University of Edinburgh, has worked in dementia care for most of professional life. Volunteer to music group for people with dementia and their carers

Evidence by Dr Orii McDermott

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

Common music-based interventions in dementia can be broadly divided into:
1) Group singing. Community-based singing groups are often run by charities (e.g. Alzheimer's Society Singing for the Brain, Lost Chord) facilitated by volunteers and sessional musicians. Music therapists also run singing groups (often time limited). Singing groups are also popular in care homes. Charity Mindsong offers singing group training for staff.
2) Personalised music listening in particular has increased in popularity in the recent years. In the UK, charities such as Playlist for Life offers training on creating individualised playlists, collects and distributes used mp3 players/iPods, and develop apps for individuals to download and use.
3) Live music making and performance. Increasing number of charitable organisations (e.g. Music 4 Memory/Tibbs Dementia Foundation), higher education (e.g. Royal College of Music 'Turtle Key Arts') and cultural organisations (e.g. Wigmore Hall 'Music for Life') offer structured, collaborative music making projects (e.g. creating an opera, composing songs to perform, interactive music making sessions) for people at all stages of dementia and their carers. Projects tend to be time-limited and are often led by highly trained musicians.
4) Music Therapy is a clinical intervention provided by qualified music therapists to meet specific needs of individuals.
5) Care home therapeutic activities typically involve a range of music activities e.g. sing-alongs, live performance by visiting musicians, music as part of Sonas and reminiscence groups.
Another type of 'activity' (non-intervention) increased in the recent years is research on music in dementia.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

1) Music therapists working in dementia care are typically employed by NHS, private care homes or charitable organisations. An increasing number of music therapists also work as freelance therapists. Some posts are permanent and others are fixes-term contracts. Private work (typically sessional work with an individual) is often advertised through British Association of Music Therapists, and the work is often paid by family carers.
2) Time-limited music projects are typically funded by individual charitable organisations and resources (e.g. trained musicians) are often provided by cultural organisations and higher educations.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

Research on music-based interventions often focuses on the reduction of behavioural and psychological symptoms of dementia as the desired outcome. Whilst there are no doubt reductions of behavioural and psychological disturbances improve the quality of people with dementia and people around them, what we should consider to be 'best practice' ultimately need to be guided by the views and values of people with dementia themselves.

Music in Dementia Assessment Scales (McDermott, Orrell & Ridder, 2015) was developed from the qualitative data investigating the importance of music for people with dementia (McDermott, Orrell & Ridder, 2014). The five VAS items: Interest, Response, Initiation, Involvement and Enjoyment were identified as the key observable, measurable components that people with dementia show when they engage in music activities. Not only reduction of behavioural and psychological disturbances but also increased 'positive' behaviours (e.g. Interest, Response, Initiation and Involvement) and 'better' mood (e.g. Enjoyment) should be evaluated when investigating the impact of music activities.

Furthermore, a greater effort needs to be made to obtain direct feedback from people with dementia. Recent studies on singing in dementia have not shown 'statistically significant' results despite wealth of qualitative data indicating the benefits of singing for people with dementia and carers. This suggests that validated outcome measures commonly used in psychology/ psychiatry research may not be the most sensitive to evaluate the impact of music interventions. Although interviewing people with dementia is not straightforward, the use of rigorously collected and analysed qualitative data should be part of evaluating 'best practice'.

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

- Music interventions often require extra resources (e.g. instruments, extra staff to support music sessions) hence often seen as additional or 'luxurious' activities, rather than part of the person's essential care.
- Limited support/interest from large scientific/medical funding bodies means it is very difficult to build rigorous evidence on the benefits of music beyond local/small-scale studies even though people acknowledge 'anecdotal evidence'.
- Lack of training sessions / supervision scheme for potential music-activity facilitators.
- Family carers of people with dementia often acknowledge the value of music, but many report they are 'not musical' and do not know how to use music at home beyond playing CDs/radio.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

- The potential benefits of music for people with dementia are gaining more attention from general public and scientists.
- The number of musicians / arts organisations / higher education institutions that are willing to provide music interventions for people with dementia is rapidly increasing.
- Although rigorous evidence is still limited, a larger number of studies on dementia and music is being conducted.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

- Music therapeutic skills sharing. Music therapists to be employed to provide training sessions for family carers and supervision sessions for less-experienced facilitators.
- Funding and support for better-designed (e.g. specifying participants' dementia severity, larger sample size, more rigorous study methods e.g. high-quality RCT, choosing right outcome measures) studies on music and dementia. Research team should include experts from established dementia psychosocial research.
- Raising more awareness of specific benefits of different types of music amongst wider dementia care providers, commissioners, policy makers, researchers and front-line clinicians.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

1 Use of different music interventions to meet different individual needs. Music is not 'one size fits all'. Some music-interventions may be more useful/suitable for people at certain stages of dementia, but no studies have taken place in the UK to investigate the different impact of different types of music-interventions for people with dementia.
2. Differentiating music therapy and music activities. Even though 'music therapist' is a protective title in the UK, differentiating between music therapy (intervention) and music activities are not always made explicit in practice (e.g. therapeutic music activities being advertised as 'music therapy') and in research (e.g. the Cochrane review on music therapy on dementia (2003, 2011) recently updated as 'music-based therapeutic interventions for people with dementia'). Both music activities and music therapy are important, but purposes and goals of interventions are different. Clarifications of the differences are essential to optimise clinical benefits as well as to make most of available resources.
3. Potential harm of using music with people with dementia; musical preference is highly individual. We choose different music to match our different mood. Playing their 'favourite music' repeatedly without interacting with the person is not therapeutic. The potential risks of using music in an un-therapeutic manner need to be made more explicit.
4. Guidance on 'how' we provide a music-intervention, A lot of work has been done on evaluating 'what' interventions may work, but 'how' to provide an intervention therapeutically (e.g. picking up cues from a resident) needs to be explored more.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

- Collaborations/better communications with established dementia psychosocial intervention researchers/institutions. Music is often seen as ‘special’ activities provided by specialists. A greater effort is needed to integrate potential benefits in context of dementia psychosocial research and wider dementia psychological interventions.
- Collaborations/better communications with biomedical scientists. A lot of work investigating the relationships between brain and music has been done (e.g. UCL) but the impact of specific music-interventions has not been explored rigorously.
- List of local music-interventions (e.g. music therapy, singing groups, drop-in centre music events, ‘dementia-friendly’ concerts) being made available & made easily accessible to family carers and care home staff.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

Since the types, frequencies, durations and qualities of music-based interventions for people with dementia are so varied, communications and collaborations between different professionals and people with dementia/carers will be crucial to take this agenda forward and to ensure the quality of interventions offered. One way of achieving this may be to develop a core working group of multi-disciplinary specialists involved in dementia care (clinicians, researchers, policy makers, funders, family carers) and people with dementia.

Increasing awareness amongst care professionals working directly with people with dementia (e.g. memory Service clinicians, social workers, community nurses, psychiatrists, care home staff, health care workers, volunteers) is also important so that they can signpost their clients what music activities are locally available. People who are newly diagnosed with dementia often seek psychological support – but not everyone wants to join in dementia support network straight away or need to engage in formal psychological therapies. Community-based music groups may offer opportunities for self-expression and co-creation and a space to support each other. However, both family carers and professionals working with people with dementia need to know what music interventions and activities (including ‘dementia friendly’ concerts) are locally available.

Securing research funding for ‘soft’ interventions such as music is always a challenge. Research proposals on music-based interventions for dementia do not easily fit into major health funding schemes (e.g. NIHR, HTA grants). Committee members involved in planning grants/assessing funding applications (not only fundraisers) also need to be involved in taking this agenda forward.

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

- Local clinical team mangers/senior staff members (e.g. care home/day service managers, charge-nurse in care home). Their direct support and encouragement for front-line clinicians who provide music interventions are crucial, since regular music activities are often not integrated part of their daily routine.

- Policy makers at national/local governmental levels. The benefits of music-interventions need be described more explicitly beyond recommending ‘therapeutic use of music’ (NICE guideline on dementia)
- Funders of arts organisations
- Trainers of health care professionals to raise awareness of the next generation of clinicians working with people with dementia
- Those in charge of research funding (see 2.5)
- Researches working on various aspects (e.g. biomedical, psychological, social) of dementia care

2.7 **What should our one, clear message be? [Max. 100 words]**

‘How’ you offer music interventions to people with dementia matters as much as ‘what’ music interventions you offer.

The use of supposedly-therapeutic music can be potentially harmful or untherapeutic if it is imposed upon the person without considering individual needs. Checking the person’s preferences and wishes, closely monitoring their responses to the intervention, and using the opportunity to collaborate with the person (e.g. encouraging them to choose the music) is crucial.

2.8 Do you have any final comments? **[Max. 100 words]**

Music is one of few accessible mediums for people at all stages of dementia. Music is closely related to personal history of an individual, and people with dementia value ‘connectedness’ through musical interactions with others. Music is a powerful medium to support the wellbeing of people with dementia but individual needs and preferences should be taken seriously when offering music-interventions. If appropriate support is given, people with moderate to severe dementia can make a choice. A collaborative working approach that both facilitators and people with dementia have opportunities to contribute to is essential to optimise the potential benefits of music.

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. 50 words]**

Dr Orii McDermott is a Senior Research Fellow at the Institute of Mental Health, University of Nottingham and the Doctoral Programme in Music Therapy, Aalborg University. She specialises in dementia psychosocial research: particularly in music therapy and music-based interventions. She also works as a music therapist in CNWL NHS FT.

Evidence by E2L

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

The positive impact of music on people with dementia seems to be better understood in recent years. The expansion of dementia choirs and sing-alongs delivered via music 'clubs' or as part of dementia cafes, most of which is charity driven. Music performance or recorded music in homes seems a more fractured in its delivery as it is largely due to private policy. Our specific experience is the provision of music playing equipment primarily for people who are not yet institutionalised and these are predominately privately funded.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

Choirs and dementia cafes – charity backed mostly.
Purchases of dementia accessible music equipment – private purchase usually by relatives.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

(we're not in the structure to sensibly comment)

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

(we're not in the structure to sensibly comment)

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

As product designers and manufacturers, cost is always an issue. However, the main conceptual message we find as a recurring misunderstanding is that music in the context of dementia is not merely a form of entertainment but a beneficial therapy, in many cases improving lucidity and cognizance.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

We believe we have developed equipment suitable for this very specific area and its growth

proves its fitness for purpose. The uptake of private purchases for people who are still living at home would indicate an improvement in daily living activity. Our designs are based on independent research by BIME (Designability).
The ability to prepare a relevant playlist and then have it on a machine accessible to dementia end users to use of their own volition prolongs their mental abilities.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

Education regarding the mental benefit, not just the entertainment value.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

We've not found any research regarding the possible negative effects of choosing inappropriate playlists. (i.e. some tunes may evoke negative memories). Generally, this is not the case but 'any music' versus the 'right music' is an unknown.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Apocryphally it seems that music has a profound impact and therefore it should have a high priority.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

(we're not in the structure to sensibly comment)

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

(we're not in the structure to sensibly comment)

2.7 What should our one, clear message be? **[Max. <u>100</u> words]**

You rarely forget a tune.

2.8 Do you have any final comments? **[Max. <u>100</u> words]**

We are concerned that some products are emerging claiming the benefits of music without any background research whatsoever. One in particular is an iPod with music and subliminal messaging added which claims to be a useful memory reminder tool for daily tasks such as drinking and exercising. None of this has any research background and its efficacy, positive or negative is not proven. A possible grading of dementia related products may be useful?

Evidence by Elaine Helam

1. **What is the current 'state of play' of dementia and music?**

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

No funding – no budget.
Local volunteers in homes.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

It is not and I am deeply involved with this!

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

Yes, it is harder and SW there is no funding.

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

Skilled and experienced singers and performers being paid to provide quality regular entertainment and therapy [unclear] that.

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

Yes, it is insulting to map cost against outcome. Everyone knows the benefits are huge.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

Lack of belief from government and local authority. Lack of interest and care.

2. **In which direction should the field of dementia and music be moving?**

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

In every dementia centre and home in UK there are daily and weekly chances to heal, stipulate, uplift and offer music, singing as treatment.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

Provide a cohesive plan organised by someone who has years of practice and involvement in this field on a grand level.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

Film local homes – speak to staff and residents and performers. Everyone knows benefits and outcome.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Liaise with home managers – local dementia groups – GPs – mental health services etc.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

An elected body run by someone who has worked/ volunteered on these like myself.

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

GPs - state and private centres and homes – the government. They will embrace benefits nationwide.

2.7 What should our one, clear message be? **[Max. 100 words]**

Music/ singing therapy and entertainment clearly benefit all with dementia in so many ways.

2.8 Do you have any final comments? **[Max. 100 words]**

I have been volunteering to sing in dementia homes for 30 years I know the immense benefits of singing/ music in so many ways.

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. 50 words]**

Actress – pro singer- vocal coach mother and many family with dementia. Singers and songs.com Elaine Helam.

Evidence by From the Harp

1. **What is the current 'state of play' of dementia and music?**

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

Singing for the Brain – Alzheimer's Society.
Playlist for Life – personal playlists
Me – From the Harp (www.fromtheharp.co.uk) taking harps into care homes.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

For me – care home activity budgets.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

I imagine there are less opportunities in the regions compared to cities.

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

I use the Arts Observation Scale (Fancourt and Poon 2016) to measure my outcomes.
I keep my costs down as low as possible so as many people as possible can access my harps.
I think a unit cost is difficult to establish as some people living with dementia may only be able to engage with musical activity for seconds or minutes. For them to engage for this time in this way may be a huge outcome for this individual, but they would not be able to tolerate an hour session so a unit is hard to establish with this client group. As an occupational therapist, I believe 'engaging' and 'doing' activity is more beneficial than passive listening activities. I also believe meeting a request for music is valuable, as people living with dementia may not get many requests met, especially not instantly. There are plenty of examples of how to map cost against outcome in the All Party Parliamentary Group report on Arts, Health and Wellbeing (2017). For example, reduced hospital / GP visits and reduction in medication.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

Care home staff attitude. I hear "they won't be able to do that" so often. Some care home staff think people living with dementia are unable to do anything for themselves, this is often not the case. It is empowering to be able to do something, and to make music they gain instant feedback which is great for self-esteem. Care home activity budgets would be another barrier.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

Lots of research to show the benefits now, health professionals are more aware, and there have been high profile examples in the media like ‘Alive Inside’.

There is evidence to show that imagination and creativity is still there when memory is gone.
I am frequently told that residents living with dementia are calmer and more relaxed after live interactive therapeutic harp music. Care home managers need to provide meaningful activity as part of NICE guidelines.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

I offer free demonstrations, which usually work.
Family members see benefits and can sway care home staff and managers.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

I’m not sure, I believe the evidence is growing for music in health. Maybe we need to build on specific evidence for people living with dementia, and grow evidence for social prescribing for people with early stage dementia still living independently.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Music with arts and crafts can allow people to be more creative with their arts and crafts while listening to music.

Personal playlists should be used to provide meaningful music to individuals.
Instruments should be available for people to play, a lot of people would have played, sung and danced when they were younger at home and in the community. This should not stop because of diagnosis or change in living circumstances.
Incorporate sensory musical walls in care homes.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

Government, NHS, NICE, Royal College of Occupational Therapists, National Activity Providers Association (NAPA).
Commissioners for more music social prescribing at GPs.

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

Clinical Commissioners.

2.7 What should our one, clear message be? **[Max. 100 words]**

Allow creativity and imagination to flourish through music when memory is gone.

2.8 Do you have any final comments? **[Max. 100 words]**

Thanks for the opportunity to contribute.

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. 50 words]**

I am an occupational therapist and harp therapist; my business is From the Harp (www.fromtheharp.co.uk). I take eight lightweight therapy harps into care homes providing engaging interactive activity. I do groups in the lounge and 1:1 work at the bedside, my harps can be played in bed, on tables, in wheelchairs and on the floor making it inclusive for everybody.

Evidence by FSHC

1. What is the current ‘state of play’ of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

Hired in musicians or musical performers attending the care home occasionally. Generic choice of music / songs performed, some performers actively encouraging resident participation, while others perform to their audience. Some homes invite school or community choirs to perform in the home. Incidental use of music, mainly radio providing little more than background noise. Choice of radio station varies, not considered nor intentionally selected for individuals or groups. Individual resident may have personal music playing in their room on CD players. Spontaneous sing- along one to one or small group initiated by individual staff members. Some residents have MP3 players and individualised playlists.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

Hired in musicians generally funded through activity budgets and fundraising activities within the care home. Community choirs make no charge. Background radio tends to be played through the TV or radio situated in communal lounge areas. Personal music collections provided by residents and families, some homes have access to communal tablets and MP3 players but these are generally funded by themselves or family.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

No regional differences although some areas of the UK have a stronger community link to musical traditions…for example South Wales and male voice choirs

1.4 What should we consider to be ‘best practice’ in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

Monitoring of distress reduction, mood and cognitive improvements, increased communication, reduced pharmacological interventions and relationship enhancements for individual residents through standardised monitoring methods, observational/feedback tools for residents, families and staff.

1.5 Is it possible to establish an average ‘unit’ costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

Yes…it should be possible. Using standard assessment tools and inventories it should be possible to measure outcomes.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

Training, budgets and lack of equipment.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

Music is easily accessible through the internet with minimal cost implications. With improved education of care home providers of the benefits; considered, individualised use of music and singing in daily care provision can be incorporated into practice.
There are opportunities that arise with the use of media and technology to widen the impact of music in day to day care.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

By educating care home organisations/staff/families and providing evidence of improvements in the quality of life for people living with dementia and care staff.
Emphasis needs to be placed on the potential positive outcomes for residents, staff, families and ultimately care providers.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

Further evidence of dementia and music in care homes – care staff using singing / music to enhance daily activities such as washing/dressing, mealtimes and communication.
Evidence around the reduction in distress and therefore the use of psychotropic medication in care homes.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Information on individual’s musical preferences should be sought prior to a person moving in to a care home, then feature throughout the person’s care plan.
Care staff can use a song as a further means to identify themselves to residents. Using a few lines from a song each time they interact with a resident improves recognition and supports strengthening trust and therapeutic relationships.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

Incorporating best practice guidance into organisations such as NICE and government dementia strategies will likely speak to those heading up care home companies.
Care providers need to be on board in order that music interventions and approaches are cascaded and adopted within their organisation.

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

Leaders in care provision (Directors/CEO’s), in order that frontline staff are educated and enabled to adopt music/singing interventions into practice.
Clinical professionals to encourage further shift from approaching dementia care from a biomedical model to a psychosocial model.

2.7 What should our one, clear message be? **[Max. 100 words]**

Music cuts through barriers that living with dementia can create for not only the person living with dementia but also their families and those who care for them.
Using music to support care provision has the potential to enhance the quality of lives of all concerned. By promoting collaboration, inclusion and relationship building, the intentional use of music has the power to change a person’s experience of living with dementia.

2.8 Do you have any final comments? **[Max. 100 words]**

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. 50 words]**

Four Season Healthcare is the largest independent residential and nursing home care provider in the UK. Co-authors of this response include Hannah Miller, Project Facilitator, Colin Sheeran, lead project Facilitator, Roberta Roccella, Head of Quality and governance, Claire Royston, Medical Director.

Evidence by Hammond Care

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

HammondCare is an independent charity and aged care provider in Australia. In 1995, HammondCare established an international Dementia Centre, providing research, training, consultancy and publications. To keep up with growing demand our UK based Dementia Centre was introduced in 2016. HammondCare has a longstanding commitment to music and music engagement in the lives of people with dementia. We have invested in a Director of Music Engagement, Dr Kirsty Beilharz. Dr Beilharz has recently published a book on music engagement in dementia care (2017)[1] [See more at: http://www.hammondcare.com.au/news/music-remembers-me-book-launch]. Music is used extensively in our residential care in New South Wales and Victoria, Australia by care staff, in conjunction with family, friends and volunteers.

We have implemented a three-pronged approach to music engagement: individualised music, group participatory music and creative expressive music-making. There is not one single approach to music in dementia care which is best. Individualised and tailored music has been found to leverage benefits of deep emotional connection to reduce pain, alleviate anxiety and address distressed behaviours. Group participatory music can foster socialisation, belonging, integration and the sense of community. Creative expressive music-making gives 'voice' and expression to people who may not be able to speak up in conversation and nurtures enablement, creativity, choice and agency. This diverse approach to music engagement enables those supporting or searching for ways to connect to a person living with dementia to use music in a way that is flexible and responsive, centred on individual need.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

Funding for the Dementia Centre pilot project music engagement program in residential care was provided by several philanthropic foundations and trusts. This sponsored pilot project has seeded resources for more than 700 iPods that can be reused in residential care – therefore equipment costs are predominantly for replacements, renewing, contingency upgrades, replacement headphones (the weakest part of the kit) or increasing the number of people supported by HammondCare. An extensive music library resource has also been established and will require fewer new acquisitions than a start-up library, bringing down the cost of music per capita. New equipment costs are currently allocated to the Dementia Centre, HammondCare.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

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[1] Beilharz, K. 2017. *Music Remembers Me: Connection and Wellbeing in Dementia*. HammondCare. Sydney, Aus.

Although our experience is in Australia we would like to comment. While there are no discernible differences in provision in regions across New South Wales and Victoria, Australia, being aware of the cultural nuance of the person with dementia is a sensitive and important distinction. Music engagement that is relevant to the person's cultural background has the ability to reinforce identity. Music is also capable of crossing cultural and language barriers and supporting relationships between residents from international backgrounds, and care staff who have English as a second language. The culture change in question is really a move from the attitude that music is peripheral or entertainment to the understanding that it has whole-person wellbeing benefits as an integral part of everyday life.

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? [Max. 250 words]

The range of beneficial impacts music has in dementia care includes reduction in pain, agitation, anxiety, sleeplessness, and increase in movement, encouraging socialisation, going outdoors, supporting emotional and spiritual needs as well as expression and identity reinforcement. There is a range of recognised tools for measuring physical and emotional condition and behavioural changes. The Dementia Centre pilot project on music engagement in dementia care utilised the Music in Dementia Assessment Scale (McDermott et al., 2015)[2] and a simplified version of the Emotional Response in Care (Fleming, 2005)[3] to gather evidence across multiple sites with a large, diverse range of residents, in conjunction with longitudinal case studies. For the individual residents, responses such as increased emotional engagement or a reduction in distressed behaviours are distinct, measurable and can have a significant effect on quality of life.

While standardised measures may be considered 'best practice', the project also noted substantial anecdotal feedback from care staff and families that people who are calmed by music demonstrate less agitation. There are also the more intangible but nonetheless valuable effects of preserving culture and heritage for individuals whose identity and sense of connection is at risk due to declining language and memory. Quantifiably measuring this impact of music on cultural identity and sense of self is challenging, however several long-term case studies recorded during this project demonstrated that music of personal and cultural significance can foster a shared connection with families and carers, as well as providing comfort and an opportunity for reminiscence.

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

Unit costs for individualised, tailored music or instruments for expressive creation can be quantified by measures such as the cost of the equipment, the music and the administrative cost for set-up and distribution. A rough estimate incorporating headphones, an iPod Shuffle, music resources, storage, etc. in an individualised music 'kit' is around £92 -£123 GBP ($150-

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[2] McDermott, O, Orrell, M. and Ridder, H.M. 2015. The development of the Music in Dementia Assessment Scales *Nordic Journal of Music Therapy* 24(3): 232-251

[3] Fleming, R. 2005. *Beyond Words. The Emotional Responses in Care Assessment*. HammondCare. Sydney, Aus.

music resources, storage, etc. in an individualised music 'kit' is around £92 -£123 GBP ($150-200 AUD), contingent on the scale of music resources in the organisation. However, the flexible, responsive and individualised approach of music engagement means that the time and labour of care staff is not a discrete measure.

While no distinct cost-benefit analyses have been conducted, music engagement has been used successfully in specific responses to people who feel distressed. Targeted music interventions to reduce agitation triggered by visitors to the home, bathing and distressed behaviours have been used in high-care and behaviour-specialist care settings. The impact of individualised music as an intervention to reduce severely distressed behaviour has emerged as profound, with the advantage of being inexpensive and non-pharmacological, i.e. without side effects or interactions with other medications. In our Arts on Prescription pilot program, providing a range of participatory arts for older people, participant feedback indicated that personal growth, accomplishment and empowerment were important benefits of arts programs, including music engagement.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

There are three main barriers to uptake of music engagement. Firstly, daily implementation and availability of music at appropriate times for maximum resident engagement hinges on the degree of staff enthusiasm and engagement. Staff need to respond to the resident to provide the music at times of need appropriate to the individual. This emphasis on responsiveness, as well as the individualised one-on-one engagement can create the perception that there is a significant time burden involved. Music engagement may initially appear to add time and responsibility to caring duties, however improvements to wellbeing and life quality will more than offset the expenditure of funds, effort and time, positively enabling residents and staff.

Uptake of music engagement may also be hindered by the funding model. Where there is no cost to the resident or family, uptake is generally higher. If there is an 'opt-in' model that is adopted, with a cost attached, it is more likely that residents and families will opt-out, unable to adopt any additional costs.

The third barrier to extensive uptake is the culture of an organisation. Music engagement in daily care is effective in an environment where there is an ethos of tailored care, one-on-one interaction, and recognition that individualised care is more important than a task-oriented focus. In addition to variety and flexibility, a culture that permits and encourages individualized care and values quality of life over a task-oriented model is essential for music engagement to work.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

The universal availability and flexibility of music provides an opportunity for music to be used as a relational way of engaging, rather than merely peripheral entertainment, or a periodic intervention by specialists. Personalised music engagement tools such as iPods can be made available across 24 hours / 7 days a week, to suit and respond to the needs of people living with dementia. The flexibility of this tailored music experience, with portable and individualised music, allows carers to provide music wherever and whenever appropriate, with relative immediacy. It requires no specialist knowledge for delivery by general care staff, empowering staff with an additional method and tool for caring and relating. This flexible availability is necessary if music is used as an intervention for distressed behaviours. Individualised music choice aims to enhance the residents' and care givers' interaction through sharing time, love, attention, a holistic view and palpable experiences beyond mere pragmatic necessities in the daily routine.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

To implement a sustainable, enduring program of music engagement, generating financial revenue to support the program is essential. Organisations may look to invite residents to invest in a program, or encourage community and donor support, particularly to donate and collect used iPods and technical equipment. Volunteers and families may be a source of technical support and music resources.

Overcoming the perception that tailored, personalised care, such as music engagement, is more time-consuming than institutional schedules is crucial. In reality, when people with dementia feel more receptive to care and enjoy more relaxed interactions, this actually reduces time needed to bathe and conduct routine daily activities, while also reducing the stress that can outlast the activity that triggers it. Generally, the quality of life benefits beyond emotional wellbeing, such as improving exercise, decreasing agitation, increasing appetite, are not well known and need to be promoted to staff.

For a music engagement program to be successfully implemented in residential aged care, music must be thought of as an integral part of caring for an individual and not merely as an entertainment activity. It has to be used within an organisational culture of tailoring care to the person, rather than being task orientated, with staff given necessary time to engage with residents. Staff enthusiasm and refreshing motivation, as well as promoting awareness and interest amongst the relatives and management are important to sustaining a culture in which music engagement is part of lifestyle.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

Previous music engagement research in aged care has been of brief duration (typically up to 12 weeks) and has used small groups of people. The Dementia Centre pilot project extended over two years, across multiple sites, with a large, diverse range of residents. In the qualitative, longitudinal case studies we have utilised objective tools (detailed in 1.4). Documented observations from this project have examined not only the effects of music while participating, but the lingering effects over time afterwards and in relation to lifestyle and recurrent distressed behaviours. There is a general paucity of evidence for the long-term sustainability of music interventions and this is an area that requires further research.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Mealtimes

There are potential synergies between music and dining. Certain music has been shown to improve flavour, enjoyment, sociability and it can be therapeutic in stimulating eating in cases of malnutrition and anorexia, and reducing mealtime anxiety for people with dementia.

Spiritual needs

Music also plays an important part in supporting spiritual needs, with positive impacts on emotional wellbeing, perception of pain, anxiety, as well as on physiological wellbeing. Ageing, in particular ageing with dementia, involves a spiritual dimension and music is one of the ways in which ageing, spiritual values, life experiences, relationships, creativity or worship is processed and expressed or observed. Music can carry associated feelings of belonging, reassurance, acceptance and hope. Supporting the spiritual wellbeing of people involves looking for opportunities when alternative approaches to spirituality, such as music engagement, can be of value.

Palliative Care

In late stages of dementia, or if people have complex conditions, people may be receiving palliative care or may be aware of their impending death. Literature supports very strongly the value of music engagement in palliative care, especially for supporting the particular spiritual needs and concerns that can be present. Music can be helpful for reflection, meditation and calming anxieties. There are also particular benefits of music in pain management, with music shown to be useful as a means to move attention away from pain and even to contribute to pain reduction when attentively managed with a person's favourite music.

2.5 Who should be taking this agenda forward? **[Max. 250 words]**

Music engagement is an important area for research, education and practice. At HammondCare our mission and values are centred on the importance and individuality of each person. Music helps us to connect with the person and as such is important for wellbeing, identity, demonstrating respect, facilitating fun and helping families to connect. It has also been shown to impact positively in issues of pain management. With respect to our own experience, knowledge and resources we invested in music engagement as an organisation, supporting a Director of Music Engagement and funding evidence based practice to support this investment.

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

Institutions and associated funders need to recognise that music must be used within an organisational culture of tailoring care to the person, rather than being task orientated, with staff given the necessary time to engage with residents. There must be an understanding that investment of time, effort and resource in music engagement reduces other costs, such as distressed behaviours. Developing a music engagement culture requires enabling non-specialist everyday care staff to provide music to residents, rather than depending on sporadic interventions, which are reliant on experienced experts or visiting music therapists, who may not offer the same flexibility or ubiquity. Music needs to be embedded in everyday care, available for all. The alignment of music engagement with organisational ethos, as well as the importance given to enabling and empowering care staff, are essential to success.

