

GREATER MANCHESTER'S ONLINE LGBTQ+ DEMENTIA SUPPORT GROUP

Project report and evaluation on the development of a group to support LGBTQ+ people affected by dementia and those who have been supporting them in Greater Manchester.



FOREWORD

by Andy Burnham – Mayor of Greater Manchester

I am delighted to be sharing this evaluation report, which showcases the work of the Greater Manchester LGBTQ+ Dementia Online Support Group.

We know that specific services and activities for LGBTQ+ people affected by dementia are still quite rare, which can leave people feeling isolated from their community.

In Greater Manchester, we have been working together to support our LGBTQ+ communities affected by dementia, as we successfully set up the online support group in August 2021, supported by Locality Commissioners, Mental health providers and VCSE groups working together with our dedicated dementia programme, 'Dementia United'.

Dementia United is the Greater Manchester Integrated Care Partnership's flagship programme for dementia and brain health. The aim is to work alongside clinicians, charities, localities, professionals, those living with cognitive impairment, families, friends and care partners to make Greater Manchester a brain healthy city and the best place to live if you have dementia or are caring for someone who does. Diversity and Inclusion is a strong priority for our programme.

In Greater Manchester, we want to make sure everyone affected by dementia, can access the information, support and advice that they want and need to live as well as they can for as long as they can. LGBT Foundation, who help our local LGBTQ+ communities with a wide range of services, has supported our work. The LGBT Foundation's work to develop the LGBTQ+ Dementia Online Support group and support monthly facilitation alongside locality hosts has been crucial to the success of the group.

We know that there is still some way to go before every LGBTQ+ person feels safe to be themselves and where health and care professionals are fully aware, and able to understand and meet the needs of LGBTQ+ communities affected by dementia. However, this report, which makes some clear recommendations for improvement, is a very positive step in the right direction and I would like to extend my thanks to everyone who has shared their stories and contributed to this evaluation.

This report includes some very honest and personal accounts. It will support us in continuing to talk about the things we can all do in our practice and in our organisations to make sure that LGBTQ+ people affected by dementia or living with cognitive impairment are included and celebrated for who they are.

We are LGBT Foundation. We believe in a fair and equal society where all lesbian, gay, bisexual and trans people can achieve their full potential.

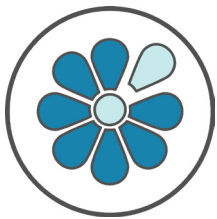
Our work started in 1975 and we've been changing the lives of LGBT people ever since. Over the last five decades, we've provided information, services and support for LGBT people who've had nowhere else to turn. We've been at the forefront of the social and legal changes that mean LGBT people in the UK have more rights than ever before.

Our work is as vital and urgent as ever. LGBT people still face persecution, discrimination and stark health inequalities. Through our services we reduce isolation amongst our communities, help people feel more confident and in control of their lives, and enable people to flourish.

Every year we serve 40,000 people - amplifying people's voices, providing support and offering hope. We work in partnership with others to build strong, cohesive and influential LGBT communities and promote attitude change in society, reaching 600,000 people online each year.

Together, we can secure a safe, healthy and equal future for all LGBT people.

Until then, we're here if you need us.



Dementia United is Greater Manchester Integrated Care Partnership's programme for dementia. We work together with people from across the system, to ensure that the voice of people affected by dementia is heard, and we co-design projects which improve the quality of support and the experience of living with dementia. We aim to make Greater Manchester the best place to live for all those affected by dementia.

Dementia United's ambitious programme spans all health and social care multi agency teams, voluntary agencies, people living with dementia, families and carers, commissioners, funders, researchers, and policy makers. Fundamental to this is a commitment to diversity and inclusion for everyone affected by dementia. The GM ICP Programme is called 'Dementia United' because partners in Greater Manchester are united in our longstanding vision to improve the quality and experience of care for everyone affected by dementia, and to work in partnership to deliver on this vision across the whole of the region.

We have made Dementia a priority through working in partnership with people affected by dementia, across all ten localities in Greater Manchester.

<https://dementia-united.org.uk/>

The Greater Manchester Integrated Care Partnership (ICP) is helping organisations work better together with people and communities.

We want people across all our boroughs to stay well, whatever their age, and whatever issues or conditions they might be managing. We're bringing together all the different organisations that support people's health and social care, so that services can join up and act faster when people need support. Integrated care means starting with the person, understanding they'll have different needs as they move through life, and connecting them with the right care.

<https://gmintegratedcare.org.uk>

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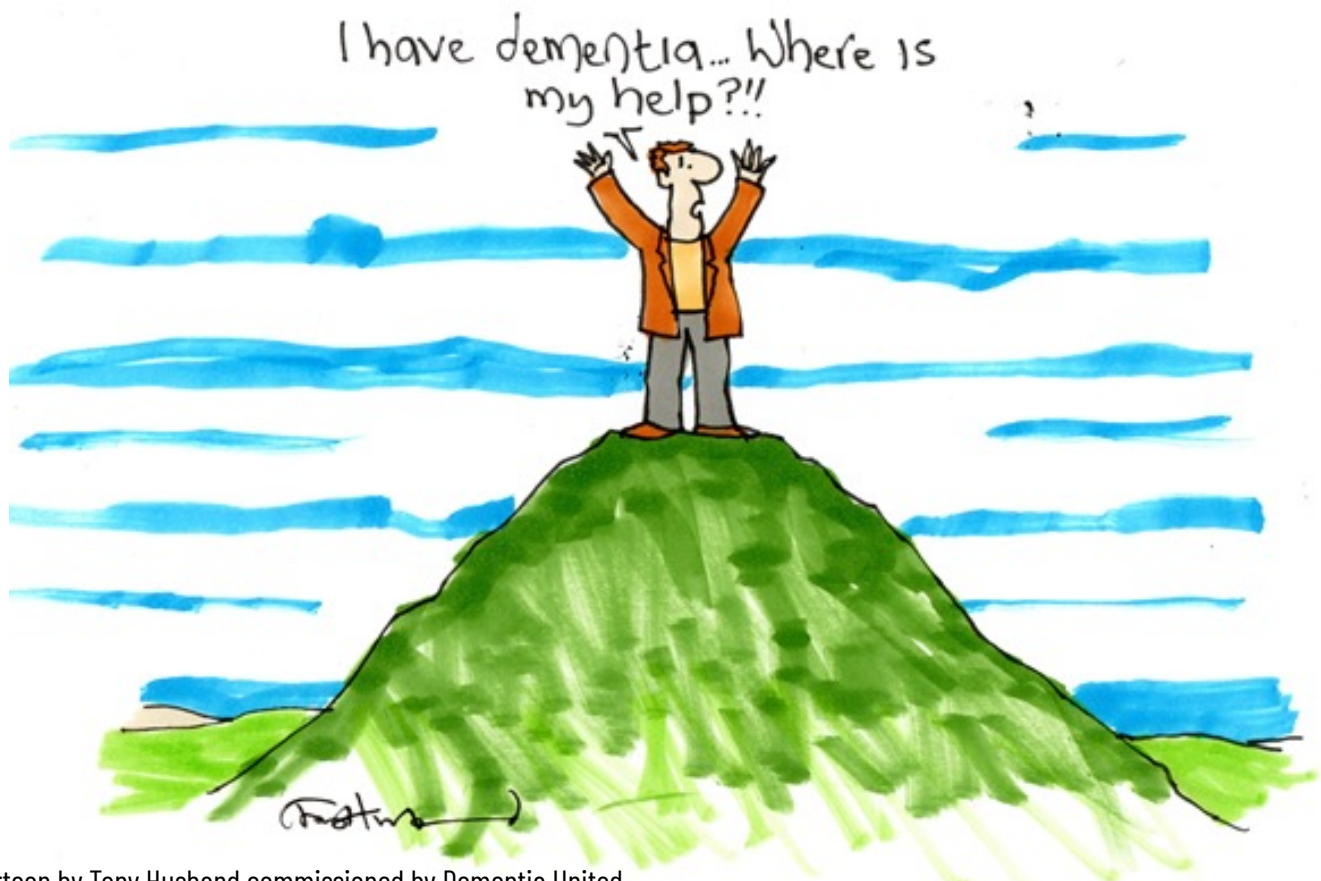
INTRODUCTION

This report is the evaluation of the group to support LGBTQ+ people affected by dementia and those who have been supporting them throughout Greater Manchester. The LGBT Foundation would like to give special thanks to Greater Manchester Integrated Care Partnership, which enabled us to run this project in partnership with Dementia United (the GM ICP Programme for dementia)

We also want to give extra special thanks to the LGBTQ+ group members, group facilitators and steering group members who all contributed to the group's success and this report.

