

The Primary Care Navigator programme for dementia

Benefits of alternative working models



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Lessons from the two pilot sites

Background

From June 2014 to February 2015, the National Association of Primary Care (NAPC) Practice Innovation Network (PIN) together with Health Education England (HEE) has been responsible for developing and running a pilot “Primary Care Navigators (PCN) for Dementia” training programme. In order to have an objective understanding of the impact of this pilot, NAPC contracted Deloitte LLP and its research hub, the Centre for Health Solutions, to undertake:

- A formal evaluation of the new training programme and the effectiveness of the PCN role;
- An analysis of its impact upon patient outcomes, GP Practice outcomes and the lessons learnt; and
- An evaluation of two case examples that the NAPC identified as the two most engaged participants (as judged by its rolling evaluation) to illustrate the impact that full engagement can have on outcomes.

This case study report is an evaluation of the two case examples identified as being most engaged by the NAPC. It presents a qualitative assessment of the two sites, based on visits and high level data and feedback received. A full report, following an evaluation of all participants of the training programme, will be undertaken by the end of April 2015.

The PCN for dementia role is intended to provide support for people with dementia who are both pre- and post-diagnosis. The PCN is trained to listen and guide people to the support and resources they need from local and national services.

Out of 20 participating pharmacies and GP practices in the pilot, the NAPC suggested that two organisations had best demonstrated the possible benefits of the PCN role:

- The Oxford Terrace and Rawling Road Medical Group, Gateshead; and
- Wellbeing Enterprises CIC, Halton.

The Deloitte Centre for Health Solutions therefore visited the two organisations in order to evaluate the available evidence. The evaluation and subsequent findings are based upon:

- Analysis of staff and patient feedback forms;
- Observations and interviews with the PCNs and project supervisor; and
- Discussions regarding the impact of the programme with other staff in the organisation.

An overview of the two case study organisations

The two organisations concerned had different foundations, with Oxford Terrace being a large GP practice (Part 1) and Wellbeing Enterprises CIC a social enterprise providing PCNs to all GP practices in the local area (Part 2). Since the organisations were allowed to develop the role as they saw fit, the number of staff trained as PCNs, patient contacts and approaches to evaluation differed and thus cannot be compared directly. However, our evaluation highlighted that both organisations share a number of key attributes.

- **Committed project supervisors.** Feedback from interviews with PCNs and other staff highlighted that the leadership observed engenders a positive culture that welcomes new ideas and initiatives.
- **High calibre staff.** Interviews with supervisors indicated that staff with the capabilities to undertake the role and develop as they saw fit was an important factor in the success of the project.

- **Communication across the organisation.** PCNs noted that they felt supported through supervisors ensuring that the rest of the organisation understood the purpose and scope of their role.
- **Character and approach.** The PCNs exhibited enthusiasm, a strong ethos of caring, and a passion for improving the health and well-being of their local population.

As a result of the differing foundations between the two sites, the staff employed had different backgrounds in terms of education, experience and working knowledge of dementia and healthcare. These differences did not appear to impact on their ability to be effective PCNs (as judged by the supervisors, the NAPC team running the training and based on observations during the visit). However these differences did influence, to a degree, how the role has evolved (as detailed in Parts 1 and 2 and summarised below).

An overview of the experience of the Oxford Terrace PCNs

At Oxford Terrace, two people share the PCN role, with each working as a healthcare assistant one week and as a PCN the next. Their role, as a PCN, is aimed at providing clinical staff with an option to refer patients and carers who they identify as needing additional non-clinical support. However, a benefit of PCNs having a clinical perspective is that it enables them to identify people with memory loss or other health and wellbeing needs and invite them to a consultation, without waiting for referral from the GP or practice nurse.

As a result, the PCNs workload is not entirely dependent on referral from a healthcare professional. Patients and carers attending an appointment are assessed and signposted immediately to appropriate resources and support.

There was an observed difference by stakeholders, regarding both pre and post-training of the role, for the two PCNs:

- **Pre-training.** Assessments showed that PCNs lacked confidence in their ability to effectively deal with dementia patients and vulnerable patients. This observation was confirmed in interviews with PCNs during the visit.
- **Post-training.** Following the training, PCNs considered their confidence and ability as carers has improved significantly. This was corroborated in discussions with GPs and other practice staff during the course of the visit.

