Primary Care Navigator training programme for dementia
Evaluation of its impact
The Deloitte Centre for Health Solutions, part of Deloitte UK, generates insights and thought leadership based on the key trends, challenges and opportunities within the healthcare and life sciences industry. Working closely with other centres in the Deloitte network, including the US centre in Washington, our team of researchers develop ideas, innovations and insights that encourage collaboration across the health value chain, connecting the public and private sectors, health providers and purchasers, and consumers and suppliers.
Facts and Figures

Number of people with dementia in the UK

685,800 people in England with dementia, 815,800 in the UK

Forecast to increase to over 1 million by 2025 and over 2 million by 2051

This represents

7.1% of over 65s in the UK

1.3% of the entire UK population

The cost of dementia to the UK is significant...

The total cost to the UK economy of dementia is now £26.3 billion or £32,250 per person

£4.3 billion healthcare costs

£10.3 billion in social care

£11.6 billion in unpaid care

...as it is to businesses

Dementia is estimated to cost UK businesses £1.6 billion per year

89% of employers believe that dementia will become a bigger issue for their organisation

Diagnosis rates are improving...

From 2009 to 2015, dementia diagnosis rates have increased 22% points to 55%

Further commitments to improve dementia diagnosis rates to 2/3 have been announced by NHS England

...yet care requirements are continually rising

Around 670,000 people act as primary carers for people with dementia

66% of people with dementia live in the community, with around 60% receiving home care

Approximately 1/3 of people with dementia live in care homes
Recent policy interventions have raised the profile of dementia...

The Prime Minister’s Dementia Challenge 2020
Aims to deliver sustained improvements in health and care, create dementia friendly communities and boost dementia research

The Health and Social Care Act (2012)
In changing how policy and commissioning decisions are made, CCGs are now responsible for prioritizing investment in services

The NHS Mandate (2014)
Aims to ensure that the NHS improves at involving patients with long-term conditions and their carers, empowering them to manage their own care and treatment

The Care Act (2014)
The Act aims to provide people living with dementia and their carers a better understanding of what they are entitled to and a positive change in the way patients are cared for

...yet a number of challenges remain

Challenges to dementia care

- Difficulty in obtaining a diagnosis
- Post-diagnosis support not available universally
- Variable provision of memory services
- The need to improve workforce skills
- Lack of consistency in provision
- Patients struggle to access support

Sources:
Prime Minister’s Dementia Challenge 2020: progress report 2015.
Executive Summary

The Prime Minister’s Dementia Challenge (2012),1 NHS Mandate (2014)2 and other recent policy initiatives have highlighted the need for greater staff training in the awareness and understanding of dementia, and for more support to be provided to people with dementia and their carers. In response, Health Education England (HEE) and the National Association of Primary Care (NAPC) have collaborated on developing a new dementia training course for care navigators in primary care, namely the “Primary Care Navigators (PCN) for Dementia” training programme.

The PCN programme

The PCN programme aims to provide a non-clinical ‘bridging role’ that connects and signposts people with dementia and their carers to the local and national services, information and support available. The pilot programme ran from June 2014 to February 2015, with 20 GP Practices and 20 Pharmacies signing up to trial the implementation of the PCN role.

To prepare PCN trainees, which comprised a range of GP Practice and Pharmacy staff such as healthcare assistants, registrars and pharmacy dispensers, the NAPC provided training in the form of web-based resources and an interactive training day. The NAPC then visited participating sites in order to provide ongoing mentor support. Feedback collected from this process was used to develop the programme for use within dementia and is now being extended to other conditions such as diabetes.

Data was collected from all participants in the pilot programme:

- GP Practice PCNs and their supervisors;
- Pharmacy PCNs;
- Patients; and
- NAPC Project management.

This feedback aimed to identify the enablers and barriers to the success of the programme, develop solutions and further improve the implementation of the PCN role through shared and ongoing learning.

This report

In order to have an objective understanding of the impact of the pilot, NAPC commissioned Deloitte 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.
- Two case studies on NAPC identified participants which they regard as being fully engaged with the programme to illustrate the impact that full engagement can have on outcomes.

This report presents an analysis of the impact on outcomes and lessons learnt from the programme. An earlier report, provided in March 2015, evaluated the case studies detailed above. This is presented in section 6.

Findings

The quantitative and qualitative evidence collected throughout the PCN programme suggests that, with full engagement from the organisations involved, the programme has the potential to:

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1 See also: http://dementiachallenge.dh.gov.uk/about-the-challenge/
2 NHS Refreshed mandate (2014). See also: http://hee.nhs.uk/2014/05/01/refreshed-mandate-launched-today/
• Provide a wide range of staff, from healthcare assistants to general staff, with training which may improve their overall confidence of the PCN role and their knowledge of dementia.

• Enhance patients’ ability to find support from their GP Practice and local Pharmacy.

• Enable PCNs, at both GP Practices and Pharmacies, to become more confident in their knowledge of dementia and the types of support required, together with their ability to signpost patients to appropriate resources.

• Improve GP Practices’ ability to provide support for patients with dementia and their carers’ post-diagnosis.

Nevertheless, findings from the analysis suggest a number of possible development areas in order to deliver the benefits of the programme across all GP Practice and Pharmacy sites:

• GPs should be made fully aware of the role and its use within practices and the wider community.

• PCNs need access to appropriate and sufficient material to promote and provide information surrounding the role to improve awareness of the service offered and attract more patients.

• Pharmacy PCNs may require a greater degree of training to instigate conversations with patients, their families and carers such that requests for support can be better identified. In cases where an individual is seen to be potentially developing early symptoms but appears not to be requesting support, a mechanism may need to be highlighted whereby they can be referred to relevant services without the ‘stigma’ of being labelled as a dementia patient.

• A lack of time to perform the PCN role in line with day-to-day roles was highlighted by PCNs, particularly at GP Practices. The selection of PCNs, supervisors, organisations and whether they are able or committed to fulfil the time requirements should be carefully assessed.

