DEMENTIA CARE COORDINATORS: A SERVICE EVALUATION INTO THE SUCCESSES AND CHALLENGES OF THE KENT AND MEDWAY PILOT PROJECT

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Executive summary

Working with the Applied Research Collaboration Living well with Dementia Implementation Lead, to undertake research that responds to system need, in October 2022, The University of Surrey undertook a small scale focus group, led by Dr Ruth Abrams, to explore the successes and challenges of a pilot project introducing a new role, that of Dementia Care Coordinator (DCC), into Kent and Medway Integrated Care Board (ICB).

Dementia is a progressive syndrome that has huge individual, family, societal and economic impact. Navigating the health and care system both pre and post diagnosis can be particularly challenging for those living with dementia and those caring for them. Diagnosis rates remain low in comparison to national targets, meaning interventions that could help people live well with dementia and support quality of life can be delayed. Community support is inconsistent and often lacking, meaning people struggle to access services that could support them often resulting in health and care interventions including hospital admissions that could be avoided. To address this issue, Kent and Medway ICB have recently implemented a Dementia Care Coordinator role (DCC). For nine months, from July 2021, the ICB funded nine DCC posts to improve care for people with dementia and their families. Each DCC was assigned to a Primary Care Network (collection of GP practices covering 30,000 - 50,000 people). The role is proactive, supporting patients and their carers to navigate the care system from pre diagnosis to end of life care including bereavement support, as needed.

Three DCCs attended a 90 minute online focus group. Data were subsequently transcribed and analysed using thematic analysis which is a rigorous analytical approach to qualitative data.

Findings indicate that, according to DCCs, the service appears to reduce anxiety and worry amongst people living with dementia and their carers across all points of the dementia journey. Knowing that a key point of contact is available to them means that when they notice a change in their wellbeing, they may feel more inclined to contact an impartial, non-clinical individual for signposting. In the meantime, DCCs weave webs of care around people living with dementia so to provide the best possible support. DCCs found it challenging at times to: (1) work with GPs; (2) to support people living with dementia whilst also living alone; (3) manage service user and carer expectations about their role and: (4) to manage their growing patient lists and workload. Overall, to ensure a sustainable service, key recommendations in need of further exploration include: (1) ensuring buy in from key stakeholders, specifically GPs; (2) facilitating staff support and training including clinical supervision/ observations, and: (3) ensuring the service is adequately staffed to protect staff workload and ensure sufficient capacity to enable delivery of high-quality care to service users.

A larger scale evaluation is currently underway, due to be completed in October 2024.

Introduction

Dementia care is a key priority for both NHS England and the Government. Improving diagnosis rates and ensuring people have access to high quality pre and post diagnosis support have been central to two Prime Minister Challenges on Dementia (2012-2015 and 2020) (Department of Health, 2015), and the NHS Long Term Plan (NHS England, 2019). The importance of care coordination is highlighted by NICE guidelines, NG97, 2018, which states that people living with dementia should have a single named health or social care professional (NICE, 2018). Consequently, dementia services are undergoing a period of transformation (Alzheimer's Society, 2016).

It is estimated that there are approximately 25,984 people currently living with dementia in Kent and Medway. In 2021, Kent and Medway ICS conceived the Dementia Care Coordinator (DCC) role to deal with issues of local importance, namely low dementia diagnosis rates and fragmented post diagnosis support. In February 2021 the dementia diagnosis rate in Kent and Medway was 54.3% of the estimated local prevalence, significantly underperforming when compared with the national target of 67%. Whilst Kent services (both commissioned and non-commissioned) provide support to people with dementia and their carers, the pathway is inconsistent across the county. People with dementia and/or their carers struggle to access the care they need and experience crisis situations which lead to hospital admission or early admissions to residential care.