Key observations as a result of the role at Oxford Terrace include:¹

- **Patient satisfaction.** Patient feedback forms indicate positive reviews of the PCN role – with regular contact, follow-up and access to support that was not previously available being the main points of satisfaction.
- **Staff satisfaction.** Both supervisors and PCNs stated an increase in job satisfaction. Other members of staff commented how the PCN role was helping them to work more effectively and provided specific examples which demonstrated how this had helped create an effective multi-professional team approach.
- **Increased referral of patients.** Both doctors and nurses increased their referrals of patients as a result of the PCN role. This is confirmed by data on referrals and feedback forms.²
- **Improvements in wider care.** The PCN role, initially aimed at dementia patients, has been extended to support all vulnerable patients that doctors and nurses consider as benefitting from the PCNs.

An overview of the experience of the Wellbeing Enterprises PCNs

In the case of the Wellbeing Enterprises CIC, 10 community wellbeing officers were selected to be trained as PCNs. Although none of the selected trainees had a clinical background, their experience included health, social care, education and nutrition. Furthermore, all were experienced in organising and holding community skills programmes focused on improving the health and wellbeing of their local population. The PCN role was therefore seen as an extension of their responsibilities.

Key observations following the introduction of the PCN role at Wellbeing Enterprises include:

¹ Source: Patient feedback forms and visit discussions.

² Source: Referral lists.

- **Increased referral of patients.** Following the end of the first three months, referrals from GP practices of people with dementia increased to 15.³
- **Patient satisfaction.** Patient feedback forms indicate that the dedicated support has improved their wellbeing and integration into the community. This is observed through an upward trend in the self-score metrics that patients submitted regarding wellbeing levels and depression.⁴
- **Patient care.** Referring GPs reported improvements in their practices' confidence and ability to help both people with dementia and their carers more effectively.
- **Reduction in primary care.** As a result of the programme, feedback and data has highlighted that there has been a reduced reliance on primary care.⁵

Following these observed benefits from the programme, steps are being undertaken to integrate the PCN offering into existing clinical pathways to widen the potential for referrals.

General lessons from the two case study visits

Wellbeing Enterprises CIC and Oxford Terrace both demonstrate a strong community based approach, as well as placing an importance on the value of building stronger relationships with partner organisations. In building directories of supporting partner organisations, they have been able to:

- **Raise the profile of organisations across the community.** Both sites have run community events to showcase the variety of support available, for example facilitating market stalls in GP Practices demonstrating first-hand the academic evidence that connected and empowered communities could lead to healthier communities.
- **Demonstrate wider patient benefits.** Organisations are able to show that mobilising assets within communities can help increase people's control over their health and lives.

Both case examples share the view that PCN training should represent part of a wider staff training and development programme, aimed at improving the ability of the staff to provide better support to a wider range of vulnerable people. A result of the PCN training has been:

- **Improved staff engagement with patients and carers.** Feedback collected in both cases shows improvement in patient and practice outcomes.⁶
- **Improved staff satisfaction.** Staff at both sites have highlighted an improvement in their job satisfaction. Further, the PCN role has a potential impact on other staff, with successful implementation having the potential to relieve some of the increasing pressures on GP practices.

The NHS 'Five Year Forward View' sets out how the health services need to change, and argues for a new relationship with patients and communities.⁷ Public Health England's strategy, 'From Evidence into Action' calls for place-based approaches that develop local solutions, drawing on all local assets and resources. It suggests integrating public services and building flexibility across each community in order to improve health and wellbeing for all and reduce health inequalities.⁸ The evaluation of the PCN role in many ways reflects the ambitions identified by these two policy documents, in particular the development of new types of staff, different approaches to working with communities, the harnessing of social capital in local communities and responding to local needs.

Lessons for the further roll-out of the programme

Although the PCN role has been in operation for a relatively short period, these two cases show that full engagement from the outset, together with continued leadership and support, are important. Organisations interested in adopting the PCN role need to understand the time and effort that needs to be invested. This not only

³ Source: Project supervisor feedback form and visit discussion.

⁴ Source: Project supervisor feedback form and visit discussion.

⁵ Source: Project supervisor feedback form and visit discussion.

⁶ Source: Feedback forms, analysis of data and visit discussion.

