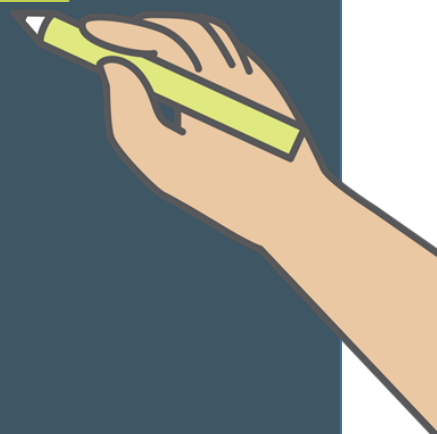


Dementia United

Prospectus (2021/22)
Who we are and what we do



1 in 3

People born in the UK will develop dementia in their lifetime (ARUK2015)



82%

Of carers and people living with dementia reported deterioration in symptoms of loved ones with dementia due to lock-down (AlzSoc2020)



95%

Of carers surveyed during 2020 reported a negative impact on their mental or physical health (AlzSoc2020)



We can reduce our risk of developing dementia

Greater Manchester has the highest number of premature deaths from heart disease in the country. Heart disease is a risk factor for dementia. But we can control this risk and reduce our chances of developing dementia.



ABOUT US

Dementia United is Greater Manchester Health and Social Care Partnership's flagship programme for dementia. It is our aim to work alongside clinicians, charities, localities, professionals, those living with dementia, families, friends and care partners to make our region the best place to live if you have or are caring for someone with dementia.

In April 2016, our dementia diagnosis rate was already higher than the national average. The devolution of Greater Manchester Health and Social Care (GMHSC) has given us a unique opportunity to build on that fantastic framework.

Our primary objective is to make Greater Manchester the best place to live if you're living with dementia or caring for someone who does. To achieve this, we are working towards three goals.

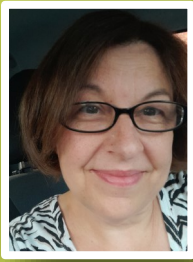
1. Providing access to dementia care services for all.
2. Increase independence for those living with dementia.
3. Ensuring equally high standard of care, no matter where you live.

Devolution has enabled us to approach dementia in a more joined-up fashion and Greater Manchester collaboration builds on integrated approaches in each locality.

We are working together to understand how we can best support and extend our locality engagement to drive forward our shared values and ambitions across Greater Manchester.

We bring together all sorts of people. From people living with dementia and their care partners, to clinicians, locality health and social care leads, Alzheimer's Society, Academic and research partners, housing colleagues and many more across Greater Manchester and beyond.

MEET OUR TEAM:



Name: Gill Walters
Role: Senior Implementation and Improvement lead
Contact:
gill.walters@nhs.net



Name: Helen Pratt
Role: Project Manager
Localities: Manchester, Oldham, Salford
Contact:
helen.pratt5@nhs.net



Name: Dr Sarah Fox
Role: Project Manager
Localities: Trafford, Wigan
Contact:
sarah.fox48@nhs.net



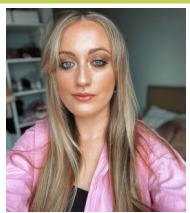
Name: Sarah Kirkland
Role: Project Manager
Localities: Bolton, Bury
Contact:
sarah.kirkland@nhs.net



Name: Alice Thornton
Role: Project Manager
Localities: Stockport, Tameside, HMR
Contact:
alice.thornton2@nhs.net



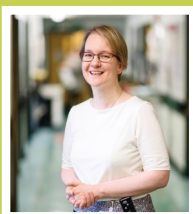
Name: Laura Blake
Role: Communications and Engagement Lead (ASC, Dementia and Mental Health)
Contact:
laura.blake10@nhs.net



Name: Georgina Bulga
Role: Programme Administrator
Contact:
georgina.bulga@nhs.net



Name: Dr Helen Martin
Role: Clinical lead
Contact:
helenmartin1@nhs.net



Name: Dr Emma Vardy
Role: Clinical Advisor/strategic board member
Contact:
Emma.Vardy@srft.nhs.uk

DEMENTIA UNITED PROGRAMME: HOW WE WORK

Networks and Stakeholders

(Local, National, Global)

Regular GM meeting groups

- Dementia Locality Leads meeting
- Dementia Carers Expert Reference Group (DCERG)

Experts by experience network

(Advisors, influencers and community drivers)