Two notable successes of the pilot have been the ongoing learning demonstrated by PCNs and the flexibility of the programme.3 PCNs benefited from shared and continuous learning, both through their experiences in the role and from the resources and mentoring provided by the NAPC.

In addition, NAPC project management collected and responded to rolling feedback throughout the project in order to develop the programme further. Consequently, steps are being undertaken to integrate the PCN offering into existing clinical pathways and other conditions such as diabetes.

The remainder of this report is structured as follows:

Section 1 – Introduction to the PCN programme, outlining the project aims and structure.

Section 2 – Description of the data collected and limitations associated with the evaluation of the PCN programme.

Section 3 – Quantitative analysis of the PCN programme.

Section 4 – Qualitative analysis of the PCN programme.

Section 5 – Conclusions and recommendations for the further development of the programme.

Section 6 – Two case studies which show what the programme can achieve with full stakeholder engagement.

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3 Training Primary Care Navigators for Dementia in Pharmacies and GP Practices, National Association of Primary Care, 2015.
1 Introduction to the PCN programme

The Prime Minister’s Dementia Challenge (2012), NHS Mandate (2014) and other recent policy initiatives have highlighted the need for greater staff training in awareness and understanding of dementia, and for more support to be provided to people with dementia and their carers. Further, the NHS Five Year Forward View sets out how health services need to change and argues for a new relationship with patients and communities.

In response, Health Education England and the National Association of Primary Care have collaborated on developing a new dementia training course for care navigators in primary care, namely the “Primary Care Navigators (PCN) for Dementia” training programme.

1.1 Project aims

The PCN programme provides a ‘bridging role’ that connects and signposts people with dementia and their carers to the local and national services, information and support available. The PCN role itself is non-clinical, and is intended to assist those who are both pre- and post-diagnosis.

Specifically, the programme has been designed with the following aims:

- To create the role of the Primary Care Navigator (PCN) to signpost people dealing with dementia and their carers to the full range of support they need for all aspects of life and wellbeing.
- To create a training programme for Primary Care Navigators (PCNs) in GP Practices and Community Pharmacies.
- To deliver training, information and tools to signpost people with dementia and their carers to the full range of support they need to maximise wellbeing in dealing with dementia and its associated comorbidities.
- To enable PCNs to share and pass on their knowledge to all Practice/Pharmacy staff to make better use of their dementia wellbeing awareness.
- To deliver the PCN role as a resource to doctors, pharmacists and all staff in Practices and Pharmacies.
- To pilot all aspects of developing a new role nationally in primary care: design, recruitment, communication, training, support and environment.
- To evaluate the impact on patients, carers, participating staff and organisations and identify lessons learnt.

1.2 Structure of the pilot

The pilot programme ran from June 2014 to February 2015. Twenty Pharmacies and 20 GP practices agreed to take part by nominating one or two non-clinical staff to train as a PCN, together with one supervisor to support the new role.

NAPC provided a variety of support to PCNs at each stage of the pilot:

1. PCN training. Supplied in the form of both e-learning and an interactive training day.
2. Ongoing support. Provided through the Guideposts Information Prescription, site visits and mentoring.
3. Feedback. Collected throughout and then used to inform the further development of the programme.

These elements are subsequently described in further detail.

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4 See also: http://dementiachallenge.dh.gov.uk/about-the-challenge/
5 NHS Refreshed mandate (2014). See also: http://hee.nhs.uk/2014/05/01/refreshed-mandate-launched-today/
6 Training Primary Care Navigators for Dementia in Pharmacies and GP Practices, National Association of Primary Care, 2015.
1.2.1 PCN Training

Training comprised of two elements, the first of which was in the form of e-learning modules, followed by an interactive training day.

E-learning

The e-learning modules aimed to help PCN trainees understand dementia and the issues that patients and carers are likely to face. Four ‘learning paths’ were identified following advice from HEE, Skills for Health, Skills for Care, the SCIE Gateway, the Dementia Action Alliance, the Guideposts Trust and NAPC. These were conveyed through web-based interactive sheets, slides and video content:

1) The Open Dementia programme: Explored the varying types of dementia; their causes, symptoms, common misconceptions, the emotional impact of the condition and how to help.
2) Communication skills and continued learning: Reviewed how to be a ‘good listener’ and possible follow-up questions. The purpose of the role, namely to guide patients, their families and carers to those who can help as opposed to fixing the problems they may face, was also emphasised.
3) Hearing from Carers and People with Dementia: Highlighted the demands of caring for someone with dementia through carer experiences.
4) The Mental Capacity Act: Advice on supporting people with their own decisions and the key messages of the Act.

Interactive training day

An interactive training day was attended by all PCN trainees, together with their supervisors where possible, both to put the e-learning in context and provide further practical preparation for the PCN role. Two further learning paths were conveyed:

5) Navigation: Projected the aims and objectives of PCN training, advice on navigation and the purpose of the role, together with an introduction to the range of online dementia information.
6) Working with your Pharmacy and the NAPC: Discussed how to promote the PCN role within Practices, Pharmacies and the community, together with how to work with the PCN community and NAPC.

Each session was characterised by open discussion surrounding what the PCN role could achieve and how to best implement the role by working and learning together. The training day was developed over time to reflect feedback from initial sessions.

1.2.2 Ongoing support

The Guideposts Information Prescription

A key tool provided to PCNs throughout the pilot was the Guideposts Information Prescription (IP), supported by a 24 hour helpline. The IP contains descriptions and contact details of all the known providers of support and care available for dementia patients, their families and carers, and is tailored to highlight the services available across different regions. As of 2015, nearly 30 tailored IPs were available. In regions where a location-specific IP had not been developed, for instance in Lambeth and Gateshead, one was created specifically for the pilot. The IP is also updated quarterly, allowing PCNs to have confidence in directing patients to the services listed.