⁷ Source: <http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf>

⁸ Source: <https://www.gov.uk/government/publications/from-evidence-into-action-opportunities-to-protect-and-improve-the-nations-health>

applies to time dealing with patients and carers, but a commitment to raise the profile of the PCN with all stakeholders – the patients, carers and communities as well as the GPs, staff and providers. Successful implementation requires clear communication from the start, a steady building of relationships and a collaborative approach. It is essential that the PCN role is fully understood and integrated with local health and care service provision to ensure the best outcomes.

There is also a need to ensure that the PCNs can put their training into practice. This requires a steady flow of patients and carers who need the support of a PCN. It also requires regular evaluation and feedback within the organisation concerned.

A Final report on the full evaluation of the qualitative and quantitative evidence collected as part of the whole pilot programme, involving 20 GP practices and 20 pharmacies will be provided in a report by the end of April. Part 1 and Part 2 of this report provides an assessment of the two pilot organisations, identified for us by the NAPC as the two most engaged participants on the programme to date.

Part 1: The Oxford Terrace and Rawling Road Medical Group, Gateshead

About Oxford Terrace and Rawling Road Medical Group

The practice comprises of 12 doctors, a Registrar, two nurse practitioners and a nursing team (comprising practice nurses, occupational therapist, receptionist, as well as administrative and other staff, led by a practice manager).⁹ Other professionals aligned to the practice include a midwife, health visitor, district nurse, physiotherapist, dietician, chiropodist and primary care mental health workers as well as medical and nursing students. The practice operates on two sites and is highly patient focused providing a multidisciplinary approach to patients' health care and combining the skills of the practice team with other health and social care workers in the community.

At the outset of the programme, the Practice Manager of the GP group revealed that they had a prevalence of 200 per cent for dementia, with the majority of this case finding being undertaken by GP and Senior nurses. Further, there was a high level of unplanned admissions, whilst staff and patient satisfaction was low. This was included in the application for the course, and was corroborated through discussions with other staff in the practice during the visit.

The practice manager (project supervisor) selected three non-clinical staff, two from their GP Practice and one from the Community Pharmacy to be trained as PCNs.

Patient feedback: "Thanks for your support and just listening", "Thank you for listening and acting so quickly", "Loving my new dancing shoes!"

The practice manager identified and supported two of the practice staff to be trained as PCNs. The PCN training programme for dementia was seen as an opportunity to build on the Medical Group's wider agenda of transforming care around the patient. While concerned to ensure that patients registered with the practice that had a diagnosis or symptoms of dementia received the best possible care and support, the project supervisor also recognised that there were other equally vulnerable patients that could benefit from exposure to the contact and support offered through the PCN role.

The training provided to those selected as PCNs provided them with confidence in dealing with dementia patients and their carers effectively. Furthermore, the programme has helped PCNs to direct people to the full range of support (both local and national) needed for all aspects of their health and wellbeing, post-diagnosis. In so doing, they have built up a growing directory of community services that can provide the required support.

The practice received no additional funding or resources other than the initial training. Funding from the Dementia Direct Enhanced Service, available as part of the general practice contract, was also utilised.

Keys to the success of the PCN role for the practice were identified as:

- Wider practice engagement.¹⁰
- Agreeing individual care plans and assigning GPs.
- Providing nursing homes with a single Point Of Contact for prescriptions and requests for visits.

⁹ <http://www.otmg.co.uk/>

¹⁰ Achieved by introduced the programme and expectations at practice meetings and multi-disciplinary staff meetings. Further, the concept was introduced to patients and carers through a 'Health Fair' and by using practice and patient champions to spread the word.

- Supporting doctors and nurses by enabling them to refer to the PCN for longer consultations.
- Supporting the nurse practitioner and frailty nurse.
- Aligning with co-ordinated care planning and MDT meeting/planning.

Dealing with patients and their carers involves:

- Open invitations to the surgery for a “catch up and cuppa”;
- “Getting to know You” events;
- Identifying people’s needs, sign-posting them to available help and contacting organisations on their behalf (if required);
- Regular fortnightly contact (via telephone or a drop in) to see how progress is being made and what is still needed;
- Updates on events that might be of interest; and
- Making contact within three days of discharge from hospital.

A comparison of outcomes on the outset of the pilot with those at the end is highlighted below. These outcomes have been developed from a review of feedback forms submitted to NAPC.