None of this work would have even happened if it hadn't been for an innovation programme first developed by Alzheimer's Society called **Bring Dementia Out**, which was later developed by LGBT Foundation.

This innovative programme was originally driven by an LGBTQ+ person with lived experience, which highlighted the importance of raising awareness and providing support for LGBTQ+ people affected by dementia in Greater Manchester.



Cartoon by Tony Husband commissioned by Dementia United

EXECUTIVE SUMMARY

Dementia United (NHS Greater Manchester ICP) worked in partnership with LGBT foundation, lived experience advisors, as well as with Voluntary Community Sector groups and Mental Health and general hospital providers from across 10 localities; in order to establish a Greater Manchester Online Dementia Support group for people affected by dementia from the LGBTQ+ community.

Read more about the group [here](#)

A key aim when establishing the group was to support LGBTQ+ people living with dementia and those who support them. Providing opportunity for people to share their experiences within an understanding, supportive and non-judgemental forum.

A Steering group was set up, along with all 10 localities support with monthly facilitation from a wide range of organisations to support the online group. **The group has met since August 2021 with 20 meetings held over 18 months, supporting 12 people.**

Dementia United commissioned and funded a role one day a week for a coordinator to support with promotion, running the online group via Zoom. The coordinator was the point of contact for facilitators, welcoming and supporting all members of the group and those who needed further information and support. This has proved to be an increasingly important role.

Further outcomes, which the facilitators of the monthly group meetings highlighted, was the **importance of having the support from each other and the regular facilitators meetings, which also raised awareness about the needs of the people affected by dementia from the LGBTQ+ community.** This has been a very beneficial way in which to engage with organisations from across each locality of Greater Manchester; plus, the learning shared from organisations such as African Caribbean Care Group, Age UK, Alzheimer's Society, Making Space, LGBT Foundation and all our partners in this project has been invaluable.

The evaluation we undertook reflects that we have met our objectives as well as identifying priorities to be focusing on for the coming years.

We have demonstrated that there is a need to continue running the online support group, with the need for an increase in the coordinators time too. The information gained from this evaluation has shown us that there is also a need for ongoing specific support for LGBTQ+ people affected by dementia.

The report shows that organisations that support those affected by dementia, need further awareness of the unique experiences of the LGBTQ+ community.

This report recommends the delivery of training for all health and care staff in understanding how best to support their LGBTQ+ service users who are affected by dementia; with lived experience members delivering this training.

The eight key recommendations from this evaluation, will be taken forward through Dementia United's governance meetings as well as seeking system wide engagement across Greater Manchester in responding the reports recommendations.

BACKGROUND

Due to the long history of discrimination experienced by many LGBTQ+ people when accessing mainstream services, this can mean that people are wary or reluctant to access services.

This is despite greater legal protection from discrimination for LGBTQ+ people (such as [The Equality Act, 2010](#)). Anecdotal evidence tells us that LGBTQ+ people living with dementia face particular challenges when accessing services.

These challenges can include;

- Organisations/services are often heteronormative and cis-orientated
- Being unable to 'come out' about sexual orientation, gender identity and trans status for fear of discrimination from care, housing or other service providers
- Being less likely to have wider family support, and therefore they may rely more on their "chosen family" (friends rather than blood relations)
- More likely to be anxious of accessing services and support as an LGBTQ+ person because of historic or current discrimination from staff, residents and service users- either real or perceived
- More likely to be isolated due to the lack of inclusive services and support

Greater Manchester has a reputation for being a place where there is a strong commitment to improving the lives of all lesbian, gay, bisexual and trans citizens.

In 2018 LGBT Foundation began following the innovative work that had been led by [Alzheimer's Society](#) to address the challenges faced by LGBT people living with dementia and those who are supporting them. It was important that we acknowledged and built on the work that had already been led and developed by [Patrick Ettenes](#), a lived experience advisor on dementia in partnership with Alzheimer's Society and LGBT Foundation ([Bring Dementia Out](#)). This has also influenced projects across the country with other organisations.

At the end of 2020, [Cliff Wilson \(Commissioner Manager Oldham\)](#) and [Helen Pratt \(Project Manager, Dementia United\)](#) started to have conversations about the possibility of setting up a support group for people affected by dementia from the LGBTQ+ community in Greater Manchester.

There is a wide network of LGBTQ+ support throughout Greater Manchester. Evidence shows that people in this community often desire to seek support from inside the community itself and to be supported by mainstream inclusive services.

AIMS & OBJECTIVES

AIMS:

- For people from the LGBTQ+ living with dementia, and those who support them, to have a **safe space** to enable them to share their experiences within an understanding, supportive and non-judgmental forum
- To **set up a Greater Manchester wide group**, where people from the LGBTQ+ community can receive advice and support from allies, professionals and stakeholders
- To **draw on our partnerships across the 10 localities in Greater Manchester**; seeking support and collaboration with organisations to facilitate an online support group
- To **learn from the lived experiences** of people from the LGBTQ+ community affected by dementia
- To share the experiences and feedback from the LGBTQ+ people affected by dementia; with organisations, stakeholders and partners, in order to **raise awareness of the needs of LGBTQ+ community**; which would be transferable to their day to day roles to ensure their **service is inclusive**
- To **establish a Steering group with key partners, including lived experience members**, who would be able to listen, take forward actions and respond to risks, challenges and issues
- To discuss and develop ideas that can lead to **improving the experiences of LGBTQ+ people living with dementia** when accessing services

OBJECTIVES:

We considered that offering this support, as outlined in our aims, to people with dementia and their carers from LGBTQ+ communities, that they would be more likely to remain stable and be less likely to require more intensive support.

The following are where the online support group and wider partnership working with dementia services could have indirect effects and were the identified system wide objectives.

- **IMPROVING ACCESS TO SERVICES**
The support and raising awareness with organisations involved in supporting the LGBTQ+ group would enable dementia services to be more inclusive.

- **REDUCTION IN CARER BREAKDOWN**
If a carer feels isolated and unable to access support there is a clear risk of carer breakdown; with support available at an early stage this can be avoided. If there is care breakdown there is a much higher possibility that the person with dementia could end up in residential care at a much earlier stage in their dementia journey.
- **PEER SUPPORT**
This reduces the likelihood of developing depression which is common in people who feel isolated and offers a preventative focus.

SETTING UP THE GROUP

We knew that there may be very small numbers of people initially who would be interested in accessing a support group from each of the localities; therefore coming together as a Greater Manchester support group may be of more value.

We recognised that there had been people affected by dementia connecting virtually because of the pandemic; this could therefore be an option for us, in establishing the group. **Oldham's Age UK had many years experience of hosting an Older People's LGBTQ+ group and therefore we were keen to build on any lessons learned from Oldham's experience.** We also built on LGBT Foundation experience, working with Patrick Ettenes as a lived experience advisor who co-founded Bring Dementia Out.

Collaboration, co-production and partnership working were at the heart of our work in establishing the Greater Manchester's (GM) LGBTQ+ Online Dementia Support Group.

In 2020, we started out by establishing a GM LGBTQ+ Steering group with membership from:

African Caribbean Care Group;
Age UK Oldham;
Age UK Trafford;
LGBT Foundation;
Bring Dementia Out Co-Founder;
Dementia United;
Making Space;
Commissioning Manager from Oldham;
and Oldham Library Services.