An essential part of 'buy in' to a music engagement program is resident/relative understanding and involvement, partnering with family and friends is key. For people with dementia and their family members, the dementia journey includes many changes, however music can serve as a constant and stable factor. Listening to music together creates meaningful, shared experiences – ways of being 'in the moment' together. When implemented well, music engagement can improve the experience of residents and involve family and friends in the care experience.

2.7 What should our one, clear message be? **[Max. 100 words]**

Music engagement in dementia care has numerous benefits, which can affect physical, mental and emotional wellbeing, improving the quality of many aspects of life and maximising the enabling of inclusive opportunities for people living with dementia. Music is an inexpensive and dignified way of experiencing far-reaching results, without the cost and side-effects of pharmaceutical interventions.

2.8 Do you have any final comments? **[Max. 100 words]**

You can read more about our work in the Australian Journal of Dementia Care (Beilharz, 2016).[4]

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. 50 words]**

HammondCare is an independent Christian charity specialising in dementia and aged care, palliative care, rehabilitation and older persons' mental health. http://www.hammond.com.au/

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[4] Beilharz, K. 2016. Engaging and connecting through music: enablement in practice. *Australian Journal of Dementia Care*, 5 (1): 21-25 http://journalofdementiacare.com/engaging-and-connecting-through-music-enablement-in-practice/

Dr. Kirsty Beilharz, Director of Music Engagement, HammondCare and Visiting Fellow, University of Edinburgh.
Dr. Julie Christie is the Dementia Centre UK Region Manager and the contact for this submission jchristie@hammondcare.com

Evidence by Hazel Child, MT

1. **What is the current 'state of play' of dementia and music?**

   1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

   In my experience, most people working in music and dementia are entertainers, who are themselves a broad selection ranging from volunteers to professional, performers and those engaging closely with their audience. Community Musicians are inhabiting a middle ground…Then there are Music Therapists, and Musicians in Healthcare, both of whom are professional musicians, but only the therapists are HCPC registered, with the accompanying support, structure and supervision.

   1.2 How is this range of activity presently being funded? **[Max. 250 words]**

   Care homes, day centres and other organisations are fund raising, and paying for short term interventions, and regular entertainers. Some people self-fund, some music organisations and music therapy CICs are writing applications to access funding. A major problem in dementia care is that the people with access to the money – adult children – are usually not convinced of the efficacy of music therapy.

   1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

   Outside my scope of knowledge.

   1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

   The meaningfulness of each encounter. Hard to prove. Which is why it's useful to have trusted professionals deliver it, and their response valued. Music enables people to deal with feelings – there won't always be a happy/positive/cheerful/obvious outcome, but there will be a sense of catharsis, or meaning achieved. It's impossible to have a blanket judgement like 'anxiety diminished' or 'more verbal following a session' although these things are often observed.

   With entertainers, it would be the sense in the room as judged by care staff or relatives.

   1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

   Very difficult. Regulated professions have a set scale of charges, and these should be clearly available, and the outcomes can be broadly and reasonably expected. Therapeutic intervention is likely to have similar outcomes in a very wide selection of cases. Other people have a sense of what they can achieve and charge accordingly – care providers and individuals have to try it and see.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

Funding. This is probably the second and third reason as well, because people often won't think beyond, 'we can't afford it' even when funding options exist.

Space. Music is intrusive, and cannot take place where it will disturb and irritate those unable to use it. Many places, struggle to find an appropriate space.

Support. Management have to value music intervention, or they undermine it.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

Active intervention. Music is entertaining, but as a communication and emotionally present tool it's vital. Music should be used as often as indicated – by carers and family. By skill sharing (see the work undertaken by Music as Therapy International) more and more people become relaxed about using their voices and natural rhythm to make connections with service users/loved ones.

Music as a communication tool, to enhance relationships and as a non-chemical anxiety alleviator. This is a clumsy sentence but I can't make the boxes bigger without moving all the words.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

Raise the profile, so people aren't afraid to spend the money. Vast amounts are spent on equipment and furnishings. People need to be educated, so they understand that no one is patronising anyone, it's not just a jolly hour of fun, it's vital, nerve healing, brain stretching, relationship building, memory refreshing activity.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

MHA (Methodist homes association) did an extensive study into individual music therapy and dementia. I think group work needs to be given the same attention. Also, when people see what can be done, they think it's simple, so don't want to pay. But they don't get on and do it, because it's harder than it looks. We need to keep breaking down the barriers to accessing simple sharing skills. See end box, also.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Everything should be integrated when we can. Teamwork, so we all pull in the same direction. Mutual respect, sharing perspectives and observations, taking the time to listen to each other. Is that what this question means?

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

Someone with the funds to do so. Lobbying groups? Certainly, it should be accessible on the NHS – we need to be able to refer people and access the funding accordingly.

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

No idea. Someone who can make things public.

2.7 What should our one, clear message be? **[Max. 100 words]**

People with dementia are worth it! They still have lives, they aren't waiting for death quietly, and nor should they be. By definition, they can't make decisions about their own funds, and this is a problem. We need to make lives better now, if not for the people who are struggling now, then for the elderly people we will eventually be.

2.8 Do you have any final comments? **[Max. 100 words]**

I ran a skill sharing project in my home town, and it was very successful. Staff are now running music groups for people who were not seeing themselves as needing 'therapy', but are very glad to share the music. Staff feel confident about running the groups, and also see the need for actual music therapy for people further along their dementia journey.
I couldn't extend the evidence box – but we need long term studies. People who use music and people who don't - what is the long-term outcome? Partly on slowing the progress of the disease, but also on quality of life and perceived relationships.

Evidence by Heather Edwards, Music and Mirrors

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

- Music therapy - by professionals
- Performances of music in care settings, hospitals, etc - professional and lay people
- Interactive performances - Lost Chord, etc
- Singing groups - led by professionals or community and voluntary groups.
  either
    a) with underlying structure of cognitive stimulation or
    b) singalongs
  Both provide social support. Carers and families may attend.
- Individual work supporting people with dementia to make written digital toolkits linking memories to sound/music for additions to care plans (Music Mirrors) - trained lay people and professionals
- Compiling individual playlists - lay community.
- Intergenerational projects

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

In my own field:
Come Singing: therapeutic singing groups for people living with memory loss. 20 groups monthly in community settings, care homes, day centres, acute general hospital, dementia intensive care and palliative care. A very small unincorporated voluntary organisation with an initial start-up grant of £2,000.00 in 2012 from Norfolk Community Foundation (NCF). We are funded by contributions to the coffee saucer, occasional gifts and legacies but work successfully by bolting on and offering our services to existing care facilities which then host our sessions (hospitals, care homes, day care, etc). Norfolk Library Service hosts one community session, and Norfolk Carer Support has given £300 annually towards our only hired premises.
Music Mirrors (www.musicmirrors.co.uk) has been supported but not funded by Norfolk and Suffolk NHS Foundation Trust and S. London Health Innovation Network hosting training of volunteers and health professionals to carry out work in the community. The Brief Community Fund via NCF has awarded £2,000 annually since 2013 towards printing, publicity, website hosting and project leader's expenses. Music Mirrors themselves are a cost-free intervention, free to those who need them, delivered by the third sector as well as by the NHS and other organisations. Use of the website for storage of Music Mirrors with confidential password is free of charge.

1.3 Are there regional differences in provision, within the UK? [Max. 250 words]

I'm sure there are but have little knowledge.

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

Gold standard is regular evaluation via QOL and other measures but this is largely impractical for many small organisations doing crucially important work. Substantial work has been done on singing groups and the impact of music therapy.

Music Mirrors were fortunate in the South London Health Innovation Network report http://www.hin-southlondon.org/resources/music-mirrors-report and are now the subject of a four-year intervention study by Zurich University http://www.zfg.uzh.ch/de/projekt/Music-Mirror.html

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words**]

No idea - not my field as someone who runs an entirely voluntary organisation. Music Mirrors too was devised as a tool which is cost-free to people living with dementia and deliverable by the third sector.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

Proper, rather than superficial understanding of the crucial role of music interventions.
Funding!
As music is known to be so helpful to those living with dementia, it is outrageous that funding is not more readily available. There is patchy funding of music therapists and other arts groups skilled in writing competitive bids have some success, but this leaves much of the work to the third sector, meaning that it is dependent on local resources and enthusiasm. The Alz Society inadvertently harmed the cause by ring-fencing Singing for the Brain with mandatory regulations which prevented many local branches setting up groups.
It is not surprising, then, that people reach for the quick fix of compiling personal playlists of preferred music without real understanding of the dangers as well as potential benefits. Much more education is needed here if these are not to be used as a substitute for person-centred care and engagement with people living with dementia.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

Opportunities' for whom?! Wording a little more person-centred, please!
The World Health Organisation defines Quality of Life as individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their

goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment. WHO (1997). Measuring Quality of Life. http://www.who.int/mental_health/media/68.pdf
Because music is processed in several areas of the brain left intact until relatively late in dementia, it has a special role in enabling those affected still to enjoy and benefit from:
Social contact
Emotional expression
Purposeful activity
Quality of life
Cognitive stimulation
Increased subjective and objective wellbeing
Physical memory - of singing or playing, and the world of reminiscence this opens.

Active musical engagement as an individual or as part of a group, can contribute, directly or indirectly, to many aspects of this and listening to music, live or recorded, may provide comfort and sustain a sense of identity. Music is a basic human right for those living with dementia.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

Education!

Of commissioners and of those working at throughout the field. At all levels people have either a simplistic understanding of the options or underlying discomfort around the topic resulting from their own musical experience or tastes. Many underestimate how musical understanding remains intact for others living with dementia and how it supports their identity.

In dementia, music is not simply entertainment but a lifeline to communication and contact with the world: the goal is to engage, enable and enhance life for people living with dementia. Music is most powerful when it builds bridges of recognition and understanding.
Other countries insist that paid care workers be able to sing: disseminate existing widespread research on caregiver singing.
eg: https://www.ncbi.nlm.nih.gov/pubmed/11858349

Encourage carer input to musical activities in residential care - music belongs to all, not just professionals.
Make commissioners aware of the distinction between music therapy and community music initiatives and importance of both.
BUT be wary of enthusiasm for quick-fix playlists: these are readily seen as a panacea but can easily lead to well-meaning neglect and thoughtlessness. Especially in institutional care they may be used in the same way as the old chemical cosh or leaving residents in front of a television.
Support musical community initiatives bringing together people with and without dementia, and of all ages.

Encourage Mental Health Trust recovery colleges to include music in Wellness Recovery Action Plans.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

Extensive research already supports the benefits of singing and music therapy in dementia.
More evidence would be welcome on:
Community music initiatives and involvement of laypersons - carers, etc - in musical interventions.
Use of music and sound as part of written patient passports: for dementia and more widely.
University of Zurich has just begun a four-year intervention project into Music Mirrors http://www.zfg.uzh.ch/de/projekt/Musikspiegel.html but despite widespread uptake these have so far been little researched in the UK http://www.hin-southlondon.org/resources/music-mirrors-report
The effect of musical interventions of all kinds within care homes, etc - not what is done, but the effect it has on the wider community and interactions between those with dementia and family, carers, domestic staff, etc.
Mental Health Recovery College programmes for people living with dementia.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Music should be:
included in initiatives such as ‘This is me’ leaflets
considered in much more detail as part of Cognitive Stimulation Therapy,
examined in research and practice,
retained on the school curriculum, ensuring that singing and music making continue in communities

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

Care home provider groups, CCG commissioners, NHS Trusts (e.g. excellent work in Norfolk via Norfolk and Norwich NHS University Hospital and Mental Health Trusts, Sutton Vanguard Trust), Academic Health Science Networks (e.g. S. London Health Innovation Network - HIN)

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

All of the above.
Crucially, those living with dementia and their families need to be aware and reassured that singing groups or other participation in music, perhaps not previously part of their lives, are neither condescending nor childish. The dread of having to sing war songs or shake a tambourine is widespread and understandable and needs to be dispelled. The status of music should be recognised as at least on a par with other forms of cognitive stimulation and it should

be made available routinely as post-diagnostic support and throughout all stages of the condition.

2.7 What should our one, clear message be? **[Max. 100 words]**

Music is a good thing - emotionally, physically, cognitively, aesthetically and socially. It creates joy and builds bridges between people. Dementia doesn't change this, and it remains a basic human right until the last breath to have access and engagement with music in whatever form best supports one's quality of life.

2.8 Do you have any final comments? **[Max. 100 words]**

You probably haven't come across Music Mirrors, made with and for people with dementia as brief written additions to care plans. These are now in use at the very least in Norfolk, Suffolk and S. London. Please do have a look at the HN report http://www.hin-southlondon.org/resources/music-mirrors-report
complete with tiny info-video
https://vimeo.com/194667249
Music Mirrors were runners-up for the Guardian award for innovation in mental health services in 2017 Advancing Healthcare Awards. www.musicmirrors.co.uk

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. 50 words]**

In 2012, having developed a neuro-rehab singing model for people living with dementia Heather Edwards founded the Norfolk voluntary organisation Come Singing to carry this work forward. Music Mirrors grew from this experience, in response to the need for people to retain individual memories and identity even when words fail.

Evidence by Iain Spink, Kent and Medway NHS Trust

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

I am a qualified Music Therapist. Music Therapists complete an approved training course at Masters level and are registered with the HCPC.
I am employed by Kent and Medway NHS and Social Care Partnership Trust (KMPT).
I work on two mental health continuing care hospital wards for people with dementia; long stay environments. I also work on an assessment ward for people with both dementia and functional mental health illnesses. I offer both group and individual sessions in theses settings. The therapy sessions contribute to the patients care and treatment, contribute to discussions regarding the care of the patients, attend handover meetings, contribute to care plans, written reports etc

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

I am employed by KMPT on a permanent contract – which began in 2008.
There are currently two music therapists employed by KMPT – we both work with the Older Peoples Service Line.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

My observation is that there are differences in provision within the NHS, in general, and the employment of music therapists varies. Within mental health trusts it is my understanding that not all trusts employ music therapists and there are not many employed to work with older people; there appear to be more music therapists employed to work with the working age group of patients (18-65).

I believe the reason for this is different commissioning decisions within the different mental health trusts across the UK. Despite a growing evidence base for music therapy with older people, there is no national directive to provide a parity of provision in this area and individual Trusts make their own decisions.

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

Within NHS settings I feel it is important that the music therapist is integrated within the care team. They can and should contribute to discussions regarding the care of the patients, attend handover meetings, contribute to care plans, written reports etc.
Use established outcome measures, where possible.

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

It may be possible to calculate the cost of provision for a music therapist working in the NHS (and other organisations) by their salary and productivity. It may then be possible to map against outcomes. Outcome measurements vary and thought should be given as to how outcome is defined.
I do not have this information. The British Association of Music Therapy (BAMT) may be able to help with this.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

Lack of funding

The NHS mental health services are underfunded. This is the main and fundamental barrier. This prohibits the commissioning of new music therapy posts, which is what is required in order to increase music therapy input within NHS settings. Whilst NHS trusts are struggling financially, other services and forms of treatment take precedence.

Lack of understanding and awareness of music therapy and the benefits of music
As a music therapist, I constantly have to explain my role. Over the years I have met many Doctors, Nurses and Health Professional who have little understanding of our role and how they can work with us for the benefits of the patients/service users.

Healthcare professionals not being able to use music in their workplace
The use of music – by other healthcare professionals such as healthcare assistants or nurses – can and should be promoted. Barriers to this may include: attitude and preconceptions: lack of awareness and understanding of how music can be of benefit: time and permission – being given the time and permission to use music with patients when this is may not be seen as the employee's primary role, for example a healthcare assistant.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

The evidence base for the benefits of music interventions for people with dementia is growing. This includes music therapy research but also within the broader field of "music and health" particularly the use of singing. Community singing such as age and dementia specific choirs are increasing as this awareness grows.

Within the field of professional music therapy there is also an increase in the employment of music therapists in care homes. Methodists Homes Association (MHA) are a leading example of this. http://www.mha.org.uk/news_archive/music-therapy-has-dramatic-effect-well-being-care-home-resid/

There has also been recent work to get music therapy included on the NICE guidelines for dementia.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

Increase the funding to the NHS.
Increase the awareness of the benefits of music interventions by trained music therapists and also non-trained music professionals.
Further increase the understanding and profile of music therapy within the health services. For example, make arts therapies awareness and understanding part of medical training – for Nurses and Doctors so that when they see music therapists in the workplace they have a better understating of what they do and how to work with them. Also make it part of job training induction for medical and healthcare professionals in workplace settings.
For music therapy to be recommended by NICE guidelines.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

I am currently undertaking PhD research into my work as a music therapist on NHS hospital wards for people with dementia. I aim to contribute to the body of knowledge in this field. My initial investigations into the literature show that there has been an increase in research in this area over the last ten years. This is encouraging but more research is needed.
There has been a call for more RCT trials – which has been answered. However, I am not sure that RCT trials are the most appropriate fit for research with this client group. I would endorse the need for research that captures the essence and realities of the work – rather than trying to make the intervention fit into the specific rigors of research design required by RCT trials.
The collaborative nature of music therapy work, within healthcare settings for people with dementia, also suggest to me that it is important to research how the music therapy is carried out and the impact on care team staff, carers and the environment as well as the impact on clients/patients. This will be a focus of my own current research.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Therapeutic music interventions by trained music therapists – can be of benefit and value to many settings for people with dementia. There is evidence to support this within long term residential settings including care homes and continuing care hospitals but also in NHS assessment wards and day treatment services. Also end of life care.
Qualified music therapists are also well placed to work with staff in enabling them to use music in their own work. For example, using music and singing during care giving. Ideas and approaches to using music can be learned from the therapist and this can be part of the therapist's role within a care setting.

The British Association of Music Therapy (BAMT)
Arts and Health organisations and providers
The NHS

2.5 Who needs to be influenced and brought on board, to further this agenda? [Max. 250 words]

NICE
The NHS
Large care home providers
End of Life care providers

2.6 What should our one, clear message be? **[Max. <u>100</u> words]**

Music is a safe and enriching medium to use with people with dementia. It can resonate and reach people for whom other forms of expression, communication, creativity and interaction have become impaired and inaccessible. It should therefore be encouraged formally and informally. Therapeutic interventions by trained music therapists have been shown to be beneficial and can have an important role in the treatment and care of people with dementia. Music can be also used in many ways and by people in many different roles and points of contact: healthcare professionals, carers, family and friends.

2.7 Do you have any final comments? **[Max. <u>100</u> words]**

I feel that this commission into music and dementia is important, timely and crucial. I welcome it and look forward to the findings and subsequent impact. Thank you for the opportunity to contribute.

Evidence by Imagine Arts

1. **What is the current 'state of play' of dementia and music?**

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

The main strands of activity would be community based singing (for example, Singing for the Brain), some instances of music therapy in residential care (Methodist Homes Association). Families are incorporating music into their daily care routines for people living with dementia. Singing for the Brain used to be trademarked and delivered by the Alzheimer's Society but they have withdrawn from this activity. Some 300+ groups exist, but the society no longer ensures their continuity. Demand for Singing for the Brain exceeds the number of places available and it is currently funded by a range of sources; charitable donations, public-sector and users' contributions. Naturally, this makes provision difficult to guarantee. Increasingly personalised playlists are being utilised in various settings.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

The measurement of outcomes of these activities is complex: outcomes for carers, people with dementia and others may be of interest, as well as effects on the wider health and social care economy. In particular, there are ethical and practical problems presented by 'measuring' effects for people with dementia. Ideally, 'in the moment' responses should be captured, and this is possible using audio-visual methods. However, there is a problem in obtaining informed consent from people with dementia. Moreover, lack of anonymity and ease of reproduction makes films controversial: would you want to be shown on YouTube in an advanced state of dementia?

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? [Max. 250 words]

Unit costs of running singing sessions are straightforward enough. There is already sufficient data about Singing for the Brain to calculate these costs. Outcomes are another matter, as stated above, and this begs the question of theory of change; what cause and effect are predicted?

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

In residential care one of the main barriers is the availability of staff to deliver and support musical activities in this setting. A secondary barrier is the financial constraints of commissioning high quality musical activities (for example, commissioning a music therapist or professional musician in comparison to playing pre-recorded music via CD). Another consideration is the enthusiasm of individuals to motivate others, particularly in care homes. Some musical activity is provided by music therapists, although access to this is limited.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

The opportunities to integrate musical activity into daily caring routines. For example, equipping care staff with musical 'tools' which can be utilised in between music therapy/musical activity sessions.
The preparation and use of personal playlists is a growing field, and this could help to equip family carers to deal with the progressive impairments of dementia.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

Educating and persuading care home managers and care staff of the benefits of musical activities in residential care. In particular, the commissioning of high quality musicians.
By facilitating a network between care organisations and high-quality music professionals which will help establish effective working relationships between the two parties.
Greater attention to the skills and contributions of music therapists in this field.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

On the implementation of music into dementia care.
What are the facilitators and barriers to integrating musical activity into everyday care and developing a model of good practice?
How can access to music be delivered, at scale to people with dementia living in the community?
What kinds of musical opportunities are suited to people with different levels of dementia?
Can the skills and knowledge of music therapists be shared with other dementia care professionals?

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Music interventions could be aligned with training for care professionals so that it becomes an integral part of dementia care. Creative arts and care do not need to be mutually exclusive.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

Local authority commissioners of dementia care.

Schools could reach out through their music departments.
Clinical commissioning groups and whatever succeeds these organisations.
Voluntary organisations that support people with dementia and their carer.
Residential care providers.
Home care providers.
Carer networks.

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

All of the above.

2.7 What should our one, clear message be? **[Max. <u>100</u> words]**

Music reaches people with moderate to advanced dementia when nothing else seems to do so.

2.8 Do you have any final comments? **[Max. <u>100</u> words]**

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. <u>50</u> words]**

Imagine is a 3-year project, funded by Arts Council England and the Baring Foundation, aiming to enrich the lives of older residents by enabling access to creative and cultural programmes. It is a collaboration between City Arts, Nottingham City Council and the University of Nottingham.

Evidence by Jerry Benjamin

1. What is the current 'state of play' of dementia and music?

1.1 what are the main strands of activity which fall within this broad field, and who are these activities being delivered by?

Having a person with dementia impacts on the whole family. Recently, there have been a lot of publications about dementia and music.

Alzheimer's disease international is the federation of Alzheimer's association around the world. According to the commission 850,000 are with dementia. Focus here is on dementia and music. Evidence based music is used to explore intervention in its prevention, diagnosis, treatment and potential role.

I reflect on a memory dance event opened by neurologist Oliver Sacks. This music evoked emotion, together with memories bringing back feelings of life. Another example of evidence based ageing and mental health little knowledge find music beneficial for their wellbeing.

1.2 How is this range of activity presently being funded?

According to NHS England they reflect on low dementia diagnosis rates approximately 160,000 people are living with dementia.

This activity presently being funded by planned NHS National Institute for Health Research. Prime ministers challenge of Dementia. People identified with dementia 670,000 people in England with 30,000 undiagnosed PMs challenged by dementia, bringing NHS and governments together, social care, research service and charitable sector for example Forever Manchester community based support & activity groups, Walk & Talk carers drop in. Dementia friends programme led by Alzheimer's funded by Cabinet Office and the Department of Health. Medical Research Council (MRC).
Www.gov.uk

1.3 Are there regional differences in provision within the UK?

- North south divide inequalities
- Divide between wales and England
- Some people have access to medications others don't
- National health postcode lottery reveals wide UK disparities
- Differences in treatment, quality, quantity and costs
- Training in Manchester for nurses is poor compared to London.
- GPs find it hard to identify symptoms early.
- Support for mental health is poor
- Difference in accessibility to anti dementia drugs in parts of the UK.
- www.BMJ

1.4 what should we consider to be best practice

- Individual based on systems and social situation, education, support, resources for patient and family, guidance on diagnosis, prognosis, treatment. Updated daily using no evidence based methodology and expert opinion
- Best practice is my reference for teaching
- Based on research
- Always updated
- Lessons need to be learnt between people
- Sharing experiences

2. In which field should the field of dementia and music be moving

- Care homes to community homes
- The breadth and flexibility of music based interventions me ns that they can be built into an individualised personalised care plans and can often be tailored according to needs

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. <u>50</u> words]**

My name is (Jerry) Jeredine Benjamin, a retired NHS Foundation Trust Nurse for 17 years. professional experience working in healthcare setting, in clinical and mental health, including caring for Older People with different multipathologies within a multidisciplinary team. I have knowledge and experience to utilise effective communication, leadership, listening and customer care, through my work with service users.

"I bring diverse range of knowledge through experiences I have gained in healthcare organisations where I served as a healthcare nurse and research administrator. My participation in national international conferences, numerous health workshops have broadened my horizons in healthcare management."

After retiring from practice, I became an active member of Salford Royal NHS Foundation trust participating in seminars, lectures, research, meetings and clinical practice updates. Patient led Assessment of the Care Environment. The ward Assessment.

I joined the Pathway Advisory team as an Advisory Member in 2015 as part of the Cardiac Rehabilitation Pathway advisor to improve the quality of life and psychological impact through use of coping skills and sharing/learning and an networking. The pathway research program is funded by National Institute of Health Research and is sponsored by Manchester's Mental Health and Social care.

I became interested in joining the board of Age Friendly Manchester Older Peoples I am committed to improving the quality of life, public involvement I am keen people are listened to and strongly believe that people should be involved in things that affect them and they are best judges about what they need to help them to be as healthy as possible.

My aim is to promote equality, diversity and human rights, were patients matters. The Health and Social Care Act 2012 put patients at the Center of Care.

Evidence by JoCo Learning and Development

1. **What is the current 'state of play' of dementia and music?**

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

One of the main strands of activity in dementia care is the use of live music delivered by independent musicians/singers. They are regarded as 'light entertainment' for residents and perceived to be a value for money way to incorporate music in care homes.

Our main activity in the field is working with frontline care staff to develop an understanding of the benefits of personalised music in dementia care. This is done using a tool called "Soundtrack to My Life" (STML) together with a learning programme. STML is a little book designed to help draw together the pieces of music that are significant to the person with dementia. It is unique in that it is not just a list of 'favourite tunes' but allows you to record accompanying life stories. It enables personalised music playlists to be made and give their care givers insight into the individuals' music memories so that you can use music in a therapeutic way. STML is an evidence based, person approach that promotes the use of personalised music as part of day to day care.

STML is about changing culture in dementia care practice where music is regarded as much more than a 'nice extra' and rather is prioritised as a useful adjunct to care best practice.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

STML is funded by care homes themselves. The programme fee is inclusive of all learning materials, STML books, training and support over the three months.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

Providing music to people with dementia has been proven to be therapeutic and beneficial. However, music has a greater role to play than being light entertainment. The delivery of music in care is also not the reserve of music therapists and professional musicians and can support the achievement of several outcomes if it is delivered using person centred principles. The STML programme focuses on these principles and as a result can produce the following measurable outcomes:

1. Delivering personalised music to individuals with dementia as part of their day to day person centred care
2. Confidence building amongst care staff and family to deliver personalised music to people with dementia

3. Promoting understanding of benefits of personalised music amongst care team and relatives
4. Providing a music based tool for life story work
5. Increasing positive regard for people with dementia and understanding of dementia
6. Improving resilience and ability to tolerate and manage challenging behaviour without resorting to antipsychotic drugs. Music as an available alternative to antipsychotic drugs.
7. Reduction in challenging behaviour and the perception of challenging behaviour
8. Frontline staff enjoying their work more
9. Sustainable team culture change from task-focussed to person centred
10. Team building experience

A combination of qualitative and quantitative tools are used to measure these outcomes and these form part of our regular programme evaluations. Some of our evaluations have been undertaken with support from the Institute of Mental Health at the University of Nottingham.

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

Unit cost for our programme delivery is £1,750 for 12 participants and 12 people with dementia receiving personalised music. This works out to £72.00 for 3 sessions or £24 per session.
This is a low cost when mapped against programme outcomes:

1. Delivering personalised music to individuals with dementia as part of their day to day person centred care
2. Confidence building amongst care staff and family to deliver personalised music to people with dementia
3. Promoting understanding of benefits of personalised music amongst care team and relatives
4. Providing a music based tool for life story work
5. Increasing positive regard for people with dementia and understanding of dementia
6. Improving resilience and ability to tolerate and manage challenging behaviour without resorting to antipsychotic drugs. Music as available alternative to antipsychotic drugs.
7. Reduction in challenging behaviour and the perception of challenging behaviour
8. Frontline staff enjoying their work more
9. Sustainable team culture change from task-focussed to person centred
10. Team building experience

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

Barriers to uptake of the STML programme are as follows:

1. Care providers lack of funding for training and development.
2. Lack of awareness and understanding of the benefits of music for people living with dementia
3. Lack of awareness of the benefits of music as a person-centred tool
4. Lack of marketing skills and resources as a provider of a music-based intervention

5. Health and social care roles operating in silos. The lack of integrated care and support means that access to music is limited. Multi-discipline professionals operate separately to meet the needs of the same individuals. This reduces the chance of musicians (and other artists accessing would be ‘commissioners’ of care and support.

