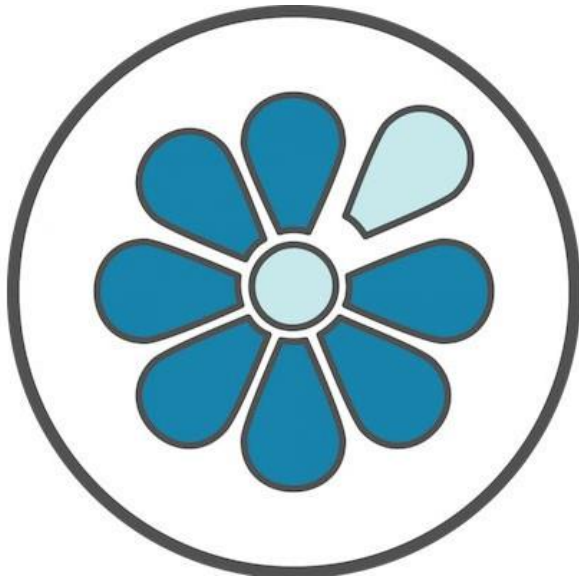


DEMENTIA UNITED

End of Year Summary

DECEMBER 2019





2019 has been a significant year for Dementia United. So much of our work has progressed as the programme grows to maturity.

The areas of work which were set out in early 2018 are advancing on their goals. Many of our focus areas now have tangible outputs emerging after months of hard work with our partners and stakeholders. We look forward to their implementation in the coming year.

Next year promises to be busy as the programme transitions to locality ownership. We plan to bring localities together in the New Year to discuss how the transition will be managed. We want to ensure that the handover in 2021 works with their plans and priorities, and that the Greater Manchester level working and communication is sustained.

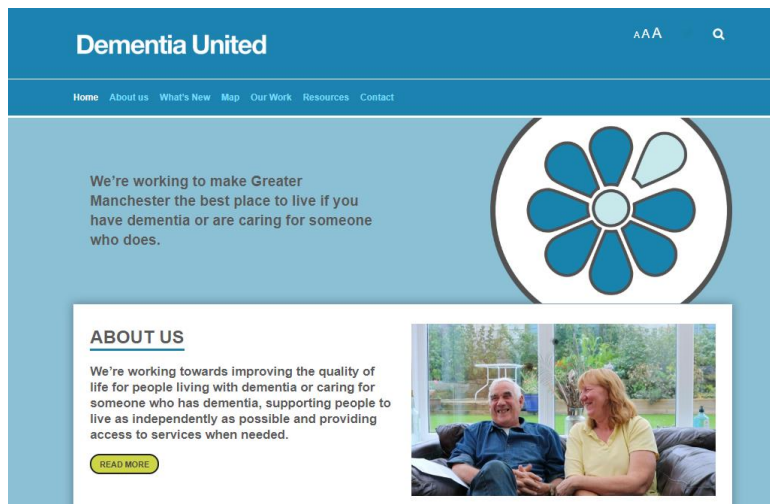
A Note of Thanks

We want to thank everybody who has been involved in the programme over the last year. There is no programme without you and it only has meaning if it relates to your daily life and work. We know that everybody has different calls on their time, and we're privileged that you've chosen to spend that time working with us.

Together we've achieved a lot in 2019 and hope to repeat the success in 2020.

KEY HIGHLIGHTS

- Dementia United held a large event for Dementia Action week to celebrate all that has been achieved over the last year, over 200 people attended.
- Dementia United have been working with stakeholders across Greater Manchester to launch our new website: www.dementia-united.org.uk



- A final report for phase 1 of the Dementia United evaluation is due at the end of February 2020. We're already seeing some excellent results and these will be utilised for the programme transitional planning in 2020-21.
- The commissioning of the Dementia Carers Expert Reference Group (DCERG) through tide
- Greater Manchester continues to perform ahead of the rest of England in dementia diagnosis rates. It has the highest 65+ estimated diagnosis rate of all NHS Sub Regions, standing at 76.2% in October 2019.
- Working with Business Intelligence teams across Greater Manchester we have developed the first draft of the Dementia United dashboard
- 2019 gives us cause for celebration. Following a year of collaboration and tireless effort from the Greater Manchester Clinical Research Network, Greater Manchester Mental Health NHS Foundation Trust's Dementia Research Centre, Pennine Care and Dementia United, it appears that we're starting to see a sustained increase in research awareness and Join Dementia Research registrations, especially for those living with a dementia diagnosis.

PROGRAMME UPDATE

Post-Diagnostic Support

In the first half of 19/20 localities have continued to work exceptionally hard together in collaboration to develop and agree common standards for Post Diagnostic Support to create documents for two key outputs: A Greater Manchester Care Pathway for dementia and a new dementia Care Plan with a focus on personalisation. Both were developed in partnership with commissioners, service providers, and people with lived experience of dementia as well as carers.

We have delivered a period of public feedback on the Care Plan to improve and refine the document. We have been working with localities to deliver a pilot of the Care since late summer and is due to take place in January 2020. We have been working with localities for the planning and organising an extensive series of public feedback sessions for the Care Pathway, in which people living with dementia and carers will give their input on the content and focus of the document.