The DCC role is proactive and intended to support people with dementia and their carers to navigate the care system. A localised pilot ran from April 2021 for nine months, in eight Primary Care Networks (PCNs). This document reports on a small-scale service evaluation of the pilot project. Starting from April 2022, the Integrated Care System (ICS) has funded new DCC roles, commissioned through two VSCE providers, that will employ 42 DDCs, on standardised contracts and terms and conditions to support each of the ICSs 42 PCNs for two years. A wider scale evaluation into this extended service is currently underway and due to be completed in October 2024.

Methods

Nine DCCs were invited to take part in an online focus group led by Dr Ruth Abrams, Lecturer in Workforce, Organisation and Wellbeing (University of Surrey). Prospective participants were emailed an information sheet providing details on the purpose and process of the focus group. Those interested in participating were asked to sign and return an informed consent form.

A total of three DCCs participated in a 90 minute focus group held on 21st September 2022. An additional two attendees joined but both had technical issues so had to leave. Participants were split across the two different providers involved in the pilot project.

The focus group followed an interview topic guide, meaning questions were semi-structured and open-ended to elicit rich and detailed experiences. The focus group was audio recorded and subsequently transcribed by a university approved supplier. Data was analysing using thematic analysis. This involves the following steps: becoming familiar with the data; generating initial codes; searching for themes; reviewing themes, defining themes; writing up (Braun and Clarke, 2006). Ethical approval for the focus group was obtained and received favourable opinion from the University of Surrey (REF FHMS 21-22 149 EGA).

The DCCs involved in the focus group came with a range of experience including in the care sector (e.g. care homes, nursing homes, domiciliary care, care coordination), school/ education sector and banking (e.g. insurance- death, taxes, power of attorney, personal finance, budget plans).

Focus Group Findings

A number of different themes were identified during the transcript analysis. The following section presents core findings and these are supported by anonymised participant quotes.

1. **Service User benefits attributed to/ since pilot**

1.1. Being a key point of contact for both current and future service users

Participants were asked what they thought or had witnessed were the benefits (to service users) of the pilot project. The majority of DCCs discussed how the project had improved the provision of support across every point of the dementia journey. Even if a service user had not directly engaged with the service, having the role in place helped service users to know where to go when they do need support such as if/when they notice a change in their own wellbeing. This spanned across the pre-diagnosis stage, all the way through to those who may have been living with a dementia diagnosis for a while:

> *"…since the pilot, it has got better for pre-diagnosis contact, which has been good, although many people don't want support, they at least know that you're there". Participant 3*
>
> *"I'd say definitely with the pilot we were able to support anybody that had a pre-diagnosis or diagnosis of any type of dementia, whatever their age, so we had those with early onset, someone that had just been diagnosed and not working, through to those who were living on their own with Alzheimer's for a long period of time, maybe a decade, but were now seeing a change, but because they lived on their own didn't have a clue where to go, but they had, bizarrely at that point, the foresight to go, 'I notice things are changing because I've had the condition for so long, I need to get help before I don't know I need help', does that make sense?" Participant 2*

The DCCs felt they provided a consistent and reliable point of contact in what had previously been a confusing terrain for service users to navigate:

> *"I think having a central person for them to go to is the thing that helps them the most. Because although we're not delivering actual services to them, we're finding the services for them, so having a person they call, us, they call us on our mobile number, we're always there for them, if they want a service we do referrals. And I think that helps them rather than trying to remember who's called from what organisation, they can come to us, and we'll take it from there for them". Participant 4*

According to DCC perceptions, having a point of contact appeared to reduce a sense of anxiety amongst people living with dementia and family members:

> *"It's reduced anxiety, it's allowed the families and the person living with dementia value, in that they've got some kind of control. They often don't feel there's a lot of control, but they say, 'I can call somebody and ask somebody that's in a non-clinical, non-judgmental kind of role to say I'm not sure about something, or I just wanted to ask, or could you repeat what you said when you came?'" Participant 2*

This service and the role of the DCC appeared to offer people living with dementia a degree of control back where that may have previously felt diminished.