A few large organisations have a large monopoly on music-based intervention provision. They have a monopoly on funding and influence on policy, research and trends. This level of influence marginalises and puts financial pressure on small groups, organisations and individuals who are providing music-based interventions. There are many small providers who offer well received music-based interventions in community, social care and health care settings who do not get recognition, promotion or evaluation support. The real losers are people with dementia and their families who cry out for creative and therapeutic resources and then spend months and years on a waiting list for services because the few large monopolies don’t even have capacity to meet demand. In the mean-time small groups, organisations and individuals who are providing music-based interventions work the periphery, under-funded, under-valued and under-utilised.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words**

In Nottingham, we are founding member of a ‘Music in Dementia’ network for professional musicians, healthcare professionals, people with dementia and their carers. It is now a University of Nottingham managed innovation group. Some of its aims are to raise awareness of music-based interventions in dementia.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

1. Devolving power and influence in the dementia space. There needs to be fair exposure of the full range of music-based interventions available to people. People need to have real choice about what would suit their needs. People with dementia need to know what is available locally. The public need to be aware that there are small
2. CCG and Adult social care support for music-based interventions
3. Collective promotion of music-based interventions by the full range of music practioners
4. Funding for evidence based music-based interventions to be used in social and health care
5. Increasing scope in health and social care training to include music in care and other arts. This should be an area that activity coordinators and frontline care staff should be able to get involved and develop interest, understanding and competence.
6. Better integration of services
7. Raising dementia awareness amongst community musicians

2.3 Where do we still need to build evidence? **[Max. 250 words]**

1. Music-based activities are a useful tool in the person-centred management of challenging behaviour
2. Personalised music-based activities delivered by frontline care staff have benefits

- benefits to people with dementia
- benefits to dementia workforce
- reduction of biomedical approach
- reduction in malignant social psychology in care settings

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Aligning music intervention with day to day care and support of people with dementia is the main aim of the STML programme. As a team with experience in music, healthcare and social care provision we have long recognised that music is not just the remit of professional therapists and musicians. The work of music therapists is vital and has specific therapeutic aims.
The involvement of frontline staff in delivery of music-based interventions is critical to continuity of person centred care that is responsive to the psychosocial needs of people with dementia. One off sessions and events are often not enough to meet specific and ongoing needs such as emotional distress, restlessness, agitation or insomnia.
The development of frontline staff music facilitation skills is a useful adjunct to the rest of work in the dementia space. There is an absence of robust learning opportunities in healthcare and social care is a need we aim to address through our programme. We aim to align music interventions with day to day care and support delivery.

2.9 Who should be taking this agenda forwards? **[Max. 250 words]**

2.10 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

2.11 What should our one, clear message be? **[Max. <u>100</u> words]**

2.12 Do you have any final comments? **[Max. <u>100</u> words]**

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. <u>50</u> words]**

I’ve been a nurse for 18 years with 10 years in workforce development. With a passion for improving quality of life in dementia I developed the STML learning programme. I enjoy developing resources that nurture music and creative arts as a competency in collaborative, person-centred care.

Evidence by John McHugh, Music in Mind

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

Music In Mind is currently touring the 'Hidden Voice' multimedia performance piece with musicians from the Royal Liverpool Philharmonic Orchestra. The piece 'gives a voice' to those living with the condition and their carers.

The aim of the work is twofold:
- To 'give a voice' to people living with dementia including care workers and family members.
- To use the piece as a tool for raising public awareness.

The piece uses the melodies of speech to form the music and in doing so highlight the emotional content in the words. We have found that it is highly successful in communicating the individual stories and in stimulating responses from the audience. This has led onto discussion forums at some of the events including Edinburgh University with Professor Ian Deary and Dr Katie Overy.

We have found that the audience engagement in discussions of this nature to be extremely high with a deep interest in exploring the condition, the research and the current 'state of play'. Hidden Voice will form part of the NHS Alliance Action Summit conference on 6th December. Music In Mind will also be running a 5 week 'Schools and Communities' project in partnership with The Everyman theatre, Liverpool. This is a city-wide initiative involving 6 schools, the RLPO and The Everyman to explore the themes within the Hidden Voice project. The project will culminate in a public performance at The Everyman Theatre on 6th November.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

The current 'Hidden Voice' project is currently being funded by private donors. We have been able to use the funding to invite other partners to participate in the events such as the Alzheimer's Society in the form of presentations, discussions and market stalls. The recent collaboration with Edinburgh University and The Luminate Festival received support from both the university and the Luminate Festival in the form of presenters, publicity and organising of the post event question and answer forum.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

We are trying to take the Hidden Voice work to different parts of the UK including Liverpool, Leeds, Edinburgh, the North East and London.

1.4 What should we consider to be ‘best practice’ in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

1.5 Is it possible to establish an average ‘unit’ costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

At Music In Mind we are able to establish a unit cost for a Hidden Voice event. This takes the form of a standard performance event with extras such as workshops, questions and answer forums, schools and colleges engagement.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

We have found there are three barriers:

- Public awareness of the activities
- Lack of partnership investment
- Funding

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

I think there is an opportunity for establishing standardised practice in regard to training and resources. I also believe there needs to be more of the ‘patient and carer voice’.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

The arts can play a vital role in raising awareness amongst organisations, practitioners and the general public. The Hidden Voice project aims to do that through high profile public performance to inspire, stimulate and educate.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

The Arts Council need to make it one of their priorities. Leading cultural organisations including theatres, orchestras and galleries need to have active representation with a formalised commitment to a unified approach.

2.7 What should our one, clear message be? **[Max. 100 words]**

Music has a positive effect on brain functioning.

2.8 Do you have any final comments? **[Max. 100 words]**

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. 50 words]**

John McHugh is a composer and educator. He is the Artistic Director of 'Music in Mind' a charity to promote the health benefits of music and the arts.

Evidence by Professor Justine Schneider, University of Nottingham

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

My concern is the dearth of professional Music Therapy for people with dementia. This led me to propose a survey to BAMT. This closed at the end of September and I have recently analysed the data. There are 900 music therapists in the UK and about 250 work with people with dementia. Two thirds of this group (N=142) responded to our survey. Most had been qualified for five years or less; this is a predominantly young profession.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

Health and social care providers (statutory) employ about 60% of music therapists working in dementia. About 13% are in private practice (self-employed) while the rest work for private or voluntary sector employers.

Music Therapists in dementia work on average 20 hours per week. Most (61%) work in hospital or residential settings.

- Music Therapists derive huge satisfaction from working with people with dementia, despite finding this tough when (for example) their clinical expertise is not recognised.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

Weekly availability of Music Therapy is about half a minute per person with dementia. Only a minority of people with dementia have regular access to music therapy. This is tiny in relation to the needs of hundreds of thousands of people with a diagnosis who could benefit from access to Music Therapy for emotional and psychological distress associated with dementia.

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

Randomised controlled trials have been completed and more could be undertaken, including cost-effectiveness studies of community-based Music Therapy. The existing evidence base is good by comparison with other psychosocial interventions.

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

Self-employed music therapists are paid £50 per hour. They have a postgraduate clinical qualification (MA) and they are also professionally-qualified in at least one instrument with a degree in music or equivalent.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

Lack of awareness of the distinctive contribution that Music Therapy can make to dementia care. This is true for health and social care as well as for the general public. Even if awareness were greater, however, the number of qualified music therapists is inadequate to meet the needs of people with dementia.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

Music therapists could systematically share their skills with other professionals, family carers and volunteers.
Music Therapy deserves greater recognition and funding. Workforce planning is indicated by the health care Professions Council. There should also be training and development to equip more music therapists to work in dementia.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

Audio-visual material has power to persuade.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

Costs of Music Therapy by comparison with other community interventions and none. There is potential for community-based Music Therapy to delay admissions to institutional care – this is an important area for research.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Pending a cure, music interventions including Music Therapy have high acceptability and low cost. Even in relation to other psychosocial interventions (art, dance, poetry) music is the most popular activity at the memory café where I volunteer.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

NICE – for Music Therapy,
The HTA strand of NIHR to evaluate it fully.

The HCPC to develop the Music Therapy workforce
NHS England to fund more music in dementia

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

Funding aside, the main barrier to greater availability of Music Therapy is lack of awareness, amongst professionals and the public alike, of the benefits it can bring to people with dementia – especially those whom no other intervention can help.

2.7 What should our one, clear message be? **[Max. 100 words]**

People with dementia and their carers can benefit from Music Therapy at all stages of the disorder, yet relatively few have access to the skills of a music therapist. This is an area where rapid growth is urgently needed.

2.8 Do you have any final comments? **[Max. 100 words]**

I am not a music therapist. I have undertaken this work because I am convinced by the evidence base that this is an undervalued and underdeveloped field.

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. 50 words]**

I have extensive experience in many aspects of applied health research using a wide range of methodologies and approaches. This includes mental health service evaluation, carers, care homes, costs and supported employment. I have published over 100 peer-reviewed papers. My current work focuses primarily on dementia and staff development, and I work with artists to disseminate research findings.

Evidence by KMBC

1. **What is the current 'state of play' of dementia and music?**

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

Within Knowsley's in-house Older Peoples day services there are regular music related activities and reminiscence activities that focus on music and songs that service users had grown up listening to. In addition, the service arranges for singers and artists to come into the centre either as a one-off event or as part of a longer-term project. The service has recently received a donation of old broken instruments which have been upcycled by the service users and have now been displayed as an art installation within the day centre.
The Alzheimer's Society delivers 'singing for the brain' in Knowsley which is popular with residents who use this service.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

Activity delivered through day provision and nursing and residential care in Knowsley is funded by the Council's Adult Social Care budget. Knowsley's Older Peoples day service has also been allocated a separate 'person needs of service user 'budget to pay for external activities and the service on occasion does apply for external funding grants.
The Alzheimer's Society is not commissioned by the council and is therefore responsible for funding their own 'singing for the brain' activities.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

N/A

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

We do not currently have any KPIs on music activities and dementia so are unable to comment on the best way in which to measure the outcomes, however information on individual effects/case studies with service users are recorded. This helps to evidence those service users who have benefited from music related activities. For example, as part of the upcycling project one service user remembered that he had played the trombone as a child and within in a few weeks was back playing the instrument.

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

For day provision in Knowsley unit costs for specific activities are currently not separated; instead a daily unit cost for the service as a whole is used. When external music practitioners are commissioned they are typically paid between £40 and £45 per hour.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

In Knowsley, the identified barriers to take-up of these activities include:

- People being unaware of these types of activities
- Difficulties in actually getting those who could potentially benefit from the activities to attend
- The label/perception of activities specifically for dementia can put people off attending.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

We do not currently look at best practice specially in relation to musical activities for dementia.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

- Better promotion of activities
- Expand target audience in order to be more preventative e.g. appeal to ‘younger’ older people (55+)
- Make it less stigmatising
- Make information for carers clearer and more accessible

2.3 Where do we still need to build evidence? **[Max. 250 words]**

N/A

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Music interventions could be better aligned to the following:

- Respite
- Community assets
- Care homes
- Extra care

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

Too vague – strategic or operational?

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

Those within wider partnerships, such as:

- Housing providers/extra care providers

- Health partners
- Carers
- ADASS
- Third sector/charities
- Community groups

2.7 What should our one, clear message be? **[Max. 100 words]**

To emphasise the evidence of how music based activities help to improve/maintain quality of life for people who have dementia.

2.8 Do you have any final comments? **[Max. 100 words**

N/A

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. 50 words]**

Anna McDougall, Policy Officer for the Policy and Research team, Knowsley Council.

Evidence by Live Music Now

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

Live Music Now is a 40-year-old charity operating throughout the United Kingdom. We train professional musicians to deliver high quality live music activities for people who would not otherwise access them; and we then employ them to provide music for care homes, hospitals, special schools and more. At any one time, we have around 350 early-career professional musicians working with us, from a diversity of backgrounds and genres; and we deliver around 3,500 music workshops each year. Most of our sessions involve active participation in music making, as well as support and encouragement for staff to continue using music after we have left.

A large proportion of our work is with older people; in adult social care, older people living independently in the community, as well as hospitals including specialist dementia care units. According to Alzheimer's Society around 70% of the people who live in residential care homes are living with dementia or have severe memory problems (PWD), and this figure is going up every year. Although we are not able to record exactly the number of PWD we reach, it is clear from this that there are very high numbers accessing our work every year.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

We are funded from a range of sources including Arts Council England, Arts Council Wales, Creative Scotland, the Baring Foundation, The Libor Fund, The Rayne Foundation, Paul Hamlyn Foundation, the Pure Land Foundation, and a range of individual trusts and foundations; as well as contributions made by individual care homes and providers and individual gifts and donations. Broadly, we find that project funding is available to us, but that support for our core running costs is very hard to find. Raising these costs diverts much of our senior staff from developing our work, which is very frustrating.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

Our aim is to provide a consistent service throughout the UK. Variances depend largely on the availability of local and regional funds, but all areas are forecasting increases this year.

During the last financial year (2016-17), we delivered a total of 3,467 sessions, which is a 22% increase on the previous year.

These involved a total of 7,434 individual musician performance opportunities. These were delivered by musicians as soloists, duos, trios and quartets (and one quintet) from a wide range of different musical genres, including Western Classical, jazz, world, folk and rock.

Of the 3,467 sessions, 1,272 (37%) were delivered for older people, and others within our 'wellbeing' work (including people in care homes and in hospital wards); 1,817 (52%) were for children and young people with special educational needs and disabilities; 224 (7%) for the general public; and there were a further 100 (3%) events in more exploratory settings.

This year, we are forecasting delivering 3,518 sessions, as follows.
SE England: 450
NE England: 600
NW England: 820
SW England: 330
Northern Ireland: 213
Wales: 475
Scotland: 630
TOTAL: 3,518

1.4 What should we consider to be ‘best practice’ in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

LMN is the UK’s leading organisation that trains and supports musicians to work in such settings, and we take the measurement of the outcomes of our work very seriously. It is vital to us that we understand the difference our work makes to our participants and can relate that to musicians practice, so that we can focus how we develop professional musicians effectively, and share our findings with the wider sector.
It was with all this in mind that we created a sector-wide initiative called “A Choir in Every Care Home”, drawing together 35 national organisations, including the CQC and Care England, to examine the published evidence base about music and dementia, gathering examples of good practice from care homes throughout the UK, and creating new tools and inspiration for care home leaders and workers. It is all published at www.achoirineverycarehome.co.uk

We worked in partnership with academic institutions in doing this, who bring evaluation and research expertise. This includes the Sidney De Haan Centre at Canterbury Christchurch University and with the Centre for Art as Wellbeing at the University of Winchester, with whom we have worked on developing evaluation protocols for both “A Choir In Every Care Home” project, and the recent Arts Council England funded residency project New Age Music

Our protocols have been based on the Public health England Arts Evaluation Framework. We have been adapting and using validated and existing measurements and tools such as the arts observation tool developed by Chelsea & Westminster hospital and the Royal College of Music, and the ONS for well-being indicators. On the former project the Evaluation protocol was developed in collaboration with the provider partners taking part, MHA (Methodist Homes), Bupa UK and the Orders of St John Care Trust, through co-creative workshops and processes to identify outcomes, indicators and tools that we all agreed on.
From an ethical perspective, there are two elements that we consider to be essential for any project in this sector, involving professional musicians: (1) They must be trained and supported appropriately; (2) They must be paid a fair professional fee, in line with guidance from the Musicians Union and ISM.

1.5 Is it possible to establish an average ‘unit’ costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

As mentioned above, we pay fair professional fees to musicians who deliver this work, at a rate that is published and consistent with advice from the Musicians' Union and Incorporated Society of Musicians. It is not ethical for any organisation to pay less than this.
For a single session, we will pay each musician £76. For a half-day session, we will pay each musician £115.

Travel expenses are in addition to this. We have musicians throughout the UK, so an average of £40 is usually enough.

We will employ two or three musicians to deliver each session.

Local LMN staff members will also spend time organising each event, in consultation with care home staff, which we estimate will take a total of 3 to 4 hours, which might cost us £50 in staff fees.

On that basis, the average unit cost of a single 60-minute session is approximately £280, or £378 for a half-day (though the costs are lower when fewer musicians are used).
If we involve 25 people in a single session, this would give us a cost per person of about £11.
This represents exceptional value for money when compared to the costs of clinical interventions, support and medications which can provide similar results. For example, the cost of counselling to support mental and emotional health can be £70 for a 30-minute session.
In addition, research has demonstrated that music projects such as ours can have a positive economic impact on care settings through a reduced need for antipsychotic medication and other expensive interventions and therapies, as well as improved staff morale and retention rates.

In order to improve the value of our services further, we have started to provide specific training and support for care workers to use music as part of their day to day activities, in between visits from LMN musicians.
Please note: the above figures do not take into account the wider organisation costs of training and support, auditions, management, marketing or office costs.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

Funding, is cited to us as a barrier by individual care homes. We ensure that all the musicians we work with are paid a professional rate, and of course there are management, administrative and overhead cost to providing our services, as well as costs of training and developing musicians, evaluating work, and disseminating the results.

However, we hear from some other settings we work with that the cost is not the main issue, as money can be raised, and a lot of what we are trying to do now is to develop the capacity and skills of the people that live and work in care settings, so that they get very good value through both receiving the high-quality music activities, but also the there is a legacy developed allowing the staff to continue with music as part of their ongoing care provision.

We think that actually the main barrier is probably attitudinal, i.e. that is to say that it is believed that music is merely entertainment, and a nice to have add-on, rather than an understanding that it can form a fundamental part of the way that person centred care provision can be delivered, and a central part of the carers toolkit, as well as a means of benefiting relationships and supporting communication within settings.
Further details about all these findings are published in the papers in our “A Choir in Every Care Home” initiative: www.achoirineverycarehome.co.uk

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

A commitment to fair pay for professional musicians working in this sector, and appropriate levels of both support and training for them.
It is vital that the work is delivered with the sector, not done to people who live and work there. There are number of ways that this can be achieved

- Working closely with adult social care providers, health providers and umbrella organisations and regulators, such as PHE, RSPH, Care England, National Care Forum, NICE, CQC, and Napa to align with the strategic priorities, work at SLT level a, get buy in and support, and work with them on driving up quality of care, the link between ASC and the wider community and the focus on persons centred care provision.
- Training for musicians who work in settings where people are living with dementia, so they can understand the challenges, and possibilities this offers, and adapt and apply practice accordingly.
- Providing training for staff and carers in ASC to develop their ability and capacity to use music as part of their care tool kit.
- Designing programs of delivery, in a co-creative and collaborative manner with the providers, their staff/carers and service users.
- Offering PWD the opportunity to take part in music as active participants, Exploring the creativity, discovering new skills and rediscovering old skills, and developing meaningful creative experiences and outputs. www.vimeo.com/224186253
- However it is equally important to ensure that PWD get access to listening to high-quality music as audiences and can choose the level on which they engage, both in and out of performance settings.
- Exploring the potential of music making as a means of communication, and engagement with the world, offering PWD new ways of living full and meaningful lives, at the same time as their cognitive function is diminishing, and their ability to communicate speech and spoken language in reduced.
- Further there is huge lack of understanding and fear and prejudice in the wider population, albeit that we all will be or are being, affected by dementia at some point in our lives. Music has huge potential to support the understanding and acceptance of PWD with other people, this can be done through the sharing of creative outputs from projects working with people

living with dementia, in public performances, online and in recordings, as well as running activities that involve people living with dementia and those who are not.
- Ensuring that there is rigorous and effect appropriate monitoring evaluation of impacts of the work.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

See above. 2.1 which has points relevant to this
Developing the right kind of robust evidence.
Peer to peer advocacy with ASC and Health sectors to bring on board those that are not convinced- see films on LMN A Choir in Every Care Home site.
Strategic joined up funding to target and grow good practice.

2.3 Where do we still need to build evidence? [Max. 250 words]

- Robust evidence that supports link between music and cognitive, psychological and potentially physical benefits for PWD.
- Evidence that very good value intervention in comparison to drug use and that cost, human interaction and relationship benefits are very high

Recognition and acceptance of the types of evidence that will be developed taking into account that the dynamics of music as an intervention and how that make it difficult to build a research program that can be judged by the same standards of a RCT drug trial and that valid evidence is also in the stories and narratives and experiences that come from the musicians, staff, carers families and PWD taking part.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? [Max. 250 words]

Closer working and partnerships between the ASC and health sector providers and the organisations offering the music services.
Joint training for arts and health practitioners - so that learning and professional development goes in both directions.
Increase in status of music professionals, an understanding that musicians and the organisations they work with are professionals and should be dealt with on same level playing field as the academic and health professionals. They all bring divergent but complementary expertise, knowledge, skills and experience and working together will achieve something they would not do in isolation.
The music and music provider organisations are not just the ‘icing on the cake’.

2.5 Who should be taking this agenda forwards? [Max. 250 words]

See above 2.4, 2.1 LMN is seeking to lead this work on behalf of the sector, and is keen to continue to lead this work both nationally and internationally.

2.6 Who needs to be influenced and brought on board, to further this agenda? [Max. 250 words]

Health Commissioners, ASC providers, CCG, and NHS trusts at high level, Govt. Health policy makers.

2.7 What should our one, clear message be? [Max. 100 words]

For people living with dementia, live music can be so much more than simply ‘entertainment’ and can significantly improve the quality of their lives. However, for it to be ethical and effective, musicians need to be appropriately trained and supported, with the latest research in mind, working in partnership with care workers. They should also be paid a fair professional fee for their work - which still represents excellent value for money for care homes, considering the wide range of beneficial impacts for both residents and care staff.

2.8 Do you have any final comments? [Max. 100 words]

3 Short biography

3.1 Short biography of yourself/your organisations **[Max. 50 words]**

Live Music Now (LMN) is a UK-wide charity, created by violinist Yehudi Menuhin in 1977. We deliver interactive music programmes for care homes and hospitals, and a range of community and healthcare settings and special schools. Our work has been endorsed by the Care Quality Commission, and we work in partnership with care sector organisations such as My Home Life, MHA, BUPA, the Alzheimer's Society and Care England, amongst others.

Our work is delivered by high-quality young musicians, who we train to deliver projects based on the latest medical, educational and healthcare research. They generally work within ensembles, rather than individually, and are drawn from a wide variety of genres, from classical to folk, jazz to world and pop. Each year, they deliver over 3,500 participatory performances and workshops, reaching over 130,000 people across the UK. In the past 40 years, more than 2.5 million people have benefited.

Working with partners such as the Royal Society of Medicine, the Sidney de Haan Research Centre and Winchester University, we have developed tools to ensure that older participants in our programmes experience measurable therapeutic, social and emotional benefits, particularly those living with dementia. Our project “A Choir in Every Care Home” has just been shortlisted for a prestigious Royal Society of Public Health Award, announced in October 2017.

Evidence by Manchester Camerata Orchestra

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by?

Music Therapy – These programmes are delivered by qualified music therapists. They include a range of activities that are aimed at improving predetermined therapeutic outcomes for people with dementia. They include active/passive music therapy or combined active/passive therapy, and are delivered either as individual or group therapy.

Preferred Listening – These programmes involve listening to personally significant music from the person with dementia's life history. For example: Playlist for Life, where personalised playlists are developed for people with dementia to listen to through iPods.

Improvisation and composition – These activities focus on the creation of new music supported by professional musicians. These activities provide opportunity for creative engagement. For example, Manchester Camerata's Music in Mind project, Music for Life (Wigmore Hall) and Scottish Opera (McCabe et al., 2015)

Reminiscence-based music – these initiatives focus on using music to stimulate reminiscence in people living with dementia and those who support them. These activities are often based around music that is significant for a particular age group, which can be listened to together or sung as a group.

References:

McCabe, L., Greasley-Adams, C., & Goodson, K. (2015). 'What I want to do is get half a dozen of them and go and see Simon Cowell': Reflecting on participation and outcomes for people with dementia taking part in a creative musical project. Dementia, 14(6), 734-750.
Dowlen, R., Keady, J., Milligan, C., Swarbrick, C., Ponsillo, N., Geddes, L., & Riley., B. (2017) The personal benefits of musicking for people living with dementia: a thematic synthesis of the qualitative literature. Arts & Health, doi: http://dx.doi.org/10.1080/17533015.2017.1370718.

1.2 How is this range of activity presently being funded?

- NHS Foundation Trusts and CCGs
- Public Health England
- Charitable Trusts & Foundations, including Baring Foundation and the Henry Smith Charity
- Arts Council England

1.3 Are there regional differences in provision, within the UK?

1.4 What should we consider to be best practice in the measurement of outcomes and impacts of these activities?

Directly involving people with dementia, and those supporting them, in design of evaluation and research programmes, as well as the collection of data.

Considering a wide range of research/evaluation methodologies to suit the project, and considering using new and innovative research methods to ensure progression in the field. Considering outcome measures that go beyond understanding the impacts of music as only ‘symptom reduction’ or cognitive enhancement, with more emphasis needed to be placed on outcomes understanding the personal benefits of music for the person with dementia (Dowlen et al., 2017).

Designing research that does not wholly rely on proxy accounts from caregivers. New research should seek to gain first-hand accounts from people living with dementia (where possible). In order for this to happen, careful consideration must be given to the fluctuating capacity of people with dementia and how this may affect their ability to take part. It must not be assumed that people with dementia cannot contribute to this evidence base, and research design must be flexible to ensure their maximum feasible participation.

1.5 Is it possible to establish an average ‘unit’ costs for different kinds of activity, and how can we map cost against outcome?

It would be challenging to establish an average ‘unit’ costs for different kinds of activity because pay scales for practitioners vary between organisations, which then influences the overall budget for the activity. Projects also take place over varying lengths of time because they are responding to the needs of the participants and the specific aims of the activity. One must also take a flexible approach to working with people living with dementia and be prepared to change the schedule to accommodate their needs.

If it was necessary to establish an average ‘unit’ cost for different kinds of activity, one would need to establish the average pay grade for a type of music professional (for example an orchestral musician, a music therapist, a composer) and establish an average cost per session or per day. This could then be multiplied by the number of sessions per days in a project.

With regards to mapping cost against outcome, it is important to note that a wealth of information would be lost if one focused only on cost outcomes when assessing the viability of an activity. Many organisations have attempted Social Return on Investment (SROI) studies to indicate how much money is being saved when a person takes part in a music intervention for a specific reason, for example to increase their mobility. A comparison can be drawn between the price of taking part in a music intervention versus a similar alternative which is known to improve a person’s mobility, for example attending a physiotherapy session. One can then assess the viability of the alternative activity compared to the music intervention.

However, this exercise is still very limited as it is imperative to find the closest ‘alternative’ activity to compare the new activity against, and there often isn’t an ideal alternative. It is acknowledged that studies which measure the cost of a range of outcomes in this way often produce extremely positive results, and are able to influence funders of the viability of the work.

1.6 What are the main barriers to more extensive uptake of these activities?

The uptake of activities varies largely depending on the setting in which the activity is taking place. In Greater Manchester for example, the amount of organisations delivering music projects for people with dementia will most likely never reach the amount of people living in care settings such as residential homes, nursing homes and hospitals. However, arts organisations sometimes struggle to reach people living at home in the community because often these people do not have carers who can take them to activities, or do not have the financial provision to pay for transport to get there. They also do not already access other activities and therefore do not appear on any records, meaning they are hard to find. Arts organisations must be prepared spend a lot of time talking to people in the local area to discover people who are most in need.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

An increase in the recognition of the benefits of music-making for people with dementia has meant an increase in available funding over the last two years, and therefore more activity taking place. This will most likely continue for at least the next two years, which could mean that organisations might be able to ensure that their activities are sustainable and improve the activity’s scale or reach.

The increase in research and evaluation studies is also helping organisations and individuals to understand how best to work with people with dementia, and to discover which approach suits all parties involved. With this increased profile also comes the opportunity for multidisciplinary collaboration. By adopting a multidisciplinary research perspective, we may begin to drive the research agenda forward rather than simply relying on traditional research methodologies which may not be suitable for researching a complex intervention such as music for people living with dementia.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music?

- The lack of available transport to take people with dementia to sessions could be addressed by Local Authorities creating provision for more transport schemes such as ‘Ring and Ride’, or by arts organisations allocating budgets for transport within their funding for activities.
- Short durations of projects, predominantly due to limited funding periods, is a challenge which must be addressed by all organisations working with people with dementia through music. They must advocate for and continue to prove the benefit of engaging people in longer projects and not settle for funding which is for an unsatisfactory duration.
- Arts organisations and organisations with expertise on dementia should continue to provide training so that the number of practitioners able to work with people with dementia can continue to increase.

- Access to music outside of formal music programmes is also an important consideration. It is important to ensure that music programmes are not just for 'entertainment purposes' but enable people with dementia to have a sense of agency and be creative in the musical space (Dowlen et al., 2017).

2.3 Where do we still need to build evidence?

There is still a long way to go in building a strong evidence base for the use of music for people living with dementia. There are a number of factors that need to be addressed in order to advance the field.

- The methodological quality of research studies needs to be improved (van der Steen et al., 2017). Poor research design and poor reporting of methods has led to a mixed evidence base which means it is difficult to draw any strong conclusions/recommendations for practice.
- There is a strong emphasis on outcome measures that focus only on 'behaviours that challenge' or cognition. In mixed-methods studies these outcome measures often show no changes over the course of an intervention, yet qualitative data demonstrates a wealth of benefits. The development of new, music specific outcome measures is needed in order to capture the true extent of the benefits of music for people living with dementia.
- The majority of research to date has relied on gathering information from caregivers, music therapists and care staff. This means the voices of people with dementia are significantly lacking in this research area. Only by understanding the lived experiences of people with dementia can we truly understand music's impacts (Dowlen et al., 2017)
- We need to consider areas that are under-researched. For example, the majority of research to date has focussed on care homes, with little consideration of people living with dementia living in the community. There is also a wealth of research into music therapy, but far less on programmes which explore the creation of new music through improvisation or composition

References:
van der Steen, J. T., van Soest-Poortvliet, M. C., van der Wouden, J. C., Bruinsma, M. S., Scholten, R. J., & Vink, A. C. (2017). Music-based therapeutic interventions for people with dementia. The Cochrane Library.