- Dementia Carers Expert Reference Group
- People living with Dementia
- Voluntary, community and social enterprise
- Primary/secondary/tertiary care
- NHS England/MH Trusts
- Academic/Research institutions
- Global Brain Health Institute



Strategic Implementation

Implementation/Operations Group

- Lived Experience (Carers and people living with Dementia)
- All ten GM localities
- Clinicians/specialist advisors
- Dementia United Programme Team reports into this meeting

Dementia United Strategic Board

GMHSCP, GMCA, ADASS, NHS England,
Lived Experience and Carers Expert Reference Group
GMMH, Pennine Care, Health Innovation Manchester
Primary and Secondary Care, clinical and locality leads
Voluntary, community & social enterprise sector

The programme is supported by the DU team (page 3) and it is part of the Greater Manchester Health and Social Care Partnership. The Senior Responsible Officers are Steve Dixon and Warren Heppolette.

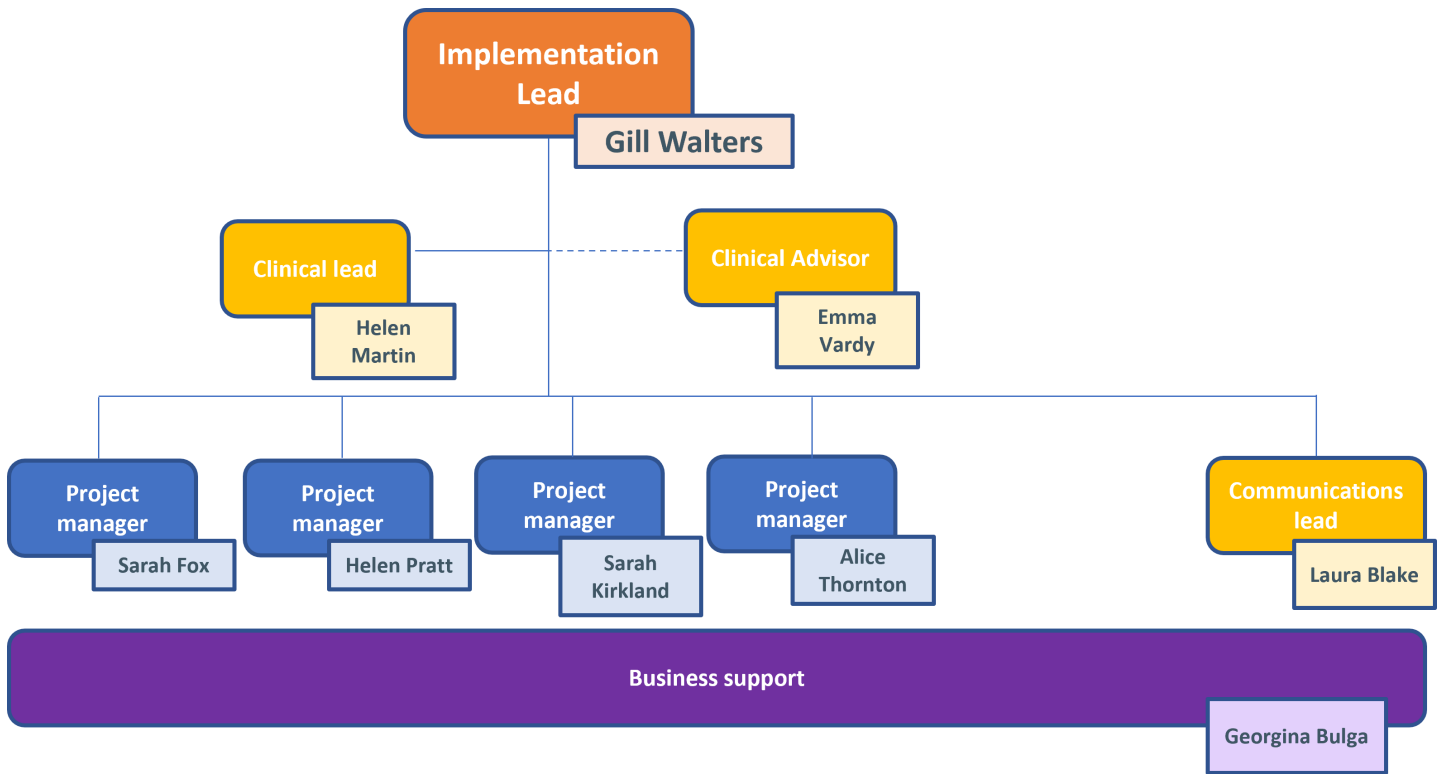
Regular meeting groups: Several key stakeholder groups meet regularly with the Dementia United team. Outcomes from these meetings drive how we implement our work.