PCN feelings at the beginning	PCN feelings after three months
<ul style="list-style-type: none"> ▶ Concerned at lack of experience ▶ Anxious and scared about ability to take on the role ▶ Fear of the unknown and what was expected ▶ Worried about time commitment to project 	<ul style="list-style-type: none"> ▶ Confident as a result of the training ▶ More in control ▶ Familiar with the role ▶ Happier in general in working for the practice ▶ Needed and valued ▶ Better organised and positive about the job

The PCN performance activities within the first three months, as presented in the feedback to the NAPC and verified during the visit, include:¹¹

Support for GPs and nurses	Support provided to patients	Other notable changes
<ul style="list-style-type: none"> ▶ Dementia Screening (+117) ▶ Assessment for Dementia (+38) ▶ Carers Register (+43) ▶ Veterans Register (+20) 	<ul style="list-style-type: none"> ▶ Care Plans (+396) ▶ NHS Health Checks (+95) ▶ Post-discharge (+86) none of whom needed a physician as PCN sorted ▶ Reduction in discharge letters suggesting avoided admissions – from 7-8 per day to 2-3 per week 	<ul style="list-style-type: none"> ▶ More effective in ringing patients following emergency admissions ▶ Less fragmentation ▶ Improved reception management ▶ Improved communication ▶ Lower prescription errors ▶ More co-ordinated personalised care

PCN feedback: “There has been really positive feedback from GPs and care homes. As PCNs we have been able to identify and tap into available money and resources to support people – demonstrating that despite it being a time of austerity, with a reduction in services and resources, there are resources in abundance once you start to look and also a lot of duplication. As a practice we didn’t have the mechanism or time to tap into the available “gold mine” – PCNs are that mechanism. Right care, right place, first time – helping to avoid duplication and reduce provision of inadequate or wrongly targeted support.”

The PCNs have developed a Directory of Services, enabling social prescribing to a range of services across Gateshead. Neighbouring practices have observed the benefits from the programme and are enquiring to have a PCN for their practice. Specifically, they have asked to co-locate them within the Oxford Terrace and Rawlings Road Medical Centre practice. This is aimed at facilitating joint working and sharing new ways of working with other practices in order to provide high quality patient centred care.

A consultant geriatrician at the service: “Cultural change was a big hurdle to setting up the service – people were used to their own ways of working or doing things. That applies to staff, and patients and service users, and their carers.”

The third PCN, from the local pharmacy, has had less success in supporting patients (with no patient contact as yet), and is finding it difficult to identify patients with needs in the pharmacy. However, the PCN training has enabled them to develop much better relationships between the pharmacy and practice, helping to reduce poly pharmacy, ensure that patients are prescribed the correct treatment and to reduce contra-indications. It is also supporting practice patients to improve compliance in medication adherence. In improving relationships with the pharmacy, prescribing costs can be reduced.

Overall, as a result of the PCN initiative, the practice has altered its working patterns. In recognition that training more new GPs and practice nurses will take time and that capacity constraints are challenging, initiatives that can free up incumbent clinical staff from some areas of responsibility, such as the PCN role, are much needed. The role

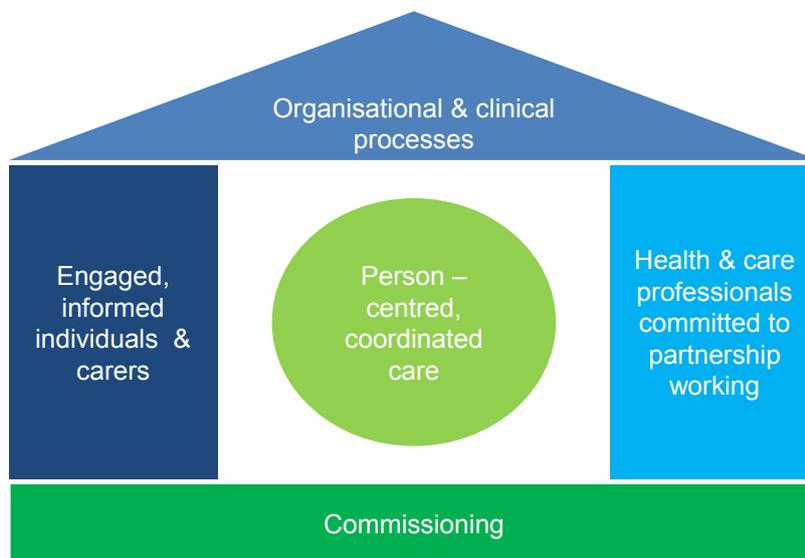
¹¹ The figures in brackets represent the number of care plans developed by the PCNs. This is based on quantitative evidence collected by the PCN. Note these figures have not been validated by Deloitte in this case study report.

can consequently enable GPs and nurses to focus more on managing complex care and co-ordinating medical care for those with multiple needs; leaving the PCN, as part of the wider multi-disciplinary team, to provide continuity while spending longer and less pressurised time with patients and carers.