2.4 How can/should we align music interventions with other areas of work in the dementia space?

Arts organisations should be encouraged to collaborate with other art forms if it benefits the people with dementia taking part. The combination of music and drama can be extremely effective; for example, Manchester Camerata have created music theatre pieces with people with dementia in which they have written the lyrics and melodies of songs and staged scenes based on the theme. The participants, aged between 50 and 92, performed this piece in a variety of local community venues and also as part of a Manchester Camerata concert at the Bridgewater Hall. Manchester Camerata have also created pieces of artwork and responded to the images through composing new music. All human beings are full of creativity and the more art forms that can be utilised to harness this creativity the better, as long as it doesn't become overwhelming for the participant.

2.5 Who should be taking this agenda forwards?

- People with dementia and their support networks
- Arts organisations
- Politicians
- Charities
- Academics

2.6 Who needs to be influenced and brought on board, to further this agenda?

- Senior professionals with the NHS – there are NHS professionals working on the ground who believe in this work and would like to see it commissioned, but their senior managers still need persuading of its benefit. Some NHS professionals also feel that there are too many disjointed organisations working on multiple agendas with regards to arts and health, and they would appreciate it if organisations could advocate for their specific approach and choose a target audience to work with.
- Funding bodies – whilst money is readily available from funding bodies, they place limits on what is possible and don't allow for flexibility when working with vulnerable people – for example one must complete lengthy reporting forms in order to make small changes to projects.

2.7 What should our one, clear message be?

Music-making encourages people with dementia to express themselves during a period of their life where other forms of expression might not be possible. All elements of life revolve around self-expression, therefore making music allows for someone to maintain their sense of identity and make meaningful connections with other people – if only for a short period of time. The value of this possibility needs to be better understood by health care professionals, funders of music projects and the general public.

2.8 Do you have any final comments?

In understanding the benefits of music for people with dementia it is important to not rely wholly on outcomes that seek to understand only the impacts of music on 'symptoms of dementia' but rather seek to understand how engaging with music can enable people with dementia to live a meaningful and fulfilled life full of opportunities for creative engagement. The involvement of people with dementia and those who support them in the development and design of music programmes and research initiatives should help us to learn what outcomes are important.

3 Short biography

3.1 Short biography of yourself/your organisations [Max. 50 words]

Lucy Geddes MusB (Hons) DipABRSM leads on the Camerata in the Community programme for Manchester Camerata orchestra and has a passion to promote social change through music, working with people of all ages in a range of community settings. Lucy is also a pianist and clarinetist in the British Army Reserves.

Robyn Dowlen is an ESRC funded student based at the University of Manchester, whose CASE partner is Manchester Camerata. Robyn's research has followed Manchester Camerata's Music in Mind project and has used creative research methods in order to ensure the active participation of people with dementia in the research project.

Evidence by Mary Granville White

1. **What is the current 'state of play' of dementia and music?**

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

Activities :
Songs included in Reminiscence Sessions by trained Reminiscence Volunteer.
Church members visiting Care Homes provide Sing for Joy Groups.
Trained Volunteer providing gentle standing and seated exercise to music with songs.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

It is not funded in North Norfolk.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

Definitely. Particularly between urban and rural areas such as North Norfolk.

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

Need to access local trainers such as Excel 2000 and Leaders of groups to agree standards.
Need to collate and review present training with aim of sharing learning and experience.
Best Practice needs to include health and safety, respect and dignity, engagement and involvement of participants and the atmosphere of joy and enjoyment of individuals.

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

Why Not! Many of us have trained at our expense and volunteer.
Costs: Venue, training, travel, hourly rate to include preparation and equipment needed.
Outcomes: Group interactions, individual reactions E.g. singing along, sharing memories, laughter, behaviour, attendance.
Observation of and records for group and individual participants.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

Presently, activities are on an informal, voluntary basis. They are neither recognised or valued by statutory, but are by participants and volunteers. It is, as always more difficult to measure quality when quantity is king and we are measuring soft but important outcomes.

2. **In which direction should the field of dementia and music be moving?**

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

In combining music and song with reminiscence and exercise, I believe, we can more readily engage those more cynical and adverse to soft outcomes. Particularly true in this time of austerity.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

By volunteering, proving our worth and gaining trust. However, nationally we perhaps need to consider funding a campaign following producing evidence.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

Have we even started?

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Already discussed.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

Campaigners and Government.

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

Government at all levels. Carers. Providers. Funders.

2.7 What should our one, clear message be? **[Max. <u>100</u> words]**

It Works – The Benefits Are.

2.8 Do you have any final comments? **[Max. <u>100</u> words]**

My Contacts are: Mary Russell BA(hons) Dip Management DCR(T)
1 Orchard Close, Roughton, NR118SR
granvillewhite@btinternet.com 01263 761419
Go for it. Let me know if I can help. Please keep me in the loop.

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. <u>50</u> words]**

Retired NHS Manager in Cancer Services. Founder of Charity Wellbeing in North Norfolk. Member NHS Sounding Board Older People, Vice Chair Age Concern North Norfolk, Past Chair Health and Older Peoples Forums, Carers Champion. Chair “Nothing About Us Without Us” campaign giving people a voice in decisions, Facilitator in Excel 2000 and Reminiscence.

Evidence by MHA

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

The activity described here concerns the music therapy service at MHA, an award-winning charity providing care, accommodation and support services for older people throughout Britain. MHA has a strong emphasis on aiming to eliminate the isolation so often experienced by older people, particularly those with dementia, and strongly believes that music therapy can play a key role in improving residents' wellbeing and quality of life, especially for those at the later stage of dementia where very little else works to address agitation and anxiety.

MHA's Music Therapy Team has provided music therapy for people with moderate to severe dementia in its care homes since 2008. MHA employs 25 qualified therapists (equating to 12 FTEs) who deliver both group therapy and weekly 30-minute individual 1:1 sessions for residents with dementia who have severe difficulties in communication, behaviour or wellbeing.
MHA is one of the biggest employers of music therapists in the country. Our highly-trained Music Therapy team run sessions in 60 homes providing dementia care. In 2016, they helped more than 2,000 residents through 1:1 sessions and group music therapy.
1:1 sessions are tailored according to individual residents' clinical needs, aiming to reduce behavioural and psychological symptoms of dementia (BPSD) (e.g. agitation, anxiety, depression and apathy), maintain functioning and maximise levels of wellbeing.

Therapists work closely with the care team to identify those most in need, and to share effective music therapy techniques for use in day-to-day care.

In addition to the music therapy service, care homes also receive visits from local musicians and entertainers.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

MHA's music therapy service costs around £500,000 per year.
It costs us approximately £43,000 per year to employ a full time Music Therapist. It costs approximately £30 per 1:1 session and £60 for a group session. A 12-week programme of 1:1 music therapy costs £360.

We offer music therapy for free to our residents with dementia which we are able to do as we fund raise to cover the costs of this, via direct fundraising appeals, approaching grant giving trusts and running fundraising events.

Last year, we provided 1:1 music therapy to 714 individual residents. However, we do have a total of 1,884 places for people with dementia in our care settings so we still have some way to go before providing as much music therapy as we would like. We call this the music therapy gap and to be able to fill it, we need to fundraise an additional £1.5m.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

MHA’s team of music therapists have each completed a Masters qualification in Music Therapy, and meet the HCPC (Health Care Professions Council) standards and proficiencies. The Masters training and continuing professional development required by the HCPC give music therapists the ability to understand the various biopsychosocial factors that can impact on a person’s long-term quality of life and care. Therefore, consistency is ensured for the quality of music therapy sessions delivered in the 60 care homes which provide a dementia care service.

However, the number of 1:1 and groups sessions and scheduling could vary in these care homes due to the residents’ needs. Some home might receive more 1:1 than group sessions if more residents are in need of tailored 1:1 support.

We should also note that our 60 care homes providing specialist dementia care are distributed across the UK. We have already described our music therapy gap in our care homes – our ultimate ambition is that music therapy is much more widely available across more care homes and within local communities to help many more people with dementia.

1.4 What should we consider to be ‘best practice’ in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

A major challenge in dementia care is the presence of Behavioural and Psychological Symptoms of Dementia (BPSD), such as agitation, anxiety, depression and apathy. In nursing homes, agitation is the most persistent and prevalent symptom although depression and anxiety decrease over time whilst apathy tends to increase (Wetzels et al., 2010). The symptoms are associated with faster progression of the disease if untreated (Rabins et al. 2013).

Review studies of psychosocial interventions (eg. Vernooij-Dassen et al., 2010; Lawrence et al., 2012; Livingston et al., 2014) suggest that the measurement of psychosocial interventions (including music therapy) should consider individual needs and how the activity improves quality of life as well as relieves Behavioural and Psychological Symptoms of Dementia (BPSD) on a long-term basis.

Therefore, our music therapy service seeks to reduce the anxiety and agitation which dementia can cause, as well as help staff understand possible causes of these symptoms. It also seeks to improve the overall wellbeing and quality life of residents with dementia and help retain some degree of communication for as long as possible.

A key part of our music therapy service is the integration with the care giving teams in the home, where insights from the therapy sessions are shared with the care team to improve overall care giving. This increases the benefits and impact of the therapy, by improving the overall wellbeing and sense of community of the home. Relatives also benefit from the music therapy provision, by seeing the impact on their loved ones.

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

MHA's music therapy service costs around £500,000 per year.
It costs us approximately £43,000 per year to employ a full time Music Therapist. It costs approximately £30 per 1:1 session and £60 for a group session. A 12-week programme of 1:1 music therapy costs £360.

The cost effectiveness of music therapy within the field of dementia can be evaluated using the method employed by Livingston et al (2014). The effect of an intervention on symptoms of dementia can be examined using an outcome measure such as the Cohen-Mansfield Agitation Inventory (CMAI) or Neuropsychiatric Inventory (NPI). Reductions in the CMAI scores can be mapped against the cost of each individual session, to give an incremental cost per unit reduction in CMAI score. These incremental costs per unit reduction values can then be compared across different interventions or activities.

We are currently exploring how best to capture consistent outcome data across our music therapy service in order to build our evidence of cost vs outcome. We do have a large amount of qualitative feedback about the benefits of our service for individuals and their loved ones and the overall community of the home.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

One of the key barriers is public understanding of music and music therapy activities. Both are important interventions, but it is vital the distinction between them is properly understood. There are also issues of access to music therapy and the costs of it.

Music activities are generally conducted by other professionals rather than music therapists. Aims may overlap with those of a music therapy session, e.g. reducing isolation through social interaction. However, the activities tend to be delivered on a group basis whilst music therapy, delivered by music therapists, emphasises the use of clinical underpinnings to address and fulfil individually tailored needs.

Recent research suggests there can be maladaptive and adaptive forms of regulating one's emotion through music, depending upon the listener's unique personality and neurological makeup. Carlson et al (2015) highlighted that for some people, listening to music that reflects their mood when they are feeling sad or angry can have an adverse effect, causing them to feel even sadder or angrier. For others, the same experience might cathartically help them to find solace, while for others still, being 'diverted' from their inner state by music of a contrasting mood can help by distracting them from their current thoughts.

It is vital that music be used with extreme sensitivity and understanding of its potential adverse effects. With their clinical training, music therapists are experts in understanding how particular music can be used without causing harm, depending on the individual's personality. This information can then be shared as appropriate.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

We feel the three main emerging areas of opportunity in the field of dementia and music are:
- Technology
- Music therapists
- Musical Interaction with care staff and sharing insight

Technology - there are now a number of wearable devices available that can be easily worn during music activities and music therapy, which measure variables such as heart rate and skin conductance. Incorporating these into sessions can allow the collection of data looking more closely at the physiological effects of music therapy on persons with dementia.
There are also a range of individual user benefits from technology, such as tailored playlists, specialist digital radio programmes tailored to individuals and other exciting ideas.

Music Therapists – they have a key role, especially with their skills in using music to help understand the cognitive functions of persons with dementia (eg. memory, cognitive abilities, sensorimotor skills). Their in-depth understanding can help to highlight residents' remaining functions and consequently, how music can be used to maximise and exercise these remaining functions within day to day life and care.

Musical interaction with care staff is another emerging area. As Hsu et al. (2015) highlighted in their feasibility study, beneficial effects of music therapy on psychological wellbeing for persons with dementia can feed into the wider care setup through sharing information with care home staff and encouraging carers to use music in their day-to-day work and in their interactions with residents with dementia. Sharing wider insight from therapy sessions also helps to improve overall care giving.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

1. Using social media and media campaigns to raise public awareness of the benefits of music and music therapy for people with dementia.
2. Commissioning and funding more clinical trials aimed at highlighting the effectiveness of music therapy in this client group. A larger evidence base for its efficacy would show potential sources of funding the need for this intervention.

3. Recognise that music therapy is a valid treatment of people with dementia and explore ways to improve access to this during the course of the condition – for example, thinking about how to build it into prescription options.
4. Encourage people to curate their musical memories and favourite music in the early stages of dementia, alongside a sharing of life history, to help improve the use of music and music therapy as the conditions progresses.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

Both music and music therapy need research which demonstrates how the interventions work in various settings such as community, intermediate/assessment and long-term care.
However, the interventions would need to demonstrate how they relate to the major factors that impact on the quality of care and life, such as mood, depression, cognition, behavioural disturbances and psychotropic medications (Beerens et al., 2013; 2014).

Health professionals, such as GPs and others, need to be aware of the benefits of music for people with dementia and to understand that music therapy is a valid and effective treatment for many people with dementia. The type of evidence that will convince them needs to be built. Public awareness and opinion also needs to be convinced by evidence in order to increase the number of people with dementia who are able to benefit from music and music therapy.

And finally, local commissioners of health and social care services also need evidence to convince them that commissioning and funding music and music therapy is effective and value for money.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Thinking about care home settings, we propose embedding music in the day-to- day life of individuals living with dementia, for example within interactions with carers or relatives. The use of music within a structured activity or entertainment session often requires resources, time and money that are not easily available. Embedding music within day to day interactions however, costs no money or planning, and can have a positive impact on individuals' wellbeing, providing a nonverbal means of communication, and potential source of stimulation for the retrieval of autobiographical memories. Our aspiration is that all care homes are able to use music and music therapy to benefit people with dementia. We would also like to see wider community access to a broad range of music interventions so as many people as possible with dementia are able to benefit.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

We propose that those on the frontline such as musicians, music therapists, or professionals who deliver music activities should collectively take this agenda forwards.

Care providers also have a key role in this, as do local commissioners of services, both local authority and Clinical Commissioning Groups, GPs and other health professionals, as well as the Department of Health and the community and voluntary sector.

2.6 Who needs to be influenced and brought on board, to further this agenda? [Max. 250 words]

We propose that the government should also be engaged in this campaign, in order to raise awareness of the importance of music and music therapy and the distinctions between the two, to commit to supporting and funding the provision of these, and for policy makers to galvanise care providers and the CQC into viewing music as an essential part of the care of individuals with dementia. The public are also a key audience in terms of raising awareness of the benefits of music and music therapy in the treatment of dementia, as are local commissioners and health professionals.

2.7 What should our one, clear message be? **[Max. 100 words]**

Embedding music in day-to-day care enhances the quality of life for people with dementia. As part of this, Music Therapists provide an important treatment option for people with dementia. More people with dementia and their carers should be able to benefit from music and music therapy as part of the treatment options available.

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Who is MHA
MHA is an award-winning charity providing care, accommodation and support services for older people throughout Britain. We are one of the most well-respected care providers in the sector and amongst the largest charities in Britain, providing services to older people for almost 75 years.

Our aim is to eliminate isolation and loneliness among older people by connecting them in communities that care.

MHA delivers a range of high quality services to more than 17,800 individuals:
- 10,330 older people supported through 61 Live at Home services in the community.
- 2,820 older people living independently in 70 retirement living communities with flexible support and personalised care, with a further seven sites in development
- 4,680 older people living in 88 care homes - residential, nursing and specialist dementia care – with two more in development

Our services are provided thanks to 7,000 dedicated staff and enhanced by the commitment of 5,500 volunteers.

References

Beerens, H.C., Zwakhalen, S.M., Verbeek, H., Ruwaard, D. and Hamers, J.P., 2013. Factors associated with quality of life of people with dementia in long-term care facilities: a systematic review. International journal of nursing studies, 50(9), pp.1259-1270.

Beerens, H.C., Sutcliffe, C., Renom-Guiteras, A., Soto, M.E., Suhonen, R., Zabalegui, A., Bökberg, C., Saks, K., Hamers, J.P. and RightTimePlaceCare Consortium, 2014. Quality of life and quality of care for people with dementia receiving long term institutional care or professional home care: the European RightTimePlaceCare study. Journal of the American Medical Directors Association, 15(1), pp.54-61.

Carlson, E., Saarikallio, S., Toiviainen, P., Bogert, B., Kliuchko, M. and Brattico, E., 2015. Maladaptive and adaptive emotion regulation through music: a behavioral and neuroimaging study of males and females. Frontiers in human neuroscience, 9.

Hsu, M.H., Flowerdew, R., Parker, M., Fachner, J. and Odell-Miller, H., 2015. Individual music therapy for managing neuropsychiatric symptoms for people with dementia and their carers: a cluster randomised controlled feasibility study. BMC geriatrics, 15(1), p.84.

Lawrence, V., Fossey, J., Ballard, C., Moniz-Cook, E. and Murray, J., 2012. Improving quality of life for people with dementia in care homes: making psychosocial interventions work. The British Journal of Psychiatry, 201(5), pp.344-351.

Livingston, G., Kelly, L., Lewis-Holmes, E., Baio, G., Morris, S., Patel, N., Omar, R.Z., Katona, C. and Cooper, C., 2014. Non-pharmacological interventions for agitation in dementia: systematic review of randomised controlled trials. The British Journal of Psychiatry, 205(6), pp.436-442.

Rabins, P.V., Schwartz, S., Black, B.S., Corcoran, C., Fauth, E., Mielke, M., Christensen, J., Lyketsos, C. and Tschanz, J., 2013. Predictors of progression to severe Alzheimer‘s disease in an incidence sample. Alzheimer's & Dementia, 9(2), pp.204-207.

Vernooij-Dassen, M., Vasse, E., Zuidema, S., Cohen-Mansfield, J. and Moyle, W., 2010. Psychosocial interventions for dementia patients in long-term care. International Psychogeriatrics, 22(7), pp.1121-1128.

Wetzels, R.B., Zuidema, S.U., De Jonghe, J.F.M., Verhey, F.R.J. and Koopmans, R.T.C.M., 2010. Determinants of quality of life in nursing home residents with dementia. Dementia and geriatric cognitive disorders, 29(3), pp.189-197.

Evidence by MindSong

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

Mindsong – Music for Dementia, is a Gloucestershire-based charity that provides music therapy and meaningful music singing groups for people with dementia across the county. There are three core strands to our delivery: music therapy for people with dementia delivered by our team of 8 music therapists in care homes, day centres, hospitals and in people's private homes; singing groups facilitated by our team of 250+ trained volunteers in 37+ care homes across the county; and training for professional musicians to perform in the most appropriate and interactive way for people with dementia in care homes (training is delivered by our music therapists and other dementia specialists).

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

Mindsong fundraises in order to subsidise courses of music therapy for care homes and private individuals, and to provide its Meaningful Music Singing Groups. Sources of funding vary, from grants and trusts through to major philanthropic giving and individual giving. Mindsong is preparing for contracting via NHS Clinical Commissioning Group. Care homes contribute to a 1st course, paying full costs for ongoing delivery.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

As far as we are aware, yes there are differences in provision across the UK. We know of music therapists being funded by care home chains in London, but haven't heard of this happening elsewhere. We are not aware of any organisations other than Mindsong that specialise in music therapy specifically for people with dementia.

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

We would consider ongoing evaluation to be best practice in measuring effectiveness for both our clinical intervention (music therapy) and our singing groups. There doesn't seem to be a 'gold standard' tool to capture benefits but we have used Dementia Care Mapping to measure wellbeing and changes in behaviour. One of our music therapists has also developed her own observation rating scales to capture any changes in levels of engagement, wellbeing and relationships, and as a music therapy team we use these scales to back up evidence from our clinical notes / reports.

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

Domiciliary work (couples) = £112.50 per 2hrs of delivery (inclusive of travel) £56.25 pp Service offered FOC.
Care home (group work + some 1-2-1 delivery. Av attenders 10) = £137 per session (ranging from 2 – 3hrs) £13.70 pp Service offered for contribution of £600 (1st course) – subsequent courses charged at full cost + 5%.
Meaningful Music groups. Budgeted costs 2018 - 300 volunteers/40 care homes / fortnightly year round. Cost per home per session = £47 Service offered FOC (some donations received)

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

Funding is a major barrier. Care home providers need persuasion to offer music therapy as clinical intervention (often seen as an activity and activity budgets are small), but this is slowly changing with major chains and charities. Domiciliary work needs to be free at point of access, although some clients are able to contribute to continuing therapy. MM Singing Groups are offered free at the end of a course of music therapy as budgets are then exhausted and music would not continue.

Communicating clear information to the right people. Sometimes finding referrals can be challenging – we have developed a new service for our area where we aim to support people living with advanced dementia still being cared for at home, where their carer (often a relative) is at crisis point. We are working with the NHS on this project but even so, it is difficult to find these people who are most in need - who often can't access other services. Access to clear data on advanced dementia at home, via Dementia Register, GP surgeries, or NHS is difficult through lack of joined up reporting. This leaves us unable to fully assess potential client numbers.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

Music therapy has enormous potential in supporting the wellbeing for people with dementia across the varying stages, and especially in later stages. As we work with carers alongside people with dementia, we are also discovering that music therapy can help to increase carer resilience, which in turn can lead to fewer acute admissions for people with dementia. Our therapists work with carers to develop skills and resources to use music at other times of the day, supporting their caring roles and their own wellbeing, as well as that of the person they care for.
MM Singing Groups act as links between care homes and the local community, breaking down barriers. Volunteers act as regular visitors and build relationships through the provision of dementia sensitive music, empathy and companionship. There is evidence of the benefits for both volunteer and resident, and a proven model for sustainable delivery.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

Clear, consistent communication about interventions and activities to the right people!
We are currently working with community dementia nurses, mental health later life teams, the Alzheimer's Society and local carer organisations (Crossroads Central and East Gloucestershire) in order to reach the right people, to make them aware of the intervention we offer and the benefits that this can bring.

Good quality, robust clinical evidence and personal testimonies encourage both NHS professionals and care home managers to take up music therapy.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

There is a growing body of evidence supporting the use of both music therapy and singing groups for people with dementia. However, the quality of evidence needs to be strong and robust, and more clinical research of high quality is needed. There are a number of areas in which research could support further use of music in the context of dementia care, particularly looking at the links between language / communication and music; the effect on carers participating in music interventions/activities, and the role music (and in particular music therapy) can play to support people going through the trauma of accepting a diagnosis.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

At Mindsong, we believe all people with dementia should be able to access good quality music interventions / activities should they wish to. This view is also supported in the recent All-Party Parliamentary Report 'Creative Health: The Arts for Health and Wellbeing'. We would like to see music therapy being offered more widely across the UK to support people with dementia and their carers, in day centres, care homes, hospitals and private homes. As we work in care homes, we are encouraging staff to use music at other times of the day, and would like to see specific individual recommendations in care plans, so that music becomes an integral part of the person with dementia's care. Training for staff could be provided as part of the visiting music therapist's role. Music therapy could also be offered at point of diagnosis, and we would like to work more closely with GP surgeries in order to develop best practice for delivering the intervention in this context.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

A strong lead needs to come from parliamentary level, with clear recognition of the role music has to play in supporting creativity and wellbeing. Including the use of music in care plans could be recommended by NICE and regulatory bodies. Anyone working in dementia care should be an advocate for using music to support care and wellbeing, including musicians and music therapists who work in this context.

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

The Department of Work and Pensions regarding funding, key decision makers in the NHS, care home / day centre managers and providers, Alzheimer's Society and Age UK.

2.7 What should our one, clear message be? **[Max. 100 words]**

People with dementia need to be respected and valued; music has a crucial role to play in supporting their emotional and psychological wellbeing.

2.8 Do you have any final comments? **[Max. 100 words]**

We would be happy to be contacted by the reviewers for further information if necessary.
Maggie Grady – Director of Music Therapy maggie.grady@mindsong.org.uk
Karen Lawton – CEO admin@mindsong.org.uk

Evidence by Music and Memory

1. **What is the current 'state of play' of dementia and music?**

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

Live music activities delivered by volunteers, musicians, activities directors.
Live music therapy delivered by music therapists.
Personalised digital music delivered by nurses, volunteers, activities directors, occupational therapists, social workers, music therapists and family.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

The Music & Memory Program is funded by a combination of contributions from the care organisations receiving the Music & Memory Program, grants and donations from local businesses/ family members, Music & Memory corporate donors and the general public
The contribution from the care organisation will typically be paid from the activities department budget or the staff training budget.

In the US the majority of the funding comes from each individual state's Department of Health in response to a Federal initiative to reduce the use of antipsychotics in care organisations (https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/National-Partnership-to-Improve-Dementia-Care-in-Nursing-Homes.html). It is expected that in the UK similar government based funding will be needed to roll out the programs in a reasonable timescale.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

The benefits of personalised digital music are:
Reduction of antipsychotic medication use as evidenced by Thomas, Baier et al (2017, Brown University, Am. Journal of Geriatric Psychiatry)
Fewer falls and fights as evidenced by Vinoo et al (International Journal of Neurorehabilitation, 2017)
Reduction in Behavioral and Psychological Symptoms of Dementia as evidenced by Thomas, Baier et al (2017, Brown University, Am. Journal of Geriatric Psychiatry)
Greater quality of life for mild to moderate dementia (using Dementia Quality of Life instrument and the Adult Social Care Outcomes Toolkit)
Less depression (Cornell Scale for Depression in Dementia and the Geriatric Depression Scale),
More efficient personal care delivery and less resistance to care.
Reduction in caregiver stress as evidenced by Alzheimer's Society of Toronto using the Caregiver Distress Scale

Cost savings due to enhanced carer wellbeing, including reduced sick leave

1.5 Is it possible to establish an average ‘unit’ costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

It is possible to estimate the cost per person in a residential care setting by taking into account the number of residents per care organisation, the costs of the equipment and the music, training and hours needed to create and evaluate the playlists. The initial set up costs could be estimated to be between £200 - £250 per resident. The ongoing costs per resident are estimated to be £25 per year. These per resident costs are based on the Music & Memory business model that raises subsidies and grants so that the Music & Memory program cost is affordable for care homes.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

Barriers to uptake include low awareness of the availability and wide-ranging benefits of music interventions for dementia. The extensive use of music in healthcare is part of a slow-moving paradigm shift in dementia care - the shift from a recreation-centered viewpoint and a ‘one fits all’ care approach to an institution-wide intervention that enables the delivery of personalised music by all carers as a standard. The benefits of music in the care of older people with dementia are not well-communicated to the nurses, geriatricians, and psychologists of the future and continues to be under-represented in the training of these health care professionals.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

Intergenerational – large scale youth involvement facilitates relationships and sense of well-being while educating youth on dementia and attract them to care for older people.

Interoperability – playlists follow older people with cognitive and physical challenges as they transition between home, adult day programs, care homes, hospital, and hospice.

The increasing recognition that personalised care needs to be at the heart of caregiving for people with dementia. Individualised music listening and music therapy are excellent markers of personalised care and there is an opportunity that these markers can help shift care home culture towards a more general personalised care approach.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

Raise awareness of the benefits of personalised music (caregivers trained to deliver a program within typical time constraints of a care home, relatively low carer to person ratio, not dependent on booking 'outside' resource (e.g. therapist/musician), supports carers in building personal relationship and delivering personalised care).

Encourage widespread viewing of the documentary 'Alive Inside' and provide video training and guidance for nursing leadership and administrators. Include modules on the benefits of music for dementia in nursing school curricula and courses for psychologists, geriatricians and general practitioners.

Lobby for the installation of subsidies for implementing QOL interventions as has happened in the Netherlands (https://www.unece.org/fileadmin/DAM/pau/age/country_rpts/2017/NL_report.pdf) during a transitionary phase until personalised care and personalised music for dementia has become the norm.

Change the assessment requirements (the way care homes are assessed by the Care Quality Commission) to include a requirement on personalised care with an emphasis on music based interventions.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

Create cost effectiveness reports on music interventions (possibly making use of a Social Return on Investment Analysis)

Study the effect of music based interventions in home care settings to determine if this helps people with dementia maintain their well being and stay at home longer.

Replication in the UK of research on the Music & Memory program completed by Brown University (US) and University of Jena (Germany) looking at reduction in antipsychotic medication use and Behavorial and Psychological Symptoms of Dementia, as well as Qualilty of Life.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

(Personalised) music should become a normal part of daily care of people with dementia - both in their own home and when they move into a care organisation - thus penetrating all activities, therapies and care interventions. Personalised music should be used as a precedent to art and dance therapy, family visits, meals, in short: to all activities of daily living as a way to maximise impact with all engagement.

Using music for distraction, relaxation, better mood, activation and raising level of engagement will maximise the benefits of non-musical interventions and activities. It will prevent agitation and anxiety during activities of daily life. Volunteer organisations and dementia friendly initiatives should actively use personalised music as part of their services to accomplish effective client-centered support. Creating personalised playlists early on in the dementia process makes it possible for the music to travel with individuals through their care journey and provide relaxation and a sense of purpose, regardless of the stage of dementia a person is in.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

Taking this agenda forwards together with the parties approached by the ILC-UK for this report could be:
Those who have used the services described. In the case of Music & Memory this would be Care Home CEOs, Managers, Activities Coordinators who have implemented the Music & Memory Program, older people with dementia who have used the services and family and friends of older people who have taken part in the programs/services described.