1.2. Weaving webs of care

DCCs talked about the number of different professionals that they worked alongside and/or came into contact with. Overall this was seen as a positive of the job, that they could form these connections and weave webs of care around the service user:

> *"that's one of the joys of the coordinator role being in primary care, I'm assuming it's still in primary care, so we did have the social prescribers and the GPs and the wider team to provide that holding hands circle around the patients and the carers." Participant 2*

These webs often included family members, power of attorney services, dementia crisis team, Carers First, social prescribing teams, Health and wellbeing coaches and GPs. Admiral nurses in particular appeared to be helpful to DCCs, raising awareness of the DCC role, contribution and potential impact, as well as stepping in with clinical support:

> *"The Admiral Nurses were an excellent source of support because they desperately knew where the gaps were and that this role is meant to fill it, and they had access to lots of people, and also because they know the clinical side." Participant 2*

The pilot programme also raised the profile of the DCC role with safeguarding officers who sought them out for support:

> *"Quite often, I have safeguarding officers coming over to us at Dartford, Gravesham and Swanley and asking us to support them, and that's all through the pilot and building that rapport with them." Participant 1*

In forming these relationships and working alongside other healthcare professionals, DCCs could act as information bridges for people living with dementia, providing them with crucial knowledge about their care pathway:

> *"I found, for me, getting access to the right people for the memory clinic… especially if a referral had gone in from a GP, where is that person within the appointment structure of how they are going to get an assessment around their memory to discern, but that was the hardest bit, 'Why do you want to know that?' and it's like, 'Well, a referral went in January, when will they know?' and once we got to know their pathway, 'Well, it'll be sixteen weeks', 'Right, okay, fair enough', it's a very important piece of information and now we can say to the person that the referral went in for, the expectation is you will not hear anything for sixteen weeks, so in that sixteen weeks, let's see what else we can help you with' to take them away from worrying about this appointment that's coming." Participant 2*

This also appeared to help reduce anxiety and worry amongst service users who may have felt nervous or uncertain about their appointments.

2. Challenges and pain points

2.1. Communicating the DCC role to GPs

Whilst DCCs talked positively about their ability to build good working relationships with other healthcare professionals, this appeared to differ when it came to GPs. DCCs stated that when GPs understood their role, this made the job much easier in terms of getting system access and patient referrals. However, GPs' awareness of the DCC role appeared to vary across practice locations. When GPs were not clear on the value a DCC could bring, this made getting access to patients and systems very challenging and led to some DCCs pursuing other, less fruitful routes to identify potential service users:

> *"I think you had a lot more success than me, because your GPs got on board, whereas with most of my people, I was visiting cafes and activity groups, I didn't have a lot of input from my surgery at all, which was a shame. Nothing was put in place, nobody got in touch with any of the doctors' surgeries to explain who we were, what we would want from them, we were literally going in cold." Participant 4*

Some DCCs felt that the misunderstanding amongst GPs about their role led to GPs thinking this would increase their workload whereas actually, DCCs may have been able to support them and in the long run contribute to reducing their workload.

> *"I think they just thought, 'Oh, we've got another load of work to do' and it wouldn't have really been like that once we'd got established, we could have actually taken quite a lot of work from the GPs around their dementia patients and made life a little bit easier for them." Participant 4*

DCCs felt that information was key to combatting this confusion:

> *"I think maybe they'd not been given enough information previously as to the pilot was coming in, what it was going to entail, what the benefits were for them The PCNs are still not being given an awful lot of information upfront as to what we're doing and why we're going in. Some of them still don't really know who the hell we are or why we're suddenly contacting them and trying to get into their surgeries."." Participant 4*

Providing information about the service, in particular the benefit and contribution of DCCs upfront, to surgeries, other healthcare professionals and particularly GPs could help the service and DCC role to become more established and embedded in existing teams.