Experts by experience: Dementia is a complex condition which requires the coming together of experts from many fields. DU works closely with multiple stakeholder networks to ensure our work is **relevant, achievable and tailored to our local community.**

Implementation Operations Group; This group, chaired by Warren Heppolette, oversees the work of the Dementia United Programme and reports to the Strategic Board.

The Dementia United Strategic Board, chaired by Steve Dixon, provides strategic leadership for Dementia United to support colleagues working across the system in order to change and improve the experience of dementia support and services for people with dementia, carers and the public.

PROGRAMME TEAM: HOW WE WORK

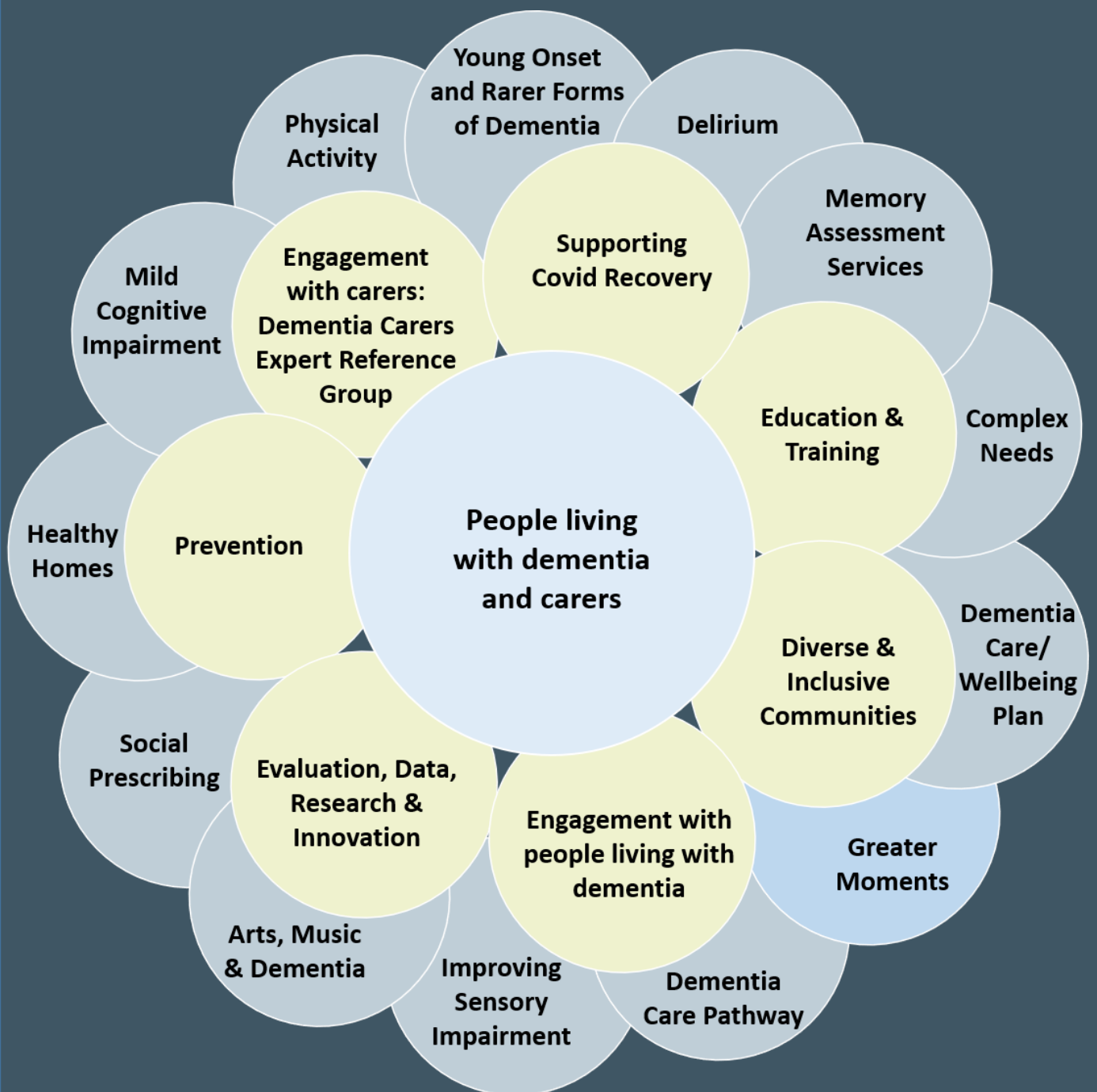


OUR WORK

Dementia United hosts an ambitious portfolio of work. Our projects cover all stages of the dementia journey, from prevention and diagnosis to living and dying well.