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

We need strategic partners in government and other organisations who will disseminate and act on the reports recommendations. Strategic partners and organisations (in no specific order of priority) could include:
Nursing/care homes and their representative groups - those most interested and able to advance the causes of culture change and person-centered/direct care.
Those ultimately responsible for quality of life and quality of care systemwide.
Creators and advocates of non-pharmacological guidelines and antipsychotic medication reduction.
David Mayhew - the Dementia Envoy, Department of Health, Clinical Commissioning Groups.
Representatives for independent care services.
Care Quality Commission.
National Dementia groups campaigning for change, including: Alzheimer’s Society, Dementia UK, Age UK
The NHS and Commissioning Board.
Home Care organisations, Client councils, Family Caregiver alliance, institutional care organisations, hospitals.
Policy boards of the above organisations (where relevant).

2.7 What should our one, clear message be? **[Max. <u>100</u> words]**

For those with early and mid-stage dementia, music has the greatest ability to reach people and impact their quality of life. That impact is multiplied when creatively applied with other arts and carers. For the 40% of those with more advanced forms of the disease, music may be the only way to provide personally meaningful activity.

2.8 Do you have any final comments? **[Max. <u>100</u> words]**

Music & Memory is unusual in its ability to scale across health care systems. For the dementia care system to implement music so that it scales to meet the needs of all individuals in need, the system must be initiated so that every care professional experiences success. Once that starts to happen, and proper incentives and funding are in place, those benefits will be widely adopted.

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. 50 words]**

Music & Memory is a personalised music program for those struggling with Alzheimer's, dementia and other cognitive/physical challenges. Piloted and developed in the United States in 2006, expanded across North America and Europe. Currently over 4,000 accredited M&M health care facilities worldwide supported by a growing research/evidence base.

Evidence by Music in Hospitals and Care

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

1. The state of play is varied. There is a wealth of evidence that supports the benefits of music, especially live music, which appears to be beneficial to most populations, including final stage dementia. The benefits not only include improvements to general health and wellbeing, but some specific benefits including reducing feelings of loneliness and isolation, reduction in stress and anxiety, as well as reducing awareness of pain and discomfort. The evidence also demonstrates benefits to the wider care community – carers, clinicians, family and friends.
2. A significant number of individuals with dementia also suffer from additional disability and in particular, sight loss. For many of these individuals, music is the only activity with which they can engage on their own terms. For such participants, music not only provides a pleasing aesthetic experience but provides the only chance they have to express their individuality, preferences, identity and personality.
3. We would suggest there are four main strands of activity which fall within the field. Each strand can be can be described according to their degree of formality / informality, set against the degree of specialism / non-specialism; in terms of training to work within the care sector. Hence: Formal –Specialist delivered by trained Music Therapists; Informal - Specialist delivered by trained, professional musicians providing informal concerts ; Formal – non specialist as delivered by volunteer musicians; and Informal – non-specialist (activity coordinators offering musical activities). Currently, most research and the prime focus appears to be aligned with the formal – specialist group with the other three sectors relatively under-represented.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

Each strand of activity tends to be funded differently and again, most current measures of costs probably arise from an analysis of the finances required by / obtained by the dominant 'formal-specialist 'group. Participants from the 'informal – specialist' group tend to be either volunteer or charity funded. These activities are funded largely through the generosity of the public, grant funding obtained from charitable trusts and foundations and funding partnerships with corporate bodies. As far as I am aware, there is little statutory funding available. Similarly, the costs of providing musical experiences within the remaining two sectors are relatively low and mainly carried by the musicians or the individual care facility.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

From my perspective, there are regional differences. Given that the provision of live music is, largely, being provided by the charitable sector, and charities, in the main, rely on donations and other funding from the public, there is an inevitability that there are regional differences. In our experience the vast majority of our funding is restricted and this can be restricted by geographic location. As a consequence, our ability to deliver live music right across the country in an even way is constrained by any limitations placed on us by the funding.

Some groups recognise the benefit so plough more of their own funding into provision of regular music sessions. There is also disparity for example, between NHS providers with each service accessing different funding streams to provide live music, depending on the individual staff member who might see the value.

1.4 What should we consider to be ‘best practice’ in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

Music in Hospitals & Care has been, for the last few years, undertaking quantitative and qualitative research on the impact of live music on all those involved in a wide range of healthcare contexts. This has included a significant focus on those with dementia. As part of the research, our partner (Dr Nigel Marshall) undertook some analysis of salivary activity, providing empirical evidence of reductions in stress and anxiety as a consequence of the live music sessions. He has also trained care staff in some locations to continue this process in order to ensure ongoing beneficial outcomes.
However, there are other areas which tend to suggest “best practise” would enable continuing beneficial outcomes. These include:

- Regular exchanges with and between musicians on best practice with regards to engagement;
- Regular “informed” feedback on observed outcomes from care and support staff;
- Feedback from musicians;
- Live music as a regular part of daily/weekly life for those with dementia;
- Informed supervision and participation by care staff, family and friends;
- The accepted wisdom that engagement of the audience by musicians during live music sessions is a crucial part in enabling beneficial outcomes.

1.5 Is it possible to establish an average ‘unit’ costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

Simply estimating or averaging a basic unit cost would not be an effective way to proceed. Any formula would need to take into account the level of savings obtained through the use of music. It would certainly be possible to map a series of base line measures and investigate changes in costs that take place relative to this.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

There are four major barriers in our view.

The first barrier is that there needs to be some acknowledgement and acceptance that live music particularly has a beneficial and positive, therapeutic impact on those with dementia in a variety of ways based on research and empirical evidence. Improving the general health and wellbeing of individuals, family and friends and care staff must be recognised as a laudable and valuable outcome in itself.

The second barrier would be cost. Although live music is, currently, delivered largely by local and national charities, the beneficial outcomes would suggest that this provision might reasonably be funded, in total or in part, by NHS and Social Care services.

Third, it is frequently the case that those staff organising activities (both in the NHS and Social Care area) are not as aware of the impact that live music can have as perhaps they ought to be. Even when they are minded to arrange for live music concerts, we have seen instances where activities staff arrange for music that suits them rather than the target audience.

Fourth, where there is some but ill-informed understanding, it is not unheard of for activity coordinators to arrange for inappropriate musicians to perform, sometimes as a “cheap and quick” alternative. This is dangerous and short-sighted and has the potential to place inexperienced and unprepared musicians into highly emotional situations.

The benefits must be articulated in “laymen’s” terms in order to broaden the understanding across the community.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

The field has room for more quantitative approaches and would almost certainly benefit from a broader research base to include specifically:

- a broader theoretical framework through which to view and interpret research findings
- a broader range of methodologies through which alternative, but equally valid research tools and data sets can be collected and interrogated
- research into a broader range of musical experiences
- Government policy to ensure access to a live music programme on a regular basis, improving the health and wellbeing of those with dementia. Therefore, changing the perception that this music delivery as a ‘special’ one off event to more that this is an ongoing and regular part of the weekly routing.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

Change attitudes

i. Validated training and CPD sessions

ii. Any activity which raises the profile of the beneficial effects of music on those with dementia

2.3 Where do we still need to build evidence? **[Max. 250 words]**

Although we have been working on this aspect of evidence with Dr Marshall, comparing the outcomes of different activities is a very useful exercise. Intuitively, some activities will produce much better beneficial outcomes than other activities, both for those with dementia but also for family and friends (every bit as important) and care staff. Indeed, our research has already established that as a consequence of live music sessions, care and nursing staff are able to provide a better standard of care.

See response to 2.1 – A review of the literature suggests that the current research base is significantly weighted towards musical experiences carried out in the 'Formal – Specialist' quadrant. More research needs to funded and directed towards the beneficial effects of music to be gained in other (cheaper) domains of experience with a focus on a broader research base arising from a more varied range f theoretical frameworks using a broader range of research tools.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Music , is currently seen as an 'intervention' which reinforces the current and dominant medical model . There were certainly some limited calls for dementia to be seen in terms of a more social model, and from this perspective, music would become a natural part of daily care in the same way that for example, careful exercise or correct hydration, is currently viewed.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

The ILC-UK has certainly taken a lead and is moving forward but we must again appeal for the commission to have a broader and more representative base of all the musical experiences which are currently taking place with care facilities

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

Department of Health, Department of Culture, Media and Sport,

2.7 What should our one, clear message be? **[Max. 100 words]**

Music is available to all – to engage with, and to appreciate on individual terms. It is the one truly inclusive activity for all. It is a soundtrack to life which begins before we are born and continues to the end.

There are many people whose physical and mental condition prevent them from enjoying the sort of live music experiences that the rest of us take for granted. In such circumstances it is only reasonable that we should be able to take the musicians to the person or people rather than them not having any live music experiences at all.

2.8 Do you have any final comments? **[Max. <u>100</u> words]**

Yes; Music in Hospitals & Care is the oldest and largest provider of live music right across the healthcare spectrum, including those living with dementia. Our experience in the field and the contemporary research we have and continue to undertake could be of immense help in the Commission's work. We stand-by to assist where we can.

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. <u>50</u> words]**

I am Stephen Rowland-Jones, CEO of Music in Hospitals & Care in England, Wales, Northern Ireland and the Channel Islands. I took over the role nearly six years ago having been CEO of another charity, The Not Forgotten Association. One of the objectives of the NFA was the provision of live music in the ex-service care home community.

Music in Hospitals & Care was formed in 1948 – the same year as the NHS – and provides about 5,000 live music sessions each year to vulnerable adults and children in healthcare. The venues in which we provide this range from special schools, through hospitals, hospices and care homes to specialist dementia and stroke units as well as Intensive Care/Critical Care units in hospitals.

Our sessions are delivered by professional musicians, each of whom is selected through a rigorous audition in order to ensure not only a high quality of musicianship but also the ability to engage with our audiences. We have a mentoring programme for new musicians and an ongoing programme for sharing best practice.

Evidence by Music in Mind

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

While the musical activities for those with dementia vary across the UK, they have similar aims to provide a multitude of benefits to those living with the condition. The benefits include increasing physical and mental wellbeing, reducing stress, increasing confidence and improving memory. Music seems to have the power to access parts of the brain that are not readily accessible via other forms of communication. The main strands of activity evident from both my role as a researcher and my role as director of a singing and social group include community singing groups (both dementia-specific and more general, inclusive groups), and musicians who go into care homes or homes to offer either interactive or non-interactive musical sessions. Community singing groups that are dementia specific are delivered by organisations such as the Musical Memories Choir in Swansea or the Forget-Me-Not Chorus in Cardiff. Non-specific groups that are not formal choirs include With Music in Mind based in the Vale of Glamorgan. The organisations that enable those living in care homes to benefit from musical interventions include Lost Chord and Golden Oldies. Some groups are registered charities or community interest companies while many are community groups reliant on volunteers.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

While a range of funding is inevitably in place for these various activities and groups, I can only inform on the funding strategy of the group in which I am directly involved. With Music in Mind C.I.C. (WMIM) was originally self-funded by the organisation, with a small set up donation by the Community Matters Waitrose scheme. During its development WMIM had received small grants from the Postcode Community Trust and Big Lottery Fund Awards for All, but the sustainability of the current groups comes from member's fees. Therefore, the organisation is able to continue and develop under a combination of members subs, funding and fundraising.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

Best practice must include a combination of quantitative and qualitative measures so that both depth and breadth of the outcomes and impacts can be assessed. There is a wealth of evidence demonstrating the benefits of group singing activities that have utilised both types of measurements. Importantly measurements of these activities MUST include the impact on the person living with dementia, their carers AND the staff running the activities.

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

This is something that I would like to explore so I would be very interested to see the responses to this question!

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

From reading the academic literature, barriers to uptake of activities relevant to community groups include cost, transport, stigma, apathy or withdrawal from socialising and lack of knowledge of the group's existence. Barriers to uptake in care homes look rather different, with lack of service provision within care homes being an issue. However, with the growing number of musicians and groups going into care homes to provide activities, this is beginning to be addressed.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

Emerging services in the field of dementia and music include more inclusive musical interactive sessions in care homes. These range from singing in groups, taking in a variety of instruments for residents / staff / carers to play, or qualified musicians playing for the residents to join in some capacity. Dementia choirs and musical groups are growing more popular as evidence consistently demonstrates the benefits to wellbeing and cognitive function.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

The barriers of apathy and withdrawal from socialising are difficult to address but multidisciplinary work with social care services should be a good starting point to encourage members of the community to join local services. Social prescribing and referral pathways from GPs and other health and social care providers should be put in place to alert people to their existence and offer "medical / health" opinions about the value of the services. Often ideas from GPs or other health care professionals are well received. Where cost is a barrier, there should be schemes in place that could subsidise places –this would involve partnership working with local authorities or organisations willing to part-fund the music services. Transport problems could be included within this type of scheme so that individuals are able to attend groups.

A way of overcoming stigma is to provide a service that is inclusive, therefore not dementia-specific. To overcome lack of knowledge, organisations must take responsibility for promoting their service in a variety of ways. Voluntary services are a great means of getting the message out there as they link with many different services.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

Evidence that many different models of service provision exist and work well is available in the academic literature and on service-provider websites. However, there is little evidence about the mechanisms of how these services actually work and provide such positive outcomes. For example, why does a dementia-specific model work for some but not for others? How do the individual models of service delivery enable value for money and sustainability?

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

It is the responsibility of everybody in social care to ensure that this agenda is taken forward but local authorities and government bodies must start to listen and understand the value of these services that offer benefits on so many levels. The evidence that demonstrates the value of early intervention and prevention services for people living with dementia should be taken seriously as it will lead to a reduction in support needs in later life.

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

Those with the capacity to change policy based on the evidence and to begin to understand that by investing in early intervention community (or care home) musical activities, the benefits will lead to a decrease in need for extra care as dementia progresses. To have activities in place at an early stage with which the person and carers become familiar enables a sense of safety and continuity, thereby enabling the activity to continue to offer its benefits for longer. Investing in these types of service will lead to a decrease in future care costs for many individuals.

2.7 What should our one, clear message be? **[Max. 100 words]**

There is a wealth of evidence that music benefits older people in general, as well as those with conditions such as dementia. Early intervention and prevention is a message that needs to be heard loud and clear. Get people involved in music at an early stage so they can begin to benefit as soon as possible is essential.

2.8 Do you have any final comments? **[Max. 100 words]**

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. 50 words]**

Managing director of a CIC offering singing and social sessions over 50s. Members include those living with dementia, Parkinson’s disease, sight loss and loneliness. Researcher in the Centre for Ageing and Dementia Research (CADR) which aims to improve the lives of older people through integration of research, policy and practice.

Evidence by Musical Moment

1. **What is the current 'state of play' of dementia and music?**

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

I feel that dementia and music is not as popular and as accessible as it should be, especially for older people living in care homes. Music is an easy and proven therapeutic tool that I feel is not used enough. It should be a therapy that is taken advantage of every day. There are many care home entertainers across the UK which is great, but more interactive musical activities should be provided, especially for those living with dementia. Musical Moments delivers such activities and we see the benefits on a daily basis to those living with dementia.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

Our activity is solely funded by the activities/comfort fund budget of the care home. I do know that some councils across the UK are providing funding for activities and projects. We were awarded £7,000 in 2015 to help care homes to be able to afford more activities but were unsuccessful earlier this year when applying for funding to run a free singing group for people in the community living with dementia and their carers. I believe projects like this should be prioritised, not just for the well-being of those with dementia, but for their families and communities.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

I feel that there is a demand from carers to have more music in care settings – our organisation is constantly receiving enquiries from all areas of the UK but unfortunately we are only able to provide our service in some of the North West areas, although we are working on trying to expand through our franchise model and to be able to fill the demand that we know is out there.

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

I feel that there should be more dementia awareness training for anyone that is going into the industry, in whatever form. All employees at Musical Moments have and do continue to have regular training sessions to ensure that we are providing the best service possible, and we reflect on every session that we deliver. Each year we release our Social Impact Survey to our clients to ensure that we are providing a service that is good value and that also produces great and meaningful results for the people that we are working with.

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

Yes, organisations that provide such activities should be able to give a fair cost to their work, as we charge the same, affordable and fair rate for any group, regardless of background, area, ability or class. The outcome can be measured by the popularity of such activities, overall enjoyment and general well-being from regular exposure to musical activities or events.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

I feel that this is funding in general. Many care providers aren't given big enough activity funds for them to be able to provide external activities or 'entertainers'. I think that an activity budget should be made compulsory (some care homes do not have an activity fund) and I also believe that more funding should be made available by local councils and governments for such projects – but using trusted organisations that are already working on tried and tested models.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

There can be many job opportunities created from this; many musicians struggle to find regular and meaningful work and using music in a healthcare setting is a new and niche way to embrace the profession and musical training to provide a much-needed service to others and the community.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

2.3 Where do we still need to build evidence? **[Max. 250 words]**

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

There is a small amount of research that has been done, but there is already a strong success rate for intergenerational projects – we know that music is also very important for development in early years and there are also clear benefits of mixing the 'old' and the 'young'; adding music to an intergenerational project could be even more successful. Many other therapies such as art therapy, doll therapy and pet therapies are also effective.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

Definitely people with a large public influence to help to spread the message further and to a larger audience.

2.7 What should our one, clear message be? **[Max. <u>100</u> words]**

That it is possible to be living well with dementia and that there are many activities that can help promote well-being and happiness of those living with dementia which should be thoroughly encouraged.

2.8 Do you have any final comments? **[Max. <u>100</u> words]**

I look forward to seeing the future of music and dementia in the UK – I myself am passionate about this field and would be very happy to be contacted to pursue the topic further, as a researcher or speaker. I believe that we need to see more music happening for those living with dementia and to make it an everyday and normal activity.

Evidence by National Ageing Research Institute

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

There is abundant room for improving access to high quality live music performances of all genres for people dependent upon home care or residential care services. Based on input from CEOs of high-functioning residential care organisations, four such events annually should be the minimum. While many such care organisations are cautious about committing to participation in such programs, those that do unreservedly assert the value of these events not just for their care-receivers but also for their staff and volunteers who are commonly thrilled when they observe the engagement in music of those in their charge.
Note that I am referring simply to providing access to music. It is not intended as a therapy for people who have dementia. It is based solely on ensuring that Article 27 of The UN Declaration on Human Rights is observed.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

I think this is a slow process. In my experience, only the very high functioning care organisations actively participate in the development of access programs. Those that engage with music providers will typically have many other innovative programs that support the active engagement of those in their care with many opportunities to be highly engaged in a whole range of undertakings including such activities as Tai-Chi, meditation, nature walks, drama productions, drawing and painting, gardening and so on.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

I believe the evidence needed to support the provision of live music events manifests in diverse ways. First, even people with late stage dementia will be observed to engage with music – both live and recorded. Some such persons can be observed to temporarily transform from virtually catatonic to fully engaged, conversational and joyful. But be aware that music is not a treatment for dementia. These responses are short-lived and there is no strong evidence to suggest that they yield a cumulative reduction in dementia symptoms. To date, evidence for a therapeutic effect of music for those with dementia is poor.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

See 2.1 above It should be argued simply as a human right to have access to the cultural life of the communities in which people live.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

Everyone! Carers, families, municipalities, governments at all levels, musicians/artists, health organisations.

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

See 2.5 above

2.7 What should our one, clear message be? **[Max. <u>100</u> words]**

That all people, regardless of their health status have the right to access the cultural expressions of the society in which they live. ……..Article 27.

2.8 Do you have any final comments? **[Max. <u>100</u> words]**

My reason for repeatedly citing Article 27 is that it is an agreed position by member nations of the UN. It is also an agreement that is notable for the disregard with which it is treated. Nonetheless, it is still persuasive and, when put into practice with respect to music, ageing and dementia it is overwhelmingly apparent to all observers that concert events are dramatically enriching for all concerned. My one caution is that it should not be argued that music in any way changes the progression of the symptoms of major forms of dementia. Repeated Cochrane Database Systematic Reviews show that access to music does not change the progression of the disease. This is despite the powerfully evident and temporarily transformative engagement of most people with dementia when they hear high quality performances of music of any style or genre. People who live in multicultural societies are open to new experiences – even when they are very old and even when they have advanced stage dementia. That music does not slow or reverse dementia progression should not, in any way, discourage us from improving access to music for those with dementia. Our goals are achieved when our audiences engage with music.

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. 50 words]**

Bruce Barber (retired) is a musician, music educator and a researcher at The National Ageing Research Institute http://www.nari.net.au/
In his honorary role at NARI he has served as a consultant to the Melbourne Recital Centre Share More Music program that provides access to music for care-dependent older persons https://www.melbournerecital.com.au/news/2015/03/share-more-music-launch/

Evidence by Nordoff Robbins

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? [Max. 250 words]

Our qualified Nordoff Robbins Music Therapists deliver music therapy to people living with dementia and their carers (both family and paid staff) in a range of settings: residential care homes, day centres, in memory clinics and our own centres. Our aim is to encourage active music-making, offering both individual and group sessions. Service users can participate in a wide range of ways - using instruments, their voices, movements or simply gestures or eye movements - and in this way can get a facilitated opportunity to lead the musical experience rather than simply playing along. Therapist and service user(s) may also share familiar songs to stimulate and promote memory recall or create improvisations based on an individual's response to the music/sound at that moment. This may take the form of a musical "call and response" or be based around the sounds an individual may be making. This is particularly helpful for people living with dementia who may have lost their language. For those people in the later stages of dementia, music therapy can take the form of playing to someone or can be used to accompany breathing, providing an experience of non-verbal companionship. which can be of great comfort. Music therapists may also contribute by running music appreciation groups, facilitating choirs or wider communal activities such as musical events.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

Our work takes place both in our designated centres across the country which is free at the point of delivery. This is funded by donations (individual and corporate), income from large and small fundraising events, trusts and foundations and work with corporates and businesses. Where our therapists work with external organisations this is funded by a service level agreement with the partner organisation.

1.3 Are there regional differences in provision, within the UK? [Max. 250 words]

Nordoff-Robbins covers England and Wales. We have a sister organisation in Scotland (Nordoff Robbins Scotland). We currently offer services across London, South West, Wales, North West and North East England. We do not currently provide services in the Midlands but it is our ultimate aim to provide services across England and Wales. Generally, there appears to be less provision in areas such as the North East where there is more economic deprivation or barriers to services due to geography.

1.4 What should we consider to be ‘best practice’ in the measurement of the outcomes and impacts of these activities? [Max. 250 words]

Nordoff Robbins places a high degree of emphasis on quality assurance and evaluation and as such have a national quality assurance programme in place. Our music therapists receive regular supervision which both supports them in their work and ensures quality. This is based on a relentless focus on the actual musical interactions that are happening, ensuring that service users are getting maximum opportunities for companionship, expression, connection and experience of their abilities. We also have a dedicated research team who undertake evaluation reports to measure impact of music therapy services. These reports use methods such as questionnaires and feedback to provide relevant data.

1.5 Is it possible to establish an average ‘unit’ costs for different kinds of activity, and how can we map cost against outcome? [Max. 250 words]

Nordoff Robbins has fully unit costed the delivery of music therapy services. Mapping of costs to particular outcomes is dependent on the clarity of those outcomes.

1.6 What are the main barriers to more extensive uptake of these activities? [Max. 250 words]

One of our main barriers at Nordoff Robbins is training sufficient numbers of music therapists in our approach to keep pace with demand for our services. We offer a Masters in Music Therapy (a 2-year full-time programme accredited by Goldsmiths, University of London, and approved by the HCPC) in both Manchester and London (with Newcastle being added in 2018, subject to HCPC approval). We aim to recruit from our graduates to increase the number of therapists who can
then expand our work. There are also significant differences in economic deprivation/barriers to services throughout the country meaning that funding for services such as music therapy can be limited.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

As the focus in dementia care moves way from residential and nursing home provision with the intention to support people living with dementia to remain in their own homes for as long as possible, we need to look at how the provision of music therapy can reach the maximum number of people. One-to-one music therapy in a person's own home is unlikely to increase because of limited resources. Moreover, often sharing music within a group has a hugely beneficial psychosocial impact both for the person with the condition and their paid or family carer. This will mean we need to look at how we can provide music therapy for groups and individuals away from a home setting which has implications for accessible community transport (which has been reduced in recent years) and working closely with other organisations who provide communal space for people with dementia such as sheltered housing and day opportunity groups. There will still need to be work to consider how we can reach the many socially isolated people living with dementia who, because of the nature of dementia, find independent travel outside the home difficult.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? [Max. 250 words]

There is potential to maximise our reach by organisations pooling their resources such as accessible transport, volunteer drivers to bring people to designated centres safely. Often music therapy is funded by "activity budgets" which are limited or restricted so one way of overcoming this would be to include music therapy in a person's 'care-plan' (for example) which may mean that resources may be made available to address the need.

2.3 Where do we still need to build evidence? [Max. 250 words]

According to the recent Cochrane review (2017), there is work to be done with regards to effects on emotional well-being including quality of life, overall behavioural problems, and cognition. Equally, there is more to be done on anxiety and social interaction and on length of impact after therapy.
Other aspects should also be further investigated. In addition to effects on feelings of identity, given the importance placed on the broader role of music therapy in the family and community around the clients – especially carers, there is more to be done on, inter-personal and social effects.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? [Max. 250 words]

There is great scope for arts-based organisations to work together to offer creative therapies across a day which people living with dementia could access according to their preference. This would reduce the need for travelling to unfamiliar places for each type of therapy and help build a sense of community. There are also opportunities to work together in places that are well known to people with dementia to make access easier. For example, we are currently working with the Royal Albert Hall to offer drop-in music therapy for people with a range of conditions.

2.5 Who should be taking this agenda forwards? [Max. 250 words]

All those working in dementia care – voluntary, private and public-sector organisations, central and local Government.

2.6 Who needs to be influenced and brought on board, to further this agenda? [Max. 250 words]

Government and local government, NHS professionals to make referral pathways clearer and more accessible

2.7 What should our one, clear message be? [Max. 100 words]

Music in all its forms (therapy, community based musicians, sharing a listening space etc.) has huge benefits for people living with dementia and their carers. It has the potential to draw generations together, reduce the social isolation caused by dementia and create shared positive communication in all stages of dementia. Musical communication can ensure individuals living with dementia can maintain meaningful companionship and connections with the world around them, helping them to live well. It can give people with dementia a space to express themselves that is unique and positive. (77 words).

2.8 Do you have any final comments? [Max. 100 words]

Evidence by Northern Ireland BAMT

1. **What is the current 'state of play' of dementia and music?**

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? [Max. 250 words]

I am reporting about music therapy services as the Northern Ireland (NI) representative for the BAMT dementia working group. There are currently at least three active music therapy services for dementia in operation in NI. Two in Belfast and one for the Western Health Trust in Derry/Londonderry. In Derry its delivered by Every Day Harmony (http://www.everydayharmony.org/), who provide a half day weekly service for group and for individuals. The other services are delivered by self-employed music therapists working in private and NHS nursing homes.

1.2 How is this range of activity presently being funded? [Max. 250 words]

The WHSCT funds the Derry service and the nursing homes fund the Belfast services (specific details not always given).

1.3 Are there regional differences in provision, within the UK? [Max. 250 words]

Yes, absolutely in Northern Ireland, considering there are only a small number of music therapy services currently in operation across the whole of NI.

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? [Max. 250 words]

The music therapy practices in operation in Northern Ireland use different ways to measure outcomes and impacts of the music therapy service offered. Of the outcome measures used, two have been listed with a preference for the MiDAS evaluation tool as its a quantitative outcome measure that explores the value and meaning of music for people with dementia measured by therapist and staff (DOI: 10.1080/08098131.2014.907333).

(1)Use of an evaluation tool (e.g. the MiDAS evaluation tool - adapted to meet music therapy series in NI), which measures parameters such as level of participant awareness, levels of participant active involvement and levels of enjoyment during music therapy interventions.

(2) Documentation of outcomes & impacts of the music therapy session in the clinical notes on the nursing home's computer system, where the outcomes are logged in a written format after each session, for example, engagement levels, responses & emotional response to music, physical responses to music, levels of interactivity, focus and concentration skills, memory & reminiscence.

1.5 Is it possible to establish an average ‘unit’ costs for different kinds of activity, and how can we map cost against outcome? [Max. 250 words]

Not possible to evaluate from the data I have received to date in NI.

1.6 What are the main barriers to more extensive uptake of these activities? [Max. 250 words]

Funding. Lack of knowledge about the benefits of music therapy. Lack of understanding about the difference between music therapy and music groups, musicians, music for entertainment etc. which many volunteers provide in nursing home settings in Northern Ireland.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

A collaborative approach where there is space for both community music activities and space for music therapy as this will address the needs of older people at varying stages of dementia.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? [Max. 250 words]

The BAMT dementia working group are one working group designed to specifically address this issue to find a place for music therapy in dementia and music services.

2.3 Where do we still need to build evidence? [Max. 250 words]

Yes, we absolutely need to continue to build evidence. All practices, both community music centred and music therapy need to delivered with an in-built evaluation tool to show how it benefits the client, carers and the setting. This is not the case in all services provided in NI at this point and time.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? [Max. 250 words]

Yes, I feel we should. Music can be included in other social activities and this can be tailored to meet client and setting needs; for example: music and drama can be interlinked to help older people recall and re-experience memorable events in their lives (i.e. getting married /going to their first dance).
Creating a song book of favourite songs /music groups and using the songs / recorded music during appropriate activities during the day.

2.5 Who should be taking this agenda forwards? [Max. 250 words]

The Health trusts (with government funding) in each region in collaboration with the many amazing working groups that are facilitating music with dementia across the UK.

2.6 Who needs to be influenced and brought on board, to further this agenda? [Max. 250 words]

We firstly need a working executive in Northern Ireland and it is difficult to figure out of this will actually happen. Information about music therapy to be provided at point of diagnosis, inclusion on list of services/groups/therapies given to people who are newly diagnosis of Dementia. More awareness among GPs, healthcare professionals who work with older adults (social workers, nursing staff, activity therapists, physiotherapists, speech & languages therapists, occupational therapists).