2.2. Managing service user and carer expectations

Another stumbling block for some DCCs was conveying their role and in particular the boundaries of this role to service users and carers:

> *"I think that's something we struggled with in the pilot, explaining the role and then getting a consent and clarifying, that we are non-clinical. There was a real kind of, 'Oh, good, what happens next?' and we were like, 'Well, actually, don't know because that's the condition but we're not medical', so I think that is really important to get across as part of that assessment, that we're non-medical." Participant 2*

> *"…managing expectations, I think that's something that was quite challenging within our pilot to understand what the expectations are of the role because it was kind of like a, 'We will be with you all the way through' but we had to have those conversations at times, didn't we, the role is there, it won't necessarily be the person, and that's quite challenging with people living with dementia or one of the dementia conditions because familiarity is a good thing for them. So every time there's a change of a coordinator or some other party in their care team, it was something we had to think about…" Participant 2*

DCCs appeared to find it challenging to explain and clarify that they were firstly not medical and secondly, might not always be the person the service user would see. For people living with dementia these were two points that may have been confusing.

2.3. Service users living alone

One DCC felt that the service may still miss those living alone:

> *"So those living on their own I would say were probably the most complex because they didn't have family to support them. They might have had neighbours that might have helped them, but from the point of view of who can care for this person and make decisions, they were quite challenging…how do we make sure that person that's on their own 24/7 has the right care package, not just for their physical needs to eat, drink and be cared for in the sense of washing and that, but actually that stimulus of somebody coming to sing with them, knit with them, write with them, reminding them that they can do something, they've got worth even if they are housebound. If we can get people out and about, we will, that's our aim, but there are people that can't and they're still very hidden." Participant 2*

They felt particularly concerned about how to identify and best support these individuals so as to maximise their quality of life.

2.4. Managing workload capacity

DCCs all felt aware of their workload and how to balance their capacity and service user demand across the service. The unpredictable nature of support required made capacity difficult to gauge in terms of how many people they might need to support at any one time, for how long and when:

> *"One of the things that came out of that with this new role, and obviously with us in the pilot, what would our capacity be as persons? Because it's emotional, it's longer-term, you've not just got a set person for three hours or six sessions of two hours, whatever it is, there is an ad hoc need, you might not see some patients for some time, then you could find you've got some patients on the call to you two or three times a day." Participant 2*

Not only was this discussed from a time perspective but also an emotional aspect, as mentioned above. Directly related to capacity and demand was also the emotional load DCCs carried alongside their cases:

> *"The emotional input… sometimes you could be on the phone, planning a home visit, you're going to that home visit, you've called in the morning or the afternoon to ask if it's still okay, 'Yes', but when you arrive everything's gone a little bit mad. Then after that visit, okay, where do I put that? So again comes… and, I mean, I've had counsellor training and stuff, so it's like I can hold that, but now where do I go to deal with that in a safe place?" Participant 2*

The DCC role encompasses a range of tasks in addition to responding to and caring for service users including diary management, self-reflection, clinical supervision, peer support, training, data entry. As such it is broad and can be difficult to contain. Over time this emotional burden, of wanting to help service users (as well as their carers) and perhaps having to juggle competing demands and priorities may take its toll and is a pain point to highlight to ensure the wellbeing of staff and sustainability of the service is protected.

3. Service Improvement Opportunities

3.1. Establish buy in and engagement from healthcare professionals including GPs

For those who had success in working with GPs, they shared that they had spent a long time communicating and conveying their role and what they wanted to do/achieve:

> *"The communication of what the service was I think we spent a lot of time, probably the first three or four months, even if we were getting referrals dripping in, trying to seriously explain who we were, why we were there, that we weren't there to take anybody's job over." Participant 2*

Since the pilot there has been some notable improvements in accessing surgeries. This has coincided with newly implemented work structures including the role of senior DCCs who now do the primary contact with PCNs:

> *"Seniors, they do it for us and make the arrangements, and we're invited along, we're included in everything, but we don't have to make the initial contact, they're doing it on our behalf, which has made life a lot easier" Participant 4*

This has also helped with access to systems such as EMIS to ensure DCCs can upload relevant information to feedback to GP surgeries and better support patients:

> *"So we did this consolidated piece of work at the end so there was, through consent, relevant information able to go across and for them to decide if they wanted to put it on EMIS or not, especially as they knew the contract was going to continue." Participant 4*

Ensuring access and communication is standardised via for example joint control agreements and information packs about the DCC role across Kent and Medway would greatly support DCCs. Otherwise they are required to find time consuming workarounds which takes away valuable hours they could be spending supporting service users. Drawing in those such as Admiral nurses, who can act as advocates for the work of DCCs may also help embed the service to greater effect.