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7 Training Primary Care Navigators for Dementia in Pharmacies and GP Practices, National Association of Primary Care, 2015
8 Ibid.
10 Ibid.
11 Training Primary Care Navigators for Dementia in Pharmacies and GP Practices, National Association of Primary Care, 2015.
Site visits and Mentoring

PCNs were supported through ongoing mentoring and site visits by the NAPC during their time in the role. This was to help identify barriers, develop solutions and share learning about how to implement the PCN role.\textsuperscript{12} Participants were also supported to raise the profile of the PCN role and engage critical individuals and groups, including GPs, patients, carers, service providers and colleagues.

1.2.3 Programme development

The pilot programme was continuously developed over the trial period in order to reflect initial participant suggestions regarding the training, management and implementation of the PCN role. This collaborative, shared learning approach is a key feature of the PCN programme.

Figure 1: The PCN programme's shared-learning framework:

\textsuperscript{12} Training Primary Care Navigators for Dementia in Pharmacies and GP Practices, National Association of Primary Care, 2015.
2 Data Collected and Limitations

2.1 Data collected

In order to measure the effectiveness of the training and implementation of the programme, three areas of baseline measures were collected from key stakeholders prior to commencement of the e-learning:

- GP Practices: Asked to score how well they thought they currently supported patients and carers dealing with dementia and how that in turn affected the GPs’ willingness to seek a diagnosis. The NAPC then asked them to identify and score three of their own measures they would like to see improved as a result of the PCN programme.
- PCN trainees: Asked to measure their confidence around understanding dementia and guiding patients and carers to the right help and support.
- Patients/carers: Upon their first visit to the PCN, asked to assess the ease in sourcing help and supporting themselves.

The same questions were then asked at the end of the pilot in order to gauge the impact of the PCN role.

2.2 Limitations

There are a number of limitations within the data that affect the robustness of the results and should be considered throughout this analysis:

i) Sample size: During the project, there were difficulties in gaining responses from PCNs, Practice supervisors, Pharmacies and patients. Among the reasons for this were email overload and the pressure of the day to day job. As a result, 90 patient responses were received, when it is accepted that the programme addressed many more. There was also a lack of response from 12 Pharmacy PCNs (of 28 registered), and six GP Practice PCNs (of 23 registered), whilst two GP Practice supervisors also failed to provide a response.

ii) Patient sample composition: A large proportion of patient respondents (43) originated from Oxford Terrace and Rawling Medical Group, which is recognised as a high-performing practice in the context of the PCN programme. As a result, the sample may not be representative of the PCN programme as a whole from the patient perspective.

iii) The nature of the dementia condition: As common symptoms include memory loss and difficulties with thinking, problem-solving or language, there is an added difficulty in performing a patient evaluation of a programme spanning several months.

iv) Subjectivity: Asking PCNs to self-score their confidence, knowledge of dementia and feelings from the role and training is subjective; this could potentially upwardly bias the results.

The remainder of this report represents a quantitative and qualitative evaluation of the success of the programme based on the data and information available. It is important, however, that the reader consider the above limitations when interpreting this analysis.

13 Training Primary Care Navigators for Dementia in Pharmacies and GP Practices, National Association of Primary Care, 2015.
3 Quantitative Analysis

This section presents an analysis of the data collected and a consolidation of the enablers and barriers to the success of the programme, as highlighted by the key stakeholders. The analysis presented in this section should be read in the context of the limitations listed in section 2.

In order to evaluate the outcomes of the programme, data was collected from the following key groups:

1. GP Practice Supervisors;
2. Primary Care Navigators (comprising of feedback from GP Practice PCNs, Pharmacy PCNs and PCN Training); and
3. Patients.

3.1 GP Practice Supervisors

To evaluate the impact of the PCN programme on GP Practices’ ability to support dementia patients and how this affects their GPs’ decision to give a diagnosis, supervisors were asked to rank, on a scale of 1-5, the following at the start and end of the programme:

1) How adequate do you feel is your Practice’s ability to provide support for patients with dementia and their carers post-diagnosis? (Where 1 is unacceptable and 5 is excellent).

2) How does that influence your GPs’ decision to give patients a diagnosis? (Where 1 is never and 5 is always).

In total, complete responses were received from 15 GP Practices. The results suggest that on the whole, supervisors felt that the PCN role enabled Practices to provide greater support for dementia patients post-diagnosis, with the average score in this regard increasing 28% from 3.31 at the beginning of the programme to 4.23 on completion. The data also suggest that this positively influenced GPs’ decision to provide a diagnosis, with the score to question two increasing 26% from 2.83 to 3.58 throughout the programme. These results are illustrated by Figure 2.

Figure 2: Practice supervisor responses

The data also suggest a possible link between Practice engagement and the level of outcomes achieved. Taking the average from supervisors at Wellbeing Enterprises and Oxford Terrace, two organisations that are accepted as being fully engaged with the pilot, shows a 36% and 32% improvement for the two questions respectively.
Secondly, Practice Supervisors were asked to review the three outcomes that they considered most important to be improved through the ability to refer patients and their carers to a Primary Care Navigator. A range of desired outcomes were conveyed and could be sorted into five distinct groups:

i) Better awareness, access and signposting of the range of services available.
ii) Improvements to patient support and welfare.
iii) Earlier recognition and improved diagnosis of dementia.
iv) Improved support for carers.
v) Up-skill staff, increasing the range of services at the Practice.

Of these categories, the greatest proportion of responses (33%) referred to desired improvements in the awareness, access to and signposting of available dementia services available, followed by improvements to patient support and welfare (29%).

Supervisors reviewed Practice performance for each outcome before and at the end of the programme, by again ranking from 1-5 (where 1 is poor and 5 excellent). The results are illustrated by Figure 3. The results indicate that the PCN programme was successful in achieving the desired aims of the GP Practices. Across all outcomes specified, supervisors ranked Practice performance an average of 0.96 points (38%) higher after the project when compared to the start. In particular, the average score of Practices’ ability to signpost the range of services available, a stated aim of the PCN programme and the most commonly desired outcome of the GP Practice Supervisors, improved 64% to 3.62 points.