2.7 What should our one, clear message be? [Max. 100 words]

2.8 Do you have any final comments? [Max. 100 words]

I personally feel that the work of the BAMT Dementia Working group will create a worthwhile clear message about roles for different kinds of music for older adults with dementia.

Evidence by Orchestra of the Swan

1. **What is the current 'state of play' of dementia and music?**

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

At Orchestra of the Swan (OOTS) as an arts provider, we deliver a series of music sessions for people living with dementia in care homes. These sessions are delivered by 2 players and all of our players are provided with awareness training on different types of dementias, working within care homes and how to communicate and choose their music for this different audience by the music therapy charity Mindsong (www.mindsing.org.uk). All our sessions are fully evaluated and several reports are available on our website www.orchestraoftheswan.org. 19 of our 35 core players have been trained to deliver this work and we recently delivered Dementia Friends training to our board of trustees. Our Learning and Participation Manager and Dementia Projects Coordinator have also been trained as Dementia Champions by The Alzheimer's Society.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

All of our work is currently funded by a network of grants giving trusts, foundations and individual donors.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

I would think so, albeit it does seem a very popular area for orchestras, music groups and individual musicians to develop projects. I think the varying genres of music could be wider represented that offer a more diverse musical experience that better represent our communities.

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

The development of a robust methodology with clearly defined aims and outcomes, with sound relationships with care providers, social care organisations and dementia groups etc. Close reference to arts and social care evaluation methodologies and collecting of quotations and photographic evidence from all involved (subject to permissions). Measurement of outcomes and impacts should be collected and delivered by using a combined evaluative tool (where one exists and if it doesn't perhaps one could be developed) so that arts and social care providers can see this impact, both in terms of a person's well-being, dementia journey but also in hard economic terms about the actual value to the NHS of engaging in musical activity that enables and encourages people to live well with dementia in their community rather than in care homes.

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

Our "unit costs" are roughly £4-8,000 per project (about £400 per half day session) which enables us to visit 4-6 care homes for 4-8 sessions per home, enabling us to build up a good relationship with care staff and residents. Cost vs outcome could be case studied in regards to enabling people to stay in their own home for longer, the use of less medication etc. It will probably need to be reported on a quality rather than quantity basis. Great impact but for a relatively small number?

Funding – or lack of and more understanding by NHS providers of the value to their work of music activity in this area. Arts providers also need to evidence their work in the appropriate language for health and social care decision makers.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

- Specialised training for professional and community musicians to ensure quality of delivery and specialist understanding. Not a music therapy course as such, but awareness raising, communication and upskilling. A quality mark of understanding for community musicians that can access current thinking on the value of arts for dementia.
- Joint conferences for health care and arts professionals, putting importance of each discipline on a similar footing – evidence and impact.
- Further understanding of how dementias and music work with the brain and how they can stimulate brain activity and help control emotions/emotional responses.
- Appreciation that a love of music needs to start when young – don't cut music in schools as you could be removing a person’s safety net when older – or their capacity to live well/better in older age
- More actively including musical activity into personalised care plans and fund accordingly. For some people access to music is a vitally important part of their daily routine which should not be denied to them, purely on the basis that they have become less able to make direct choices for themselves.
- Training embedded within undergraduate music, nursing and care courses to educate students in the value and impact of this work before they get into the workplace

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? [Max. 250 words]

Better communication of the value and impact music can have on the lives of those with dementia – as mentioned above in more robust evidencing and cases for support. GP surgeries, health care providers, training bodies, funders etc and actually prescribing musical activity rather than medication (in some cases!). Social integration. Better and more supported training care and nursing staff to enable them to experience and witness the power of these sessions for themselves so they can act as advocates for this work. Also – a safe understanding that people without a musical aptitude can appreciate you don't have to be a professional musician to engage with, develop, deliver or join in a musical activity. Just listening, tapping feet etc can be enough to bring a roomful of smiles.

2.3 Where do we still need to build evidence? [Max. 250 words]

The impact that working in this area can and does have an effect on the deliverer too and that we need to find time and training for reflection in this area. How do our musicians deal with the emotions delivering such would no doubt bring up?

2.4 How can/ should we align music interventions with other areas of work in the dementia space? [Max. 250 words]

Make it part of the normal day. Allow free-flow for people to join in and leave as they wish so the individual has the choice to stay or go. Don't set up lounge spaces as mini concert theatres as certainly our sessions are far more interactive and free form than a traditional concert platform. Break down barriers and prescribe activity – measure how people feel, behave etc at the start and end of a project/period of music on prescription. Provide musical interventions in a person's own home too, if invited in via appropriate partner organisations.

2.5 Who should be taking this agenda forwards? [Max. 250 words]

Arts Council has a role to play in this alongside the obvious health and social care providers/NHS. GP and Care Trusts/Care Homes need to likewise advocate for this work. Alzheimer's Society and Age UK – in essence a multi-disciplinary task force that's also brings in other training organisations/universities.

2.6 Who needs to be influenced and brought on board, to further this agenda? [Max. 250 words]

Funders, GPs, universities, MPs, NHS decision makers.

2.7 What should our one, clear message be? [Max. 100 words]

Music is a universal medicine – a human language that doesn't need words to break down barriers and communicate a message; music transcends physical condition and ability to bring a person into the present moment, whilst also helping to access past memories and emotions. It is something every community, culture and people have in common so we must embrace the power of music to reach people and help us to all live well together.

2.8 Do you have any final comments? [Max. 100 words]

OOTS fully support this research commission and look forward to reading the published findings which will no doubt be of great value when building a case for support for music and dementia based projects. Thank you.

Evidence by Professor J Quinn

1. **What is the current 'state of play' of dementia and music?**

   1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

   1.2 How is this range of activity presently being funded? **[Max. 250 words]**

   1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

   1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

   It is very difficult to measure what music can do for people with dementia. Indeed the very terms 'outcomes' and 'impacts' do not fit well in this context. In the Beyond Words project, funded by Arts Council England research grants programme we found that a longitudinal, qualitative approach was the best practice in showing how their lives are enhanced by music. Time is very different for those with dementia. A moment can be vitally important, even if it is fleeting and never-repeated. Thus it is essential to trace these subtle changes and explore such moments.

   1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

   1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

   Money is the main barrier. The musicians need to be skilled and more than one person is needed for each session. In order to plan ahead music organisations need a secure pattern of funding. The activities also require the co-operation of management and support workers in the settings. Support workers are poorly paid and need better training so they understand how to improve care, including facilitating working with community music organisations.

2. **In which direction should the field of dementia and music be moving?**

   2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

   One important discovery we have made is that dementia does not mean the end of lifelong learning and that music can facilitate new learning opportunities, rather than just providing access to memories of the past. Another important opportunity is that music can help support the families of those with dementia, showing them that their loved one is still there, even in advanced dementia. Music activities should seek to involve family members.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

Music should be provided as part of a package of care and health benefits for people with dementia and their families
Skilled community music organisations need secure funding to support their work with people with dementia
Support workers in care homes need improved pay, conditions and training

2.3 Where do we still need to build evidence? **[Max. 250 words]**

There is very limited longitudinal evidence, particularly with larger numbers of people

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Music needs to be part of holistic provision for people with dementia and their families. At the moment, all provision is fragmented and it is very difficult to find a way around the system.
Information needs to be shared across NHS/Social Work/ Care providers/Music Organisations.
Training for Social Workers, NHS workers, Psychologists needs to include sessions on using music.
Support workers need better pay, conditions and training to help them work with music.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

Policy makers need to pass legislation to improve care of people with dementia. This should include providing funding to ensure they have access to professional music making.
Arts organisations should be funded to develop their expertise in this field.
Professional organisations should work with universities to improve training

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

MPs
Professional organisations, NHS, Private Care Homes
Universities

2.7 What should our one, clear message be? **[Max. 100 words]**

People with dementia should not be treated as if they are dead. They need and deserve quality of life and that includes access to music making. It will enhance their lives, support their families and facilitate their lifelong learning.

2.8 Do you have any final comments? **[Max. 100 words]**

We need to understand and value the difference of people with dementia. To do so we need to think beyond being able to speak or articulate clearly and appreciate their way of being in the world: the importance of textures, bodies and sounds, for example. In our research project, Beyond Words, we found posthuman ideas very helpful in making this conceptual leap. https://www.plymouth.ac.uk/uploads/production/document/path/9/9063/Beyond_Words-_Final_Report-12-6-2017.pdf

Evidence by Professor Martin Green

1. What is the current ‘state of play’ of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

The main field of activity is communal singing, or musical performances in care homes. The majority of these activities are delivered by specialist staff that are brought into the care home specifically for this purpose.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

The vast majority of this activity is being funded by the care home provider, usually from their activities budget.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

I'm not aware of any evidence that there are regional differences in the provision of this type of activity.

1.4 What should we consider to be ‘best practice’ in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

The majority of this activity is not properly measured in terms of its outcomes to residents. The activities are popular with residents, so to that extent they are seen to be worth-while. However, there is a need to formulate some clear outcome measures which relate to both well-being and cognitive function.

1.5 Is it possible to establish an average ‘unit’ costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

I'm not aware of any evidence on what the unit costs of these activities are and it is dependent on local circumstances.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

I think there are two main barriers to more extensive take-up, the first is where to get the money for this work, and the second is how do you evidence is effectiveness.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

It is my view that dementia and music need to be moving towards some clear evidence base and measurement criteria. We need to know that this activity improves well-being and helps with reminiscence and improved cognitive function.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

One of the ways in which we can overcome the barriers are to clearly show the benefits. We also need to get a clear narrative so we can engage relatives and friends of care home residents to advocate for more music in care settings.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

We need to have some clear outcome measures and one of these should be around enhanced well-being, but they should also be some of the measures related to cognitive function, and reminiscence.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

The best way to align music with other interventions in dementia is to provide clear evidence of the benefits to people living with dementia

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

This agenda needs to be taken forward by a multidisciplinary group of people. Care providers should be in the vanguard of promoting this activity in care services, but we also need to encourage specialist and generalist, clinicians to understand the benefits and possibly to prescribe music to people living in care settings as part of their treatment plan. We also need to put music at the centre of care planning, but for this to be achieved, we need some datasets and some outcome measures

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

I think we need to influence care providers, clinicians, residents and their families.

2.7 What should our one, clear message be? **[Max. 100 words]**

The clear message should be about the benefits of music to people living with dementia and this message must be backed by evidence.

2.8 Do you have any final comments? **[Max. <u>100</u> words]**

It is clear anecdotally the music makes a big impact on the quality of life of people living with dementia, and we need to develop clear measures so that we can champion this cause on the basis of clear evidence and outcomes. I think there is also a need to look at the quality of performance which in some instances is poor.

Evidence by Professor Thomas Wosch

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

Main strands are music therapy in dementia care, music therapy and music therapy informed training of professional care givers in dementia care at home and in care facilities and family care givers in dementia care at home, and finally music therapy informed group and community activities in and with music.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

Single case decisions, included service of large care home enterprises, private funding, private money of users, some health care money in psyche-social service, in treatment of agitation (challenging behaviour), in geriatric psychiatric treatment, in leisure time and community activities.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

As far as I know: yes. It depends from large cities and care home services and if both is close to master programs in music therapy (British universities, offering these programs).

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

Reduction of agitation (challenging behaviour) in individual music therapy, increase of motivation and activation (treatment of depressive symptoms of dementia and symptoms of severe dementia), increase of quality of life (becoming cognitive oriented, increase remained capabilities in all physiological, psyche, cognitive and social competencies) of people with dementia and also of professional and of family care givers (including reduction of burden and of burn out, and being able to communicate with PWD), decrease of anxiety of people with dementia.

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

Yes, it is. Calculate use cases including medication (psychotropics), efforts of professional care givers, burden and burn out of professional care givers and of family care givers, frequency of service of medical doctors. Calculate use cases contrary to first once taking into account outcomes of reduction in agitation and depression of PWD with its effects in needs of care, decrease of burden and burn out of professional and of family care givers, needs of medical doctor services and of medication (psychotropics).

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

Enough qualified music therapists in this field, development of trainings music therapy informed interventions for all care givers and finally mandatory music therapy in shared practice (severe cases and first introduction by trained music therapist, continuing daily service and use by all care givers in cooperation with music therapists).

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

Individual regulation (reduction) of agitation, individual regulation (increase) of activation, individual regulation of cognitive orientation (reduction of disorientation and anxiety), and most of all cognitive compensation mechanisms. This is a future arising field and based in first findings of neurosciences in music therapy in dementia care and in case examples of music therapy (reminiscence of new created songs in individual music therapy!). Moreover, focus also in research and capabilities of dementia caregivers (compare severe special needs and oncology).

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

Health economics calculation in the field plus qualify enough music therapists, specialized in the field, and finally built up trainings in music therapy informed techniques for all caregivers (professional and family) plus for community musicians working with communities including early stage and mid stage people with dementia. Models in this are just developed in Denmark, Germany and Australia.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

See answers 1.4 and 1.5. We must run large scale trials in both.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

See answers 2.2.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

Health service money givers, dementia care money givers, all dementia and older adults associations.

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

Law makers, MHS, etc.

2.7 What should our one, clear message be? **[Max. 100 words]**

Dementia is a severe special need. Dementia needs the same service to care for PWD in the same way as society does for children with strong developmental disorders and their families. The growing number of PWD needs best assistance and service for future. The unique and so far, lone standing treatment and even compensation of dementia symptoms with music therapy and with music therapy informed music activities will save money, increase quality of life of PWD and will reduce a lot the burden and increase communication of all dementia care givers.

2.8 Do you have any final comments? **[Max. 100 words]**

You do great work! (by the way: In Germany we'll have in 2050 some 3 Mill. PWD, who will be that time almost 5 percent of German citizens.

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. 50 words]**

Prof. Dr. Thomas Wosch, University of applied sciences Würzburg-Schweinfurt GERMANY, Director of Master of Arts program in developmental music therapy and music therapy for patients with dementia, Research projects in neuroscience of music therapy in dementia care, Songwriting in dementia care (University of Melbourne), family care giver project (Alzheimer Society, Germany), Erasmus-teacher in Anglia Ruskin University Cambridge since 2006

Evidence by Professor Jorg Fachner

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

In terms of research we are looking into several strands

1. Intervention studies that focus on the effect of music as reflected in certain testing procedures aiming to measure cognitive deficits, agitation, behavioural responses and comparing this to matched controls / units where possible.
2. Case based interventions and in-depth descriptions of how music worked with the different interventions.
3. Studies describing action mechanisms of music on memory retrieval and recall.
4. Brain research describing, analysing and predicting responses of PWD to music.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

Private and governmental funding in terms of research grants (Alzheimer society, EPRSC, NIHR, etc.).
Private donations.
Interest groups.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

The south part of the country seems to have a better spread of provision

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

Study designs and measurement techniques investigating process of treatment delivery and responses to biomarkers.
To involve patient's perspectives as much as possible and to accept high drop-out rates in studies because of degenerative nature of the disease and the limitations of compliance to study goals.
To use mobile biomarker technology that adapts to the patient's abilities and integrate into daily living.

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

To do brain imaging research, costs correspond to the intervention and measurement tools applied. Hospitals may have a range of brain research applications and costs are depending on the amount of time needed for the preparation, recording and analysis of data and tools applied.

In a home setting music therapists may calculate a cost of about £85 plus travel etc. to get paid for the work.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**.

To do brain research, applying measurement tools seem to impede the freedom of the individual patient and are of ethical concern. Depending on dementia severity there are limitations to comply with instructions and behaviours needed to ensure data quality. Patients may not adhere to time needed to apply the tools (for example EEG) and discomfort felt when being wired up and hooked to machines. Hospital settings may allow to handle the applications of measurement tools and monitoring patients more easily then care home settings.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

To understand the disruption of memory and the opportunities that retaining musical memory offers for maintaining identity are promising. To research effects of music on memory may need more attention in research and further studies.
To understand how PWD interact in music is crucial as they temporarily seem function according to their former identity, rhythm allows control over passing time spans and playing and singing is activating procedural and emotional recourses.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

Reduce fear of loosing memory and identity.
Early detection and intervention strategies.
Make smart living and intelligent homes more accessible for public.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

- That music reduces agitation, fear, aids memory processes and helps maintaining identity and positive emotion.
- How music influences strong emotions and how state-dependent memory and recall functions when retrieving songs and sound structures of individual significance.
- How we can target individual arousal reduction with individualised music.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Music information retrieval, music data mining and intelligent home applications are of vital interest.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

2.7 What should our one, clear message be? **[Max. 100 words]**

Music maintains identity and brings back lives.

2.8 Do you have any final comments? **[Max. 100 words]**

Some of my comments are written in a haste.

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. 50 words]**

I am a Professor of Music, Health and the Brain at Anglia Ruskin University interested in translating neuroscience thinking into music therapy practice research and vice versa. ARU has a strong history on researching music and dementia and focuses on this research.

Evidence by Royal College of GPs

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

- Singing (formal and informal), dance, playing musical instruments.
- Communities: adjusting music and dance groups so that people with dementia can participate.
- New third sector organisations: Arts4Dementia, Singing for the Brain, Dance For Life (a collaborative project between New Adventures & Re:Bourne and Dementia Pathfinders).
- More care Homes are providing activities that include music and dance therapy.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

Most are charities that rely on fund-raising activities.
A very few services are commissioned as part of the Dementia Pathway.
Personal health budgets – people with dementia and their carers need more encouragement to embrace this.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

- I have most knowledge of the South-East region where there is marked variation in provision. Usually better nearer larger cities and towns but events may only occur once a month.
- Activities in Care Homes usually occur once or twice weekly if the Care Home organisations supports an Activities Leader.

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

Outcomes:

- QoL measurement for people with dementia and their carers.
- Benefit on Behavioural and Psychological symptoms of dementia (apathy, motivation, anxiety, depression, sleep.
- Documentation in Personalised Care Plan.
- Inclusion in commissioning for the Dementia Pathway.

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

Need to consider:

- Individual and group costs separately for participating in a service already provided by the community.
- Individual and group costs for a specific provision in the community or Care Home.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

- Knowledge about their benefit and the evidence to support this.
- Stigma of dementia that people can't begin to continue to participate in activities for people without dementia.
- Resources to support participation – person to accompany, transport.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

- Use of technology e.g. iPAD.
- Availability in Wellbeing centres.
- Engagement and support from well-known figures e.g. Matthew Bourne and Dance for Life.
- Engagement with choirs, music organisations locally.
- Care Homes engaging with their local communities.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

- Include in Guidance – e.g. NICE, commissioning guidance.
- Promote value and included activities in CQC assessments of Care Homes

2.3 Where do we still need to build evidence? **[Max. 250 words]**

Across dementia subtypes, BME groups.
Decrease in Behavioural and Psychological symptoms of Dementia; these are a major cause of Carer stress, nursing home placement and use of psychotropic drugs.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Engagement with:
- Dementia Friendly Community initiatives.
- Collaboration with Dementia Friends and Champions.

Important for the Dementia Well Pathway – Living well and Supporting Well

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

All relevant stakeholders:

- National: politicians, policy makers.
- Regional / Local: Commissioners, Public health including Joint Strategic Needs Assessments, commissioning intentions.

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

Commissioners
NICE / SCIE.
Umbrella organisations that include the third sector e.g. Dementia Action Alliance.
Organisations that provide Nursing Homes e.g. Barchester, BUPA. Four Seasons, SunRise.

2.7 What should our one, clear message be? **[Max. <u>100</u> words]**

Music Matters in Sickness and in Health; it bridges, cultures, religions, ages, languages.

2.8 Do you have any final comments? **[Max. <u>100</u> words]**

Music therapy needs to be defined and should have as broad a definition as possible to include most of the “Arts”.

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. <u>50</u> words]**

Dr Jill Rasmussen is RCGP Clinical Lead for Dementia; she has a special interest in mental health, dementia learning disability.
The Royal College of General Practitioners is the professional membership body and guardian of standards for family doctors in the UK, working to promote excellence in primary healthcare.

Evidence by Salvation Army

1. **What is the current 'state of play' of dementia and music?**

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

The Salvation Army provides a diverse range of services for people experiencing dementia, as well as their families and friends. Through our network of eight hundred churches (corps) and centres, spread right across the United Kingdom and the Republic of Ireland, we offer general and specialist support – not least through music making. Our local and national brass bands, choral groups (Songsters) and fellowship clubs have been a source of interest and comfort to dementia sufferers for many years. In addition, we are developing pioneering approaches. 'Singing By Heart' is a new resource designed to help individuals and groups set up and run dementia-friendly choirs. Created collaboratively by our Older People's Service and Music and Creative Arts Unit, the pack includes publicity materials, a guide for leaders, the offer of training and a new book of sacred and secular songs which also includes prayers and readings. We wish to recognise the ongoing spirituality of people with dementia and how faith can contribute to their prolonged health and wellbeing. The resource has been trialled locally and will be released nationally in September 2017. We believe that this project will compliment others and plan to evaluate it quantitatively and qualitatively within the year.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

The 'Singing By Heart' project has been funded internally, making use of the existing experience and expertise of our volunteers, employees and officers. It will be available to local expressions of The Salvation Army free of charge. Our other services and programmes for people with dementia are funded as part of our ordinary activities

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

Salvation Army churches and centres can be found across the United Kingdom and Republic of Ireland, including some of the most challenging and remote communities. Provision varies locally depending on local needs and resources.

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

Training is a major barrier. Our regional specialists are now offering dementia training to our volunteers, employees and officers so that they can better meet the needs of service users and adapt their existing skills.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

All of our churches and many of our centres have contact with older people and their families and friends. As a result, we are well aware of the barriers to participation that dementia can generate. In this context, we find that remaining within a set of community relationships, such as church, can help people to retain their sense of self-worth and identity.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

We would like to see more research into the relationships between dementia, faith, health and wellbeing. The Salvation Army's experience is that every person has a mind, body and soul and therefore has social, physical and spiritual needs. Humans are integrated beings and so our care for them must be integrated too. We believe that spirituality is an all-too-easily neglected factor in the equation.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

2.7 What should our one, clear message be? **[Max. <u>100</u> words]**

2.8 Do you have any final comments? **[Max. <u>100</u> words]**

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. <u>50</u> words]**

The Salvation Army is a Christian church and registered charity. Founded in the United Kingdom in 1865, we now work in 128 countries. Our aim is to demonstrate Christian love through practical support, offering unconditional friendship and help to people of all backgrounds and needs.

Evidence by Sidney de Haan Centre

1. **What is the current 'state of play' of dementia and music?**

   1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

   1.2 How is this range of activity presently being funded? **[Max. 250 words]**

   1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

   In order to answer this and subsequent questions in section one, the ILC may be interested to read A Choir in Every Care Home, a substantive document prepared for Live Music Now and the Baring Foundation, investigating what is going on in care homes in terms of music and people with dementia (PWD). A follow-up paper is being prepared looking at best practice implementation.
   https://achoirineverycarehome.wordpress.com/

   1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

   1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

   1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

2. **In which direction should the field of dementia and music be moving?**

   2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

   We undertook a highly detailed literature review for A Choir in Every Care Home and the following information is drawn from that. Full referencing can be found in the paper – link below.
   https://achoirineverycarehome.files.wordpress.com/2016/04/wp6-research-review-v2-1.pdf

   - Lesta and Petocz (2006) in an Australian care home noted a marked improvement in mood and social behaviour for people with dementia after participation in group singing programmes, to aid disorientation and agitation at the end of the day, such as participants sitting together, using eye contact, moving to the music, and reminiscing. There was also a significant decrease in non-social behaviour.
   - Svansdottir & Snaedal (2006) report on nursing homes and psychogeriatric wards in Iceland for a small number of patients with moderate to severe dementia and a range of behavioural and psychological symptoms (BPSD). After six weeks, there was a significant

decrease in symptoms rated as activity disturbance, aggressiveness and anxiety in the therapy group.

- Bannan & Montgomery-Smith (2008) report on three exploratory, group singing sessions for people with Alzheimer's (PWA) in a community setting. Participants benefited from being better able to communicate, having a stronger voice after singing, and having improved memory recall, including to learn and perform a new song.
- Wall & Duffy (2010:112) outline that levels of agitation were reduced, including verbally aggressive and non-physically aggressive behaviour through music for people with dementia.
- Skingley & Vella-Burrows (2010:41) explore the benefits of community singing groups, especially for individuals who are socially isolated.
- Sarkamo (2012) illustrates how music is a complex and multi-dimensional stimulus for the brain that not only activates auditory regions, but engages a wide network of temporal, frontal, parietal, cerebellar, and limbic regions. Studies have indicated that music has a powerful effect on improving emotional and cognitive functions in dementia.
- Ueda et al. (2013:639) recommend music therapy for the management of behavioural and psychological symptoms of dementia (BPSD) especially after considering the adverse effects of pharmacological intervention on health.
- Camic et al (2013) found that although people with dementia were deteriorating slowly over the course of the study on all measures (such as mood, behavioural and psychological problems) they and their carers' had high engagement levels, and quality of life remained relatively stable. Qualitative data gave strong support to the group having promoted wellbeing for all participants.
- Vasionyte & Madison (2013:1210) claim music interventions seem to be effective and have the potential of substantially increasing the quality of life for patients with dementia.
- Ells (2014:10) notes that the use of music as a valid nursing intervention can relieve anxiety and depression, help manage pain and improve quality of life.
- Clements-Cortes (2013, 2014, 2015) reports on a series of studies in Toronto, Canada. The qualitative evidence gathered identify five broad benefits: friendship and companionship; ease of engagement, feelings of happiness and being uplifted; feelings of relaxation and reduced anxiety and fun.
- Zeilig et al. (2014:26) notes that feelings of peace may be generated by the participative arts for people with dementia.
- Osman, Tischler and Schneider (2014) found that social inclusiveness and improvements in relationships, memory and mood, plus coping with dementia were found to be especially important to participants (cares and people with dementia).
- Dassa and Amir (2014) found that singing familiar songs elicited significant memories for people with Alzheimer's in middle to late stages of the illness. Although a small sample, conversations relating to the singing became extensive and spontaneous in response to the group singing experience. Furthermore, the group members expressed positive feelings after each singing session, with an increased sense of accomplishment and belonging. Singing served to strengthen the deteriorating capacity of spontaneous speech that is often prevalent in middle to late stage Alzheimer's.

- Ing-Randolph et al. (2015:887) believe that [music therapy] is a safe non-pharmacological intervention that may reduce agitated and distressed behaviour in older people with dementia, and that it is inexpensive and uncomplicated to deliver with strong potential for wide-scale implementation in routine practical settings.
- Ahessy (2016) studied 40 residents in both residential and day care who partook in a music therapy choir in a randomised control trial. He found that depressive symptoms in the music therapy group were reduced by 54%, mean quality of life score improved by 57%, and there was a statistically significant increase in cognitive functioning. All 20 participants in the treatment group felt that singing was good for them, and attributed their positive feelings to the choir; half of them said that feeling lasted all day, and some for a week or more. Participation in the choir made them feel part of the community, improved their mood and made them feel valued, giving purpose in their lives. Interestingly, participants chose to learn new songs, and felt this was the main benefit of the choir.

The benefits of care-giver singing are manifold:

- Clair (1996), studied late-stage people with dementia, who were no longer ambulatory, with no discernible language, and noted that alert responses were more frequent during singing.
- Chatterton, Baker, and Morgan (2010) concluded that 'live' singing to people with dementia may be an under-used but highly accessible resource for their caregivers.
- Davidson and Fedele (2011) found that caregiver group singing for people with dementia improved patient's lucidity, as well as their social interaction.
- Gotell, Brown and Ekman (2003) noted care-giver singing was very effective at drawing out capabilities that appeared to be lost to people with dementia, regaining skills necessary for daily living, and demonstrated that they could perform tasks with intention, purpose, and competence. In 2009, the authors further found that positive emotions were enhanced, and aggressiveness was diminished. Caregiver singing enhanced the sense of sincerity and intimacy in the interaction.
- Hammar et al (including Gotell) (2011), studied how people with dementia and their caregivers express verbal and non-verbal communication and made eye contact during getting dressed each morning. Music therapeutic caregiving (MTC) saw people with dementia mostly respond to caregivers in a composed manner, by being active, compliant, and relaxed, though some were also resistant or incongruent. The authors conclude that MTC could be a way for people with dementia and their caregivers to successfully interact and co-operate during caregiving.
- Särkämö et al (2013) notes how singing and listening to familiar songs improved the emotional state of people with dementia improved clearly: positive emotions (happiness and energy) increased and negative emotions (tiredness, confusion, tenseness, fearfulness) decreased.
- Särkämö et al. (2014) found that caregiver-implemented musical leisure activities, particularly singing, are cognitively and emotionally beneficial especially in the early stages of dementia.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

2.3 Where do we still need to build evidence? **[Max. 250 words]**

It is not so much where evidence is lacking, more so the robustness of evidence itself.

