SCHOOL OF HEALTH SCIENCES

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Implementing and sustaining

the Dementia Care Coordinator Service in Kent and Medway:

Executive summary and recommendations

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A long form report is also available. Should you wish to read this, or if you have any questions relating to this project, please email: r.abrams@surrey.ac.uk

Executive summary

Across Kent and Medway Integrated Care Board (ICB), Dementia Care Coordinators have been implemented in each of the 42 primary care networks. This service, first conceptualised in 2021, has been designed to address the low dementia diagnosis rates in Kent and Medway and the need for extra support, both pre- and post-diagnosis, for people with dementia and their carers. The DCC service has been jointly commissioned by Kent County Council and the ICB. It is delivered by two third-sector providers who employ, train and support the Dementia Care Coordinators (DCCs). These DCCs undertake non-clinical work, supporting people living with dementia and their carers to navigate the health and care system, responding proactively to service users' needs across the dementia journey. They collaborate with GPs as well as other health and social care professionals, to encourage uptake of dementia assessments and diagnoses for people who are experiencing cognitive decline. However, little is known about how the DCC service how it works for people living with dementia, their carers, and the people delivering the service.

Since 2022, a team of researchers at the University of Surrey (funded by NIHR KSS ARC) have been conducting an evaluation to explore how the service works, who it works well for and under what circumstances. We have collected data across the entire Kent and Medway ICB, including a two time point survey with DCCs in February 2023 and March 2024; interviews with 57 participants (DCCs; service managers; healthcare practitioners; people living with dementia and their carers); and a review of key performance indicators and resourcing. Further information about our study design and methods can be found here, and interim findings from 2023 here.

Our evaluation indicates that the DCC service is achieving several of its intended outcomes, including: (1) providing both proactive and responsive case management and prioritisation; (2) signposting to community support and joining up care across the system; (3) contributing to an increase in diagnosis rates across the ICB; and (4) de-escalating potential crises. The DCC service can enhance the quality of life for both people living with dementia and their carers by enabling them to draw on DCC expertise, and having them as a reliable, consistent presence in their dementia journey.

Furthermore, outcomes are optimised when person-centred, knowledgeable, well-trained, organised and experienced individuals are appointed to the role, and can operate within a work culture that fosters peer to peer learning.

There are, however, a range of pain points across the wider healthcare system may inhibit the service's success. Local support provision differs across the county, meaning certain services and groups are not always widely available for DCCs to refer onto. Waitlists across the wider system can also slow down support for service users (e.g. accessing memory clinics; art classes/dementia cafes). Engaging busy healthcare professionals including GPs can be challenging, while those with early onset dementia, advanced dementia, and/or minoritised groups may have needs that are currently beyond the capacity of the service. As the DCC service becomes more successful, with more people being diagnosed and living longer with dementia, the more the wider, local healthcare system may struggle to meet the population's needs. This may mean that ultimately, the DCC service could become a victim of its own success. We also suggest that, with ever increasing caseloads, the risk of burnout in DCCs is high, despite their current high rates of job satisfaction. We speculate that, if not addressed, this combination of factors could lead to high rates of attrition and decreased rates of satisfaction in DCCs and service users. More positively, we also speculate that when DCCs are employed across an ICB, then they can facilitate effective service utlisation, because what they refer onto is appropriate. Thus, whilst initial costs may be encountered, over the long term, appropriate service utilisation, executed by professionals experienced in dementia care prove to be cost effective. The relationship between implementation and impact now requires further research.

Our evidence-based recommendations for those wanting to implement and sustain a DCC service can be found below. These are grouped into: (1) Supporting the workforce; (2) Meeting the needs of service users; and (3) Wider system working. The DCC service is a much-needed intervention, capable of supporting people who are pre, during and post dementia diagnosis, at a time where the care system is both fragmented and under strain.

Recommendations for service implementation and sustainability

In this section, we outline the key actions for improving the DCC service and ensuring its sustainability.

Supporting the workforce:

Evidence	Recommendation
We know from our data that this service works well when the right people are appointed. This includes appointing people who are: person-centred; experienced in dementia care delivery/dementia care qualified; and capable of being highly organised.	Actively recruit for these characteristics and have them as desirable qualities, visible in job adverts and person specifications.
Our data indicates that DCCs need to have dementia expertise, along with other training including: sharing knowledge on local services; systems training including internal databases such as salesforce and EMIS; coping with the emotional load of the role; carer support; advocacy; conflict resolution and formal dementia qualifications.	Provide continuous/on-going programmes of training opportunities to be completed during protected time. Training needs to take into account the location and spread of DCCs so they are not impeded by travel, and/or access to technology (if online).
DCCs thrive when they can share learning about local referral services such as dementia cafes or new classes. They also value sound-boarding and learning from one another about what to do in a	Foster a working environment that facilitates peer to peer knowledge sharing and learning so that DCCs can collaborate, pool resources and support one another to provide high quality dementia support. This may include space for informal gatherings;