We have worked with people living with dementia and carers to ensure this is an accurate reflection of what the gold standard should be in Greater Manchester. A first draft of a third output, a single standard for Dementia Navigation, has been produced and will be circulated for comments from commissioners and service providers in the new year.

End of life care

There has been a focus on collaborative working with the established [Strategic Clinical Network Palliative and End of Life Care team](#). Task and finish group consisting of health and social care professionals, commissioners and those with lived experience asked what their priority was for this area. This included training to initiate early end of life conversations, which is why the free one-day Advance Care Planning training has been promoted to health and social care staff working in the dementia setting.

Working jointly with Post Diagnostic Support, a condensed version of this is also included in the training of those who are involved in the Dementia United dementia care plan pilot. In support of other priorities, the task and finish group were also involved in the Strategic Clinical Network Pain and Symptom Control Guidelines consultation providing a dementia perspective and a plan is being made to work with Greater Manchester Hospices around training on caring for those living with dementia in their last months of life.

Mild Cognitive Impairment



The task and finish group for Mild Cognitive Impairment has continued to work in collaboration with localities and individuals affected by Mild Cognitive Impairment to develop and agree a set of common standards to develop the Mild Cognitive Impairment Post Diagnostic Support leaflet, which was launched in May 2019.

In November, we also hosted many senior leaders from across the country for a round table discussion to inform a consensus statement around Mild Cognitive Impairment in the absence of NICE guidance.

Young onset and rarer forms



The project to undertake mapping interviews across Greater Manchester to establish a baseline of support for those with young onset and rarer dementia is almost complete.

With so many forms of rare dementia, the interviews were designed by the task and finish group to cover main functions affected e.g. memory, personality, reasoning, language, vision as well as support for those under 65.

The aim was not to present a 'best picture' but a considered honest view of challenges for the person living with dementia, families, health and social care professionals and commissioners. For this reason, where the interview was piloted in Salford it was found this was best done as a team exercise where possible. With the task and finish group members carrying out interviews rather than handing out questionnaires, there was more opportunity for deeper discussion and sensitivity when discussing topics such as end of life. The exercise has informed the group's priorities and next steps.

Lived Experience Barometer



We have been working with stakeholders, people living with dementia and carers across Greater Manchester to develop the Lived Experience Barometer. We have reviewed current and past research and projects to develop a literature review to explore and reduce the risk of duplication.

Due to this we are now working closely with the Local Health Care Record Exemplar team to ensure both tools feed into each other. We have travelled across Greater Manchester to get the feedback from the public on what really matters to them. This research highlighted the importance of relationships, social engagement and everyday function, addressing poor physical and mental health and ensuring high quality care.

Five common themes were: Safety, Social, Activities, Inclusion and Accessible. We developed an accessible survey requesting feedback and opinion on the potential platform features included. Results from the survey highlighted that 76% of people liked the features we presented, with local information and wellbeing scoring the highest, 77% did not like the current 'Lived Experience Barometer' name. Due to this we are now in the second phase of the draft design and currently reviewing the proposed name of 'Greater Moments' and the branding with stakeholders.

Delirium

Our work is aligned with the developed 7 Greater Manchester delirium standards and questionnaires completed by each acute Greater Manchester hospital trust. Questionnaires highlighted key staff to engage with in the hospital setting, existing practice regarding delirium and barriers/gaps to be addressed particularly around links with the community. Using the relationships established through Dementia United the development of a successful Salford Royal electronic delirium assessment tool will be supported in Bolton and Wythenshawe by Health Innovation Manchester, whilst Dementia United ensures all acute Greater Manchester hospitals have a clinical delirium guideline in place.

Dementia Carers Expert Reference Group

Since the inception of the Dementia United programme, we have been working closely with [together in dementia everyday \(tide\)](#) to agree a model for a sustainable involvement strategy for carers of people living with dementia.

This year saw the successful establishment the Dementia Carers Expert Group. The group has developed a strategy to combat social exclusion by giving people a voice, especially in marginalised populations, recognising the diversity of local communities. The group has been working closely with localities to ensure the group is representative across Greater Manchester to ensure community ownership and ultimately the long-term sustainability of service redesign to meet local needs, moving beyond what is delivered through a medical model.



The Dementia Carers Expert Group model was presented by Ruth Turner, Kim Wrigley and Micheál McLaughlin at the UK Dementia Congress in November where living grief was also discussed.

Lived Experience Network



We have been working with local organisations, including the Alzheimer's Society and DEEP, and have launched our Lived Experience Network for people living with dementia, enabling individuals to have a voice throughout the entirety of the programme.

The group represents the voices of people living with dementia in Greater Manchester. We will influence local decision making that impacts on the lives of people living with dementia, and the services that support them.