An Age UK navigator is due to join the team in March. The PCN will bring 250 different organisations that the team can refer to. The pharmacy is also in discussion with head office, supported by the practice, to develop the pharmacy as dementia friendly organisation with the PCN role at the centre of self-care.

The ultimate vision for the practice is for it to adopt the House of Care model, depicted in Figure 1 below.

Figure 1: House of Care model



This model of care involves specialists working across secondary, primary, community and voluntary sectors and is intended to make services more joined up and provide quality care more consistently. The PCN role is an important building block for this model. Supported self-care for those with multiple long term conditions will be a key evolving role for the PCN and the Clinical Commissioning Group (CCG) has agreed to work with the practice on implementing this care model.

Finally, feedback from PCNs is that whilst their role is non-clinical, including a clinical component would add value and enable them to care for the patient in a more meaningful way, particularly in relation to self-help and issues linked with the social determinants of their health. This was seen as being very important in the next phase, when the PCN role as part of the multi-disciplinary team is extended to complex care management. The key part of the PCN role regards the single point of contact aspect and the relationships that they build with patients and their carer (caring for the person not the disease/patient). This should not be underestimated.

Formal feedback from the two practice PCNs in post-training survey: “Working closely with networks in the area has enabled us to navigate through all the channels necessary. We have been working closely together with our GPs, reducing workloads, hospital admission and appointments. We have brought the community closer together, providing Christmas Day lunch for people who would otherwise have been on their own. This was extremely successful. As well as working with dementia patients, we have also extended our role to enable us to work with anyone with complex care needs”.

Part 2: Wellbeing Enterprises Community Interest Company, Halton

About Wellbeing Enterprises CIC

Wellbeing Enterprises CIC is a social enterprise whose mission is to support individuals and communities to achieve better health and wellbeing. They achieve this by educating the general public and working co-productively with other partners to tackle the underlying causes of poor health.¹² It provides services to a population of 126,000 across 17 GP Practices and has used the pilot to build on the skills of all non-clinical staff.

The approach adopted was to select 10 community wellbeing officers to be trained as PCNs. The selected officers were already delivering over an estimated 3500 interventions each year to patients across the 17 Practices. The PCN for dementia training builds on their existing training and development, reflecting the organisation's learning culture. This has equipped the community wellbeing officers to deal with more vulnerable members of the population and strengthened their ability to support health and social care professionals, especially GP practices.

The approach undertaken is designed to provide a holistic intervention that helps people to develop the skills and knowledge to improve their own wellbeing. This involves working collaboratively with residents and local organisations to mobilise the skills of the local population and empower them to gain a greater sense of control over their own health and wellbeing. An important aspect of the role is in connecting people to assets in the wider community. These skills are subsequently used to support people with dementia and other needs.

The feedback from staff showed enthusiasm and a belief that they are achieving their ambitions for improving wellbeing and patient care. Their involvement in the programme has given them the confidence to work effectively with primary care to support an improvement in people's wellbeing, regardless of their clinical diagnosis or long-term condition.

Summary of involvement in the PCN programme

Activity during the pilot phase, using community wellbeing officers trained as PCNs, was as follows:

- Fifteen PCN Dementia Wellbeing Reviews were carried out based upon referrals from eight practices (four practices referred one patient each, four referred two and one referred three patients¹³; and
- Five patients referred by a GP, four by community wellbeing officers, two by a nurse and one from the local hospital discharge team.¹⁴

Patient and staff reported outcomes of engagement with the PCN pilot, documented in the feedback report to the NAPC and corroborated as far as possible during the visit, were:

- **Patient support.** On average, patients reported that they receive more support in their local community, including support from their GP practice and from their pharmacy as a result of attending the PCN Dementia Wellbeing Review;
- **Wellbeing.** 60% of patients showed an improvement in their wellbeing levels, and 50% showed a reduction in their depression symptoms after attending their PCN Dementia Wellbeing Review;

¹² www.wellbeingenterprises.org.uk

¹³ Two patients were aged 60-69, 13 were over 70, the eldest 94. 60 per cent were female.