One of the strengths of this programme continues to be the building of networks and bringing all partners/stakeholders together to work in collaboration. We strive to ensure that all our work is co-owned, designed and shared with our partners and that each project offers opportunities for your involvement and support. Please browse our project portfolio and get in touch if you would like any more information or would like to share your views and expertise on any of these projects (contact information: page 13).

What we do: The DU Flower



People living with dementia and carers are at the centre of all of our workstreams



These cross cutting themes feed into many of our key focus areas



These are our key focus areas

OUR WORK AT A GLANCE:

Delirium	<p>GM wide implementation of Community Delirium Toolkit.</p> <p>Raising awareness about delirium across GM with a resource to support this; including translated resources – focus on education and training.</p> <p>Deliver a GM Hospital Toolkit; making this available to all acute trusts/ Mental Health Hospital trusts.</p>
Dementia Care Pathway	<p>Delivery of clear Greater Manchester standards and good practice framework; underpins all the Dementia United programme. Digital procurement for the pathway to enable all users to navigate and use it.</p>
Dementia Care/ Wellbeing plan	<p>The care plan enables a person-centred conversation with the person with dementia and family/friends; tailored to their personalised needs. This will be available digitally for all to access and use it.</p>
Memory Assessment Services	<p>Identify and support good practice in MAS, including work by Leeds Beckett University research team to identify good practice criteria, through consultation, and work to ensure appropriate use of funding.</p>
Complex needs	<p>Identify opportunities to engage with Adult Social Care Complex needs programme. This includes offers to support; lived experience engagement, education/training and locality-led good practice examples.</p>
Social Prescribing	<p>Develop a support offer for social prescribing link workers and VCSE community providers alongside provisioning a pathway to allow people living with dementia or an MCI to access social prescribing services.</p>
Mild Cognitive Impairment (MCI)	<p>Follow up the work commissioned through the neurology academy in terms of sharing good practice examples from resultant QI projects.</p>
Arts, Music and Dementia	<p>Support Greater Manchester’s brilliant work on the arts and dementia, working across the GM localities and with national initiatives such as Music4Dementia and local partners.</p>
Physical activity/ Greater Sport	<p>Identify opportunities to work with Greater Sport to create opportunities for physical activity.</p>
Young onset & Rarer forms	<p>Identify how best to work with the Admiral Nurse Programme and utilise their match funding offer in collaboration with commissioners and locality partners.</p>
Greater Moments	<p>To promote and share the Greater Moments app.</p> <p>To support the Social Sense team in their ongoing work to ensure the Greater Moments app success and sustainability.</p>
Healthy Homes	<p>Seven recommendations across a broad multi-agency partnership involving local government, NHS organisations, the housing sector, VCSE organisation and communities themselves.</p>
Hearing Trailblazer	<p>Better recognition of importance of hearing for people with dementia and in reducing the likelihood of developing dementia.</p>

Projects: Deep dive

Arts for dementia:

Aim: To support Greater Manchester's exceptional work in the field of arts for dementia, creating a platform for innovation and shared learning.

Project description: A growing evidence-base suggests that participation in high-quality arts and cultural activities can have a beneficial impact on a range of chronic conditions, including dementia. Indeed, the social and creative elements of arts-based programmes may even reduce an individual's risk of developing dementia, or slowing the progression of existing conditions. Greater Manchester is a global leader in research and practice in the field of arts for health and wellbeing. **We want to support this exceptional work across the city by creating a platform to share activities, advice and best practice.**

How can you get involved?: If you host an art-based activity for people with cognitive impairment we'd love to include your activity in our growing database. We are also happy to advise anyone who is interested in embedding arts and music into their existing groups and services.

Delirium:

Aim: Improve the detection, assessment, treatment and management of delirium across Greater Manchester.

