



**The Greater Manchester Dementia Carers'
Expert Reference Group (DCERG):
The Story So Far...**

Introduction

This evaluation was instigated by Together in Dementia Everyday (tide). DCERG members contributed their views and helped to shape the recommendations. Although not a direct part of the process, the Greater Manchester Health and Social Care Partnership's Dementia Programme – 'Dementia United' – has provided feedback and their comments are included in the report.

Lena O'Connell, Sarah Butler-Boycott and Ruth Eley from tide produced the final report.

Acknowledgements and Thanks to:

Current DCERG members:

Ruth Turner (Chair), Geraldine Vesey, Jeff Seneviratne, Liz Brookes, Marion Coleman, Ann Booth, Paul Carter, Kim Hughes

Past DCERG members

Chiang Kwok, Denise Horrovkd, Jackie Gandy, Jag Brar-Orgill, Margaret Booth, Rachel Roberts-Newman, Sue Metcalf

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List of acronyms and abbreviations

Carer Involvement Lead	CIL
Dementia Carers Expert Reference Group	DCERG
Dementia United	DU
Greater Manchester	GM
Greater Manchester Health and Social Care Partnership	GMHSCP

Integrated Care System	ICS
Strategic Clinical Network	SCN
Together in Dementia Everyday	tide

Background

The language and concepts of lived experience involvement and co-production in service planning, development and evaluation have been around since the 1970s and are rooted in the mental health service user/survivor-led and other lived experience movements. There is no consensus on the language of involvement – engagement, empowerment, participation, co-design and co-production are all terms that have been used. Whilst language is important, it is the involvement itself that is the crucial factor. Active involvement ranges from the individual level through to the operational and strategic, including training, education, peer support, monitoring, evaluation, recruitment, service provision, planning, commissioning, governance, policy and research. DCERG is a real example of how such active involvement can be initiated and sustained.

The historic devolution of GMHSCP in April 2016 offered a unique opportunity to approach health and social care in a more joined-up way across the ten localities (equivalent to the local authority boroughs), bringing together organisations from both inside and outside the NHS. Tackling dementia was identified as an early priority, and Dementia United (DU) is the programme that addresses this priority. DU aims to make the region the best place to live for people living with or caring for someone with dementia, bringing together those living with dementia, family carers, the NHS, universities, Transport for Greater Manchester, Greater Manchester Police and many other partners. The programme works towards three goals:

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

In 2019, DU agreed to commission and work in partnership with tide to co-design and deliver a model for the sustainable involvement of carers of people living with dementia in Greater Manchester. The model recognised the important role and contribution of carers as ‘Experts by Experience’

The Terms of Reference for the group, agreed in May 2019, set out the core purpose of the group as members using their individual, local and collective knowledge and expertise to advise DU and its work-streams on the direction and content of their work from the carers' perspective, influence the Greater Manchester-wide Carers strategy and promote tide within the region. These Terms of Reference can be found in Appendix One.

Carer representatives were drawn from a wide and diverse group of carers of people living with dementia to form the Dementia Carers Expert Reference Group (DCERG). Members sit alongside health and social care professionals and other leaders as equals, having a voting representative seat on the DU Strategic Board and the DU Implementation and Operations Group, both of which meet bi-monthly.

The whole involvement programme, funded by DU, was initially supported by a two-year Carer Involvement Lead (CIL) post, hosted by tide. tide was funded by DU to support DCERG until April 2021. tide was unable to continue this support from February 2021 due to unforeseen circumstances, but DCERG has continued to operate and since April 2021 DU have been offering continued support through its own project team. A Memorandum of Understanding between DU and DCERG is being co-designed with carers to ensure that carer representation continues to be fully embedded in all aspects of DU Governance. This is will be a continued commitment as GMHSCP evolves into an Integrated Care System (ICS) model in April 2022.

Evaluation scope and methodology

Purpose of the evaluation

tide's evaluation of the DCERG model is based on the summative approach which has been adapted to include the following points for consideration (Brown University, 2021):

1. Is the programme to be continued?
2. Is it possible to replicate and implement the programme in other settings?

3. How sustainable is the programme?
4. What elements could have helped or hindered the programme?
5. What recommendations have evolved from the programme?

We limited the scope of the evaluation to tide's input and support provided to the Group and to DCERG members' reflections on being involved in the model. The evaluation does not extend to assessing the input and work of DU.

Methods

This evaluation utilised qualitative research methods. Firstly, a review of available documents was completed to gain an insight into the functioning of the group. The documents reviewed covered the period from 2019 to 2021 and included:

- Minutes of DU Implementation and Operations Group and Strategic Board meetings
- Minutes of DCERG meetings
- Delivery Plans
- DCERG's responses to consultations
- Background historical documents

The project's 'Theory of Change' was developed by DCERG members at two workshops facilitated by tide's Impact Reporting Manager. Documents from these workshops outlining the Group's collectively agreed outcomes, stakeholder groups affected by the project and indicators for measuring outcomes were included in the document review.

Data on the members' experiences were gathered at two focus groups. Topics discussed are included in the Appendices Three and Four of this report.

In addition, a written contribution was provided by the former CIL whose role was dedicated to supporting all aspects of DCERG's work and the Groups' members and liaising with DU.

The evaluation was conducted independently of DU but the programme was approached for comments at the draft report stage and these comments are included.

Data collected through the documents review and the focus groups were analysed thematically. Themes derived from the analysis are discussed in the sections below.