Figure 3: Practice performance regarding desired outcomes

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Before</th>
<th>After</th>
</tr>
</thead>
<tbody>
<tr>
<td>Better awareness, access and signposting of the range of services available</td>
<td>2.20</td>
<td>3.62</td>
</tr>
<tr>
<td>Improvements to patient support and welfare</td>
<td>2.92</td>
<td>3.58</td>
</tr>
<tr>
<td>Earlier recognition and improved diagnosis of dementia</td>
<td>3.40</td>
<td>4.33</td>
</tr>
<tr>
<td>Improved support for carers</td>
<td>2.75</td>
<td>3.29</td>
</tr>
<tr>
<td>Up-skill staff, increasing the range of services at the Practice</td>
<td>2.25</td>
<td>3.50</td>
</tr>
</tbody>
</table>

Enablers

Supervisors’ comments following the programme highlight that Practices which fully embraced the role were able to signpost the range of services more readily, improving support for patients, their families and carers, whilst in one case also reducing hospital admissions and GP workloads.
‘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. (The programme) brought the community closer together, providing Christmas Day lunch for people who would otherwise have been on their own. This was extremely successful.‘

‘We have found new ways to support, educate and listen to our dementia patients.’

Barriers

In three of the Practices, a lack of patient take-up, referrals, resources and information surrounding the scheme meant that the additional support that PCNs could offer at the GP Practices was limited. This was highlighted as a development point of the programme.

‘The “Information Prescription” was delayed and we did not receive this until towards end of project. This did have an impact on what we were able to achieve.’

‘Although the surgery advertised the role of our PCNs clearly we found that there was minimal take up. Our receptionists work on a staggered rota and find time a premium and were thus unable to encourage/talk to patients as much as would wish.’

‘I would like the PCNs to be more visible in the Practice i.e. more leaflets in the waiting room. Dementia is probably not an area where PCNs have had much to do in the surgery.’

3.2 Primary Care Navigators

PCNs at Pharmacies and GP Practices were asked to rank the following before and at the conclusion of the programme:

1) How confident are you in your knowledge of dementia and its prevention? (Where 5 = totally confident and 1 = totally unconfident).

2) How confident are you in signposting those diagnosed with dementia or their friends/family/carers to the most appropriate resources in their wellbeing needs? (Where 5 = totally confident and 1 = totally unconfident).

Consequently, PCNs at both GP Practices and Pharmacies were specifically asked for the barriers and enablers facing the scheme, allowing for an analysis into potential improvements to the implementation of the role.14

PCNs at both Practices and Pharmacies reported increased confidence in both regards on completion of the programme; average PCN confidence in their knowledge and prevention of the condition increased 36% to a score of 3.52, whilst the score of confidence in signposting patients and their families to appropriate resources increased 56% to 3.82 points.15

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14 Self-scored confidence measures may be subjective and susceptible to upward bias. A combined total of 18 PCNs also gave no response, limiting the representativeness of the PCN sample.

15 GP Practice and Pharmacy PCNs are subsequently analysed individually in detail below.
3.2.1 GP Practice PCNs

Seventeen PCNs located at 15 GP Practices provided complete responses to the questions surrounding their confidence in their knowledge of dementia and signposting patients to the most appropriate resources. GP Practice PCNs showed an increase in self-scored confidence in both regards; average PCN confidence in their knowledge of dementia and its prevention increased 34% from 2.76 points to 3.71, whilst confidence in signposting families, relatives and carers to appropriate resources rose 58%, from 2.65 points to 4.18. These results suggest an increase in confidence when interacting with dementia patients, their families and carers. Again, the data appear to suggest evidence of a link between practice engagement and outcomes, with PCNs at Oxford Terrace and Wellbeing Enterprises PCNs scoring a 38% and 63% improvement for the two questions respectively.

Figure 5: GP Practice PCN confidence of dementia and signposting ability

Enablers

Enablers identified by GP Practice PCNs can be collected into five distinct groups. Of these, support from peers was identified as most important to the success of the programme, with 30% of responses within this category. Also identified as being important to the success of the role was support from local services, together with the training and NAPC resources provided at the start of the programme, in particular the Guideposts Information Prescription supported by a 24 hour helpline.

Note, PCNs often gave multiple enablers, adding to several categories.
Barriers

Four key barriers to the success of the role were identified by PCNs at GP Practices. In particular, a lack of time and resources (for example, rooms available) in fitting the role in with daily surgery duties was identified as the largest barrier to the success of the role, representing 44% of responses (seven PCNs).

There is also suggestive evidence of a degree of difficulty in fully engaging some GPs in the project. This finding is in line with the qualitative evaluation contained within the NAPC Final Project report.17

Figure 7: Barriers identified by PCNs at GP Practices

3.2.2 Pharmacy PCNs

Fifteen Pharmacy PCNs provided full responses to the confidence analysis. The Pharmacy PCNs reported increases in their confidence regarding dementia and their signposting ability over the course of the programme. Prior to the start, PCN-scored confidence of dementia and its prevention averaged 2.40 points. This advanced 39% to 3.33 points at the programme end. PCN confidence regarding their ability to signpost patients and their families and carers to appropriate resources increased 53% over the course of the programme, from 2.27 points to 3.47. These percentage increases are similar to those experienced by the PCNs at GP Practices (34% and 58% respectively).

17 Training Primary Care Navigators for Dementia in Pharmacies and GP Practices, National Association of Primary Care, 2015.
Similarly to GP Practices, engagement from the Pharmacy is a potential determinant of Pharmacy PCN’s knowledge of dementia and signposting ability. One particular group of Pharmacies were noted to be non-engaged with the pilot study. This may have resulted in the average scores across this group improving by only 19% and 37% respectively.

**Enablers**

The Pharmacy PCNs highlighted peer support, in particular fellow pharmacists and project leaders, as the most important factor in determining the success of the PCN role. PCN training and resources provided at the start of the programme by the NAPC were also recognised as an enabler of the scheme.