Project description: Delirium is a condition which causes a short-term confused state and develops over hours and days; as a result of underlying illness. People living with dementia are more likely to experience delirium and if undetected and treated, it can lead to much poorer outcomes. Dementia United has three areas that form the programme of work, focusing on improving the detection, assessment and management of delirium:

- Community delirium toolkit and resources
- Hospital delirium toolkit and resources
- Delirium training resource

Dementia United have piloted the community delirium toolkit in 2020, with community teams in Bolton, Salford, Stockport, Manchester and Trafford. 70% of the people with delirium who were supported by these teams, were able to be safely managed at home.

How you can get involved: Please feel free to download the resources from our website (dementia-united.org.uk) and utilize these. If you are interested in finding out more about our training approaches please get in touch.



Projects: Deep dive

Healthy homes:

Aim: Our ambition is to reduce, avoid or delay avoidable admissions (whether to care/nursing homes or hospitals), for as long as possible and to maximise personalisation in every setting, including care homes.

Project description: The homes people living with dementia and their carers live in have an enormous impact on their quality of life. Lack of choice and rising demand can lead to people having to choose between living at home independently in a house which is increasingly unsuitable for their needs or moving to a care home. At dementia united we are:

Opening communication channels on housing options: providing transparent accessible information and signposting for everyone.

Commissioning dementia-friendly housing: creating links with adult social care, analysing existing gaps in available provisions and developing a housing position statement for Greater Manchester.

Training across the housing sector: co-produced training alongside tenants, social workers and dementia expert reference groups targeted to identify need and appraise options.

Lived Experience

Aim: We aim to engage lived experience in all aspects of the programme. This can be through existing groups and networks or directly as part of specific pieces of work. Our governance structure includes lived experience contributing the vital perspectives which comes from real lived experience, both from people living with dementia and their carers.

Project description: The Dementia Carers Expert Reference Group (DCERG) was set up in 2018. The DCERG consists of a group of current and former carers of people with dementia who are passionate about improving the lives of carers of people living with dementia and those they care for across all Greater Manchester.

Linking in with Dementia Leads across 10 localities and a variety of communities across GM, the DCERG members are equal partners in DU's governance structure and are represented at each DU Task & Finish Group, and multiple additional projects. Members also represent other none-dementia specific organisations, building bridges and essential links sharing best practice. Within their localities and networks, they ensure the carers collective voice is represented in the feedback of the development and implementation of all work streams.

How you can get involved: If you are, or can facilitate an introduction to, an individual living with dementia or a carer or former carer of an individual living with dementia, that would like to be involved in the programme's governance or a workstream – please get in touch!

Contact: For carers of individuals living with dementia please contact sarah.kirkland@nhs.net
For individuals living with dementia please contact alice.thornton2@nhs.net



Projects: Deep dive

Post Diagnostic Support:

Aim: To improve the support and services which people affected by dementia receive leading up to and after diagnosis.

Project description: Dementia United have aligned our work with NHS England's dementia well pathway, to cover preventing, diagnosing, living, supporting as well as dying well. Over 200 people living with dementia and carers have been engaged with and, or assisted with co-producing the post diagnostic support work programme projects. We have two key projects;

Dementia Care Pathway

A dementia care pathway will set out the support and services that people should receive, wherever they live. It brings together information about services in each locality, along with the reasons and best practice behind those services. It will be available online as a digital resource allowing people to find the services and support available, and also compare post-diagnostic support across localities.

Dementia Wellbeing Plan

The dementia wellbeing plan promotes personalised planning conversations with people living with dementia about their needs and wants. It will ensure an improved standard of care planning for people living with dementia and also facilitate sharing across the system. This plan will be available as a standardised plan which can be accessed and shared digitally between practitioners. Alongside the plan there is a training suite for practitioners using the wellbeing plan.

How you can get involved: If you are interested in finding out more about this work please get in touch.



Projects: Deep dive

Prevention:

Aim: To raise awareness of how individuals can improve their brain health, and subsequently reduce their risk of developing dementia at any time in their lives. It's never too early or late to think about your brain health!

Project description: Dementia is usually caused by a mix of factors, including: age, genetics and environment. Although we can't alter the risks which come with advancing age and genetics, research has found that an individual can reduce their overall risk of developing dementia by managing various lifestyle and 'environment' risk factors (see 12 dementia risk factors below). It's estimated that around 40% of dementia cases are preventable through lifestyle modifications. Therefore, we want to help share this information and support residents of all ages to improve their brain health and reduce their risk of developing dementia.