The Steering group's initial focus was on;

- How best to establish and sustain an online support group for people affected by dementia
- The purpose and role of the Steering group
- How to facilitate the group

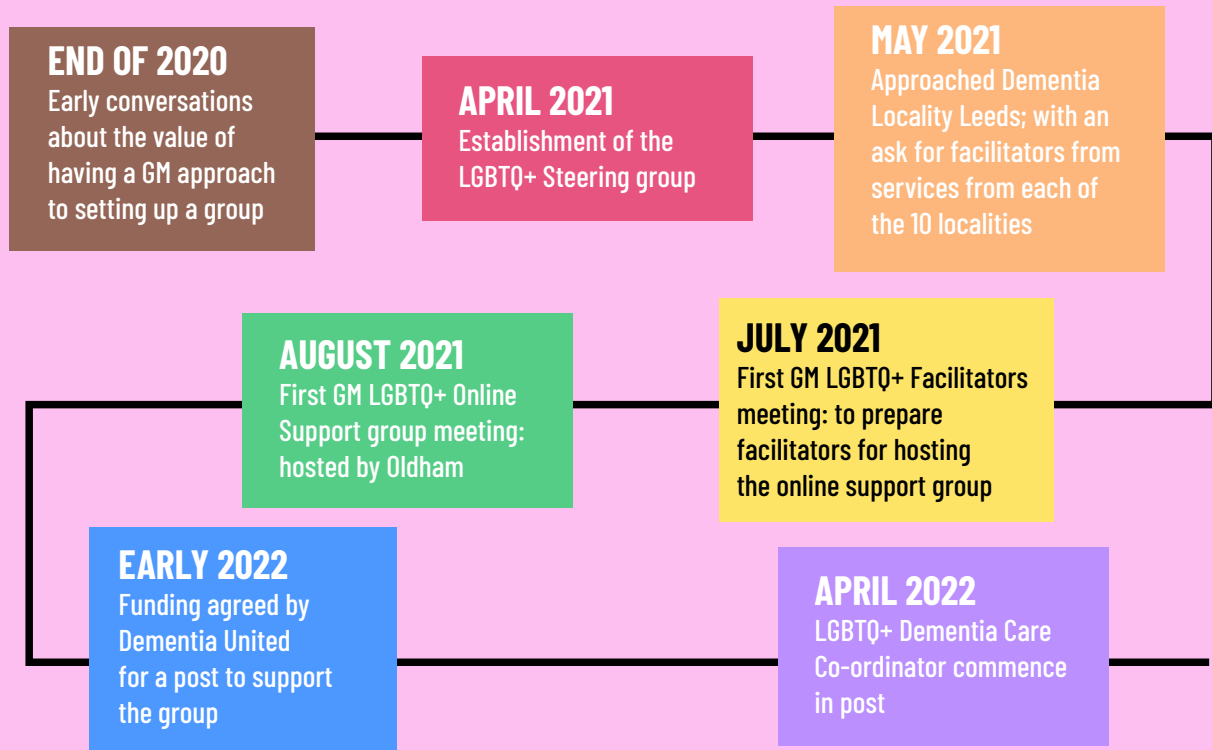
We already had **ongoing commitment from all 10 localities focusing on a GM dementia programme**, with established regular Dementia Locality Leads and Dementia United governance meetings. At one of these meetings we approached the Dementia Locality Leads for their support with the establishment of the group.

We want to thank all the 10 Dementia Locality Leads who nominated a service from their locality, that would be able to work with us and take on hosting the virtual online support group. We agreed that the online support group would meet monthly via Zoom. This meant that each locality would only facilitate and host the group once every 10 months, as per an agreed rota.

The Steering group provided the facilitators from each of the 10 localities, with an initial briefing session about why the group has been established agree how the meeting will run. As well as the providing any information that they would need, to support the establishment of the online group.

The Steering group also committed to providing the facilitators with quarterly Facilitators virtual meetings; to enable the sharing of lessons learned from hosting and facilitating, as well as bringing in key speakers to provide any education and information that would be of value.

TIMELINE FOR THE ESTABLISHMENT AND SUSTAINING THE GM LGBTQ+ ONLINE SUPPORT GROUP



RELATIONSHIPS THAT SUPPORTED THE ESTABLISHMENT OF THE GM LGBTQ+ ONLINE SUPPORT GROUP

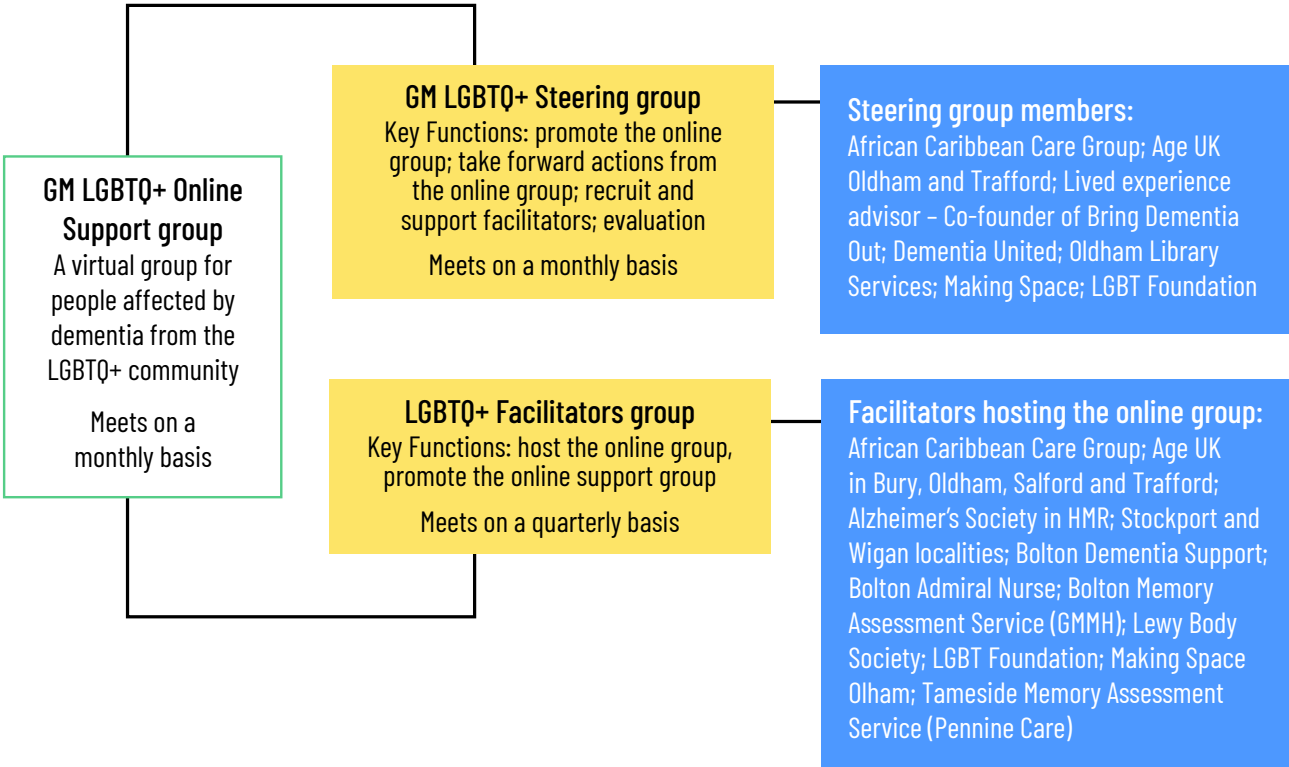
This really was an innovative partnership project; from across the whole of Greater Manchester, the following stakeholders, from all 10 localities, supported and facilitated the online group.

- African Caribbean Care Group in Manchester
- Age UK in Bury, Oldham, Salford and Trafford
- Alzheimer's Society in Heywood Middleton and Rochdale, Stockport and Wigan
- Bolton Dementia Support
- Bolton Admiral Nurse; Bolton NHS Foundation Trust
- Bolton Memory Assessment Service; Greater Manchester Mental Health NHS Foundation Trust
- LGBT Foundation
- Lewy Body Society in Wigan
- Making Space in Oldham
- Tameside Memory Assessment Service, Pennine Care NHS Foundation Trust

STEERING GROUP

INTERDEPENDENCIES

The image below, outlines how the different groups all worked together ensuring that there were ways for all members to feedback on risks, challenges, shared learning, and any best practice examples.