- Vink et al. (2010:12) Cochrane review notes poor reporting and uncertain methodological quality.
- Clift (2012:113) notes a lack of common approach and little attention to developing a coherent model of the mechanisms by which singing could affect health. Little attempt has been made to build a body of knowledge in a coherent way.
- Raglio et al. (2012) identifies the need for:
- Clearer definition of the population of patients and of the type of interventions
- Further studies aimed at identifying which types of dementia have the greatest chances of improvement due to different kinds of music and MT interventions
- Assessment of a possible dose–effect relationship of the different interventions
- Evaluation of the cognitive and physiological aspects, by identifying adequate assessment tools
- More comparative studies on the effects of music therapy versus music
- McDermott et al. (2013) notes there are no high-quality longitudinal studies that demonstrate how and why music therapy might have worked.
- Vasionyte & Madison (2013) claim many studies in this area suffer from poor methodological quality, which limits the reach of meta-analysis
- Ing-Randolph et al. (2015) again add to the litany of methodological critiques offered in earlier reviews.
- Petrovsky et al. (2015:1664-6) review music interventions and their effects on symptoms of anxiety and depression in older people with mild dementia and reiterate the low methodological rigour and the variable quality of studies and the lack of consistent evidence.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Clift and Camic (2015) notes the growth in national and international conferences in the field of Arts and Health. The Royal Society of Public Health operates a Special Interest Group for researchers in the field of arts, health and wellbeing, with the aim to promote the role of robust evaluation and research in establishing arts interventions for health on a secure evidence base. The All Party Parliamentary Group on the matter has recently launched a report on the subject https://www.rsph.org.uk/resources/special-interest-groups/arts-health-wellbeing.html

The Arts Enterprise with a Social Purpose (Aesop) organisation ran the First National Arts and Health Conference and Showcase for Health Decision-Makers at the Southbank Centre in February 2016. This presented 24 creative arts for health initiatives with one of the four strands focusing on the value of arts participation for older people.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

Spiro, Farrant, and Pavlicevic (2015) in the UK Department of Health document, Living Well with Dementia: A National Dementia Strategy argue that both music therapy practices and government strategies on dementia care may benefit from being mutually informed.
The National Institute for Health and Care Excellence (NICE, 2015) published guidelines for the independence and wellbeing of older people. The first tool it highlights for this is group-based activities and the value of 'singing programmes, in particular, those involving a professionally-led community choir' followed by other 'arts, crafts and creative activities'. Thus, the values of singing for the wellbeing of older people has been formally recognised by this national body as supported by robust evidence.

Reagon et al. (2016) note the need for larger, well designed RCTs as well as in-depth qualitative investigation (including longitudinal studies) to explore the mechanisms that underlie positive change through group singing as well as any negative effects. (2016:9)

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

2.7 What should our one, clear message be? **[Max. 100 words]**

Any future studies should follow a model of strict methodology and robust evidence collection if they wish to show the cost effective, socio-economic benefits of music and health.

2.8 Do you have any final comments? **[Max. 100 words]**

There have been hundreds of studies and meta-analysis of data supporting music and health; the next step forward must be to implement the processes into mainstream care and building awareness.

3 Short biography

3.1 Short biography of yourself/your organisations **[Max. 50 words]**

Professor Stephen Clift leads the Sidney De Haan Research Centre for Arts & Health at Canterbury Christ Church University and has published numerous papers on music interventions for the benefit of health in a variety of settings.
Rebekah Gilbert is an Associate of the University who has published several papers with Stephen.
https://www.canterbury.ac.uk/health-and-wellbeing/sidney-de-haan-research-centre/sidney-de-haan-research-centre.aspx

Evidence by Singing for the Brain Hereford

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

There are numerous charities working in this area. Singing for the Brain, run by the Alzheimer's Society, is exclusively for people in the early stages of dementia and their carers, and is run in community settings, using a trained musical facilitator with the support of a Society Co-ordinator. Lost Chord is run for similar reasons and with a similar set-up, but is run in care homes. These sessions vary more, so that people in the later stages of dementia can still benefit from music therapy. Also, people can access the service before they have a dementia diagnosis. Music for Life is also run in day centres and care homes. Golden Oldies uses a more intergenerational approach, as well as rejecting the medical model and appealing to older people across the board in recognition that everyone can benefit from the sessions and that we have a serious problem with so many older people feeling segregated and lonely in their homes in the UK. Live Music Now is Britain's largest music outreach organisation, bringing all styles of live music to people who could not easily access concerts.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

Much of this activity is currently funded through charities. Whilst professionals are involved in most of the delivery, charities are relying more and more on volunteers to facilitate and deliver sessions, compromising the musicality of the session leaders and the time and rigour of session planning.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

Within the Alzheimer's Singing for the Brain alone, there are huge differences in provision, with some areas benefitting from more funding and others expected to run with volunteers. The rigour of the training also varies hugely, as does the format of the sessions. Many charities have been set up in a certain area, such as Lost Chord, which started up in Rotherham. This has spread rapidly in the north of England, and has satellite areas of activity in London and Wales, leaving gaps still to be covered.

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

People with dementia should be given a voice over the outcome and impact, as well as their carers. In my role, I receive constant feedback regarding the impact of Singing for the Brain on the mood, behaviour and communication of people with dementia. The call is strong, and it is for regular sessions with an appropriate number of attendees. Observation is also a good method of assessment. It is easy to overlook the power of music in supporting someone with dementia before having the opportunity to observe the change in outward behaviour, the participation in the singing from someone who otherwise finds communication difficult, and the way in which people quickly find warmth and companionship in such a group.

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

Provision is varied partly due to the differing costs. Venues can be costly for example. Although charities send people into nursing/care homes at a cheaper cost, these people can be cut off from the larger community if they do not have opportunities to go elsewhere. We also have a problem with larger organisations taking a cut towards management costs. This makes the costs unwieldy. However, the alternative of franchised units would run a real risk to the musician delivering the service, especially in harder to reach areas, so that people who are not located in a city who often already lack services, would be unable to afford to sustain support.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

Geographical location is a real barrier, as transport is so expensive and many older people or people living independently with dementia cannot drive. Geographical location also makes it costlier for a session leader to attend. Stigma can also be an issue in some areas, so that a group may not be attended by all those who could benefit because they do not want to be associated with and segregated due to their illness. Singing for the Brain is only aimed at people at a certain stage on their journey. People who have concerns about their memory but have not yet been diagnosed are not eligible. Likewise, there is no follow-on service to refer people to once their dementia becomes too advanced.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

Opportunities are emerging to work more closely with people from different fields. One example is the links being made between the uplifting power of music on both children and people with dementia, and the benefits of having younger people around older people. This holistic approach to music and community is a real opportunity. Professionals working in the field of support for adults with learning disabilities are also realising a need for sharing of expertise. People with a learning disability, and particularly with Down's Syndrome, are statistically much more likely to have dementia. Singing for the Brain has been run as a pilot scheme with groups of people with learning disabilities, with results suggesting a positive impact. New groups are now being run championing the beneficial effect of singing on lung function. These benefits are helpful for everyone across the board, and musical facilitators realise the need to share expertise and to ensure that everyone shares all the benefits of music and singing.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

It is important for charities funding groups to be able to share resources. The regulations can be complex as there is an obligation to those who have donated money to each charity. However, there is a far greater obligation to those who need to access services. There are, for example, transport charities who would happily support people to access more central groups in our area, however they cannot do this due to their commitment to serving the whole population rather than people with a specific condition.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

We still need to build evidence of how people with dementia can live well within our communities. There is still a stigma, and there are still those who fear people with dementia, believing that they may be at a risk of violent behaviour at any point. The more evidence and research, and the more this is presented to the public, the further we can break down these barriers. Also, we need research to discover what younger generations will need and respond to in terms of singing. Community singing has become a smaller part of life over the last sixty years or so, and musical facilitators need to prepare to cater for groups who have listened to different musical styles, as well as for some people who may have only sung when at school.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Music should be offered as a community resource. Although there are those who have been choral singers and who can no longer continue with such a rigorous programme of singing due to their dementia, this should not mean that they cannot sing as part of their community. Groups for older people need to be more individualised to the needs of the specific group. Particularly in the cities, where there is a great need for singing groups amongst the elderly, it will become increasingly important to have a range of singing groups available. This is due to the hugely differing musical backgrounds within society and the type of singing and music which people need to experience. These groups should not be offered to people with specific medical needs however, but to community groups who can then support each other.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

My belief is that charities need to pool their resources and designate money for each area, to be used to reach out to as much of the population as they can. The emphasis needs to be on music for health and community. Communities should be empowered to regulate their own care, but this should not mean the withdrawal of support. Communities should be given support to run groups catering for their needs, with the financial support of charities and also the health service, which will benefit from reduced usage.

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

Charities will need a strong directive to influence them to change policies radically and to make the decision to work alongside other charities to provide services. The health authorities could be key in persuading larger charities to lead the way. Communities need services, but many people are isolated and this makes it difficult to organise a strong persuasive force. Also, people may not know what services they could be accessing. One thing is certain: older people are aware that their services are slowly disappearing, and that they have to pay out for more and more of the beneficial activities and support that help them to maintain health and independence within their communities. They need to be educated and to ask for the changes to take place.

2.7 Do you have any final comments? **[Max. <u>100</u> words]**

Community singing has incredible benefits for individual people's general health and wellbeing, including the health of the brain, lungs and body, communication, reduced isolation and a sense of community support. It is a key to re-energising communities and is an economical way of providing huge benefits to large groups of older (and younger) people.

2.8 Do you have any final comments? **[Max. <u>100</u> words]**

It seems impossible to answer some of the questions about costing services. I believe strongly that music can reach so many people. Many independent charities and bodies are working towards the same end - helping people to find health and happiness. To work separately is also to segregate, and it puts people into artificial groups often based on a medical model, and is also wasteful of limited budgets.

3 Short biography

3.1 Short biography of yourself/your organisations **[Max. <u>50</u> words]**

My name is Sarah Hoyle. I am a trained primary school teacher with twelve years' experience. I am now working as a Singing for the Brain leader and co-ordinator for the Alzheimer's Society. I have been involved in training new leaders, and also in promoting Singing for the Brain.

Evidence by Singing for the Mind Liberal Jewish Synagogue

1. **What is the current 'state of play' of dementia and music?**
(Just us = Singing for the Mind)

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

Singing for the Mind at the Liberal Jewish Synagogue - London NW8. This is a stimulating and social activity, led by a trained singing leader, for people with memory problems and their carers Sessions are run by a singing leader together with specially trained volunteers. Together we aim to reduce social isolation by creating an environment for friendship, enjoyment and mutual aid. Singing for the Mind enhances social activity. A precious sense of community can be restored and brings fun and confidence to lives affected by memory problems. Through music, people share a joy of creating, learning new songs and rekindling memories through old favourites. These sessions can give people with dementia and their carers a more positive view on life.

Sessions are run by a singing leader together with specially trained volunteers. Together we aim to reduce social isolation by creating an environment for friendship, enjoyment and mutual aid. Our warm and friendly group sits together, everyone lending strength to each other and no-one is identified by illness. Here, a precious sense of community may be restored. Singing for the Mind enhances social activity and brings fun and confidence to lives affected by memory problems. Through music, people share a joy of creating, learning new songs and rekindling memories through old favourites. These sessions can give people with dementia and their carers a more positive view on life. Sessions are run by a singing leader together with specially trained volunteers. Together we aim to reduce social isolation by creating an environment for friendship, enjoyment and mutual aid. Our warm and friendly group sits together – everyone lending strength to each other and no-one is identified by illness. Here a precious sense of community may be restored. at venues in the United Kingdom.

Singing for the Mind meets once a week. We have light refreshments and a chat followed by some exercises to warm up our voices. We continue with well-known songs and the occasional simple musical instrument. The session ends with tea and biscuits and a chance to relax among new-found friends.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

Generous sponsors

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

N/K

1.4 What should we consider to be ‘best practice’ in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

Feedback and Audit
Long-term clinical outcome studies

1.5 Is it possible to establish an average ‘unit’ costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

N/K
We have audited accounts

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

1. Limited size of group to keep it personal
2. We require participants to come with a carer, friend or family member. This is not always possible

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

Reduction of stigma. Use the D word
More knowledge
More experience and training opportunities
More activities offered, charities and local authorities

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

Less stigma
More knowledge

2.3 Where do we still need to build evidence? **[Max. 250 words]**

Good research with long-term outcomes

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Whenever possible

2.4 Who should be taking this agenda forwards? **[Max. 250 words]**

Government

2.5 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

Government
Local authorities + charities working together
Voters

2.6 What should our one, clear message be? **[Max. 100 words]**

Music relieves stress and stimulates the brain.
It is a good investment

2.7 Do you have any final comments? **[Max. 100 words]**

Singing for the Mind is a voluntary group within the Liberal Jewish Synagogue NW8. Replies reflect our hands-on experience rather than committee work. We were trained by Alzheimer's Society
For further details of SFM access: http://www.ljs.org/a-place-of-meeting/clubs-and-societies/1969/singing-for-the-mind/

Evidence by Singing for the Brain Gloucestershire

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

In Gloucestershire Alzheimer's Society, we have a very well-established service providing Singing for the Brain sessions for people living with dementia and their carers. These run in community settings, facilitated by a paid service provider, with a (usually) paid singing leader, a local dementia advisor and well-trained volunteers. These run twice a month in each locality covered, to aid continuity and access. The first half hour is an invaluably sociable coffee, cake and chat time where participants chat amongst themselves as well as to volunteers and staff. Chairs are in a circle where everyone is included and takes part as much as they wish. The host welcomes, gives notices, then the SL introduces any themes and begins a gentle vocal warm-up, building-in easy actions, usually bringing a smile and sense of belonging. The SL will walk round the circle while all sing the welcome song and greets every single person by name and in song. Birthdays and anniversaries are also celebrated in song. Clearly printed songbooks are given out, with well-known songs, old and new. The SL encourages singing, even four-part rounds. Instruments or a stretchy friendship band are given out which are fun and enable movement and engagement. Later, slower songs are used but leaders are mindful to choose songs to lift the mood when necessary. Requests and reminiscences are encouraged. A goodbye song is sung with the SL going round the group. People leave in a markedly uplifted mood, looking forward to the next session.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

I have limited knowledge of this; Society staff are salaried and the Singing leaders are paid on a sessional basis with travelling expenses. Participants in the sessions are encouraged to make a donation, but the service is funded by the local office, with funds from the main organisation.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

My understanding is that, currently, each county Alzheimer's Society local office decides on the services it feels are most needed. If Singing for the Brain sessions are offered, they may differ from one area to another, though the SFTB template should ensure that a participant going from one session to one in another area would find familiar elements. Leaders may have different styles and strengths - some play instruments - and most adapt their sessions to the participants, the season, topical issues and the locality. The service is currently under review by Head Office.

1.4 What should we consider to be ‘best practice’ in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

The Alzheimer’s Society regularly visits SFTB sessions to canvass participants’ views on the service. Oral responses are recorded by the assessor and are fed back to all concerned. The popularity of the different elements e.g. using musical instruments, action songs, song choice etc are considered and any requests for changes are discussed. The majority of the responses comment on the service being “uplifting”, “a lifeline”, “highlight of the week”, “great fun”, “so friendly”, “a great place to get help”, “comes to life when she’s singing”.

1.5 Is it possible to establish an average ‘unit’ costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

The discrete cost of the service involves venue hire; the cost of compiling, updating and printing 40 songbooks; one-off purchase of musical instruments with occasional replacements; Singing Leader’s session fee and travelling expenses. A salaried Group Facilitator needs to be host and, ideally, a Dementia Advisor who is working in that ‘patch’ will chat to participants, give out information and make follow-up appointments. A de-brief session at the end gives volunteers a chance to raise any concerns, confidentially. The Dementia Advisor can see many of his/her service users all in one convivial place. The host explains and advertises other appropriate activities so that participants are encouraged to try other sessions, widening their social circle. With groups of 30 to 45 people, it’s very good value per person!

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

Of course, sustainable funding needs to be in place; people would be very upset if they thought the singing session they’ve come to rely on might not be able to continue. I have personally started and led the singing at an additional singing session in my area for the last three years, as the Alzheimer’s Society did not have funds to start up a group. I was aided by a charity to buy my instruments, but we only survive because I do not choose to take a singing leader’s fee and we are given our venue free of charge. Suitable venues in the community, with adequate disabled access, circle space, parking and toilets are not always readily available. We need more easily accessible community centres providing early to late café and room hire, where all members of the family and all abilities can be welcomed.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

I have a personal view, not backed up by a particular study, but formed from many years of relevant experience, that many activities are enhanced by singing and music. There is a deep human need to experience shared music together, from singing lullabies to babies; encouraging and teaching toddlers with rhymes and chants; laughing at funny songs round the camp fire; singing in, or watching an all-consuming musical production; experiencing the improvisation of jazz; relaxing, or singing, at a festival. Like anyone else, a person living with dementia may enjoy some or many of these activities for a very long time, both as an observer and/or as a participant.

But in addition to making sure a person with dementia has access to all these experiences, I believe there may be a way of creating songs for life which can help to reassure, orientate, amuse, soothe and provide opportunities for very gentle exercise or dance. I used to do this for my children, customized bits of familiar songs for my dad, and have noticed that some people respond well to a song they like being linked to an activity that formerly brought anxiety. As well as particular songs for a person, a musical tone of voice and phrasing, as opposed to anything harsh, rushed or monotonous, can all be important, to encourage a person with dementia, and indeed their carer, to feel heard, included and valued. There is a special form of energy and warmth in musicality.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

1) Keep funding the Arts in society so that there are plenty of good, reasonably-priced live musical events for people of all ages to attend in the community: brass bands, Saturday jazz schools, community choirs (my dad came with me as long as he could), ceilidhs, tea dances and dementia-friendly screenings of musical films.
2) In terms of well-being, I believe less money would be needed for blood pressure and depression medication if activities like Singing for the Brain were more readily available – many participants would like there to be a session every week!
3) In the residential sector, I would like all care homes to have specialist music therapists employed as a necessity, not as a luxury, so there are musical activities available on a daily basis for everyone’s benefit i.e. residents, carers, visitors, ancillary staff.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

Conduct MA/ PhD studies on the impact of music on the well-being of people of all ages in communities where there is easy access to live music and a musical culture is encouraged.
Conduct MA/ PhD studies on the impact of music on the well-being of people with dementia, their carers and the volunteers and staff of Singing for the Brain. (Happy staff remain in post productively for longer.)
Conduct MA/ PhD studies on the impact of music on well-being of residents, family, paid carers and all other staff in care homes where there is easy access to live music and a musical culture is encouraged.

Formally assess, with a cohort of volunteers in a study, the impact of Singing for the Brain.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

1) Music should not be seen as a luxury or extra service but as a major therapeutic service for both the person with dementia and their carers, be they members of the family, support workers or residential staff. It should be as readily available as the Memory Cafes.
2) Dementia advisors find the Singing for the Brain service invaluable for meeting people in a feel-good forum where there are good opportunities for discussions with the person living with dementia and their carers, other staff and volunteers.
3) I have a passionate heart for both the person living with dementia and their carer. Taking care of the carer too, will benefit both parties. Music can be for everyone in the room.

2.4 Who should be taking this agenda forwards? **[Max. 250 words]**

Government - find ways to encourage business to sponsor community music to lessen the likelihood of social isolation and propensity to develop memory problems. (Tax relief?)
Teaching Hospitals - research feel-good factor of music on people living with dementia (as evidenced by MRIs?).
Schools - celebrate the importance of music for health! Encourage children to interact musically with people living with dementia, in the community and in residential homes.

2.5 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

Local MPs should be invited to attend Singing for the Brain and, if they see the value - as I think they would - they will then bring pressure to bear on their party leaders to implement change. The money invested in this service would lead to a great deal more happiness.
Local planners need to plan ‘people-friendly’ communities with large accessible community centres with good networks to all the care agencies.
An ambassador for music (or several from different musical genres) could lead a public campaign in the country to recognise how music helps with memory problems.

2.6 What should our one, clear message be? **[Max. 100 words]**

Music can help all of us live and feel better. Take time to listen, sing or play music with a friend or someone you love living with dementia, and feel better together. Find the places in your community where there is music you can enjoy together and let it lift you up!

2.7 Do you have any final comments? **[Max. 100 words]**

Thank you for the opportunity to talk about something so close to my heart. I realise I haven’t conducted any scientific studies myself and haven’t, sadly, been able to train as music therapist because of financial and health restraints, but I’ve seen with my own eyes how music affected my dad when he came to community choir with me; I’ll never forget how he learnt a completely new song, reading the words and holding the tenor line as I sang the alto line beside him. We had never sung like this before he had memory problems but it is one of my dearest memories.

In his care home, we discovered he loved to play the drums in the group music sessions and those times were great sources of happiness for all of us, residents and carers alike - we had a wonderful music therapist. I felt inspired to share this experience and so I asked to train as a Singing for the Brain leader with the Alzheimer's Society and it is now my absolute privilege to lead my groups. I wish there were no such thing as dementia, but what we do with music is good for (nearly) everyone and that's why I want to celebrate singing!

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. 50 words]**

Love music, play recorder, guitar, piano (violin?). Secondary English, Drama teacher. All ages small village school Yorkshire Dales, specialising music. Married jazz drummer. Cared for Dad who lived with dementia in our home and till the end in his care home. Freelance Singing for the Brain leader - Gloucestershire Alzheimer's Society.

Evidence by St Andrews Parish Church

1. What is the current ‘state of play’ of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

St Andrew’s Parish Church of Scotland Carluke has members who offer assistance and support to those with dementia to create Playlists which are personal and meaningful and can be used in a variety of settings. Some Playlists are for people in long term care, some are for those in their own home. ‘Detective work’ for the playlist may be at church or in someone’s home. A group of members also lead worship with singing in a local care home where many have dementia. A local special needs primary school visits our drop-in to sing, so our work is also intergenerational.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

Just under £1000 funding to purchase some iPod shuffles, headphones, splitter cables and iTunes vouchers was secured through application to the Aviva Community Fund. This involved getting as many people as possible to vote online for our project. Other funding is drawn through local and regional Church support and by small donations to the Drop in Support run twice monthly in our Church hall. Church members provide voluntary assistance.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

1.4 What should we consider to be ‘best practice’ in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

Measurement of outcomes has to be through feedback from people and families – either written or recorded.

1.5 Is it possible to establish an average ‘unit’ costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

No – costs will vary depending on requirements for individual which can vary greatly.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

Time commitment of volunteers and funding for equipment. Doing ‘detective work’ can be time consuming and so if paid staff are doing this it will be costly.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

Playlists – and using them therapeutically
Singing groups being developed in local areas which may be intergenerational
Links made with schools, churches and music therapists

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

Education, training and the experience of seeing the effects of music and personalised playlists. Playlists in nursing homes demands staff time and therefore investment.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Music works as part of integrated activity. A local special needs primary school comes to sing for our drop-in-support users, and this provides intergenerational activity using singing and allowing children with learning difficulties to share their love of music and enthusiasm with their audience who are always appreciative. It benefits all. Nursing homes could develop the use of therapeutic music and playlists which can see dependency of medication lessened.

2.4 Who should be taking this agenda forwards? **[Max. 250 words]**

Hospitals, care homes, churches and faith communities, schools, community organisations i.e. all those who have an interested in offering quality support and care for those with dementia in the community and in hospitals and care homes.

2.5 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

2.6 What should our one, clear message be? **[Max. <u>100</u> words]**

The use of music for those with dementia has a therapeutic effect, allows families to be actively involved in doing something positive to assist their loved one and is an intergenerational activity which breaks down barriers when communication can be challenging

2.7 Do you have any final comments? **[Max. <u>100</u> words]**

Churches should be included as they often have outreach to those with dementia either directly or indirectly.

Evidence by St Monica Trust

1. What is the current ‘state of play’ of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

There are a variety of music related interventions used across St Monica Trust for residents living with dementia in our residential / nursing services. Musical memories is a similar activity to the Alzheimer Society ‘Singing for the Brain’, which we conduct ourselves, as well as screenings of concerts (such as Andre Rieu) or musicals projected onto a large screen, or live music evenings.

Alzheimer Café’s - we also incorporate music at both the beginning and end of the session. We also use iPads and headphones for more 1:1 connection for people in the later stages of dementia.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

By St Monica Trust itself

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

Not applicable

1.4 What should we consider to be ‘best practice’ in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

Observational techniques on the impact for people, such as monitoring the person’s level of engagement, emotion, singing, foot tapping, and facial expression. Impact of the music on word forming and the ability to recall words to songs, where there may be little other verbal communication etc.

1.5 Is it possible to establish an average ‘unit’ costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

We currently include these activities within the allocated budget. The biggest outlay is the technical equipment used to support the activity such as projectors, iPads, music players etc., There is also the often-un-costed time of choosing and selecting the appropriate music / apps etc.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

The use of technology is increasing the ability to engage at different levels and stages of dementia. Wireless headphones can be used for an individual to have a very meaningful musical encounter, if the music chosen has meaning and context for them. iPads, and apps can help people to engage with music without the need to travel a long way, as transport is often an issue for people.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

We often struggle with the funding to buy the equipment, and I am sure that we are not alone. There is also a range of technical knowledge and ability of carers – both paid and unpaid which can mean that technology is not used to its fullest extent. Music licensing is often unclear as well as to what constitutes a 'pubic performance' and this can dissuade some people from using music at some gatherings.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

In the impact that music has on the later stages of dementia.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

2.4 Who should be taking this agenda forwards? **[Max. 250 words]**

2.5 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

Funding agencies and developers of apps / music streaming services and downloads to increase the availability and usability of musical related technology.

2.6 What should our one, clear message be? **[Max. 100 words]**

That music has a demonstrable and positive impact on a large majority of people living with dementia.

2.7 Do you have any final comments? **[Max. 100 words]**

In my experience music can have a profound and positive impact on large numbers of people with dementia, particularly those with vascular and Alzheimer type dementia's rather than frontal lobe dementia where there is not always the same level of engagement. The impact of a person with dementia who is communicating verbally through singing, when the person otherwise has problems with word finding and verbal communication. It is equally important though that the music chosen has meaning and context for the individual to engage.

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. 50 words]**

I am the Dementia Lead for St Monica Trust, a charity that proves care, support and accommodation for older people. I have extensive practical and strategic experience of working with people with dementia and designing high quality dementia services. I work closely with Skills for Care as a former Board Member, and current South West network member.

Evidence by Stirling University

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

A survey was conducted by colleagues at the University of Stirling (Reynish and Greasley-Adams 2015) with 106 carers, musicians and academics, mainly from the UK, asking about music and dementia. They found a broad range of activities in different settings.

In hospitals the following took place: Unnamed musical programme where musicians attend sessions in wards, 'Music in Hospitals'/'Music in Hospitals Scotland', Music Therapy and impromptu singing and playing CDs.

In care homes: live musicians, 'Playlists for life', informal music and singing and karaoke. In the community there were more examples: Unnamed Community singing sessions, Singing for the Brain, Musical Memories/musical minds, Music therapy, Choirs for people with dementia, Luminate festival events (Scottish Arts and ageing festival), Singing Together, Silver notes, Silver brain, Scottish Opera , Scottish Chamber Orchestra, Big Sing, Beat it Percussion, and going to theatre to listen to bands.

Reynish, E. and Greasley-Adams, C. (2015) Music and Dementia: Development of a Conceptual Framework. A Report for the Life Change Trust. Available at: http://www.lifechangestrust.org.uk/sites/default/files/Music%20and%20Dementia%20Conceptual%20Framework%20FINAL%20REPORT%20JUNE%202015.pdf [Accessed 30/08/17]

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

This was not clear from the survey but 39 respondents identified funding as a barrier to providing music for people with dementia.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

The evidence here follows an evaluation of a musical project for people with dementia and their carers (McCabe et al. 2015). For this project, the collection of qualitative data was important to ascertain the more subjective experiences and outcomes for both carers and people with dementia. In the opera project, in-depth interviews were undertaken with people with dementia, their carers and the staff and volunteers who worked on the project. These interviews allowed us to understand the different experiences, and also how the experiences of different groups interacted and influenced each other. While there were common experiences and outcomes noted there were also individual differences that were explained through the qualitative data that might have been missed without this.

McCabe, L., Greasley-Adams, C. and Goodson, K. (2015) 'What I want to do is get half a dozen of them and go and see Simon Cowell' reflecting on participation and outcomes for people with dementia taking part in a creative musical project, Dementia, vol. 14, 6: pp. 734-750.

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

The survey (Reynish and Greasley-Adams 2015) identified several potential challenges and barriers. Unsurprisingly, the main barriers identified were financial but practical challenges were also noted such as finding the right people to deliver an activity or intervention. Those providing music activities need to have awareness of those taking part and understand that not everyone will like all kinds of music or musical activity. It can be difficult to achieve an individual approach and it is also possible that musical activities can have a negative impact on participants.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

There is increasing recognition of the contribution made by people with dementia in their own and others' lives, and so peer-led music activities that are self-sustaining are an important part of how things might develop from now.
The potential of volunteers is also under-researched in dementia care but it is clear that there are many volunteers engaged in different ways in dementia care. A recent project completed at the University of Stirling highlights the huge potential of volunteers as well as the challenges in the support and retention of volunteers in dementia care (McCall et al 2017, see www.asume.co.uk). Many of the volunteers in this project were involved with music-related projects such as dancing, choirs and 'Singing for the Brain.'
Self-sustaining projects within communities and settings such as care homes are important areas to develop.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

By promoting knowledge-transfer from examples of best practice who can share how and why they have been successful and help others set up similar projects.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

We need to build evidence on knowledge transfer that would enable successful projects to share their work and support others to initiate new projects. We know that music has a range of benefits, the barriers are in the implementation of sustainable programmes.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

2.7 What should our one, clear message be? **[Max. <u>100</u> words]**

2.8 Do you have any final comments? **[Max. <u>100</u> words]**

It is important that music interventions/activities are not time-limited and that, if people gain benefit from the activity, it is not withdrawn at the end of a research project or funding scheme. This can only be achieved through more integrated activities that are part of community life, whether people are living at home or in institutional settings.

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. <u>50</u> words]**

Louise McCabe, Senior lecturer in dementia studies with twenty years of experience in dementia care practice and research and significant experience of qualitative research that engages with people with dementia and their carers. The School of Social Sciences, University of Stirling has an international reputation for dementia research and service development.