How you can get involved: If you work with people who may benefit from brain health advice or if you want to know more about dementia prevention please get in touch. This project is new to our portfolio, so we are keen to make contacts and support existing work across GM.



Social prescribing:

Aim: We will create local referral pathways for those with cognitive impairment and their care partners to access social prescribing services alongside providing the necessary support for social prescribing networks to feel confident to support these patients.

Project description: Social prescribing provides holistic support for many people living with long term conditions across Greater Manchester, however, pathways do not currently exist linking those with dementia or mild cognitive impairment into these services. To achieve this goal we intend to:

- Develop a support offer for social prescribing link workers who connect with people living with dementia, mild cognitive impairment and their care partners.
- Create local referral pathways for patients with a cognitive impairment and their care partners, facilitating better access to social prescribing offers.

How you can get involved: This project is new to our portfolio. We would love to hear from anyone who has experience of social prescribing or who is interested in building a social prescribing offer for people with dementia into their service.

Projects: Deep dive

Young onset and Rarer forms:

Aim: To improve confidence and capacity in diagnosing young onset dementia and to facilitate support provisioning for those with a diagnosis In Greater Manchester.

Project description: It is estimated that there are over 42,000 people in the UK diagnosed with young onset dementia. Having young onset dementia brings unique challenges. For example, diagnosis can be more difficult as a person is a lot more likely to have a rare form of dementia that won't present as memory loss; it is also more likely to be inherited. We are lucky enough to have a specialist diagnostic centre at the Salford Cerebral Function Unit, however referrals from across Greater Manchester vary. So far we have:

- Hosted a clinical webinar on diagnosis and one on post diagnostic support.
- Worked alongside Pennine Care to develop awareness materials, including some fantastic awareness films and a toolkit for professionals working with people living with primary progressive aphasia: <http://dementia-united.org.uk/young-onset-and-rarer-forms/>

How you can get involved: Dementia UK is a national charity that specialises in helping families to face dementia through the provision of specialist dementia nurses, known as [Admiral Nurses \(AN\)](#). Due to an extremely successful fundraising year in 2020, they are looking to invest **£60,000** in a specialist Young Onset Dementia (YOD) Admiral Nurse Service for GM.

Following on from our previous Young Onset Rarer Forms (YORF) work, **Dementia United** are working with Dementia UK to develop, roll out and evaluate this service.

We are looking to pilot a 'trailblazer' model for this service and require up to three localities in Greater Manchester to invest a combined amount of £60,000 match funding, in order for the service to run for two years. If two localities take this offer forward, this would mean an investment of **£15,000** pa each. If three localities come forward then it reduces to **£10,000**.

All participating locality partners will be fully supported by both Dementia UK and Dementia United to run this service, throughout the entire pilot process and beyond.





GET IN TOUCH

 @dementiaunited

Enquiries: gmscp.dementiaunited@nhs.net







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

Events:



GM LGBTQ+ ONLINE DEMENTIA SUPPORT GROUP

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

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

Join our online peer support group for people living with or caring for someone with dementia, who identify as LGBTQ+ (lesbian, gay, bisexual, trans, queer). We are here to provide you anonymity in a friendly and safe environment where you can share your experiences or concerns with like-minded people.

FIRST TUESDAY OF THE MONTH

2PM - 3.30PM

Zoom Meeting

To obtain the details to join the Zoom meeting, please contact Magie Hurley as below.

FOR MORE INFORMATION

0161 622 9252 | Maggie.Hurley@ageukoldham.org.uk

If you are from the LGBTQ+ community and would like some advice on any other services or would like to speak to someone please contact the LGBT Foundation on 0345 330 3030



Dementia United are working in partnership with the Alzheimer's Society, guided by a steering group of people affected by dementia, to plan a joint event for Greater Manchester. The audience for the event are people affected by dementia, stakeholder's, VCSE partners, health and care staff.

The focus of the event will be the 4 R's – ***Reflect, Review, Refocus and Recovery.***

The event is intended to be a respectful reflection, acknowledging the impact of the pandemic, as well as reviewing and highlighting some of the innovations that have taken place in the last year.

Looking to the future and showcasing great practice examples from GM and across the UK, as part of a refocus on recovery; working to make Greater Manchester the best place to live if you are affected by dementia.

How can you get involved: If you're interested in finding out more, please get in touch.