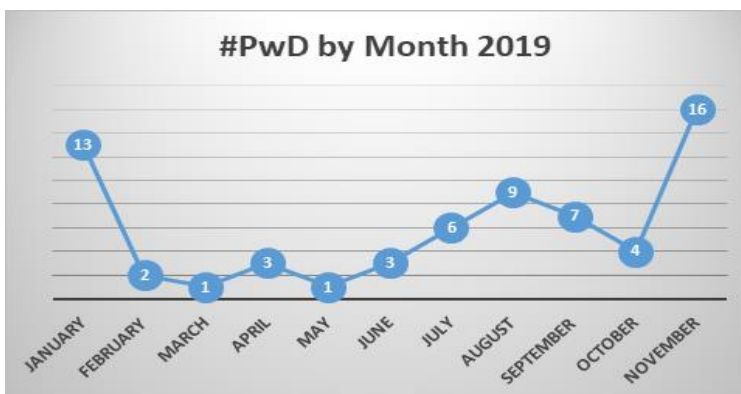
GOOD NEWS

Dementia diagnosis rates

Greater Manchester continues to perform ahead of the rest of England in dementia diagnosis rates. It has the highest 65+ estimated diagnosis rate of all NHS Sub Regions, standing at 76.2% in October 2019.

Sustained increase in Join Dementia Research registrations

November has seen 16 new patients with a diagnosis register to the service, the most we've seen in a single month all year. This now places 2019 on track to be the second most successful year for research registrations since Join Dementia Research was launched in 2014.



We want to thank everyone who has helped us raise research awareness in 2019 from memory assessment teams, community groups through to GP surgeries – your efforts are hugely appreciated. We're currently planning a range of new initiatives for 2020, including workshops, talks and activities. If you would like to know more or would like to get involved please e-mail sarah.fox@gmmh.nhs.uk

WELCOMES AND GOODBYES

We said goodbye this year to several longstanding members of the programme and were joined by others.

Goodbyes to

- **Anthony Hassall**, who was a Senior Responsible Officer for the programme for many years will be leaving his role at Salford in January for a secondment with NHS England.
- **Dr Jeff Schryer**, who had been Clinical Lead for primary Care in Dementia has left the team. Jeff provided the programme with his clinical expertise, especially around Mild Cognitive Impairment of which he helped to greatly raise the profile.
- **Rachel Volland**, who had led Dementia United since its inception (and before) left in November to take up a new role with the Advancing Quality Alliance in Salford.
- We will also soon be saying goodbye to **Kim Wrigley** when she retires in March 2020. Kim has 38 years' experience working in the NHS, predominantly in dementia services, as a Registered Mental Health Nurse, and is very proud to be a nurse. Since 2005, her career has developed within the area of palliative and end of life care, initially with the Strategic Health Authority then in numerous roles within network organisations, landing with the Strategic Clinical Networks in 2014. Kim's approach is to keep the person and those close to them at the centre of all we are aspiring to achieve as "we are the they". We wish Kim the very best for her retirement.

Welcomes to

- **Dr Helen Martin**, GP/Primary Care Clinical Lead, Dementia
- **Laura Blake** joined this summer to provide dedicated communications support. Laura works with the programme 1.5 days a week.
- **Dr Ross Dunne**, a Consultant Later Life Psychiatrist with GMMH, has joined the programme as Clinical Advisor, Dementia.
- **Sarah Fox** has joined the team and Patient Involvement and Engagement Lead with an expertise on research. She has also been undertaking a similar role with Greater Manchester Mental Health, leading the recruitment of research volunteers for Join Dementia Research in Greater Manchester.

There will be more information on new recruits to the team in the New Year.

KEY DELIVERABLES FOR THE REMAINDER OF THE YEAR

- Launch and complete the care plan pilot
- Seek stakeholder feedback on the Post Diagnostic Support pathway
- Lead on an Equalities analysis for dementia diagnosis and care and progress a number of key projects responding to this analysis
- Continue to work with the Local Healthcare Record Exemplar in ensuring the Post Diagnostic Support care plan is digitalised
- Launch of Greater Moments (formally Lived Experience Barometer)
- Locality event, to support the transitional planning of the programme
- We will host our third World Delirium Awareness Day event launching our work with urgent community response teams to identify and manage delirium, as well as a delirium leaflet suitable for the community and hospital setting; including those diagnosed with dementia regarding prevention techniques.
- We will work collaboratively with Greater Manchester Hospices for bespoke training around end of life care for those living with dementia. We will see a Young Onset and Rarer forms event to share the findings of the mapping exercise and launch next steps. These include recruiting Cerebral Function Unit Link Workers within localities to aid timely and accurate diagnosis (of young onset and rare dementia); implementing the Young Dementia UK tool to facilitate age-appropriate conversations with dementia advisers and the launch of a personal budgets leaflet providing specific examples for those living with young onset dementia.
- Carry out a full evaluation of our programme.
- We will deliver training around Mild Cognitive Impairment to Greater Manchester localities so Dementia United's Mild Cognitive Impairment innovation projects and Mild Cognitive Impairment support across Greater Manchester are consistent and well informed.
- Revisit the comms strategy creating bi-annual strategic updates on the programme to all stakeholders
- Set out a future vision for the sustainable implementation of the Dementia United change programme, outlining how Greater Manchester can ensure localities implement a consistent Greater Manchester standard. This will also include a commitment to the consistent Greater Manchester wide monitoring of both implementation and future locality outcomes.

GET IN TOUCH

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