CHALLENGES & RISKS;

HOW THE STEERING GROUP RESPONDED

From the outset, the Steering group recognised how important it was to ensure there were feedback mechanisms back and forth from the facilitators and Online Dementia Support group members on a monthly basis.

There was also a need for the Steering group to be able to respond in an agile way to any asks, issues or sharing of best practice.

The Steering group therefore met every month, which occurred a week after the GM Online Support group meetings.

Having these established feedback mechanisms and great partnerships were so important; as we did experience some homophobic abuse within the initial GM LGBTQ+ Online Support Group meeting. This was from one attendee who was removed from the meeting, who then also called the Age UK telephone number and was abusive.

The Steering group were able to seek immediate guidance from senior executive members from Greater Manchester ICP and provide information on how to ensure that facilitators and people affected by dementia were able to continue to meet in a safe space.



MAINTAINING THE SECURITY AND CONTINUITY OF THE ONLINE LGBTQ+ SUPPORT GROUP

The following was put in place to ensure the security of future GM LGBTQ+ Online Support Group meetings, following the homophobic abuse experienced in the first meeting:

- A **new Zoom link** was provided
- **Removal of the Zoom link from the public domain**; the link would only be provided to people who got in touch to join the group
- **Age UK Oldham continued to be the initial contact**; this enabled some level of vetting of attendees
- **Amended flyers were sent out**; this included Age UK Oldham contact details only, for people to register interested in joining the group
- A **password was required to access the meeting**; this was only shared with Steering group members, facilitators and people who rang Age UK expressing an interest in joining the group
- The **Zoom link that enabled a waiting room feature**; which ensured that the host was able to review who was in the waiting room, before enabling them to enter the meeting

The following was put in place to support the facilitators:

- **Facilitators quarterly meetings**
- A **Steering group member attended all Zoom meetings**, hosted by the locality facilitator (where there was only one facilitator to host); thereby ensuring that there was a minimum of two people hosting and supporting the meeting
- **All facilitators/steering group members were able to log issues/concerns**; these were considered by the Steering group meeting who focused on what mitigation and actions were needed. This included any considerations to report the issues to the police as needed. The homophobic abuse was reported to Greater Manchester Police via their online hate crime reporting service.
- **All facilitators had access to training about how to ensure Zoom/virtual meeting security**; Making Space offered their free training on education around phishing which covered how meetings can be hacked and the steps that can be taken to prevent this with all facilitators.
- **The Greater Manchester Resilience Hub details were shared as they provide emotional and psychological support** to anyone who works in the health and care sector, as well as their families

<https://www.gmp.police.uk/advice/advice-and-information/hco/hate-crime/how-to-report-hate-crime/>

<https://www.penninecare.nhs.uk/gmrh-covid>

COMMISSIONING AND FUNDING OF THE LGBTQ+ DEMENTIA CARE COORDINATOR ROLE

We were hearing feedback from the facilitators hosting the meetings, that they would welcome support with hosting, as there were times when there was only one facilitator (due to sickness or short terms cover difficulties) and Steering group members did not have the capacity at short notice to support. Plus, the facilitators were asking for support with wider promotion of the group, as there were low numbers of group members attending.

The Steering group's suggestion was to have an allocated person working one day a week to address these issues and support sustaining the GM LGBTQ+ Online Support group.

Dementia United agreed to fund and commission this post, initially for six months, which was approved by the Dementia United governance boards, supported by the Dementia Locality Leads. Following consultation with Steering Group members and partners, the contract was awarded to the LGBT Foundation for the LGBTQ+ Dementia Care Coordinator role one day a week.

This role was intended to run from April to September 2022; however, following the success of this work, Dementia United agreed to extend the role for a further six months up to the end of March 2023.

The agreed role of the LGBT Dementia Care Co-ordinator from April 2022

- The **first point of contact for facilitators**
- **Hold a list of people living with dementia (PLWD) and carers/friends/family attending the meeting each month.** Sharing this list in advance with each facilitators that were due to host the meeting
- **Responding to enquiries** from PLWD and/or family, friends and carers who wished to attend the group
- **Sending out an email to all** PLWD/carers/friends/family attending the group, every month; providing the Zoom link details for the meeting
- **Sending the Zoom link details out** to the locality facilitator and all LGBTQ+ steering group members every month
- **Generate a Zoom link** for the Online Support group meeting
- **Co-facilitate the GM LGBTQ+ dementia online support groups** on the first Tuesday of every month, 2-3:30pm Working alongside each locality as they co-host

Other tasks

- **Build relationships** between LGBTQ+ sector, Dementia sector and other care sectors
- **Share LGBTQ+ promotional resources** with dementia and care providers throughout GM
- **Work collaboratively and promote the programme** across GM Hubs and Networks
- **Evaluation of the group and role;** hold focus groups with LGBTQ+ communities across GM

PARTNERSHIPS, COLLABORATION AND CO-PRODUCTION

Below are some examples of how the Steering Group took forward collaboration and co-production

To promote the GM LGBTQ+ Online Support group as widely as possible; it was agreed that we needed a flyer that could be printed off as well as being available online. The African Caribbean Care Group members offered to design a flyer; working in partnership with the Steering Group members.

Meetings were held between partners across Greater Manchester to promote the ongoing work as needed.

Flyers and social media promotion was widespread across Greater Manchester including throughout partner organisations, care and primary care services.

- A Facebook group was set up to promote wider awareness.
- A Steering group member linked in at a national level to promote LGBTQ+ inclusion and awareness around dementia; within a voluntary organisation.
- We have worked to cross-promote and raises awareness about the support available. This has allowed the group coordinator to work with services that aren't exclusively aimed at LGBTQ+ communities to raise awareness of how LGBTQ+ issues intersect with dementia care needs.





Patrick Ettenes Lived Experience Advisor & Co-Founder of Bring Dementia Out.

On the 6th June 2022, Dementia United with key partners hosted and co-produced an event titled 'Living well with dementia in Greater Manchester; Join us, we need each other'. A wide range of partners and lived experience members came together at this event (244 in total in person and virtual) to undertake a respectful reflection of the impact of the pandemic, as well as a refocus on recovery moving forward.

A breakout session was on 'Living well with dementia as a LGBTQ+ person in Greater Manchester'. This session hosted by Patrick Ettenes (Lived experience member) and Andrew Gilliver (LGBT Foundation) received very positive evaluation as noted below.

Three key messages from the breakout session at this event in June 2022 were

- Better awareness of, and support for LGBTQ+ people affected by dementia in all localities in Greater Manchester
- All organisations to be introducing inclusive LGBTQ+ monitoring
- Improved signposting for LGBTQ+ services

"I am a Palliative Care Nurse, Thank you for sharing your story, this has been so informative for me and I will take so much of what I have heard today forward in my practice."

"Thank-you so much, really informative and inspirational."

EVALUATION

METHODOLOGY: FOR THE EVALUATION

Evaluating the impact of the GM LGBTQ+ Online Dementia Support group was a priority from the outset. The Steering group outlined a methodology, in order to evaluate the impact against intended aims and objectives which included capturing process factors as well as quantitative and qualitative outcomes.

CAPTURING AND EVALUATING THE PROCESSES FACTORS

The process factors are the planning and establishment of the group which we have noted above. This includes all of the wonderful partnerships involved in the steering group and facilitation from the localities and the co-production with people with people with lived experience. We were also able to respond in an agile way to issues as they arose from the monthly meetings.

We have seen a steady but constant growth in the number of attendees. This started with just a few individuals and now there are up to a dozen people we engage with on a regular basis. Joining a new group is daunting, especially online where a person has never met the contact who introduced you to the group. The group co-ordinator organised pre-session Zoom calls with prospective attendees who felt anxiety around attending. This allowed prospective group members to feel more comfortable going to a meeting where they already recognise a face in the room. Additionally, the coordinator met with attendees individually if they still needed support or a catch up but couldn't attend the group meeting.