**Figure 9: Enablers recognised by Pharmacy PCNs**

**Barriers**

The lack of patient involvement in the scheme was identified as the most important barrier to the success of the PCN role at Pharmacies; 33% of the Pharmacy PCNs highlighted that they had seen no patients, with a lack of staff, issues with identifying patients requiring support, and sufficient services already in place cited as reasons for this. Feedback from project participants has suggested that identification of patients requiring support at Pharmacies proved more challenging than at GP Practices, both due to the lack of visible dementia symptoms for Pharmacy PCNs to observe, and as GP Practices have access to patients’ records, they are able to identify patients more readily.

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18 Source: NAPC discussion.
3.2.3 PCN Training

Both GP and Pharmacy PCNs highlighted the importance of the PCN training in enabling their role, in particular by increasing their confidence in interacting with dementia patients, their families and carers. This training involved both e-learning modules and an interactive training day, held at six locations in England and attended by all trainees, including 21 Pharmacy PCNs and 24 GP Practice PCNs. Participants were asked for their confidence (on a scale of one to ten) at the start and end of the training day.

Trainee confidence increased by an average multiplier of 4.32 across the six locations. In particular, Gateshead and Runcorn yielded the greatest improvements. Notably, all participants in Gateshead had completed the e-learning and were aware of the NAPC and relevant resources before the interactive training day, whereas in Darlaston, attendees and their supervisors had received little or no information about the PCN role from their organisation prior to the training day and had been unable to access the e-learning or other online resources. This may have contributed towards average confidence in Gateshead improving by a multiplier of 9.7, whereas only 2.1 in Darlaston.

Enablers

The open discussion, role-play, casual approach and opportunity to speak openly were identified as particularly positive aspects of the course. The course was also consistently well provided, with respondents at all locations highlighting their increased awareness of the PCN role and knowledge of dementia. Nevertheless, a lack confidence and knowledge of dementia and its symptoms was identified as a barrier to the success of the role in a

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19 It should be noted that given trainees’ lack of knowledge at the start of the course, confidence levels may reasonably have been expected to improve during the training.
small number of cases at both the GP Practices and Pharmacies, suggesting that some respondents may not have fully taken in the course content.

**Barriers**

At a particular group of Pharmacies, trainees were unable to access the e-learning and appropriate resources, acting as an initial barrier to embracing the role and for the interactive training day.

A suggested improvement is to include case studies of where the PCN role has been a success, in order to further trainees’ practical experience of the different ways that they are able to recognise dementia. Lastly, a recurring theme suggested that greater advice and encouragement could be given in how to promote the PCN role. This corroborates with the above finding regarding difficulty in advertising the role to patients and their families at both Pharmacies and GP Practices.

### 3.3 Patients

Approximately 90 patients from 11 Practices and Pharmacies were interviewed regarding their ability to find support, the support received for their GP Practice and the support received from their Pharmacy over the course of the PCN programme. The evidence suggests that patients’ support from GP Practices and Pharmacies, together with their ability to reach out and access relevant resources, improved. On ranking from one to five (1 = Don’t Know, 5 = Easy), patients’ self-scored ability to find support improved 34% to 3.96 points. Moreover, their ability to find support from their GP Practice and Pharmacy improved 21% and 20% respectively.\(^{20}\)

**Figure 12: Patient observations regarding the ability to find support**

In 33 cases, the number of visits received by a patient were recorded, enabling an analysis of the effect of visits on the support scores. Patients with a greater than average number of visits across the programme displayed higher scores across all three criteria.\(^{21}\) This highlights the role that patient interaction, together with the role’s use as a point of contact, can play in improving patient care and patients’ ability to utilise the resources available in dementia care.

\(^{20}\) Difficulties in recording patient responses have led to a lower sample size than the true number of patients seen by the programme. Further, a large proportion of the sample is from Oxford Terrace, recognised as a leading performer within the context of the programme. Difficulties in asking dementia patients to self-score, should also be considered when interpreting the results provided.

\(^{21}\) The average number of visits was 3.51, hence any patient with 4 or more visits is included. The average score for those with greater than 3 visits at the start of the programme was similar to that of the total sample.
Figure 13: Patient observations regarding their ability to find support

**Enablers**

Nearly all comments received (circa 45 observations), highlighted patients’ gratitude for the service, for example PCN efforts in keeping in touch, willingness to hold a conversation and the ability for the patient to reach out if unaware of where they should go for help.

**Barriers**

Few comments suggested more should be done to promote the role and highlight the range of services on offer, a recurring theme throughout the above analysis.
4 Qualitative Feedback

The qualitative evaluation of the PCN programme is based upon:

- Site visits and feedback from NAPC Project supervisors and management over the course of the PCN programme.
- Case study visits to Oxford Terrace and Rawling Medical group and Wellbeing Enterprises sites.\(^\text{22}\)

The feedback received allows for a qualitative analysis of the enablers and barriers to the success of the programme experienced throughout the pilot, together with an analysis of how the PCN programme has developed throughout the pilot study.

Barriers and enablers are expressed at each stage of the PCN programme:

1. The PCN training, comprising of both the e-learning and interactive training day provided;
2. Implementation of the role; and
3. Follow-up support provided through the Guideposts Information Prescription together with site visits and mentoring.

4.1 Training

4.1.1 E-Learning

Enablers

The e-learning provided a comprehensive review of the dementia condition; its causes and symptoms, together with the impact that the condition can have upon others. Common misconceptions were addressed, providing trainees with an informed view of the condition. Moreover, advice on communication and the personal experiences of carers demonstrated requirements and the demands faced by those interacting with dementia patients.\(^\text{23}\)

The e-learning also highlighted the core functions of the role, such that PCN trainees arrived at the training day with a clear understanding of what the programme entailed. Those who had completed the e-learning showed greater increases in confidence surrounding the role across the training day than those who had not.

Barriers

PCNs at one group of Pharmacies noted that they were unable to access online resources required before the day. This was due to both local issues and company policy that prevented access to online facilities.

At GP Practices, PCNs were able to access the e-learning, although a few suggested that they had difficulty finding the time to complete the e-learning together with their daily duties, especially where Practice management was not engaged or fully aware of the PCN role.