Brief History of DCERG

In November 2018, DU and tide hosted a joint workshop with facilitators of carer support groups across Greater Manchester. Feedback from this workshop provided a clear steer on what carers of people living with dementia wanted, including how they wanted to be involved in the future programme of work. Carers agreed that the role and function of a DCERG should include the following:

- Priority given to identifying the needs of carers of people living with dementia
- DCERG to have a wider role and remit than merely advising on the ten areas of work outlined
- DCERG should be embedded within the wider governance and management arrangements of DU
- Systematic involvement of carers of people living with dementia at a locality level
- Input and workload of carers to be coordinated through DU and tide to ensure that their workload does not become too burdensome
- Involvement process underpinned by a rights-based approach, with carer involvement seen as 'core' business and a legal obligation on DU and the localities.

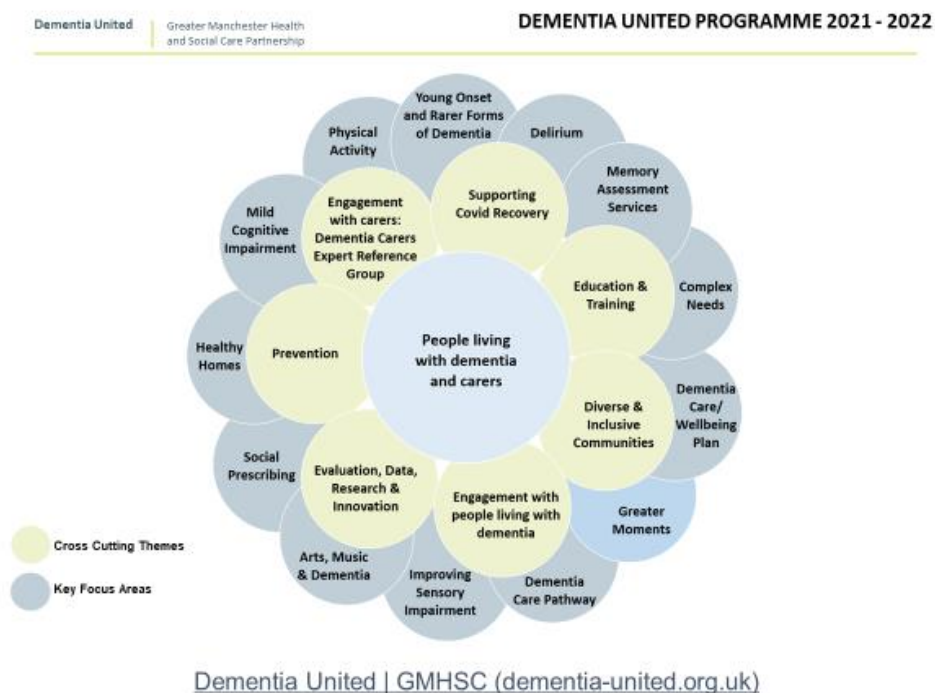
tide drafted the Terms of Reference and role description for a carer expert reference group in January 2019 and carried out a carer mapping exercise. Following a welcome event in February 2019, the Greater Manchester DCERG was launched in May 2019, with two CILs recruited by tide to support the carer involvement model. The Implementation Lead and Senior Programme Manager at the Strategic Clinical Network (SCN) for GMHSCP at the time stated:

'It's absolutely essential, in my view, that we are very genuine in involving carers in everything we do related to our dementia work. We've now had the experience of working with tide and being able to translate that into the

Dementia United programme through the commissioning of the DCERG, and into our governance system in Greater Manchester. And it's not hard to do that now because we've got that partnership agreement with DCERG through tide, so it's a natural consideration...It feels really equal.'

A recruitment process was put in place through the localities and carers were invited to express an interest in joining the group.

DCERG Work and Influencing the Dementia United Programme, as part of GMHSCP



The DU Programme is based on a number of key focus areas, with cross-cutting themes that run throughout the programme, as shown in the graphic above.

These themes include: evaluation, data; research and innovation; prevention; engagement with carers; engagement with people living with dementia; supporting Covid recovery; education and training; and diverse and inclusive communities. The Key Focus Areas have changed over time, but currently (November 2021) these are:

- Mild Cognitive Impairment

- Physical Activity
- Delirium
- Young Onset and Rarer Forms of Dementia
- Memory Assessment Services
- Complex Needs
- Dementia Care Plan/Wellbeing Plan
- Dementia Care Pathway
- Improving Sensory Impairment
- Arts, Music and Dementia
- Healthy Homes
- Social Prescribing
- Greater Moments

‘It’s about having a voice. Dementia United had Key Focus Areas and we’ve been involved in a lot of them. They’ve been listening to the voice of carers rather than token representation and there’s been a lot of positive change.’ (DCERG member)

Some of the former Key Focus Areas have moved as planned to other programmes within the GMHSCP; for example, End of Life Care was initiated and developed within DU but having been financed accordingly is now being taken forward through the Strategic Clinical Networks across a broader geographical area.

Task and Finish Groups

Task and Finish Groups were set up to progress work on the Key Focus Areas and DCERG members identified their areas of interest and involvement in these groups.

‘As the group developed, the DCERG members themselves started to specialize in different Key Focus Areas, taking on roles within their communities or other sectors, linking across health and social care platforms and organisations. This added both knowledge and an essential route for information to be passed between all tiers of Dementia United and out to communities and organisations without a direct link.’ (DCERG CIL, tide)

Members commented that there had been ten Task and Finish Groups, and that Transport, Underserved Populations, and Prevention were initially 'dropped' as workstreams were changed within the DU programme and moved to other parts of GMHSCP.

DU undertook a full review of its priorities and key focus areas in 2020-21 and listened to members of the programme, including DCERG.

Prevention and Underserved Populations remain as key themes across the DU programme and several other active areas of work have expanded, as shown in the revised 'DU flower' graphic on page 7. Transport, however, continues to be led through GMCA.