CAPTURING ANY QUANTITATIVE OUTCOMES

We quadrupled our contact list over the past 12 months and have welcomed multiple new members to the group.

We have facilitated delivery of:

- 20 Online support group meetings
- 5 Facilitators group meetings
- 20 Steering group meetings

We have had success in promoting our group to individuals who would benefit from attending. This demographic can be difficult to market to, for a variety of reasons. Many older individuals are less likely to actively use social media. Also, individuals with dementia and their carers have more challenges leaving the house, so getting physical flyers and posters in places where they may be able to access the information can pose a challenge.

QUALITATIVE EXPERIENCES AND LESSONS LEARNED

The feedback we received can be seen over the following pages; from group facilitators, group members and the Dementia Care Coordinator. This feedback was gathered by sending out evaluation forms as well as asking questions directly to individuals concerned, or as part of the group meetings or in individual conversations.

The group co-ordinator regularly worked with group attendees and those who showed an interest in the group but were not always able to join in on the sessions for various reasons. The support offered to these individuals was ongoing both during the course of the facilitated group sessions and one-to-one support from the co-ordinator. This meant that people were able to be supported either directly or via referrals to both local services and LGBTQ+ specific services. It has often been important to help to reduce anxieties experienced by our group members.

Having a support group that benefits both individuals living with dementia and dementia carers, provides a space for both groups to share the challenges they each face and understand each others' experiences. For example a carer may be struggling and want advice on how best to help the person they support. Our group members living with dementia help to advise how they would perceive the same situation and promote understanding and support. Lots of support groups cater to only one of these two groups, but we have had clear benefits to all group members due to the groups combined nature.



EVALUATION

FEEDBACK FROM GROUP FACILITATORS

HAVE YOU BEEN GIVEN ENOUGH INFORMATION ABOUT SUPPORTING LGBTQ+ COMMUNITIES?

'Yes, I already feel well informed in this area'

'Yes the support has been good. I got a background from the teams meetings and what issues LGBTQ+ people face.'

'Yes, lots of useful information shared in the steering group'

'I found the LGBTQ+ facilitator meeting really useful, in particular in relation to the importance of LGBTQ+ monitoring and the value of collecting this data. I have also used the LGBT Foundation website to increase my knowledge of supporting people from LGBTQ+ communities.'

WHAT HAVE YOU LEARNED FROM BEING PART OF THIS WORK?

'How difficult it is to attract this group of people for this type of support'

'I have learnt the needs of people from the LGBTQ+ community can be so different, and their voices and concerns should be heard.'

'I have learned that there are very few people from the LGBTQ+ community with a diagnosis of dementia that are accessing dementia services in GM.'

'Being involved in the group has been a positive experience.'

'Prior to starting this work I have never thought about the specific challenges people from LGBTQ+ communities may face when diagnosed with dementia. As the work has increased my knowledge and awareness, it has taught me to think about those challenges when I now work with people with dementia in the LGBTQ+ communities it has helped me to work with them to address the challenges which they face.'

'That there is still prejudice and a lack of understanding from some communities and I have a clearer understanding of the fear that was more prevalent in earlier years.'

HAS THERE BEEN ANYTHING YOU HAVE LEARNED THAT HAS HELPED YOU IN YOUR WORK?

'It has taught me that (my organisation) should look to capture LGBTQ+ data using the monitoring of sexual orientation and trans status. It is something which needs to be addressed, to ensure we're meeting the needs of LGBTQ+ people with dementia.'

'A better understanding of the difficulties people from LGBTQ+ communities face in accessing services.'

'Yes. I am now promoting the network at the trust making it more diverse and conclusive in the delivery of Dementia topics'

'Active listening skill and non-judgmental attitude are important to help me in my work. Acceptance towards different values and perspectives make my work more effective.'

'It has shown me the lack of people from the LGBTQ+ that are attending our Dementia activities.'



EVALUATION

FEEDBACK FROM GROUP FACILITATORS

DO YOU FEEL CONFIDENT SUPPORTING SOMEONE FROM THE LGBTQ+ COMMUNITY?

'Yes, I think so. If I have more opportunities to talk with them and understand their needs, I will feel more confident supporting someone from the LGBTQ+ community in the future.'

'I do feel more confident supporting someone from the LGBTQ+ community but I would like to ask people how as a service we could help if they wished to join our Dementia Craft group. We have quizzes and crosswords, singing and armchair exercises.'

IS THERE ANY AREA OF SUPPORT YOU FEEL THAT EITHER YOURSELF OR YOUR TEAMS WOULD BENEFIT FROM IN FURTHER SUPPORTING MEMBERS OF THE LGBTQ+ COMMUNITY?

'If more people are identified in the LGBTQ+ data capture and monitoring exercise, it would be helpful to be aware of any local physical LGBTQ+ groups, in addition to the online monthly meeting.'

'I think the wider team could benefit from more awareness and training on LGBTQ+ issues and dementia'

'More information and support for the trans community.'

WHAT WORKED WELL?

'The relaxed feel of the group that I know people enjoyed. The support and affirmation that people received from being part of this group'

'I have only hosted one monthly meeting but it went well. The conversation flowed and the people who attended were able to express themselves freely at the meeting.'

'Integrated working and information sharing'

'We have the meeting on a regular basis to discuss the situation happened, so we can make modifications in no time'.

'Persistence has paid off and now more people have joined the group. Having a dedicated facilitator is definitely better for people living with dementia.'

WHAT COULD HAVE WORKED BETTER?

'Widening the number of participants'

'Access to the system if you are the facilitator.'

'It is good to know the members' expectations and interests, so it can help the facilitators to prepare the materials relevant to their needs'.

'Regular training might help us identify older people who are not open about their sexuality and may be missing out on support.'

'Being able to converse with LGBTQ+ community with people with Dementia and their carers.'

EVALUATION

FEEDBACK FROM ONLINE GROUP MEMBERS

HOW DOES HAVING A GROUP LIKE THE GREATER MANCHESTER LGBTQ+ ONLINE DEMENTIA SUPPORT GROUP AFFECT YOUR LIFE?

'Eight years ago when I was first diagnosed with early onset dementia I had nowhere to go. I felt very lonely going to a mainstream support group and I didn't understand why I felt so isolated until I was with other LGBTQ+ people. I wanted to be with my community and it's taken such a long time to get this kind of support. Previously I felt so misunderstood and going to other (non-LGBTQ+ groups was just a constant reminder of all the support I didn't have in my life.'

'I am able to connect every month with people I can relate to and with organisations that support us. I learn about what is going on in Manchester, from peoples experiences and share what is happening where I live. I am able to attend via Zoom as I live outside Greater Manchester and wouldn't be able to travel to Manchester every month to meet face to face.'

'It is a very valuable lifeline, especially for older LGBTQI+ people dealing with ageing brain issues. The dementia journey can be a scary one, but the GM LGBTQI+ online dementia support group is a great way to connect with others who may be experiencing similar things.'

'It keeps me involved and connected with appropriate support as most support is cis white British heteronormative'

WHAT HAS BEEN YOUR EXPERIENCE OF THIS GROUP?

'Heavily needed and extremely welcoming. Everything that I had begun to realize that was needed was verbalised by other members of the group. No-one else could possibly understand what it's like to be an LGBTQ+ person living with dementia - unless it's yourself'.

'It has been wonderful to connect with the group, there is nothing here in Sheffield although I have set up an LGBT Dementia group but nobody attended the first meeting'

'It has been wonderful to connect with other queer folk who are also dealing with ageing brain issues. The facilitators are terrific and the content is valuable'.

'I look forward to the monthly Zooms. It is a friendly informative group, facilitated well. It provides a safe space to talk and share, learn and support'

HOW WOULD YOU LIKE TO SEE HEALTH CARE PROVIDERS AND SUPPORT SERVICES MOVING FORWARD FOR LGBTQ+ PEOPLE AFFECTED BY DEMENTIA?

'I'd like to see more training about LGBTQ+ experiences in dementia, in healthcare and in care homes. Let us demonstrate the difference that this kind of support can make to a person.'