\(^{22}\) These case studies are presented in full in section 6.

\(^{23}\) Training Primary Care Navigators for Dementia in Pharmacies and GP Practices, National Association of Primary Care, 2015.
4.1.2 Interactive training day

Enablers

Feedback from participants at the training highlighted the open discussion, role-play, casual approach and the opportunity to speak openly as particularly positive aspects of the course. The training day was also seemingly well provided, with respondents at all locations highlighting their increased awareness of the PCN role and knowledge of dementia at the end of the day.

The NAPC also observed a number of enablers to the success of the PCN training and role:

- Great enthusiasm for the PCN role from both Practices and Pharmacies.
- PCNs were capable and motivated when training was combined with informed support and encouragement from their organisations.
- Whilst the staff employed at the sites 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 supervisors and the NAPC team running the training day.

Barriers

A suggested improvement from the feedback received is to include case studies of where the PCN has been a success, in order to further PCN trainees’ practical experience of the different ways that they are able to recognise dementia. As above, some trainees were also not given access to the e-learning and appropriate resources at their organisation, acting as an initial barrier to embracing the role and for the interactive training day.

A recurring theme suggested that greater advice and encouragement could be given in how to promote the PCN role, with examples being social media profiles and promotional material that could be taken from the training day. This corroborates with the finding that at times it was difficult to advertise the role to patients and their families at both Pharmacies and GP Practices. Nevertheless, during the pilot, social media did not appear an effective mechanism to raise awareness of the programme, whilst greater promotional material was later made available at the training.

4.2 Implementation of the PCN role

Enablers

The key observation has been the correlation between participant engagement levels and the successful implementation of the role at both GP Practices and Pharmacies. Full engagement from senior management on a day to day basis resulted in the Navigator role being fully integrated into Practice and Pharmacy policies, systems and services. This enabled PCNs to perform their role and provide crucial support for patients, their families and carers.

In the most engaged Practices, four key factors were found to underpin the success of the programme and development of the role:

i) Commitment and peer support from 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.

ii) 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.

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24 Training Primary Care Navigators for Dementia in Pharmacies and GP Practices, National Association of Primary Care, 2015.
25 Ibid.
26 NAPC feedback.
iii) 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. The PCN role was most effective where the service was highlighted and awareness raised.

iv) 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.

The successful implementation of the role was further driven by the ongoing support received by PCNs. This is discussed in section 4.3.

**Barriers**

Where Practice and Pharmacy staff were not fully engaged, the PCN role was less successfully implemented. One reason for this range of management engagement was the wide variation in how organisations “volunteered” their staff for the PCN training, which only became apparent at the implementation stage. These can be classed into three categories:

- Fully-engaged. Invited staff with enthusiasm, appropriate skills and experience - supervisor(s) determined to gain benefits from the project.
- Semi-engaged. Invited/volunteered staff with varied skills and experience - supervisors interested but not fully aware of what they had agreed to do.
- Non-engaged. Volunteered staff with little consideration of skills or experience - supervisors unaware of their agreed role, or non-compliant.

Where supervisors failed to promote and integrate the PCN role, awareness, and hence the support that PCNs could give, was constrained. At GP practices, the clear issue was convincing GPs of the benefit of the PCN role at their practice, and to take the time to give the required support within their already full schedules. At Pharmacies, the barrier was more that company management simply did not promote or integrate the role to anywhere near the extent possible.

**4.3 Ongoing support**

**4.3.1 Guideposts Information Prescription**

**Enablers**

The Information Prescription (IP) was often mentioned as a vital, accessible and easy to use source of contacts from the range of services available. There appears great demand for the information provided, whilst the resource was hugely valued and needed. As a result, a number of PCNs felt more confident in introducing themselves to patients, knowing they could direct them to the required support.

‘I would say that the information prescription really helps and I made contact to some of the agencies direct to introduce myself and to find out how that agency works so that I could pass on valuable information to the patients, carers and family members.’ – GP Practice PCN

The IP has also been updated quarterly, hence PCNs were able to have confidence that the contacts and information provided was up to date and could be used to support patients, their carers and families. That the IP is location specific also helped PCNs to feel confident that they were able to direct patients to support within the area, whilst contributed greatly to the ongoing learning experience of PCNs throughout the pilot.

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27 Training Primary Care Navigators for Dementia in Pharmacies and GP Practices, National Association of Primary Care, 2015.
28 Ibid.
29 Stakeholder feedback.
30 Ibid.
This corroborates with a recent analysis of the IP which found that 87% of health and social care providers (including GPs) considered that the IP is either very good or excellent as a post diagnostic tool for people living with dementia.\(^\text{31}\)

A number of PCNs also mentioned that they had made use of the 24 hour helpline that supports the IP. Where utilised, it appears as if this also provided a helpful resource where PCNs were uncertain.

> ‘I did ring the help line number at the beginning and they were very helpful.’ – Pharmacy PCN

### Barriers

There were a small number of occasions where access to the IP was delayed, perhaps constraining the support they could give.

> Barriers to the PCN programme? - ‘Not receiving the information prescription for a long time, therefore this caused problems as I didn’t have the resources to assist the patients and their families’ – GP Practice PCN

#### 4.3.2 Site visits and Mentoring

PCNs and their supervisors received site visits and mentor support from the NAPC in the period following their training up until February 2015. This aimed to share learning surrounding the implementation of the programme.

### Enablers

Feedback received from PCNs suggested that the mentoring and NAPC support had provided them with confidence in approaching the PCN role.

> ‘The help and support from the leaders were great and they were there if I needed them whether email or a phone call, they always got back to me. In my opinion, if I had a patient that needed help they would be there to help me if I was unsure.

Question: Who are the leaders you are referring to? ‘I was referring to yourself and your [NAPC] colleagues, you have been there with support if I needed it and always got back to me if I was unsure.’ – Pharmacy PCN

This mentoring support from project leaders contributed to PCNs’ ongoing learning throughout the programme. Moreover, these visits enabled project organisers to further develop the programme to reflect the views of all participants at the organisations involved. Examples of the ongoing learning of the programme itself are illustrated in section 4.4.