Evidence by Turtle Key Arts

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

Sessions singing existing songs e.g.: music facilitators in care homes or Singing for the Brain in the community.
Creative music sessions in the community e.g.: our project Turtle Song (ETO, RCM, Turtle Key Arts) where participants create their own songs (lyrics and music) , also many opera companies and orchestras around the UK have interactive creative projects running.
One to one/ music therapy sessions e.g.: Music for Life at Wigmore Hall or other music therapy organisations.
Concerts or other sharings and relaxed performances open to people with dementia

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

The projects that we run at Turtle Key are mainly funded through public and private funders e.g.: Arts Council/local councils or foundations including: Henry Smith Charity, Rothschild Foundation, Headley Trust (Sainsbury), Swire Trust, Scouloudi Foundation and others. We also get funding from individuals (often family members of previous participants). We have collaborated with the NHS but have never had any funding through them. I know that there are some projects – particularly in care homes – that have received funding through the health sector.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

There are big differences between rural and urban environments since many of the arts providers are in cities. Transport is a big issue for people with dementia and if they are in an isolated area then there is no way to get to places that provide projects. Therefore, transport needs to be built into project budgeting. However, even in cities the dementia organisations/ health providers often don't recognise the value of the work and therefore don't pass on opportunities to their members/patients.

In our experience, over the last ten years in very different parts of the country, provision still often relies on engaged professionals and good communication networks more than on specific funding e.g.: the Alzheimer's Society in one area can be an invaluable partner whereas in another they are completely unhelpful.

1.4 What should we consider to be ‘best practice’ in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

There are many fairly good evaluation tools in use at the moment for arts projects, but evaluation is easily flawed since some feedback understandably comes from carers rather than people with dementia and it is hard to collect hard data from an arts intervention.

We feel that our sharings and the films of the projects double as a memory for participants and a very visible measurement of outcomes and impacts – these also include direct comments from participants.

We like to learn from evaluations and welcome more in-depth work by others (recently a psychologist from Goldsmiths) but would not be able to afford to have those skills with the team for every project – however if there was a way of feeding in specific data to a national evaluation database then we would be happy to do that.

1.5 Is it possible to establish an average ‘unit’ costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words**

We know our unit cost (roughly £30/£40 per person per week) and our projects are always free to participants.
Coming from an Arts organisation, we are not best placed to establish how this can be mapped against outcomes more generally, but we have much anecdotal evidence of less need for medical or psychological intervention following on from our projects.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

Communication – in this new world of new methods of communication, it is extremely hard to reach people with dementia who are living in the community. Unless there is a specific charity that takes up the cause (e.g.: Young People with Dementia in Reading or Young Dementia UK in Oxford) information is not passed on by organisations or doctors or other health groups to potential participants. Certain individuals in professions like Occupational therapists can be a wonderful resource but it can be hard to find them within large NHS organisations.

Transport – for people with dementia, travelling outside of their home can become a very scary proposition. Without transport run by trained, helpful and friendly people, it can be impossible to attend projects or events.

Parking and access – people may have their own transport, but if they have any mobility issues or the inevitable anxiety, then knowing that you can park at the destination is a major concern. Equally many people may need good access, decent disabled toilets and friendly staff who understand the need to be helpful and not patronising.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

The UK has an enviable wealth of music venues, orchestras, universities and music conservatoires and all of the artists that perform or study in these – most of them are publicly funded in some way. Many of these are already involved in outreach work, but more can still be done to train people and roll out the work to every corner of the country.

The digital opportunities for playlists etc are really important and very simple to roll out nowadays, but that is still a very different opportunity to going to an Arts building or spending time with music students or musicians.

We have persuaded a number of universities to see our projects as an opportunity to teach their students how they can use their music skills in a different way and to give them different career opportunities. At Oxford University this has resulted in students applying for music in the community MA courses and graduates of our projects have started their own groups.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

Communication – I believe that if health and charity workers are convinced by a more extensive campaign that they should take up opportunities that come their way rather than seeing them as extra work, then the time that arts organisations spend recruiting would be spared and musicians and artists can concentrate on delivering the best work rather than finding the participants.
Transport – many towns and areas already have good community bus projects, and these need to be supported and encouraged. There may be ways of also working with local taxi firms in areas who already provide transport for hospitals etc who are already trained and able to pick up more vulnerable people in their area.
Parking and access – this is usually about flexibility of organisations e.g.: universities allowing more people in on that particular day or giving participants free car parking vouchers. In town centres, the local car park may also be persuaded to help during the course of a project. Access in most arts venues is already good but it may just be good to give all staff a dementia training session (e.g.: by Dementia friends) to ensure their understanding.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

We are quite interested in why being creative (i.e.: writing the music and lyrics) is different from just singing songs from the past or listening to music. Creativity does not rely on memory and yet the pride in creating something new at a time when a person seems to be failing in many areas seems to be extremely empowering

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Interventions can definitely collaborate with memory cafes or other groups that meet regularly through Adult Mental Health Teams.
Groups could be persuaded to meet in local arts spaces which would create this link automatically e.g.: West Yorkshire Playhouse have one day per week where older people use the building for many different arts activities.
Music on prescription has been trialled by some GPs and this is another good way of embedding music in local community thinking.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

I think it would have to be a partnership between health professionals and the arts – there have been similar initiatives on a wider basis e.g.: Aesop or the National Arts and Health Alliance. For dementia-specific work it would also need to get the large national charities on board.
The larger opera companies, music organisations and orchestras are already doing a lot of good work. If they can collaborate with other smaller, more rural artists and organisations then the work can be spread much further.
One organisation would probably have to lead on the agenda to ensure that all those involved do carry out work. I would suggest that this be an organisation that understands both arts and health agendas.

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

The Health Secretary and Health department.
The Arts Council
Music conservatoires and universities that teach music
Opera companies, orchestras, music organisations and venues.

2.7 What should our one, clear message be? **[Max. 100 words]**

Research and experience have proven that music interventions have a positive effect on people living with dementia – we aim to provide access to high quality music projects in all parts of the country and to ensure that people living with dementia and their families are aware of the benefits of music and get support to come along to projects.

2.8 Do you have any final comments? **[Max. 100 words]**

We have been running our projects specifically for dementia for over 10 years and the awareness around dementia has increased immeasurably during that time. Music often in tandem with other artforms e.g.: dance, drama, film, puppetry or poetry does have a profound effect on those living with the condition. There has been a great deal of good research to underpin this. If arts providers were empowered to deliver good art work without constantly having to prove the same facts and if they felt they were not all competing for the same funds but rather were encouraged to collaborate with each other then it would be far easier to reach the goal of access to music for all those affected.

Evidence by University of Worcester

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

Therapy, music for health, community music and lay music (family members and friends) are the main strands of music activity currently being used for and by people living with dementia. All of these strands may incorporate live or recorded music. Music therapists undergo considerable training and certification towards providing goal-oriented improvements in emotional wellbeing of people within all health settings including for those living with dementia. Music practitioners may or may not have training, and training is often specifically targeted at specific health areas such as end of life or dementia. Practitioners are generally less goal specific when working with people living with dementia – focusing more on using music to foster engagement and the basic human needs all-too-often lacking for people who are living with dementia (Kitwood, 1997) in the moment.

Music therapists and music practitioners provide music for individuals and for groups. Music can be used in an 'active' form wherein the recipient(s) are encouraged to interact with the music by singing, moving, or co-creating, or in a 'receptive' form wherein the recipient(s) are encouraged to simply listen to music and are free to respond in any way they choose/are able.
Music used for people living with dementia can be familiar music of all genres (country, classical, folk, popular, etc.), improvisational, or music that is not necessarily familiar to the recipient(s).

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

Funding generally comes via private sources, some care homes provide some funding, and funding also is generated through research grants, and some (not many) research grants – generally, this means that music interventions are only offered for a limited length of time as predicated by the design of the funded research project.

People with dementia who are living within the community generally rely on charities and private funding in order to have access to music – particularly live music, unless they are fortunate enough to have connections to family/friends who are musicians.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

Although there are different care commissioning standards within the different regions of the UK, care providers are often keen to incorporate provision and access to music as a sign of quality care.

However, there are no explicit guidelines on the topic of music provision and the incorporation of music in care planning.

One example of regional differences in provision of music for people with dementia is the Alzheimer's Society's 'Singing for the Brain', which is provided on a regional locality basis, meaning that some regional localities have several groups while others have none. There are likely numerous other examples of regional differences regarding provision music for people who have dementia within the UK. From the experience of the Association for Dementia Studies, we have observed that different providers will adapt the music according to the cultural, spiritual, regional, and age of the client group they are supporting.

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

The issue of 'best practice' for measuring the outcomes and impacts of, in this particular case music, for people living with dementia remains relatively elusive. The primary barrier is the heterogeneity of people living with dementia, which requires whomever is providing music to have the ability to respond to often nonverbal cues of each recipient in the moment. Thus, although there is growing research in this area, it remains predominantly qualitative (i.e. textual rather than numerical), and includes small cohorts of participants.

Recognising that medical organisations require bottom-line numerical/financial measures, perhaps the most effect numerical/large-scale outcomes can be generated from measurements in terms of changes in medication dosages, reductions in hospital admissions, and perhaps falls etc. However, there will always be a need to incorporate researcher/carer observations, interviews and self-reports from people with dementia whenever possible, as well as interviews with family members, carers, and others connected to the music interventions – these more qualitative measures should focus on positive psychology outcomes and wellbeing.

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

This again is quite difficult to agree upon as there is such heterogeneity amongst the population regarding personalities, forms and degree of dementias, the extensive changeability of dementia, and the wide variability of music and of those who would be providing music. This is where the importance of funding suitable training for all people who might provide either live or recorded music to a person with dementia is very important. So that there is a guaranteed safeguarding in place, each person delivering music will have a clear working knowledge of nonverbal communication and cues and different forms of dementia.
One example of what an average 'unit' might cost for group music activity for people with dementia, can be extrapolated through findings of an RCT focusing on the cost-effectiveness of community singing on mental health-related quality of life of older people (Coulton et al. 2014). This study estimated that the average cost per participant in a singing group was £18.88 per session. But of course, this figure will vary considerably depending on the size of group, the costs for the musician(s) involved, costs for venues, etc.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

Funding and education. Relative to medication, music – even live-music costs considerably less. Also, the structure of the care sector (e.g. financial insecurity, training of healthcare staff etc.), as well as chronic underfunding of health and social care pose considerable barriers to extensive uptake of music activities. There is a need for greater dissemination of the benefits of music with people who have dementia for medical professionals, care institutions, hospitals, hospices, and the general public.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

There is great need for more appropriately trained musicians to work within this population. There is a lack of knowledge and therefore some trepidation on the part of many musicians regarding dementia, and a lack of an agreed upon method of providing basic training to musicians and the general public. To this end, those organisations that currently provide in-house trainings for musicians/the general public should be called-upon to create an agreed-upon recognised form of training which ensures a basic knowledge of the various forms of dementias, nonverbal communication, working within various institutional settings (care/nursing homes; hospitals; hospices; acute care settings; private homes), and which includes – and this is very important - mentorship, internship, and ongoing training and support for all trainees.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

Greater dissemination regarding the benefits (i.e. improvements in engagement, connection, interaction, occupation, identity, evocation of memories, etc.) for people with all types and levels of dementia, as well as its ability to be taken to persons who may have mobility problems. Also, highlighting the lack of risks (particularly if each person providing music has been appropriately trained), and the comparative low-cost – particularly as compared with medications etc. It is also imperative that policy makers in government, as well as higher-ups in the medical professions, be educated regarding the above, as they will be the gate-keepers – important to also emphasise the benefits for staff/professional carers/family carers regarding connection, mood elevation, and general wellbeing for all who are involved. Advocacy through policy groups such as the 'All Party Parliamentary Group for Arts Health and Wellbeing' is also very important.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

Ongoing research is still needed in all areas connected with the impacts of music for people living with dementia. Research is also needed to measure/understand the beneficial impacts of appropriate training for music practitioners. To this end, it would be very helpful if leading researchers with expertise in this particular field of research be brought together to review present methods of collecting evidence, and to create an agreed upon standardised method of collecting evidence for a protracted period of time, towards pooling evidence from necessarily small research projects looking at the impacts of various forms of music interventions on people who are living with dementia.

Currently, seed-funding for a Doctoral Training Centre focusing on researching the creative arts and dementia was provided by the Alzheimer's Society to the University of Worcester and the University of Nottingham. The Arts and Dementia (TAnDem) began with four funded PhD studentships in 2015, with each university supporting one additional studentship starting in 2016, bringing the total to six. These PhD studentships are providing the necessary deep understanding of how best to provide the arts for people living with dementia, and hopefully more such studentships will be funded.

2.4 How can/ should we align music interventions with other areas of work in the dementia space?

Yes, we should align music interventions with other areas of work within the dementia space. This can be done through dissemination/education. Also, there is undoubtedly knowledge from research looking at other art forms (e.g. drama, dance, poetry, visual art, etc.), and other forms of activities (e.g. nature, sports, etc.) provided for people with dementia, as well as from the use of music and perhaps other arts/activities within other similarly difficult to reach populations (e.g. autism, mental illness, brain injury, stroke, etc.).

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

Researchers and practitioners/therapists specialising in the field of music for people with dementia; also, policy makers, medical professionals, staff, people with dementia and their family and friends who have experienced the benefits of music.

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

Policy makers, medical professionals and staff, institutional managers, media and press, social care professionals including social workers, commissioners of health and social care services, arts organisations, people with dementia, supporters of people with dementia. Also, music conservatories and other such institutions regarding the importance of training students for this valuable work, while also enriching their ability to communicate through their music. Also grant funders towards increased collaborative research as discussed previously (see question 2.3).

2.7 What should our one, clear message be? **[Max. 100 words]**

Music of all kinds – particularly live, but also recorded - can be of invaluable benefit to people living with all forms and levels of dementia, as well as for those who support and care for them. This is because music can reach people for whom verbal communication may have diminished or disappeared entirely. Music can provide occupation, identity, connection, engagement, and interaction for all who are involved – whether in active participatory music-making, or receptive music listening. Music has the ability to transport people into the past and also out of time entirely – 'removing' people from their current realities.

2.8 Do you have any final comments? **[Max. 100 words]**

Those of us working in The Arts and Dementia (TAnDem) doctoral training centre and the Creative Arts research cluster within the Association for Dementia Studies (ADS) at the University of Worcester thank you for providing this platform for expressing what we are dedicated to - providing quality research towards improving the lives of people living with dementia who are often especially difficult to reach, and thus are generally isolated and marginalised within society as well as within their own smaller communities. The thoughtfulness of these questions provides hope that substantial improved change and thus increased support is at hand.

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. 50 words]**

The Association for Dementia Studies is an active research and education centre. Our multi-professional team are experts in the field of person-centred dementia care and support, making cutting-edge contributions to building evidence-based practical ways of working with people living with dementia and their families through research, education, consultancy and scholarship.

Evidence by Wigmore Hall Learning

1. What is the current 'state of play' of dementia and music?

1.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

Music for Life is a pioneering programme for people living with dementia and their families, friends and carers. The project was founded in 1993 by Linda Rose and has been led by Wigmore Hall since 2009. Over the years, the programme has developed from working primarily in care settings to also include a range of projects and events in community settings and at the Hall itself. The work is delivered by a team of experienced professional musicians who continually shape the programme in response to those who take part.

Through established projects in care settings, musicians improvise music alongside people living with dementia and their care staff over the course of 8 weeks, with an emphasis on valuing everyone's contributions equally. This process enables creative communication with people with advanced dementia, drawing out their individuality and empowering them to make choices and express themselves. Care staff are also encouraged to build their skills and confidence, expanding their understanding of person-centred care through experiential learning and reflection.

Through our expanding programme of projects and events in community settings and at the Hall, we provide opportunities for people living with dementia to share experiences alongside their family, friends and carers. In January 2017, we launched a new community choir for families living with dementia in partnership with Westminster Arts. In addition, we are delighted to have started developing a new project alongside people with young onset dementia and their families, friends and carers in partnership with Dementia Pathfinders.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

Music for Life is funded through support from trusts and foundations, individual donors, partner setting contributions and commissions from Clinical Commissioning Groups.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

Music for Life projects are delivered across London in addition to providing training and support for organisations, including CBSO and Saffron Hall, and individuals further afield in order to share learning and expand the reach of the work. This has included accredited musician training programmes and multiple research projects in the UK and The Netherlands.

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

We utilise a combination of methods to acquire qualitative and quantitative data, ensuring we have a rich and wide-ranging set of information. After each Music for Life session, there is a reflective debrief which allows the team to share and explore thoughts and ideas together. This provides an opportunity to constantly assess how the project is working and think about ways of responding and adapting to those involved in each project. We aim to create a space in which everyone can contribute in whatever way is meaningful for them, celebrating what it is that makes each of us unique. This looks different for each person and, as a result, means that the outcomes and impact will change from project to project. Information is gathered in a report written up by the dementia facilitator which can then be used be staff to share the learning of the project more widely within the setting. In addition, we are committed to being involved in research projects and have contributed to publications including 'While the Music Lasts', a book on research into the practice of Music for Life. More recently we have been involved with research projects with Created Out of Mind through the residency at the Wellcome Collection.

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

When working in care settings, it is sometimes difficult to ensure consistent staff attendance over an 8-week period as there are increasing demands on time and the number of staff that need to be on duty at any point. Each project requires commitment and investment in terms of time and energy and, as a result, it can be difficult to deliver projects unless there is the commitment to this from management at the outset.

The cost of each project is significant too, and knowledge and expertise are needed for delivery, which means that it would be difficult to replicate this type of activity on a larger scale without compromising the integrity of what is being delivered. It takes time to develop a team of people who are able to work in this way and this cannot be rushed.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

Music for Life works in a person-centred way and, as a result, the programme continues to evolve as gaps in provision become apparent and needs change. We are currently developing projects alongside people living with young onset dementia and their families, friends and carers as there was an identified gap in provision. In addition, we recently launched our first community choir for families living with dementia, in response to the growing need for more ongoing activity. We are currently exploring the concept of co-creation through long term residencies within care settings, which would allow for more responsive and integrated collaboration.

Beyond this, there is the opportunity to shift perceptions of what is thought possible and to influence cultural and social attitudes.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

By having an open dialogue with staff and management and trying to find ways that we can adapt, in order to provide the most benefit for each setting. In order to ensure the legacy of each project, there are certain things that need to be in place but it is equally important for us to contribute where we can to any identified needs within each setting.

We are committed to sharing the learning from our projects and to training new musicians. This allows the work to reach further than we would be able to deliver it ourselves and creates a larger body of people who are exploring and sharing ideas in this way.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

2.4 How can/ should we align music interventions with other areas of work in the dementia space? [Max. 250 words]

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

2.6 Who needs to be influenced and brought on board, to further this agenda? [Max. 250 words]

2.7 What should our one, clear message be? **[Max. 100 words]**

We believe that dementia should not stop people from doing the things they love, or from trying new things. Wigmore Hall is committed to this goal: helping to build a dementia-friendly society and enabling people living with dementia to continue accessing high-quality, life-enriching musical experiences.

When you create a space where there is a freedom of creative expression, you open up new possibilities. This can transcend any label or diagnosis, and provide opportunities to connect and communicate on a human level in whatever way is most authentic and meaningful.

2.8 Do you have any final comments? **[Max. 100 words]**

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. <u>50</u> words]**

Wigmore Hall is passionate about the impact music can have on our lives and on our society. Through a wide range of projects and events, the Learning programme provides opportunities for people of all ages, background and abilities to engage in high-quality, creative music making in a meaningful way.

Evidence by Wishing Well

1. What is the current 'state of play' of dementia and music?

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

Activities are delivered by a range of practitioners including therapists, community musicians and volunteers in community, care and healthcare settings with a high proportion of work targeting people living with the earlier stages of dementia.

Activities range across a spectrum from entertainment to active participation, from artist-led to person-centred, from reminiscence to the creation of new music and creative improvisation. Health or Care staff may lead music groups, often supported by recorded music which may or may not be personalised.

The Rhythmix, Wishing Well programme reaches across Sussex and Surrey, bringing live participatory music making into healthcare settings. We currently partner with 7 NHS Trusts and work in psychiatric assessment wards, community and acute hospitals.

Key features:

- we create person-centred interactions at patients' bedsides and in group sessions and include families and staff in our music making.
- work is delivered by professional Musicians in Healthcare, trained by Rhythmix to work in acute settings with people with dementia. Training includes a 5-day Foundation course, 2 days of music and dementia training and a year-long apprenticeship with ongoing CPD.
- we work in partnership with healthcare professionals; occupational therapists, nursing staff and doctors to deliver and evaluate our work. We aim to be a resource for each ward we work on, gently
- altering the hospital soundscape while the everyday work on the ward carries on around us.
- we measure our impact through identifiable outcomes; reducing anxiety, reducing isolation and increasing self-expression through participation in the arts.

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

Work is sustained through short term grants from Trusts and Foundation, commissions from Public Health and CCGs, public donations, research grants and in some cases, through NHS core funds.

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

We can't comment on the wider field of music and dementia but we are co-founder members of the National Alliance of Musicians in Healthcare. Many of our members are working with people with dementia in both community, health and social care settings: http://www.namih.org/

1.4 What should we consider to be ‘best practice’ in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

It is important to measure the impact not only on the person with dementia but on families/carers, professionals involved in care and the musicians/organisations delivering the activity. At our recent NAMIH conference in July, Karen Deeny (Patient Experience Lead for NHS England) talked about the interconnectedness of staff and patient wellbeing; measuring outcomes for both are important.

Wishing Well was part of a Feasibility Study led by Sussex Community NHS Foundation Trust, investigating the impact of live music making on patient wellbeing and staff/patient engagement levels in a community hospital setting. Results are due to be published in November 2017.

The following tools were used and demonstrate good practice in using a variety of methods to capture verbal and nonverbal feedback/responses from participants and the impact on the whole community involved in the intervention:

- Dementia Care mapping: a very effective way of capturing the difference that participation in music made to wellbeing and engagement levels as mapping was carried out before and immediately after sessions.
- Structured interviews with Healthcare assistants and Nursing Staff. (film and audio). Also, effective in gathering open and clear dialogue (positive and negative)
- Demqual evaluation forms (filled out by HCAs on behalf of patients). These were less useful perhaps due to differing perceptions of what differing levels of well or ill being might look like.
- Musicians kept reflective journals and compiled regular reports including feedback they had received, case studies, perceived outcomes and personal impact.

1.5 Is it possible to establish an average ‘unit’ costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

It would be possible to create average unit costs, but the mapping of these against outcomes would present significant challenges. Establishing a best practice guide that maps specific outcomes against their local unit costs might be a way to create such a document over time.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

The main barriers include:

Lack of funding, in particular, sustainable sources of income that prevent organisations having to repeatedly apply for relatively short-term grants that make planning difficult.

Lack of support for organisations in delivering training and ongoing CPD for their workforce.

Our experience is that support for music based interventions is very high in healthcare settings amongst staff working “on the ground” who witness the impact that music making has on patients and families. However, culture change is needed within NHS Trusts for music making to be seen as a necessary part of care for people with dementia.

2. In which direction should the field of dementia and music be moving?

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

- Musicians, appropriately trained to work in acute settings are a highly valuable resource for hospital settings caring for people with dementia. Our evaluations demonstrate improved social cohesion in assessment wards, increased engagement, participation and self-expression on hospital wards. We have numerous case studies of anxious behaviour being calmed by the skill and responsive playing of our musicians, avoiding the need for further de-escalation by nursing staff. Healthcare staff report that after 2 hours of music making in the afternoon, the ward feels calmer for the rest of the day.
- Music can be used as an education tool for healthcare professionals and undergraduates. Music making can demonstrate principles such as person-centred care and can help staff build rapport with their patients. Music helps to reveal personality, people's tastes and background. Lucy Frost, Dementia Lead for Sussex Community Trust told us "when we have rapport with people we can look after them better. Music helps us do that", Students can learn valuable and transferable skills from engaging with this field; empathy, problem solving, communication skills and many more.
- Music can act like a glue to help hold the family unit together at every stage of dementia from encouraging participation in community choirs to helping families maintain a connection even in the very last moments of life.

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

The respective fields of Arts and Health would benefit from taking steps towards each other to create mutual understanding and collaborative working. As an arts organisation, we understand the need for robust evaluation (for internal learning as well as for advocacy and income generation) but our evidence can be overlooked by Health and deemed less robust than clinical research. Health organisations need to understand that challenge of capturing outcomes from music interventions in a clinical trial, particularly when working with people with dementia who may be living with co-morbidities. If more value were placed in the extensive practice examples and case studies generated by this work, budget holders within the NHS may have more confidence in supporting music as part of care pathways.

2.3 Where do we still need to build evidence? **[Max. 250 words]**

A huge body of evidence already exists in this field to demonstrate the positive impact of music; huge amounts of anecdotal evidence, practice examples and case studies as well as robust academic studies. It is important to consider the burden of continually building evidence (certainly in academic terms) on organisations such as ours whose primary concern is in making sure people with dementia actually get to take part in something meaningful.

With significant cost restraints within the NHS, cost effectiveness versus outcomes is a key impact area that needs additional evidence. If the need for clinical interventions is reduced by creative activity, evidence that directly tracks the saving in those costs against the cost of the activity would be an important additional element.

There is a need for evidence which is specifically public facing and robustly tied to clinical outcomes or cost savings in an atmosphere in which any expenditure on arts or creativity might attract media criticism. While public sector wages are suppressed as a means of cutting the overall health bill, a story about the frivolous nature of creative activity can significantly damage public support. We need to build evidence which can describe with clarity the specific health and clinical outcomes so that we can combat the impression that cultural work is an 'add on'.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Work in this field already interacts with other cultural and creative activity, either through an organic, natural process (there is music, so there is likely to be dancing) or through a specifically designed intervention (such as asking people to design a poster about the music taking place). The music-making we do already includes interaction with technology. More formal interactivity could be designed; we undertake a great deal of cross artform work in other areas of our delivery.

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

The National Alliance for Musicians in Healthcare is a network of organisations and individuals working in this sector. A grouping of the members working in dementia could provide a good source of evidence and test case studies to develop more evidence. The organisation should be developed and supported to bring forward this evidence, and to further its network of practitioners.

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

The recent APPG report on arts and health creates an opportunity for further discussions with both this APPG and the APPG for Music. A joint approach to further embed and support this work at parliamentary level should be pursued.

Ultimately the cost of delivering this work to a significant number of locations dealing with dementia greatly outweighs the availability of cultural funding, and this activity must seek to be contained within the envelope of health provision and the funding available to support health, wellbeing or clinical outcomes.

Cultural agencies wishing to support and develop this work should invest in programmes which can produce evidence which can be directly used to address that larger question. A succession of funding for cultural programmes which focus purely on creative outcomes runs the risk of creating expectation which cultural funding will be unable to match.

2.7 What should our one, clear message be? **[Max. 100 words]**

Music should be part of the care and support that people with dementia and their families should be able to access, at every stage of their journey. Music has a vital role to play in helping people live and die well with dementia and in making health and care settings better places to them to be.

2.8 Do you have any final comments? **[Max. 100 words]**

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. 50 words]**

Rhythmix is a music charity transforming lives through music. We created the Wishing Well Music in Healthcare programme in 2013, specifically to support the wellbeing of children and older people in healthcare settings. You can view 2 very short films about our work with people with dementia here

Evidence by World Federation of Music Therapy

1. **What is the current 'state of play' of dementia and music?**

1.1 What are the main strands of activity which fall within this broad field, and who are these activities being delivered by? **[Max. 250 words]**

Our group is working with professional caregivers to teach them how to incorporate music into their daily tasks such as bathing, dressing, wound healing, to improve the quality of life of dementia patients in advanced phases of the disease as well as that of their caregivers

1.2 How is this range of activity presently being funded? **[Max. 250 words]**

Private organization

1.3 Are there regional differences in provision, within the UK? **[Max. 250 words]**

NA

1.4 What should we consider to be 'best practice' in the measurement of the outcomes and impacts of these activities? **[Max. 250 words]**

To measure patients' outcomes and also caregivers' impressions and satisfaction

1.5 Is it possible to establish an average 'unit' costs for different kinds of activity, and how can we map cost against outcome? **[Max. 250 words]**

I think it is possible. For instance, group versus individual intervention, and to measure if people who receive music therapy intervention need - for instance - less medication, if they are more relaxed, therefore they need less staff attention.

1.6 What are the main barriers to more extensive uptake of these activities? **[Max. 250 words]**

Lack of knowledge about music therapy and the evidence which exists on the effectiveness of the intervention with people with dementia.

2. **In which direction should the field of dementia and music be moving?**

2.1 What are the main emerging opportunities in the field of dementia and music? **[Max. 250 words]**

To address not only the direct clinical intervention with patients, but also their caregivers (professional as well as family)

2.2 How do we overcome identified barriers to the more extensive uptake of dementia and music? **[Max. 250 words]**

To persevere with educating the public as well as investing more time and resources in research

2.3 Where do we still need to build evidence? **[Max. 250 words]**

Testing different protocols for people in the different phases of the disease.

2.4 How can/ should we align music interventions with other areas of work in the dementia space? **[Max. 250 words]**

Working in collaboration with other professionals

2.5 Who should be taking this agenda forwards? **[Max. 250 words]**

Music therapists as well as policy makers

2.6 Who needs to be influenced and brought on board, to further this agenda? **[Max. 250 words]**

Different professionals in the field of dementia as well as policy makers and administrators.

2.7 What should our one, clear message be? **[Max. <u>100</u> words]**

Music therapy is effective for people with dementia

2.8 Do you have any final comments? **[Max. <u>100</u> words]**

3. Short biography

3.1 Short biography of yourself/your organisations **[Max. <u>50</u> words]**

Melissa Mercadal-Brotons, PhD., MT-BC. Music therapist, specialized in the field of dementia with over 30 years of clinical experience. She has published extensively nationally and internationally in the field of dementia. Current President of the WFMT.