'Health care providers and support services need to move away from the one size fits all "Medical Model" of care to the inclusive, individualised "Social Model" of care.'

'Integrated care is sorely lacking. Too often, medical care and social care operate independently and that's where people fall through the cracks'.

'Professionals need to stop their unconscious bias, to stop seeing us as invisible, by seeing us as human beings, an individual in our own right, not treat us as invisible because we have an invisible disability. They should provide services from the point of diagnosis until our death and afterwards for our families, enabling us to take part in the things we already enjoy and to enjoy doing new things.'

EVALUATION

FEEDBACK FROM ONLINE GROUP MEMBERS

WHAT HAVE YOU FOUND LACKING IN THE DEMENTIA SUPPORT YOU'VE BEEN OFFERED SINCE DIAGNOSIS?

'Covid and the pandemic really took a lot of existing support away. I'm still struggling now to get a support worker and it's really just so hard to get that personal support that I really need.'

'Support and services tend to fail to provide culturally and gender appropriate services which leaves many isolated and goes against their right to be involved in their community -under Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). In most areas there is a lack of post-diagnosis support, an important time when enablement can improve quality of life and mental well-being for us and our families, including the right to rehabilitation and habilitation'.

'I was diagnosed in March 2017, given 2 leaflets, told to put my affairs in order, all with no post diagnostic support. I carried on working for 6 months then sat indoors getting depressed. I had to do a 130 mile round trip once a week for 6 weeks in March-May 2018 to access the post diagnostic support I needed. There is no NHS support for under 65's but I have successfully got the Sheffield Dementia Advice Service, A Young Onset Group and an LGBT Dementia Group funded. There also needs to be more support for family members.' (feedback from group member living outside GM)

'Culturally competent care is very hard to find, especially for gender-variant people with dementia. While there are many well-intentioned carers, too often that care is heteronormative, full of assumptions and biases that do not reflect my lived experience'.

WHAT ELSE WOULD YOU LIKE PEOPLE TO KNOW ABOUT YOUR EXPERIENCES AS AN LGBTQ+ PERSON AFFECTED BY DEMENTIA?

'It's lonely. Crippling to be part of a community that when you are sick and services don't really understand you. It's difficult to explain the damage that dementia does to you. It makes you extremely vulnerable and I've found that too often not much empathy comes from health care professionals. I would like them to know that we need them to step up and open their minds to more learning and understanding.'

'Support and services should be appropriate and inclusive for all. The LGBT community is frequently invisible due to the challenges, stigma, and phobic views of society, the media and politicians. For a transwoman who also has a diagnosis of Alzheimer's, it is a double whammy of stigma, inappropriate or non-existent support and services and transphobia.'

'There are many barriers to inclusion but it is incumbent on professionals to explore ways to break down those barriers. I am still me, the same person as I was before I was diagnosed but with new challenges, new restrictions on my ability. Give me time to talk, to say what I need to say and provide me with information in a format I can understand. It is not just our diagnosis of Dementia that affects us but other health conditions that may make our Dementia worse, it can be a lonely place in a room full of people when you can't process all the voices talking at the same time.'

'I would like to see an inter-generational residential care home operated as a pilot project to demonstrate how older and younger queer folk can come together to help and celebrate each other, as they navigate their way in a culture that is still sadly rooted in ageism, ableism, racism, homo/bi/transphobia.'

EVALUATION

LGBT DEMENTIA CARE CO-ORDINATOR (LGBT FOUNDATION)

THIS FEEDBACK WAS FROM OUR LGBT DEMENTIA CARE CO-ORDINATOR WHO HAS BEEN WORKING ON THE PROJECT FOR ONE DAY A WEEK SINCE MARCH 2022

Personally, I've loved working with this group. I was initially interested in the project based on my own previous experience working as a dementia carer at an assisted living house. As a queer person myself, I was interested to see what training and guidelines were in place for working with LGBTQIA+ individuals, but found that there were none. In fact, the house manager had informally disclosed to me that I would not be safe to be openly out at work as one of the residents was openly homophobic and displayed challenging behaviours when presented with something they did not agree with.

If it was not deemed 'safe' for me to be openly out at work, what did that mean for any other resident who may have been assigned to that house?

There was no acknowledgement that LGBTQ+ people with dementia may have any related needs or required support. **This showed me an overwhelming lack of LGBTQ+ focused dementia care and a need for other services to compensate and drive change.**

While working with this group I've seen that this isn't an isolated incident, and a real worry for people of this demographic.

Being able to meet other people with shared lived experiences is invaluable, as it allows everyone to express worries like this in a safe environment. Plus, it also allows individuals to hear about other services that are accepting such as **LGBTQ+ Extra Care Schemes** (one of which has been developing in Manchester), which allows for comforting future planning. Being able to discuss and share resources available like this is invaluable for LGBTQ+ community members, because there are extra considerations for them when thinking about their dementia care.

Further to that, we have individuals who may join fleetingly. While they may not have a diagnosis of dementia, they experience memory difficulties which they find distressing in relation to the lack of LGBT specialized support within dementia services. Coming to this group and seeing other members living well and being able to share support opportunities and future care plans, is **comforting to these new attendees.**

LGBT DEMENTIA CARE CO-ORDINATOR (LGBT FOUNDATION)

Additionally, the benefit of this group isn't just about what happens during our support sessions. **We meet once a month for an hour and a half, but the networks formed through this session extend further.** Our members are passionate about social change with one member even running their own group for people local to them. We have worked together to share contacts, promote services and give individuals as many options as possible when it comes to getting support. I work with other local groups to share similar services through our Facebook page.

This includes groups such as the Rainbow befriending service (a weekly LGBTQ+ call buddy for individuals of 50+ years), plus the services run by our locality leads who co-host each support session in turn.



Overall, based on the feedback I've had within sessions LGBTQ+ specialised support is **deeply important to LGBT individuals and needs as much promotion as possible.** Even if a practitioner is an ally, unless LGBT+ needs are highlighted when discussing dementia care, individuals may not feel comfortable to ask for support surrounding how this impacts their care needs.

Groups like this can help practitioners understand how best to support LGBT+ individuals based upon their specific concerns, plus it supports individuals to create a safe place to discuss any such fears and get direction for appropriate support.



THEMES EMERGING FROM THE EVALUATION

THEMES EMERGING AND LESSONS LEARNED FROM THE EVALUATION

The following themes and lessons learned emerged from the analysis of the process factors and quantitative and qualitative outcomes; reflecting delivery of our key aims and objectives.

The online support group required the establishment of a Steering group who responded in an agile and flexible way to issues that arose each month; which we felt was definitely needed for the first 18 months in establishing a new Greater Manchester support group.

The **qualitative feedback demonstrated that facilitation of the online monthly meeting required support from a care coordination role**; to enable new members to join virtually, promote the group and support the facilitators from the localities. It was therefore **essential to have commissioned a group coordinator to support the ongoing needs of the group members** and respond to ongoing enquiries about the group.