3.2. Prevent burnout

DCCs do this role because they want to help. They are emotionally invested in doing the job well and ensuring they have wide reach and provide high quality signposting and support. The individuals drawn to this role may have a predisposition to go above and beyond. This needs to be rewarded rather than capitalised on to ensure a sustainable workforce/service and protect job satisfaction:

> *"This is the only job I've ever felt you do something that's so worthwhile. It draws you in and you feel part of that." Participant 1*
>
> *"We don't give up on anybody." Participant 2*

As this service grows, consideration needs to be paid to staff capacity/ workload. Ensuring DCCs retain the ability to organise their own workload and be responsive to patient needs may help:

> *"We could determine our own diary. We had the scope as well to make those decisions to go and do visits in the evening if that best suited, especially for carers that were working, so I did do several evening visits as well. But that didn't mean everybody had to do that, it's just that from that assessment with the actual patients, we could determine what was best fit." Participant 2*

Supporting staff to put healthy boundaries in place as well as ensuring the service is adequately staffed is an opportunity to consider. Oftentimes DCCs felt conflicted between caring for the service user whilst also recognising that the carer may also require additional support.

3.3. Informal and formal support

DCCs spoke highly of each other in terms of the informal support they provided to one another:

> *"In a way we're one big work family, and we all just help each other, and that's how it's been since the beginning. We can always go to other coordinators who are working at the time and say, 'Look, I've got a really difficult case, I'm not sure how to deal with this' and they would help." Participant 1*
>
> *"We communicated with each other a lot and supported each other. Sometimes we would meet for a coffee and a bit of lunch to talk about how things had been going to give each other some support. We were lucky to have each other to support because we just had nothing at all." Participant 4*

Providing opportunities and protecting staff time so that they can come together to support one another and share their knowledge and current challenges may foster a positive working climate and benefit service users because of the shared information passed between staff about how to navigate challenges:

> *"I would have liked that clinical supervision to actually be with somebody in the GP surgery itself rather than in our Imago team because I think it would have raised the reality around the patient and the bigger picture could have become a mini-MDT, for want of a better word." Participant 2*

Participants spoke highly of the formal training/ induction process delivered by ADSS. However not all had access to this. Others spoke about opportunities they'd engaged in such as observing memory clinics. This gave them a greater sense of confidence to explain the process to people living with dementia, particularly those who felt nervous or reluctant to engage with the process and get a diagnosis:

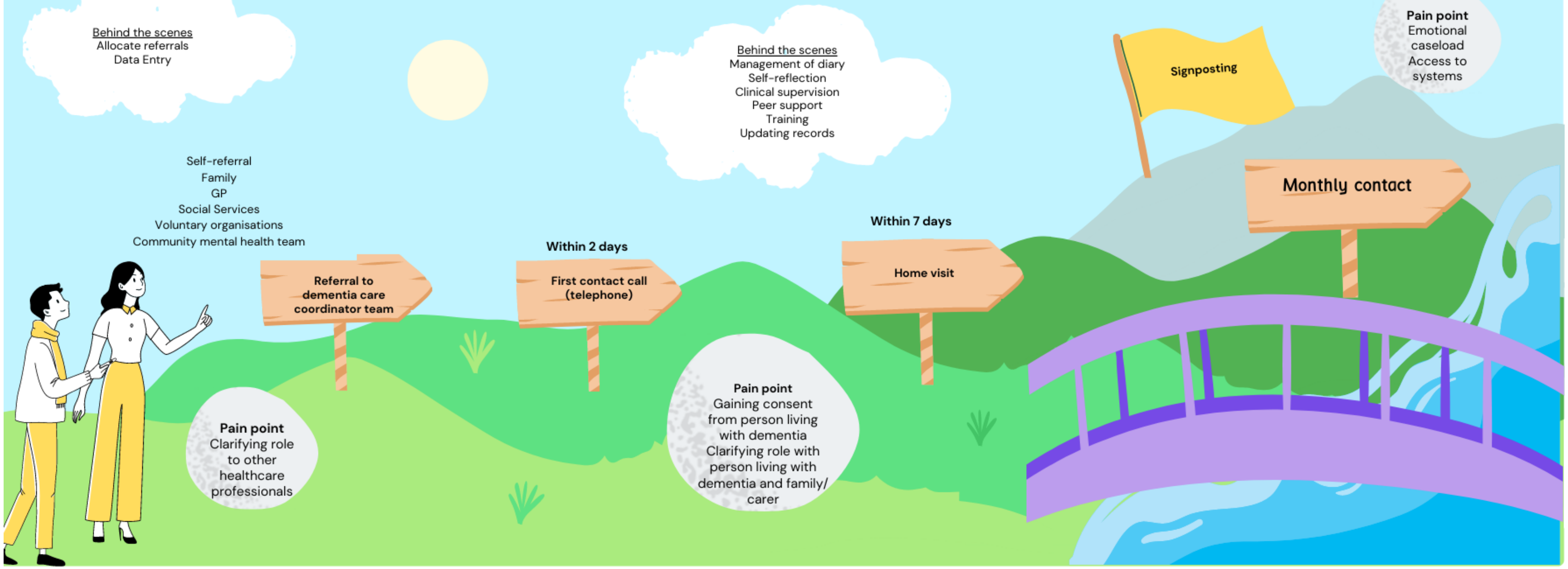
> *"I've been lucky enough to go to the memory clinic to sit in and see what they do, so that's really helpful because then you can go away and speak with confidence to people. There are a lot of people who don't want to go because they don't want it to be confirmed and you can speak to them quite confidently and tell them what the procedure is." Participant 4*

Ensuring that all DCCs have this knowledge and confidence could be a facilitator in increasing pre-diagnosis support.

Summary

The diagram below provides a visual depiction of the service user journey in relation to DCC contact. The scope of the DCC role is detailed in the behind the scenes tasks. Specific pain points are apparent in the service user journey. These pain points are potential areas to address in order to improve the overall DCC service.

Dementia Care Coordinator Pilot Service, Kent and Medway (2021)
Focus Group Analysis
Dr Ruth Abrams, Oct 2022



Behind the scenes
Allocate referrals
Data Entry

Self-referral
Family
GP
Social Services
Voluntary organisations
Community mental health team

Referral to dementia care coordinator team

Pain point
Clarifying role to other healthcare professionals

Within 2 days

First contact call (telephone)

Behind the scenes
Management of diary
Self-reflection
Clinical supervision
Peer support
Training
Updating records

Pain point
Gaining consent from person living with dementia
Clarifying role with person living with dementia and family/ carer

Within 7 days

Home visit

Signposting

Monthly contact

Pain point
Emotional caseload
Access to systems

Conclusion

This document reports on findings from a focus group held in Oct 2022 with DCCs involved in the pilot service across Kent and Medway in 2021. This focus group had three participants whereas an ideal number of participants for a focus group is eight. Additionally, this focus group did not include the perspectives of service users. Further data are needed to support any service improvement recommendations and these issues will be mitigated in the larger evaluation currently underway. However, the DCC role appears to benefit service users by providing them with a reliable point of contact, even if they don’t engage with the service immediately. The DCC role works well when there is awareness across and within PCNs. Ensuring the service is appropriately staffed to protect staff time and wellbeing, as well as standardising communication about the role across Kent and Medway may enhance service provision.

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