'Good links have been maintained with Task and Finish Groups throughout the pandemic' (DCERG member)

Locality Work and Projects

In 2019/2020, the Dementia United programme worked across the ten Greater Manchester localities. This included awarding up to £10,000 to each locality to support an innovative project relating to one or more of the Key Focus Areas or system enablers (Golden Threads):

- Bolton: Enhancing the Bolton DAA, empowering local communities to build on the work, and provide talking therapies to support carer resilience and coping strategies
- Bury: Mild Cognitive Impairment Pathway
- Heywood, Middleton and Rochdale: Music and Arts Therapy Scheme
- Manchester: Increasing awareness of dementia in South Asian communities
- Oldham: Oldham Cares - eradicating the myths around End-of-Life
- Salford: Mr Alzheimer's School Campaign
- Stockport: Building blocks to further implement dementia care
- Tameside: Uniting for dementia in Tameside and Glossop
- Trafford: Mild Cognitive Impairment – physical activity sessions

- Wigan: One-Stop-Shop event for statutory, voluntary and community organisations – ‘Under One Roof’

DCERG members commented that locality work has been a bone of contention as, for most localities, there was no link with a specific Dementia Locality Lead. One member did describe links with their locality lead and said they had met before the pandemic, but this has not happened in all localities and many people did not receive locality briefings. The DCERG CIL stated that they had called for a link between Dementia Locality Leads and the DCERG, but that this was only partially successful:

‘This was because the involvement of the locality leads was not a formal relationship so there was no accountability. In the final year of the project, we worked on outlining a sustainable structure. This was formalised in a DU document, The Locality Based Model. The Terms of Reference linked directly to the Terms of Reference for the DCERG.’

A member added:

‘There are [currently] ongoing tensions with locality groups as some are not functioning as well as others. There’s also an issue over Microsoft Teams and digital inequality. If you don’t have a business account, it’s a barrier. This means it is not a holistic approach. Same people; same results.’ (DCERG member)

Greater Manchester collaboration builds on integrated approaches in each locality and DU is working with the localities to understand how they can best support and extend carer engagement, to drive forward shared values and ambitions across Greater Manchester.

From Summer 2020, the DU programme introduced a number of measures to support this transition to a locality-based model. These included:

- Inviting a representative from each locality to join the DU Governance Board, on which carers are already represented
- Strengthening the regular meeting taking place with the ten locality representatives and inviting carer representatives to that meeting
- Undertaking a series of interviews with locality teams to understand their priorities and preferred ways of working with the programme

- Strengthening relationships within a restructured project team, with new staff assigned to specific localities

On this last point, DCERG members were optimistic that the new DU posts have attracted people with a real interest in dementia and that there will be increased knowledge and skills amongst these staff to work with localities.

DU commented:

“We also feel very optimistic about this transition and we are delighted that DCERG feel so positively about the closer working relationship we have all developed with localities, and the knowledge and enthusiasm of the DU team. This gives us a strong basis for the further development work needed to enhance current work and ensure a strong carer offer in all areas. We are also continuing to develop and review all our key focus areas and task and finish groups to ensure appropriate inclusion and representation, in conjunction with DCERG members and others with lived experience.”

Achievements

DCERG aimed to have a representative from each of the ten Greater Manchester localities. Although this was not achieved in full, the Group attracted members from Manchester; Heywood, Middleton and Rochdale; Tameside and Glossop; Stockport; Salford; and Trafford. The arrival of the pandemic meant that some carers had to step back from their DCERG role as other responsibilities increased. The Chair of the group continues to communicate by email to "retired" members with appropriate information relevant to them as carers. Members participated in eight specific feedback projects, Task and Finish Groups, locality work and other meetings. Members also worked on a variety of events and activities requiring carer co-production and expertise, such as the Greater Manchester Carers Strategy Summit and the Chair sharing their experience at the National Dementia Action Alliance. The Chair of DCERG also sits on the DU Implementation and Operations Group and the Strategic Board alongside other carers, as well as the DU Locality Leads meeting. So far, members have been instrumental in the development of:

- Delirium (Hospitals) Programme and Toolkit
- Delirium Leaflet, Toolkit and training resources

- Dementia Care Navigation Standard
- Dementia Care Pathway
- Dementia United Mapping Document
- Dementia Wellbeing Plan
- Development of a digital app to track wellbeing, offer localized information, scheduling events, rate services and reflective journaling
- Diagnostic Support – GM Dementia Care Plan and Supporting Information
- End of Life Care Strategy, training and educator packs
- Healthy Homes Toolkit
- Local Health and Care Record Exemplar (LHCRE) project on Patient-Held Records Engagement and Onboarding/This is Me document
- Mild Cognitive Impairment - Co-produced approach to post-diagnostic support

The previous tide CIL for the project cited the following achievements:

- Non-tokenistic involvement of carers of people living with dementia
- Valuing and investing in carers who grew in confidence and expertise and created real change to the systems in place
- Carer Involvement from development through to end product
- The system was responsive to change to support carers once they realised the wealth of experience and value they could bring to the programme.
- Carers had voting rights alongside organisational representatives and were treated as peers with equal expertise and knowledge
- Carers received an honorarium for meetings while supported by tide up to March 2021, which will continue directly from DU for the financial year 2021-22

In relation to the Local Health and Care Records Exemplar programme, DCERG members wrote a paper titled '*An Exemplar of Positive Engagement*' outlining the ways in which the project had exemplified best practice in carer co-production and engagement (see Appendix Two). The DCERG wanted this project to be recognised and highlighted, as the end product not only fitted the overarching clinical and digital aims but enabled those at the centre of personal information to be fully supported, to have autonomy and control in a manner that was accessible. The paper highlighted

the following points that are relevant to this evaluation in considering future support for carer engagement and involvement:

- Carers were asked for involvement even before the initial meeting. They were asked to write up their ideal wish list of things they would like to see incorporated into a digital record. From the carer's report, 21 out of 23 improvement points were included in the project work.
- Carer invited to the initial planning meeting
- Initial meeting established the needs of both the carer and person living with dementia and included language, contact, environment, changing needs, time of meetings, notice periods to allow for planning, respite if required, and how meetings may need to adapt to support involvement.
- After a carer questioned the use of jargon in the first meeting, programme leads quickly picked up on this and used more inclusive language.
- Willingness to discuss changes to the project with relevant groups, ensuring that the groups set up to ensure public and patient involvement were approached as the first port of call.
- Quickly adapted to any suggestions made, ensuring meaningful and purposeful engagement

Limitations highlighted in the project

- Lack of Black Asian and Minority Ethnic involvement earlier on (diverse workforce)
- Length of meetings too long (this can also be health dependent)
- Meeting physically involves a lot of travel and can exclude individuals altogether

Impact of Covid on Group Activities

In response to Covid-19 restrictions, DU, tide and DCERG needed to work differently to maintain their partnership connections. Because of the lockdown, all face-to-face DCERG meetings stopped and some aspects of the DU Programme were aligned to

support the Greater Manchester system response to Covid-19. Despite the expectation of fewer requests for DCERG input, members described being busier than ever during the pandemic.

‘Some of us are on Task and Finish groups and there has been a lot of work there, with meaty work on the Dementia Wellbeing Pathway’ (DCERG member)

The DCERG Report for the DU Strategic Board meeting in July 2020 noted this increase in demand and the need for a strategy to attract new and diverse carers by identifying carers in GP practices. The report also highlighted that no action had been taken on work relating to Quality Markers in Primary Care and Registration of Carers of people living with dementia in GP Practices. The group requested and was given a designated slot on the agenda for DCERG to update both the Strategic Board and Implementation and Operations Group. This remains a priority for continued development within the programme and the prevention workstream still has the above work within its scope, to identify dementia carers more readily across primary care areas and link them to social prescribing. Clinical and non-clinical staff from across the health and care system were naturally expected to be fully available to their employing organisations during the last year so not all projects could be prioritized as previously anticipated. However, some of these areas are now picking up again.

Members felt a huge sense of responsibility and took on a lot of things locally as well as the DCERG-specific work, including keeping in touch with other carers, sending out Easter gifts, developing a newsletter for their locality, developing and delivering memory boxes with the Palliative Care Team and disseminating Covid updates. At the same time, the pandemic restricted the group’s ability to grow in numbers.

‘It’s difficult because you feel that if you don’t do something then carer voices won’t be heard’ (DCERG member)

‘Carers were, by and large, abandoned [by health and social care]. It took about 4 months before there was any kind of contact. Support came from non-dementia organisations and carers had to sort it out for themselves.’ (DCERG member)

In January 2021, and in response to the Mayor of Greater Manchester's request for responses on what was important, the group prepared a paper for his information. The Mayor attended the Strategic Board and discussed these issues directly with carer representatives. They outlined work by a DCERG member in Tameside and Glossop, together with the Locality Lead, to ensure Covid-restriction regulations were followed, along with risk assessments and PPE to allow for physical carer support meetings to take place. Another DCERG member worked on a Green Space initiative, supporting the ability of essential services to meet in public green spaces to provide essential services. Members supported the Dementia UK proposal to ensure the place of Admiral Nurses within Primary Care Networks and the community across Greater Manchester. The importance of including people living with dementia and their identified family carer as priorities for the Covid-19 vaccine was also noted. Crucially, the paper asked why specific dementia support had all but disappeared during this time and why it was left to family carers to find alternative support during a time of increased need, distress and isolation:

'During COVID and the COVID Bill, Care Act reductions and reduced service support, carers and people affected by dementia are in a worse position than ever before, and we want councils, local authorities and national government to recognise the huge failings still taking place and address the injustice that has left carers and people living with dementia in a state of continued crisis.'
(DCERG member)

Members stated that it was useful they had stayed together as a group and that meetings were opened up half an hour beforehand to support each other. Zoom was felt to be invaluable, and members agreed that the group wouldn't have continued in the same way without it. One member had set up social meetings between the more formal ones which had helped with forming relationships and connection.

Members from some ethnic minority groups did not continue through the pandemic due to an increased need to provide support for their relatives. Two members had been long distance carers but had to either move nearer to care or travel long distances frequently to support and advocate for their relative. However, both expressed a desire to return to DCERG and one member returned in September.

The DCERG paper, outlining priorities to the Mayor, has given DU an invaluable understanding of key priorities from a carer's perspective and is now in the process of being reviewed and updated by the team to understand what has been achieved and what remains to be taken forward, either through DU or across the system.

Member Experiences

Members spoke about the DCERG group as offering a genuine carer voice, a sense of purpose, a source of support and connection and the hope that services and support will improve:

'It's given me a voice, in a sense, that I might not have felt I had before... It gave me a feeling that, by being involved, things might change. It's important that there is a group.' (DCERG member)

'I didn't really have anyone to communicate with about my own experience, so I've found, in this group, a very supportive bunch of people. Not so much for tea and sympathy, but I actually found it really useful that all the people felt so strongly.' (DCERG member)

'It's reassuring to have such a cohesive group. I was involved with Dementia United before the formation of DCERG and this group has helped spread the load and stop the tokenism of being the lone carer.' (DCERG member)

'Without the group you can feel like a very quiet voice in the corner' (DCERG member)

The group also talked about challenges relating to the operation of DCERG, DU and tide, including:

- The need for the system to be responsive to a range of experiences
- Challenges in ensuring diverse membership of the group
- Difficulties in the line of communication between the DCERG, tide CIL and DU, including lack of feedback about what involvement has achieved
- Difficulties in promoting the group and attracting new members

- The impact of Covid and the DCERG being the only group to continue working through the early stages
- Sustainability

Although one DCERG member commented that DU was focused on institutional care rather than homecare, it was clarified by DU that the Greater Manchester Adult Social Care Team's programme already works closely with home providers, and whilst DU is keen not to duplicate any of this work, both programmes are relevant to people living with dementia and carers in any setting, whether at home, in supported living or in hospital. DU has a strong commitment to enhancing support at home and in the community, including social prescribing. To support communication between the programmes and to ensure opportunities for carers to be involved in this broader range of work, the Adult Social Care Team have attended the last two DU locality meetings, attended by carers, to outline areas where the programmes are working together, to share information and to demonstrate all the work that is being done in this area.

'A lot of the time, we didn't know what was going on. We now have a more direct link with DU and have got involved in other projects, such as frailty and palliative care, adding to the richness of the data.' (DCERG member)

Members also reflected on information about DCERG and how to access it:

'How do you attract members? I came through an email from Age UK Trafford. You need to work closely with other organisations to get people on board.'
(DCERG member)

'Culturally, everyone has their own stories. Some other communities tried to join the group but couldn't carry on. But they need to be included.' (DCERG member)

Role of/Support from tide

The group acknowledged that it was largely the drive of tide's CEO at the time that enabled the vision of a sustainable carer engagement model to come to fruition in Greater Manchester, along with the influence of the Senior Programme Manager for the SCN at GMHSCP.

Over the last two years, since the launch of DCERG in 2019, the work has grown exponentially, and tide was commissioned to support the group through its project CIL. Members felt that the support had been good from both the previous tide CEO and CIL, particularly in relation to support for presentation preparation and delivery, although they noted that whereas support was always offered, in reality the CIL often had too many other things to do. The group also noted that a skills audit had been started but nothing came of it.

'It was clear at the time that tide felt the group was a key role for the carer voice. The CEO's drive and personal relationships made it happen... It's the sort of thing tide should be trying to do everywhere and that was the model in trying to set it up.' (DCERG member)

'[DCERG] is my idea of what tide was all about' (DCERG member)

'It's about the authority the organisation has as a dementia carer organisation and particularly the values in being able to support activities. That's what I saw with tide at the time. Its task is to maintain that and spread it out across the UK. A national organisation is important in that because DCERG needs the support of a more formal structure.' (DCERG member)

DCERG's relationship with tide changed as a consequence of the prolonged sickness absence and eventual departure of the CEO and the promotion of the CIL to a different post, early in 2021. This presented tide with serious capacity difficulties which meant they were unable to support DCERG to the same extent, despite their commitment to the project and the desire to see it succeed. Up to this point the CIL had supported the group, facilitating agendas, minutes and arranging speakers, for example. Before he moved on in February 2021, tide set up and funded dedicated e-mail and zoom accounts for DCERG and provided information about how to set up as an independent voluntary group. After February 2021, meeting preparation was taken on by the Chair of DCERG. Staff turnover was also taking place in DU; several key staff left and it was not until May 2021 that they were able to confirm staff support for meetings.

This transition happened more quickly than had been planned. The original commission was funded by DU up to the end of March 2021, with the longer-term goal of DCERG becoming self-sufficient. Although there was the possibility of a

further funding to extend tide's role beyond the original end date, tide was not in a position to commit to continuing the same level of support that would be required due to organizational pressures and the departure of key personnel. All this clearly had an impact on DCERG members and some of tide's suggestions were received as unhelpful:

'We were sent information about how to run as a separate group with our own bank account and it was very dismissive.' (DCERG member)

'We've accomplished so much that we weren't prepared to let it go. It was the dramatic suddenness of the change in the relationship with tide. It was a shock. (DCERG member)

Despite this, the episode demonstrated the resilience of DCERG members, particularly those with current caring responsibilities for whom every day can be unpredictable, and their determination to keep going:

'There is some bitterness about tide, but we carried on regardless with both social and formal meetings. It has taken a lot of the Chair's time, but we all go to Locality meetings now.' (DCERG member)

'On reflection, I think we relied too much on tide as the intermediary between DCERG and DU. While the early part of 2021 was difficult in that we felt cast adrift, I now feel quite positive that DCERG will become embedded in future dementia work within the Greater Manchester Health and Social Care partnership.'

Members were advised that after March 2021 they should no longer contact tide to claim the honorarium payments they had been receiving. This was addressed by Dementia United who made a commitment to pay outstanding honoraria, including those to date since tide's support ended.

The then CIL stated that the transition to their new role happened much more quickly than expected, which led to some confusion. Tide allocated one day a week out of his new role up to the end of February to hand control over to the DECRG with support from DU:

The loss of two key tide staff within the same month, along with staff changes in DU, had not been planned or anticipated by tide, DCERG or DU, so the change in direct support happened more suddenly and less smoothly than as a planned transition.

However, the eventual outcome of this transition appears to be positive, with both DU and DCERG developing a more direct relationship, building on previous work by all partners, with a strong legacy from the earlier work and sustainability for the future.

Legacy and Sustainability

As indicated above, sustainability of the DCERG had started to be discussed well before the planned end date of tide's support in March 2021. The CIL confirmed to DCERG in September 2020 that tide would carry out an evaluation, including arrangements after March in line with the locality-based model. In January 2021, DCERG raised a number of formal concerns regarding its sustainability with both DU and tide.

Since then, the overall picture for DU changed. At the time the concerns were raised, DU's transformation funding was awaiting confirmation so there was uncertainty about the programme. Subsequently recurrent funding for Dementia United was confirmed, along with the continuation of the priorities and above workstreams.