THEMES EMERGING FROM THE EVALUATION

OUR GREATEST SUCCESSES

- **Support and commitment from all 10 localities across Greater Manchester**, with partnership working from VCSE groups
- **Wider connections being made** with GM Dementia programme/events/national groups
- **Continual engagement with group members** – both those attending the online group and community members seeking other means of support.
- **Ongoing connections with wider organisations involved** in supporting LGBTQ+ people affected by dementia across the country
- **Over time the numbers accessing the group have increased** as word has got around
- The **facilitators valued the support they received**, they also brought a wide range of knowledge, expertise and experience as well as a willingness to learn about the experiences of LGBTQ+ service users
- The **peer support that has been shared by group members** has clearly demonstrated the support for those group members living with dementia and those who are caring for them
- Our successes demonstrated that we have been **working to our objective of improving access to services for LGBTQ+ people affected by dementia.**

OUR BIGGEST CHALLENGES

- **Promotion of the group has been an ongoing process.** We know that there are many in the LGBTQ+ community affected by dementia. The recent national census gave us data for the first time about the number of LGBTQ+ people in the country who felt comfortable in sharing details about their sexual orientation, gender identity and trans status. Perhaps more significantly this also showed us the greater number who felt unprepared to do so now. This possibly highlights how much more work there is to do to reassure those within the LGBTQ+ community that whatever their needs and however they identify, it is **essential that they feel comfortable in acknowledging and sharing their identity first before they may be able to discuss what further support, they may need.**

THEMES EMERGING FROM THE EVALUATION

LESSONS LEARNED; FUTURE CHALLENGES

FURTHER FUNDING

Further funding is needed to support the role of a coordinator for the Greater Manchester LGBTQ+ Online Dementia Support Group. **The group has gained new regular attendees with the addition of the support from the Dementia Care Coordinator, demonstrating a desire for this type of service.**

Having a regular coordinator is important, especially for attendees living with dementia who benefit from continuity. Additionally, older LGBTQ+ individuals may feel less comfortable being openly out than people from younger generations. **Having a constant welcoming coordinator helps to reduce this anxiety by eliminating the need to 'come out' to a new host each session.**

As this group has been meeting exclusively online it has been necessary to support group members being able to join virtually through the zoom platform.

RESOURCES TO PROVIDE TRAINING

We require further resources to provide training as we have received many requests to deliver but have been unable to do. This is not because we do not have the knowledge or expertise to deliver this; however as funding for the group coordinator has been for one day a week, the focus of the role to date has been to ensure the successful running of the group and the evaluation.

The LGBT Foundation has a proven track record of delivering excellent training and support. The organisation has been able to offer diverse training such as the Bring Dementia Out project, the highly successful LGBT Training Academy or through work in primary care (Pride in Practice) Secondary Care (NHS Rainbow Badge) Support for older LGBTQ+ people (Pride in Ageing) and in the housing sector (Manchester's LGBT Extra Scheme) - just to mention some of the initiatives serving Greater Manchester residents.

THEMES EMERGING FROM THE EVALUATION

LESSONS LEARNED; FUTURE CHALLENGES

- We have also learned that there is much still to be done across Greater Manchester for seldom heard communities e.g. for those affected by young onset dementia. There is the possibility of considering the **innovative partnership model adopted to support the LGBTQ+ online group for these seldom heard communities**. This model has overcome barriers in reaching people from different communities in a cost-effective way and could be replicated for other hard to reach dementia groups.
- Working directly with the group members with lived experience brings irreplaceable insight into the current issues faced by the individuals we support. It would be beneficial to dedicate time to creating up-to-date awareness training from this information to share with a wider demographic. Funding could then be used to **compensate lived experience group members for their valuable input** – we would be able to offer them the opportunity to combine helping others with their experiences and an opportunity for paid work, assisting us in the development and delivery of training.
- There is an increasing amount of **research in the area of LGBTQ+ people and dementia**. Supporting ongoing research is crucial to improving daily life for LGBTQ+ individuals living with dementia and dementia carers. It is well documented that LGBTQ+ individuals are too often underrepresented in research, so involving the Greater Manchester LGBTQ+ Support Group with the research opportunities we are offered would enable us to highlight further those seldom heard LGBTQ+ voices.

Throughout the course of this project we have been able to support our colleagues and their organisations to recognise the importance of visibility of LGBTQ+ people via effective demographic monitoring of sexual orientation, gender identity and trans status to help all services better understand the diversity of their service users.

BENEFITS TO THE OVERALL HEALTH AND SUPPORT SYSTEM

Over the last 18 months, the GM online support group has enabled people with dementia and their carers from LGBTQ+ communities, to remain connected and supported and indirectly this means they are less likely to require more intensive support.

The following areas are where the online support group and wider partnership working with dementia service have had indirect effects

- **Reduction in carer breakdown** – If a carer feels isolated and unable to access support there is a clear risk of carer breakdown. This can result in the person with dementia and the carer turning up at the Emergency Department and an unnecessary admission. If support is available at an early stage this can be avoided. If there is care breakdown there is a much higher possibility that the person with dementia will go into residential care at a much earlier stage in their dementia journey.
- **Peer Support** - Feedback from the group has highlighted the person with dementia finds great comfort in talking to other people from the LGBTQ+ community. This reduces the likelihood of developing depression which is common in people who feel isolated. This preventative support reduces the need to access IAPT services.
- **Improving access to services**
The training and support from the LGBTQ+ Dementia Care Co-ordinator has enabled dementia services to be more inclusive. This enables people with dementia and their carers to live in their own homes longer and happier.
- **Facilitators Experience**
The feedback from facilitators suggests that they have learned a lot from being involved in the group which is transferable to their day-to-day roles to ensure their service is inclusive.

Establishing the Greater Manchester LGBTQ+ Online Dementia Support group has demonstrated that we continue to support the key challenges recognised by Greater Manchester ICP. **We have been addressing inequality, inspiring and supporting community action** and the partnership model and collaboration is an example of removing the barriers between social, community, VCSE and secondary care services, across physical and mental health.

The establishment and delivery of the Greater Manchester LGBTQ+ Online Dementia Support group features within **Greater Manchester ICP's two-year Dementia and Brain Health Delivery Plan for Dementia United**. Support for the LGBTQ+ in Greater Manchester, extends beyond the immediate team and is endorsed by the wider system and senior leadership team.

BENEFITS TO THE OVERALL HEALTH AND SUPPORT SYSTEM

The outcomes from the evaluation tie-in with the NHS long-term plan objectives of prevention and proactive support addressing inequalities

- **Tackling prevention**, helping people to stay healthy and supported and reducing the demand on the NHS and other services
- **Helping to tackle health inequalities experienced by LGBTQ+ people** and providing a more accurate assessment of health inequalities and unmet need in this community. Increased awareness and understanding of the needs of people from LGBTQ+ communities due to the groups facilitation by partnership working across all 10 localities.



COST BENEFIT ANALYSIS

THE LGBTQ+ GROUP IS COST EFFECTIVE

We have demonstrated that the GM LGBTQ+ Online Dementia Support Group is a preventative service; as by supporting people at the earliest stage, they are less likely to find themselves in a crisis requiring more intensive and expensive support.

The annual cost for one day a week for the LGBTQ+ Dementia Care Coordinator was approximately £12,000. Supporting a service that covers the whole of Greater Manchester. This equates to £1,200 per annum per locality. By investing in this service the breadth of support can be expanded to support services to be more inclusive and reduce isolation and the impact that has on people with dementia and their carers.

Dementia United consider this report to be an opportunity to highlight and share some of the many achievements and resources developed in Greater Manchester in relation to the LGBTQ+ and Dementia group, building on our strengths and capabilities from across the wider partnership system to address issues of quality improvement, diversity, and inclusion across the whole system.

RECOMMENDATIONS AND NEXT STEPS

EIGHT KEY RECOMMENDATIONS TO BE TAKEN FORWARD

1. Co-production

Supporting the continued importance of engaging and harnessing lived experience. Engagement with lived experience needs a commitment of investment of time and resource.

2. LGBTQ+ Dementia Care Coordinator role Continuation

- Will enable increased promotion and raising awareness of the needs of the diverse community
- Will enable continued support for new members joining the online group; inclusive of IT support

3. Funding requirements

- Continuation of the LGBTQ+ Dementia Care Coordinator role, for one day a week
- Increasing the funding of the Care Coordinator role to full time given the value of prevention, addressing unmet need for the LGBTQ+ community and the potential for training to be part of the role (as noted below).
- Wider promotion of the group; materials, activities and resources to engage widely across care homes, all community settings.

4. Steering group support

Continuation of the Steering Group in order to respond to challenges and issues and take forward actions as needed via the GM Dementia United Locality Implementation Forum.

5. Partnerships with localities

We are seeking continued commitment, from all 10 localities, to support the organisations facilitating the meeting.

6. Delivery of education and training

Focusing on the needs of the LGBTQ+ community affected by dementia for all communities in Greater Manchester; as a regular offer for facilitators and wider health and social care staff.

7. Innovative partnership model across GM

The GM wide partnership working with 10 localities supporting the facilitation of an online group has overcome barriers in reaching people from different communities in a cost effective way. This model can be replicated for other hard to reach dementia groups such as young onset and people from minority ethnic groups.