### Barriers

The site visits to each participating group or individuals suffered as a result of a few issues, including:\(^\text{32}\)

- There appeared a lack of requests, perhaps due to the decision to make site visits voluntary.
- The late decision to make site visits mandatory highlighted a lack of a mechanism for capturing the learning from site visits.
- Poor engagement from Practice/Pharmacy senior management to gain commitment for PCNs to attend a site visit.

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\(^{32}\) Training Primary Care Navigators for Dementia in Pharmacies and GP Practices, National Association of Primary Care, 2015.
• Poor attendance from PCNs and supervisors even with the recognition that support was needed. A case in point was the agreement to attend an evening workshop to help implement the PCN role, but only 50% of participants attended.

4.4 Further development of the programme

As a consequence of the rolling feedback and site visits conducted throughout the duration of the pilot, the NAPC was able to continuously develop the programme to improve the effectiveness of the PCN role and the resulting impact that it was able to have on patient care. As highlighted by the NAPC, examples of this include:

Training

• In some locations respondents would have liked to run through answers to the training questionnaire during initial sessions. This was subsequently implemented for future iterations of the programme.33

• In discussion PCNs came up with the idea of a leaflet which could be put in every prescription bag. This was acted on by the NAPC and made available for all participants.

Implementation

• A joint mentoring session with a GP Practice and Pharmacy produced the idea of A3 posters to raise PCN profile in GP Practices, Pharmacies and other premises, to inform people in other locations.34

• A site visit to Community Pharmacy produced the idea of printing small flyers to advertise the PCN role to patients, friends and families. This was then suggested to all PCNs in both Pharmacies and GP Practices.

• A group site visit to PCNs and supervisors in Lambeth produced a “what does good look like” information sheet for PCNs, including the barriers and enablers discussed among the eight attendees.

• Participants also suggested how the evaluation of the programme could be improved. For example, the Patient Experience forms were improved using feedback from PCNs already conducting face-to-face meetings with patients and carers.

Following the observations from this pilot, steps are being undertaken to integrate the PCN offering into existing clinical pathways to widen the potential for referral, and the concept is being expanded to other conditions. The PCN Plus programme aims to provide a similar service for diabetes, and has acted upon the initial feedback collected during the pilot, for example by ensuring greater engagement from Practices and the wider community. Furthermore, PCNs are required to have knowledge of interacting with the public around wellbeing issues and behaviour change at least to the level of ‘health champion’.35

33 Discussion with NAPC.
34 Training Primary Care Navigators for Dementia in Pharmacies and GP Practices, National Association of Primary Care, 2015.
35 Discussion with NAPC.
5 Conclusions and Recommendations

5.1 Summary
The quantitative and qualitative evidence collected throughout the PCN programme suggests that the programme has the potential to:

- Provide a wide range of GP Practice and Pharmacy staff with informative training which may improve their overall confidence of the PCN role and their knowledge of dementia.
- Enhance patients’ ability to find support from their GP Practice and their local Pharmacy.
- Improve GP Practices’ ability to provide support for patients with dementia and their carers, post-diagnosis; this positively influenced the GP’s decision to give patients a diagnosis.
- Enable PCNs, at both GP Practices and Pharmacies, to become more confident in their knowledge of dementia and its provision, together with their ability to signpost patients to appropriate resources.

Enabling factors related to the evidence of positive outcomes included:

- GP Practice PCNs highlighted that when the scheme was fully embraced within the Practice (i.e. GPs and staff were aware of the benefits of the programme and provided necessary resources to facilitate the role), they were able to raise awareness of the scheme and work with the community to contribute to improved patient care.
- PCNs at both GP Practices and Pharmacies recognised the support of their peers and the training provided as key drivers for the success of the role. The support from local services was also appreciated.
- The open, relaxed, interactive training day, which combined information surrounding dementia and relevant services, role-play scenarios relevant to the role and open discussion, actively engaged and educated trainees for the role.
- Patients valued the contact with PCNs, and felt more confident in finding support with the number of visits they received.
- The ongoing support from the NAPC; mentoring, site visits and resources such as the IP, was greatly valued by PCNs and increased their confidence in the role, whilst the continuous development of the programme in response to feedback also enabled PCNs to maximise the support they could provide.

However, the experiences of some GP Practices and Pharmacies also suggest that a degree of refinement and improvements within some areas of the scheme could be considered were the programme to expand, both within dementia care and across other conditions. Practice supervisors and PCNs highlighted similar barriers to the progression of the PCN role:

- Practice supervisors highlighted a lack of patient uptake and difficulty in finding time to promote and raise awareness of the PCN role on top of their day-to-day role. These views were echoed by GP Practice PCNs, who often struggled to make time for the role together with their daily surgery duties, and often faced difficulties in raising awareness of the role.
- Pharmacy PCNs, in a number of cases, stressed that they had seen very few or no patients throughout the scheme. This was due to the challenge of identifying patients that required support, difficulties in raising awareness and support already in place.

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36 This process has already begun with the development of the PCN Plus programme for diabetes. (Source: NAPC discussion).
• A wider problem highlighted by GP Practice and Pharmacy PCNs involves convincing GPs, who already face a full schedule, of the possible longer-term benefits of the scheme and to embrace the role. This may have constrained the success of the PCN role.

• In some cases, access to PCN training resources such as e-learning was restricted due to company policy or specific local issues, resulting in trainees arriving at the interactive training day with little knowledge or confidence of the role. In a small number of isolated cases, access to the Information Prescription was also delayed.

5.2 Recommendations

The quantitative and qualitative evidence suggest that when the scheme is fully embraced and the role of the PCN highlighted, the programme was has the potential to improve the quality of care at GP Practices and Pharmacies by signposting patients to the range of available services. However, where information, promotion and awareness of the role were limited, this constrained the potential impact of the PCN in improving the services provided for patients with dementia.