Since May 2021 DCERG have met regularly with Dementia United and have some dedicated time from a part-time DU Project Manager to support the group, develop a recruitment strategy and ensure DCERG's reach and influence continues to grow. In the past, the group has felt some responsibility to promote the model to share best practice and support replication, but there has now been agreement that DCERG should concentrate solely on Greater Manchester:

'We now have to focus on what's going on in Greater Manchester. Outside of that, it's up to tide to promote the model.' (DCERG member)

'Initially we were led by tide and we've had to adopt a rapid transition. We've developed credibility within Dementia United, but we haven't yet fully

established our links and the lack of in-person meetings has made it difficult.’
(DCERG member)

‘All the people in this group are experts in their own field, strong and passionate. That’s why DCERG didn’t fold when the tide Carer Involvement Lead left. The continuation of the group has been because of the membership.’ (DCERG member)

DCERG has continued to function and to contribute to significant developments in Greater Manchester.

We are a dedicated group with firm beliefs to improve things for the person living with Dementia and their carers in Greater Manchester. Members continue to be involved in key focus areas. These include End of Life, Young Onset and Rarer forms of Dementia, Lived Experience, Post Diagnostic Support, Prevention. In addition, we attend various meetings in our localities, Hospital Steering Groups and training, Locality Meetings, Carers Hub and University of Salford Institute. Several Activity Groups have been set up and led by a DCERG member based in Tameside.

The full list of current DU projects is shown in the graphic on page 7. DU is keen to support the local groups pro-actively established by DCERG members within their localities.

Findings

- DCERG members’ experience is that involvement has been positive, not tokenistic, offering a genuine carer voice, purpose, support and connection
- The creation and progress of DCERG have raised challenges both for DU and for tide, but a healthy and strong consensus has emerged which has led to better outcomes
- The primary aim of getting unpaid carers round the table and included as equal partners has been achieved
- The transition for DCERG from relying on tide support to becoming a self-sufficient group was more rapid than planned, causing some communication difficulties and tensions about sustainability

- Good links have been maintained between DU Task and Finish Groups and DCERG
- DU has strengthened its commitment to DCERG's future as part of the new ICS in Greater Manchester
- DCERG members believe there has been a lack of clarity about how DU feeds into the wider GMHSCP work programmes, for example concerning home care and end of life care, creating concerns for DCERG that the DU focus was more institutional and less on community and care at home
- In response to this, DU arranged for the Adult Social Care team to outline its current work on complex needs and home care to DCERG and the DU locality leads, detailing how the work feeds in and how Carers can get involved.
- DU has demonstrably broadened its scope and remit over the last year to incorporate more preventative, healthy ageing and community aspects of its work, as shown in the revised 'DU flower' (page 7)
- tide's offer of specific, tailored training for DCERG members was partially delivered. Following the Covid lockdown, tide's Carers Development Programme transferred onto zoom and some DCERG members have taken the opportunity to join virtual sessions; these are run regularly and specific sessions could be delivered for DCERG if requested.
- The pandemic had a major impact on how DCERG operated, resulting in a switch to virtual meetings, with some loss of membership and an increase in feelings of responsibility to be the carer voice, but no reduction in activity
- There has been a lot of responsibility placed on a small group of carers and the planned-for deputies were not in place
- Black, Asian and Minority Ethnic representatives did not, in the main, stay with the group because of increased caring duties and there were challenges in maintaining diversity in the membership

Comments from Dementia United on working with DCERG

"The Dementia Carers Expert Reference group has a strong, valued and long-standing connection with the Greater Manchester Health and Social Care Partnership. The role of DCERG is to ensure that there is a strong voice for

carers and that they are 'around the table' in terms of influence and governance. There is a substantial evidence base demonstrating that carers are 'experts by experience' and therefore best placed to advise health and social care organisations on the needs of people living with dementia and carers. Our aim is to support active carer support and influence in every area; carers are represented on all our DU Programme boards.

Greater Manchester collaboration builds on integrated approaches in each locality and we are working with the localities to understand how we can best support and extend carer engagement to drive forward our shared values and ambitions across Greater Manchester. We are supporting DCERG to manage a recruitment campaign with the aim of having active carer leads in all ten GM localities, as well as for specific under-represented groups and for each key focus area. Carers participate in regular Dementia locality meetings.

Our Dementia United Programme will continue in Greater Manchester as part of the ICS. We listened carefully last year to all our stakeholders, including Carers' feedback that the programme needed to ensure that the health and social care system focused on community-based intervention, prevention and inequalities in relation to people living with dementia and carers. Our priority themes this year include a continued and enhanced focus on lived experience, quality of life, prevention and social prescribing, healthy homes and addressing inequalities, in addition to the programme's existing strong clinical, educational and research links, and of course continued alignment with GM's approach to post Covid recovery.

The revised 'DU Flower' graphic on page 7 of this report shows that we have an increasingly broad ranging and ambitious programme, made possible with the continued and valued partnership and support of people with lived experience, carers, partners, and colleagues from across all the GM localities.

Working with DCERG we're also developing a memorandum of understanding to help embed this valued partnership and enhance its influence as part of the ICS. Thanks to the passion, commitment, experience, and dynamism of its members, DCERG continues to go from strength to strength. We are confident that this will

continue to ensure that people with lived experience have a real voice in making Greater Manchester the best place to live for people living with dementia.”

Conclusion and Recommendations

DCERG is an example of how the lived experience of carers of people living with dementia can move into the mainstream and be placed at the heart of the DU programme in Greater Manchester.

We now return to the questions posed in the methodology.