8. Research

Ensure members and the group facilitators are engaged in research opportunities

RECOMMENDATIONS AND NEXT STEPS

NEXT STEPS

- Dementia United will continue to build on the lived experience engagement and co-production; as well as promoting the value of this when working with stakeholders and partners across Greater Manchester.
- Dementia United and the 10 Greater Manchester Dementia Leads are committed to taking forward the recommendations from this report; utilising governance that Dementia United have in place.
- The GM Dementia United Locality Implementation Forum will be an opportunity for us to be seeking further guidance on taking forward the eight recommendations; as we would be looking for system wide engagement across GM as part of the next steps.
- All relevant GM organisations - including LGBT Foundation and VCSE groups can build on the work undertaken so far to develop a whole system approach that is aware of and is inclusive of the needs of LGBTQ+ communities who are affected by dementia.

Below is a final thought from Patrick Ettenes co-founder of Bring Dementia Out who is one of our LGBTQ+ group members, a member of the Greater Manchester LGBTQ+ Dementia Steering Group and who is also a lived experience advisor on dementia.



Patrick Ettenes
Lived Experience Advisor
& Co-Founder of Bring Dementia Out.

'This work is personal to me. Nine years ago when I found out I had frontal lobe atrophy, there was no support for me as a young queer person of colour in Greater Manchester. Even though I have worked non-stop to raise awareness of the support needs for people like myself the work really has only just begun. It feels like there is much more to be done to support all people affected by dementia in Greater Manchester with the hope of a safe and secure future with appropriate support. Without a symbiotic relationship between funders, care givers and communities over the long term, I feel there will be no support for people like me. No-one should be left alone in the dark. There is still much work to be done to support our communities and before all hope is lost I want to ensure everything that can be done is done to support anyone living with or affected by dementia anywhere in Greater Manchester, especially LGBTQ+ people and people of colour, like me.'

FURTHER INFORMATION, SUPPORT AND REFERENCES

We know that there is support and information available both for those affected by dementia and for LGBTQ+ communities separately. However this means nothing if professionals and service users alike are not aware of the services that are currently available to them. To this end we have compiled a short list of some of the groups and organisations that have been integral to our ongoing learning and with further support, we hope to be able to add many more to this list.

GM LGBTQ+ Support group

Dementia United. Flyer in the appendix

<https://dementia-united.org.uk/greater-manchester-lgbtq-online-dementia-support-group/>

Dementia United

Working to make Greater Manchester the best place to live if you have dementia or are caring for someone who does.

<https://dementia-united.org.uk/>

Bring Dementia Out film

Short film on the Bring Dementia Out innovation project <https://www.youtube.com/watch?v=io6600RFDbU&t=7s>

LGBTQ+ Dementia Advisory Group

National network of people committed to improving support for LGBTQ+ people affected by dementia

<https://www.lgbtqdementiaadvisorygroup.net/>

Speak Out With Dementia

Online group for LGBTQ+ people across the UK who are living with a diagnosis of dementia

<https://www.dementiavoices.org.uk/group/lgbtq-group-working-towards-an-identity-and-a-name/>

Sheffield LGBTQ+ Dementia Support

Providing a safe space for people from the LGBT+ community with dementia -with support, information and friendship

<https://www.sheffieldmind.co.uk/lgbt-dementia-group>

The Dementia Project at Brighton & Hove LGBT Switchboard

Provides information and support to LGBTQ+ people affected by memory difficulties, cognitive challenges or dementia, and to their carers

<https://www.switchboard.org.uk/what-we-do/dementia-support/>

Oldham Out & About Group

An informal social support group for older lesbian, gay, bisexual and transgender people in Oldham.

<https://www.ageuk.org.uk/oldham/our-services/leisure-and-social-activities/olgbt-out-and-about-group/>

Out in the City

A self-organised project (supported by Age UK Manchester) to support members of the LGBT communities.

<https://outinthecity.org/>

Pride in Ageing

Was set up in response to concerns that too many LGBT people over the age of 50 are living in isolation and facing discrimination as a direct result of their sexual orientation or gender identity.

<http://lgbt.foundation/prideinageing>

FURTHER INFORMATION, SUPPORT AND REFERENCES

FURTHER REFERENCES

The LGBT Dementia Toolkit was designed by Alzheimer's Society Scotland to help health and social care staff to reflect on and develop their practice in working with LGBT people with dementia. <https://www.lgbthealth.org.uk/resource/lgbt-dementia-toolkit/>

LGBT: Living with dementia | Alzheimer's Society: <https://www.alzheimers.org.uk/get-support/daily-living/lgbt-living-dementia>

Supporting an LGBTQ+ person with dementia: <https://www.alzheimers.org.uk/get-support/help-dementia-care/supporting-lgbtq-dementia>

LGBT dementia care: Changes in society: <https://www.alzheimers.org.uk/get-support/help-dementia-care/changes-society-lgbt-people>

Proud to Care: LGBT and Dementia
(a Healthcare Guide) A guide to support health and social care staff develop their practice in working with lesbian, gay, bisexual and transgender (LGBT) people with dementia. <https://www.lgbthealth.org.uk/resource/lgbt-dementia-toolkit/>

Can You See Us
Experiences of LGBT Carers in England. <https://lgbt.foundation/canyouseeus>

Dementia UK page on LGBTQ+ dementia: <https://www.dementiauk.org/lgbtq-and-dementia/>

Interview with Patrick Ettenes
On living with early onset <https://www.nationalcareforum.org.uk/members-news/interview-with-patrick-ettenes-bring-dementia-out-ambassador>

Bring Dementia Out film
Short film on the Bring Dementia Out innovation project <https://www.youtube.com/watch?v=io6600RFDbU&t=7s>

LGBTQ+ Voices in Dementia Together magazine <https://www.alzheimers.org.uk/get-support/publications-and-factsheets/dementia-together>

Phil Harper - an academic and LGBTQ+ Dementia activist features in a My Care Matters newsletter. <https://mycarematters.org/about-mycarematters/>

Sex, gender, sexuality report
Alzheimer's Europe report on sex, gender and sexuality in the context of dementia. <https://www.alzheimer-europe.org/sites/default/files/2022-02/2022-02-25%20Alzheimer%20Europe%20ethics%20report%202021.pdf>

LGBT: Living with dementia | Alzheimer's Society <https://www.alzheimers.org.uk/get-support/daily-living/lgbt-living-dementia>

LGBT dementia care: Changes in society <https://www.alzheimers.org.uk/get-support/help-dementia-care/changes-society-lgbt-people>

Learning framework for knowledge, skills and values for working affirmatively with LGBTQ+ people in later life. <https://www.skillsforcare.org.uk/Support-for-leaders-and-managers/Supporting-a-diverse-workforce/LGBTQ-learning-framework.aspx>

NHS Long Term Plan: <https://www.longtermplan.nhs.uk/>

ACKNOWLEDGEMENTS

Dementia United and LGBT Foundation would like to give extra special thanks to the LGBTQ+ group members, group facilitators, steering group panel and to the Dementia Locality across all 10 localities in Greater Manchester.

All of the above have supported with linking us in with the wide range of voluntary and statutory organisations who have supported the group.

Special thanks also to all who contributed to this report, they are; HP,CW,AG,KM,DN,MM,SC,PE,AC,MP,SO,LB.

APPENDIX



ONLINE DEMENTIA SUPPORT GROUP



Greater Manchester | LGBTQ+

A safe and friendly space to express yourselves
and support each other:

- Speak or listen in an LGBTQ+ safe space
- Be anonymous if you prefer
- Make friends / connections
- Talk about issues that are important to you
- Guest speakers
- Fun monthly quiz



First Tuesday of the month | 2PM - 3.30PM



Zoom meeting



Contact Kathryn Mellor – kathryn.mellor@lgbt.foundation
for zoom details and further information

Supported by:



LGBT
foundation

lgbt.foundation



gmhscp.dementiaunited@nhs.net

info@lgbt.foundation

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