¹⁴ Of the 15 patients who accessed a PCN Dementia Wellbeing Review, nine complete patient experience records were completed. Patients rated their satisfaction of the PCN Dementia Wellbeing Review as 9.25 out of 10.

- **Clinical ability.** Clinicians self-reported scores regarding their practice’s ability to support patients with their dementia and their carers increased; and
- **Staff satisfaction.** PCNs reported numerous intended and unintended outcomes as a result of taking part in the pilot; including feeling more confident about receiving an increasing number of referrals from clinicians.

More specifically, as part of the standard Wellbeing Review evaluation process, patients were asked to self-score themselves against a range of validated health metrics to measure their subjective wellbeing levels (SWEMWBS) and depression symptoms (PHQ9). The pre-intervention mean score was 25.00 and the post-intervention mean score increased to 27.80 - although this included only a small sample size, the 2.90 points difference is a meaningful change in wellbeing levels.¹⁵ Three out of five patients (60%) showed an improvement in their SWEMWBS score, one patient’s score stayed the same and one patient’s score deteriorated. The pre-intervention mean score was 6.83 and the post-intervention mean score improved to 5.83 (demonstrating a reduction in depression symptoms). Three out of six patients (50%) showed an improvement in their PHQ9 score, two patients’ scores stayed the same and one patient’s score deteriorated.

The frontline Community Wellbeing Officers trained as PCNs reported back the following expected and unexpected outcomes after completing the pilot period. This is depicted below.

Expected outcomes	Unexpected outcomes
<ul style="list-style-type: none"> ▶ Being able to receive more referrals from multi-disciplinary meetings in GP practices (x4 CWOs) ▶ Improving confidence of supporting people with dementia ▶ Improving knowledge and awareness of dementia and how it affects people (x3 CWOs) ▶ Recognising early symptoms of dementia and making appropriate referral diagnosis 	<ul style="list-style-type: none"> ▶ Building stronger relationships with partner organisations (x2 CWOs) ▶ Supporting partner organisations (e.g. Alzheimer’s Society) to integrate their services into primary care e.g. facilitating market stalls in GP practices

Wellbeing Enterprises consider that the benefits they have seen as a result of taking part in the pilot have strengthened their links with partner organisations at a strategic level. The benefits include:

- The PCN service being monitored through the local Halton Dementia Partnership Board;
- Wellbeing Enterprises working collaboratively with a local mental health provider’s ‘Later Life and Memory Services’ to integrate the PCN Dementia Review service into their clinical pathway, thereby offering another layer of support for local residents who have been diagnosed with dementia;
- Access to additional resources to support people with dementia and their family/carers – such as teaming up with local libraries to offer dementia ‘Books on Prescription’ and memory boxes/books that are offered to people who attend a PCN Dementia Review; and
- Signing up to the local Dementia Action Alliance, in which all local partner organisations are making pledges to support Halton becoming a more dementia friendly community.