1. Is the programme to be continued?

DCERG has more than demonstrated its value, bringing the benefits of the lived experiences of carers to the GMHSCP and enabling their voices to be heard and acted upon. As discussed, DU has confirmed its commitment to embed DCERG in the new ICS and continue its financial and project management support to the group.

2. Is it possible to replicate and implement the programme in other settings?

It is important to recognise that the DCERG model arose in the context of devolved health and social care and may be more difficult to replicate in non-devolved systems. However, the implementation of Integrated Care Systems across England presents significant opportunities for similar approaches to embed carer involvement in the emerging infrastructures. Meeting the needs of increasing numbers of people living with dementia remains one of the biggest challenges for the whole health and care system and unpaid carers, as the biggest dementia care workforce, play a crucial role in the spectrum of care. It follows that their inclusion in service planning, commissioning and design is crucial. However, the development of DCERG has demonstrated that such involvement does not come without an investment of resources and cannot happen overnight. Issues such as the recruitment of carers, their status and connections with other networks, payment of honoraria, mentoring arrangements and reporting mechanisms take time to develop, test out and embed.

3. How sustainable is the programme?

Consistency of project support during periods of system change and upheaval can be difficult to maintain. DU has maintained its investment in DCERG and picked up the reins of project support, including a part time designated project manager, following the conclusion of tide's contract. The enthusiasm and resilience of DCERG members are strong indicators of continued success and the strengthening of the locality structure, with the recruitment of Dementia Locality Leads, should enable a further recruitment of carers to be undertaken to widen DCERG's reach across the city region.

4. What elements could have helped or hindered the programme?

The initial development of DCERG was aided by the tenacity of the then CEO of tide and the championing of the proposal by the SCN Programme Lead, supplemented by the efforts of carers themselves to make the case for their involvement as equal partners. The subsequent commissioning of tide by DU to establish and support DCERG funded the provision of the necessary infrastructure support and mentoring to enable its members to operate effectively. A smoother conclusion to the contract with tide would have been easier for all parties, but circumstances at the time made this very difficult. tide remains committed to working with DCERG as a significant carers involvement group in the region and has had productive meetings with the chair, resulting in involvement in various projects.

The strong commitment and tenacity of key individuals – in DCERG, in tide and in DU – were crucial to establishing the group and embedding it into the health and social care infrastructure.

The pandemic restrictions, along with the unpredictable and progressive nature of dementia, meant that some carers were unable to maintain their involvement.

The limited success in attracting carers from all ten regions to join DCERG has meant its reach has not yet been as extensive as anticipated.

5. What recommendations have evolved from the programme?

The following recommendations are highlighted:

- The link between Locality Leads, their work programmes and DCERG needs continued strengthening
- DU to strengthen feedback concerning work within GMHSCP with communities and care at home, facilitating and enabling community connections, and on the outcome of any involvement to DCERG members
- Identify training and personal development needs of DCERG members to complement their existing skills and strengths.
- Use the good practice highlighted in '*An Exemplar of Positive Engagement*' as a basis for supporting future involvement with DCERG
- Implement the original commitment to recruit two carers or former carers from each locality to strengthen the group and spread the workload.
- Attract and recruit diverse membership from communities across Greater Manchester through collaboration with vibrant networks, such as the LGBTQI community, deaf community, disability advocates and Black, Asian, Minority Ethnic and Refugee groups
- Consider where DCERG can have the biggest impact and agree Key Focus Areas to work on
- Provide DCERG with consistent, well-resourced support, including forward-planning for any future transitions
- Confirm arrangements for how the DCERG work will feed into the wider Greater Manchester integrated care structures
- Share the learning from this report across regional and national networks to inform the development of ICSs across England.

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Further Reading

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Terms of reference – DCERG

- Advise and guide the development of tide within the Greater Manchester and Dementia United partnership and ensure that it is well positioned within the policy and political context in order to deliver our respective strategic objectives.
- Ensure that the continued development and focus of all tide and Dementia United 10 key focus areas are driven by the experience and perspectives of carers of people living with dementia across Greater Manchester.
- Ensure that other streams of work reflect the views of carers of people with dementia, including Care at Home, Residential and Nursing Homes.
- Advise on content within the Dementia United programme of work, including the 10 key priority work areas at locality and strategic level activity.
- Inform and enrich the credibility and focus of the Dementia United work programme and the Greater Manchester-wide Carers Strategy, based on Carers' lived experience.
- Advise on the strategic development and sustainability of tide as a strategic partner in the ongoing work on dementia across Greater Manchester, including identifying funding and resources.
- Seek and explore opportunities to ensure a more inclusive approach to involving carers from a diverse range of communities, including those from BAME, LGBTQI, Irish, gypsy and travellers, male carers, carers of people with dementia from the deaf community and other sensory disabilities as we grow our networks with these communities.
- Co-design research questions and become involved in the whole research process from question setting, design, implementation and dissemination.
- Share learning and evidence of good practice from each of the localities and beyond to continually improve the offer for carers of people with dementia across Greater Manchester.
- Co-produce the key performance indicators on which we will deliver over the next 2 years.

- Promote tide and champion the collective voice of carers across all networks and platforms across Greater Manchester.

Individual members of the group:

- Contribute to the Advisory Group and inform the development of tide across Greater Manchester-wide
- Utilise their individual roles and networks to proactively inform work of the group both at a locality and strategic level across Greater Manchester
- Speak on behalf of tide at conferences, to the media and prospective funders
- Consider and advise on specific issues and queries pertaining to the development of the Dementia United programme 10 Key Focus Areas
- Receive and comment on papers, as requested, between meetings
- Inform tide of any conflict-of-interest issues that may arise as a result of being a member of the DCERG
- Respect confidentiality as requested, regarding work arising from the DCERG and Dementia United
- Actively promote the work of tide and Dementia United, where possible, to assist with raising the profile and enable them to reach diverse communities, particularly those that are seldom heard
- Contribute to specific projects and themed pieces of work as requested
- Proactively participate in the collection of data on activity both at locality and Greater Manchester level which will inform the evaluation of the DCERG over its lifetime.
- Challenge and question the activities, outputs and outcomes of the Strategic Board and Implementation and Operations Group.