tricky or difficult situation, especially when there is a mix of experience and backgrounds in the workforce.	WhatsApp groups; or co-designing other repositories and infrastructure.
MDT meetings are an essential part of connecting care – DCCs are drawn on for their expertise about dementia, patients and local service provision. Being invited to and attending MDTs helps them become trusted members of the care team and is integral to relationship building as well as supporting service users.	Ensure DCCs have a seat at the right table by making the service highly visible to healthcare professionals. This can be achieved by communicating the DCC offer clearly across several different platforms, perhaps by working closely with another professional or provider e.g. a GP practice manager, to ensure visibility and understanding. Consideration may need to be given to who the best person to speak to is at each organisation. This may also need to happen at multiple points across the year due to high rates of turnover. DCCs' time must be protected so they can attend MDTs with GPs and other healthcare professionals to share their expertise. DCCs' identities as non-clinical dementia experts must be nurtured.
DCCs enjoy their job and have high rates of job satisfaction. This needs cultivating and sustaining. At present, DCCs are concerned about their increasing caseloads and some are experiencing burnout.	Ensure all DCCs take their annual leave and foster a work culture that encourages supportive team meetings, sharing the load where necessary and support and encourage psychological detachment from work by, for example, turning work phones off once the day is over, having core hours and so on; ensure that the service is

	appropriately staffed to protect staff wellbeing and service user satisfaction. This may include employing more DCCs and/or admin staff or, if this is not possible, by redesigning the role in a way that retains the core caring elements of the role whilst reducing the burden on staff. Give staff printed emergency contact cards so they know who to contact out of hours for support. Flexible working hours plus appropriate pay including workforce planning for pay rises also need consideration to aid retention of these valuable workers.

Meeting the needs of all service users:

Evidence	Recommendation
The DCC service is currently designed to support people living with dementia and their carers, from pre diagnosis to end-of-life care, where necessary. However, those with extremely advanced symptoms, and/or those living alone have proved difficult for DCCs to support. This group likely need more specialist care, and whilst a DCC might be able to signpost to this, these people may require greater or different intervention.	Service providers need to consider how they might be able to support DCCs to care for those with advanced dementia and/or those living alone or establish a specific intervention for this group. This might include utilising palliative care services for service users with advanced dementia or a database of specific support from local councils or churches for those living alone.
At the other end of the journey are people with early onset dementia. Feelings of stigma and denial can sometimes be higher in this group. These people may still be working and have capacity to describe and engage in a different type of support. DCCs stated that local provision often did not meet the specific needs of this group.	This group could provide valuable input into service design and may even want to set up their own support groups. Therefore, service improvements for this population could be co-designed with people with early onset dementia. DCCs themselves may also be able to suggest helpful adaptations to groups for these people.
Minoritised groups such as those from different cultural, ethnic and LGBTQIA groups may not see themselves in the DCC service,	Service providers could collaborate with people from minoritised groups to improve or co-design a service capable of meeting different cultural needs. Providers could also enhance their

which is comprised predominantly of white, mature women. This may affect service engagement and utilisation.	recruitment processes to actively employ staff from minoritised backgrounds, to ensure that these voices are represented within the workforce.

Evidence	Recommendation
Essential to the success of any new service is its ability to integrate with the wider system, including existing healthcare professionals. The DCC service is no different. When it worked well, this was often a result of pre-existing, trusting relationships, mutual respect, and an understanding of the service on offer.	DCCs themselves need to be visible and enabled to form, or build on, positive relationships across the health and social care sector to ensure stronger collaborative working.
The DCC service has not been implemented in isolation; it forms a wider network of care designed to support patients. Even though the DCC service has achieved certain outcomes, it is still operating within a stretched healthcare environment. For example, when and where the service receives more referrals, caseloads will rise. Over time, this may negatively impact on DCC wellbeing and service user satisfaction. Additionally, the more cases a DCC receives, the more they will need to signpost on to other services (e.g. memory clinics, dementia cafes, social services). This all has a knock-on effect of demands on an	Data linking across primary, community and secondary care may help to better demonstrate the impact of the DCC service including its impact on wider system referrals; uptake of these referrals; as well as hospital admissions/reductions. Ensuring there is enough local provision to accommodate any new referrals is also necessary, such as increasing the number of dementia cafes and/or carer respite provision, to ensure access.

already stretched health and social care system that needs planning and accounting for.	
One of the most powerful things the DCC service can provide to service users is accompaniment on their dementia journey. This reassurance not only supported people living with dementia but also their carers too.	Reassess the service intentions/outcomes. Whilst diagnosis rates are important for the ICB, service users need continuity of care and to feel supported by a single point of contact; they report relief and gratitude when this happens as well as improved quality of life and a reduction in carer burden, all outcomes that warrants equal attention. There is also potential for reduced loneliness in people living with and their carers, another worthy outcome.

Conclusion

This evaluation provides evidence to demonstrate that the DCC service is a much needed, welcome intervention, capable of supporting people living with dementia and their carers pre, during and post diagnosis, at a time where the care system is both fragmented and under strain. The information in this document is based on a comprehensive report written by the DCC realist evaluation team. You can read more about this study and see our various outputs here. For further information, please contact Ruth Abrams on r.abrams@surrey.ac.uk