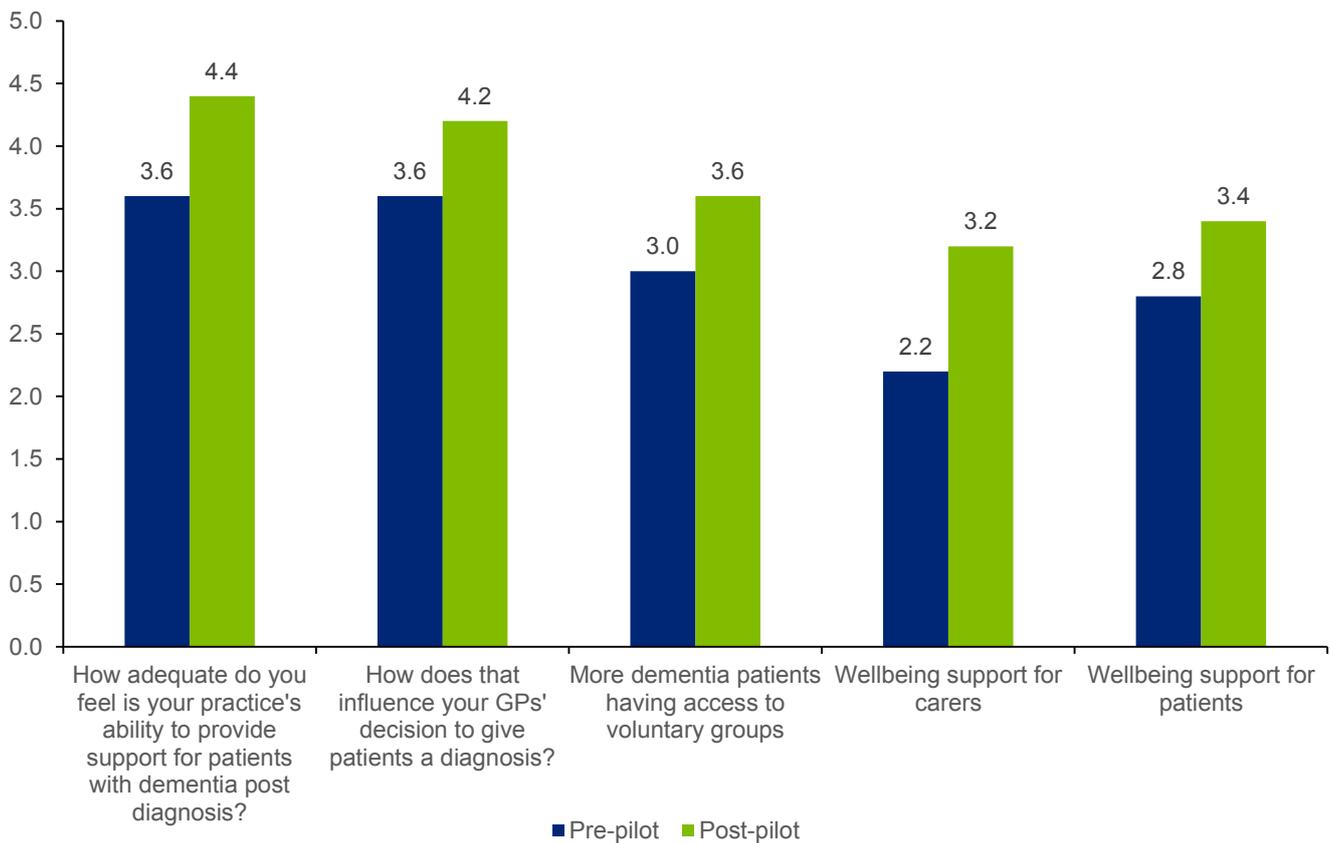
Frontline community wellbeing officers also identified a number of limitations that they have experienced as part of the pilot period. These include:

¹⁵ A meaningful change in wellbeing scores is defined as an increase of 2.00 or more SWEMWBS points.

- Difficulties asking people with memory problems to complete questionnaires and recount experiences of services, as the patient often struggled to remember or answer accurately;
- Conducting a PCN Wellbeing Reviews with both a dementia patient and their family/carer resulted in family/carer members contradicting what the person with dementia was saying, which made it difficult to ascertain accurate information about the patient;
- The need for additional resources to support people with dementia, for example, the directory of local resources from the Guide Post Trust was not received until a couple of weeks before the pilot period ended; and
- The CIC is currently working on integrating the PCN offering into clinical pathways in order to increase the number of referrals.

Feedback was received from six clinicians at the start of the pilot, on how well they felt their GP Practice was able to support patients with dementia and their carers; at the end of the project five end of project record sheets were completed. On average, clinicians reported higher scores after the PCN pilot, the question with the highest increase in score was the GP practice’s ability to provide support for patients (and their carers) post-diagnosis, depicted in Figure 2 below.

Figure 2: GP responses on key questions pre and post-PCN pilot



GP comment: “The PCN role has helped patients to access the service and feel supported in their diagnosis. It has enabled them to access available services following signposting, and referrals from the Community Wellbeing Officer.”

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Acknowledgements

The following are a sample of those who were interviewed for this project;

Sheinaz Stansfield, Practice Manager, Newcastle Gateshead CCG Alliance Board Member, Oxford Terrace and Rawling Road Medical Group; **Julie Bray**, Primary Care Navigator, Oxford Terrace Medical Group, Gateshead; **Jayne White**, Primary Care Navigator, Oxford Terrace Medical Group, Gateshead

Mark Swift, Co-Founder and Chief Executive Officer of Wellbeing Enterprises CIC; **James Dunningham**, Operations Director; **Helen Trahar**, Senior Community Wellbeing Officer; **April Lander**, Social Prescribing Coordinator; **Helen McPeake**, Community Wellbeing Officer

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