An Exemplar of Positive Engagement

Local Health and Care Records Exemplars (LHCRE) programme

(Greater Manchester Digital Platform)

We begin with a common thread woven through all carer stories that result in positive engagement and greater change, and that is the invitation for a carer of a person affected by dementia to share their unique personal story.

In this case the carer was invited to speak at the first “World Dementia Delirium Day” for attendees to hear first-hand the unique experiences and difficulties carers of people affected by dementia lived through each day. The impact of this story was received with realisation and reflection from the registered paid professionals in attendance. The result was an invited to speak to a parallel meeting of NHS Digital on the day. A request to write up their ideal wish list of things they would like to see incorporated into a digital record came 6 months later.

The carer was contacted shortly after their submission and was invited to the initial planning meeting for the mentioned project. Twenty one out of the twenty-three points of improvement identified by the carer were selected to be included in the project work. The first meeting, supporting both the carer and the person affected by dementia, started not with the project work but concentrated on language, contact, environmental needs, how meetings may need to adapt to support the degenerative condition and the unique needs of the individuals being asked for involvement.

There were many alterations that needed to take place within the meetings themselves. The project was for a digital platform, therefore including both a variety of clinicians and software engineers leading to a large quantity of both medical and programming-based jargon. The carer had to ensure that this was broken down and produced in ‘lay’ terms continually throughout the first meeting to ensure inclusion. The carer indicated that very quickly the program leads picked up on this and started to translate and correct and move the language to be inclusive. This small realisation and speed at which the change was interpreted correctly and adopted was a huge indication to the carer involved that they were not a tokenistic participant, but that the program leads actively listened and then proactively changed their approach. This

inclusion of the American architects came after a year/18mths. During the intervening time, the carer didn't have much contact – indeed there was quite a long gap in communications. However, when they contacted the program lead to ask for an up-date, they were very responsive. The carer believes the language used and the correspondence with the American companies involved solidified this as underpinning the project and make it unique to any involvement they had experienced to date.

As this project is fast approaching the pilot stage, requests for the carer to join meetings, to consult and check on developments have increased – and again, active listening and responses have been consistent. Additionally, if they have suggested/requested taking any key changes to relevant groups – the Dementia Carers Expert Reference Group (DCERG) or another Lived Experience group such as the Dementia Associates of Salford Institute for Dementia Studies – the team has been very willing and keen to do so. The degree of openness and engagement has been remarkable.

The carer included other well managed projects developed and support by carers and people affected by dementia. One example of this is the Dementia United Care Plan, which had extensive development and consultation. The project leads have continued to ensure that the groups set up to ensure public and patient involvement are utilised as the first port of call. The LHCRE project continues its positive engagement with asks for attendance at the DCERG, be it for a 30-minute development session, or for a review of a specific piece of work already underway to ensure it had been correctly interpreted and implemented.

The DCERG wanted this project and how it was implemented to be recognised and the below strengths and limitations to be highlighted for all current and future projects. It is an exemplar model that all individuals involved continue to praise. They believe it has managed each element in a responsive, malleable, inclusive, dignified way. This has resulted in a product that not only fits the overarching clinical and digital aims but equally supports those at the centre of personal information to be fully supported to have autonomy and control in a manner that is accessible.

Strengths

- Asked for input before initial meeting. Spoke directly to person affected by dementia directly consistently
- Quickly adapted to the suggestions made, ensured meaningful and purposeful engagement
- Held meeting initially to establish the needs of both the carer and person affected by dementia which included; Language, contact, environment, changing needs, time of meetings, notice periods to allow for planning, respite if required, etc.
- Broke jargon down into understandable terminology
- Being Person Centred first and foremost
- Large network of involvement
- Provide plenty of options for date/time to suit
- Balanced lay out and approach to prevent over burden

Limitations

- Potential to miss having BAME involvement earlier (there was a diverse work force)
- Jargon always needs to be addressed
- Length of meetings can be too long (this can also be health dependent)
- Meeting physically could involve a lot of travel and may exclude individuals altogether

Focus Group Meeting 1 held on 02/06/2021

Five attendees

Discussion Topics

1. Individual member experiences: how being a member of DCERG impacted on you as an individual?
2. COVID – 19 pandemic: how did it affect the group’s activities, work in the localities and members?
3. Influencing the system: how have the Group’s activities impacted on the work of the DU?
4. Legacy: what legacy has been developed by the Group and how can this model be replicated in other regions across the UK?

Focus Group Meeting 2 held on 09/07/2021

Three attendees

Discussion Topics

1. How have the Group members grown in confidence and influence?
2. How DCERG have coped with COVID restrictions - how this has affected PLWD and carers - how this has affected the members individually?
3. Were there any increasing demands on DCERG members' time during the pandemic?
4. You sent a really comprehensive paper to the Emergency Committee in January. Did you get any response to this?
5. Were you satisfied with the amount of communication you received from professionals about what had happened to your feedback and recommendations?
6. What was your experience of working with and trying to influence Dementia United?
7. We're interested in finding out a little bit about the Task and Finish Groups and Locality work that you were involved in.
8. What are your views on the support and training offered by Tide?
9. What have the challenges been, both with DU and Tide?
10. Did you receive a response to the concerns and recommendations discussed in your January meeting to put to Anna and Gill around sustainability of the group?