Based on this a number of potential improvements that could be made to the role:

• Ensure that GPs are fully aware of the role and its use within practices and the wider community, such that they attain the confidence in utilising the PCN role at the Practice.

• PCNs should have appropriate and sufficient material to promote and provide information surrounding the role to improve awareness of the service offered and attract more patients. The latter is of particular importance at Pharmacies. Patient uptake may perhaps be improved by highlighting how the PCN role differs from other services, for example the dementia navigator provided by the Alzheimer’s Society.

• Pharmacy PCNs may require a greater degree of training in instigating conversations with patients, their families and carers such that requests for support can be better identified. Difficulties in holding necessary conversations, and hence in providing guidance to patients that required support, was highlighted in verbal feedback from this group. In cases where an individual is seen to be potentially developing early symptoms but appears not to be requesting support, a mechanism may need to be highlighted whereby they can be referred to relevant services without the ‘stigma’ of being labelled as a dementia patient. This may enable PCNs to provide a greater number of people with the support they need.37

• A lack of time to perform the PCN role in line with day-to-day roles was highlighted by PCNs, particularly at GP Practices. The selection of PCNs, supervisors, organisations and whether they are able to fulfil the time requirements should be carefully assessed before assigning candidates for the role, whilst PCNs and organisations should be made fully aware of the commitment necessary to make the role a success.

• Ensure that Practices and Pharmacies provide access to resources such as the e-learning and the IP in order to improve the effectiveness of the training day and the PCN role. Specifically, organisations should be helped to understand and abide by the undertakings agreed with the NAPC in the initial stages of the programme.

37 The PCN Plus programme may already be acting upon this feedback by ensuring that PCNs have knowledge of interacting with the public around wellbeing issues and behaviour change at least to the level of ‘health champion’.
6 Lessons from the two pilot sites

The following two case studies demonstrate what the PCN programme is able to achieve with full engagement from the GP Practices and Pharmacies involved.

**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.
- 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.

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 participating 20 Pharmacies and 20 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.
- 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 supervisors; 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.

i) 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.
ii) 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.

iii) 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.

iv) 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:

i) 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.

ii) 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:38

i) 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.

ii) 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.

iii) 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.39

iv) 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

38 Source: Patient feedback forms and visit discussions.
39 Source: Referral lists.
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:

i) Increased referral of patients. Following the end of the first three months, referrals from GP Practices of people with dementia increased to 15,40

ii) 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.41

iii) Patient care. Referring GPs reported improvements in their Practices’ confidence and ability to help both people with dementia and their carers more effectively.

iv) 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.42

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:

i) 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.

ii) 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:

i) Improved staff engagement with patients and carers. Feedback collected in both cases shows improvement in patient and practice outcomes.43

ii) 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.44 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.45 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.

40 Source: Project supervisor feedback form and visit discussion.
41 Source: Project supervisor feedback form and visit discussion.
42 Source: Project supervisor feedback form and visit discussion.
43 Source: Feedback forms, analysis of data and visit discussion.
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 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.
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). 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% 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.

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.
- Agreeing individual care plans and assigning GPs.
- Providing nursing homes with a single Point Of Contact for prescriptions and requests for visits.
- Supporting doctors and nurses by enabling them to refer to the PCN for longer consultations.

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

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- Providing nursing homes with a single Point Of Contact for prescriptions and requests for visits.
- Supporting doctors and nurses by enabling them to refer to the PCN for longer consultations.

46 http://www.otmg.co.uk/
47 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 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.

• 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.

<table>
<thead>
<tr>
<th>PCN feelings at the beginning</th>
<th>PCN feelings after three months</th>
</tr>
</thead>
<tbody>
<tr>
<td>► Concerned at lack of experience</td>
<td>► Confident as a result of the training</td>
</tr>
<tr>
<td>► Anxious and scared about ability to take on the role</td>
<td>► More in control</td>
</tr>
<tr>
<td>► Fear of the unknown and what was expected</td>
<td>► Familiar with the role</td>
</tr>
<tr>
<td>► Worried about time commitment to project</td>
<td>► Happier in general in working for the Practice</td>
</tr>
<tr>
<td></td>
<td>► Needed and valued</td>
</tr>
<tr>
<td></td>
<td>► Better organised and positive about the job</td>
</tr>
</tbody>
</table>
The PCN performance activities within the first three months, as presented in the feedback to the NAPC and verified during the visit, include:

<table>
<thead>
<tr>
<th>Support for GPs and nurses</th>
<th>Support provided to patients</th>
<th>Other notable changes</th>
</tr>
</thead>
<tbody>
<tr>
<td>► Dementia Screening (+117)</td>
<td>► Care Plans (+396)</td>
<td>► More effective in ringing patients following emergency admissions</td>
</tr>
<tr>
<td>► Assessment for Dementia (+38)</td>
<td>► NHS Health Checks (+95)</td>
<td>► Less fragmentation</td>
</tr>
<tr>
<td>► Carers Register (+43)</td>
<td>► Post-discharge (+86) none of whom needed a physician as PCN sorted</td>
<td>► Improved reception management</td>
</tr>
<tr>
<td>► Veterans Register (+20)</td>
<td>► Reduction in discharge letters suggesting avoided admissions – from 7-8 per day to 2-3 per week</td>
<td>► Improved communication</td>
</tr>
</tbody>
</table>

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

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48 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.
free up incumbent clinical staff from some areas of responsibility, such as the PCN role, are much needed. The role 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 14 below.

**Figure 14: 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”.

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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. 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 3,500 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 patients).
- Five patients referred by a GP, four by community wellbeing officers, two by a nurse and one from the local hospital discharge team.

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.

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49 www.wellbeingenterprises.org.uk

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

51 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.

• 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.52 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.

<table>
<thead>
<tr>
<th>Expected outcomes</th>
<th>Unexpected outcomes</th>
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<tr>
<td>► Being able to receive more referrals from multi-disciplinary meetings in GP Practices (x4 CWOs)</td>
<td>► Building stronger relationships with partner organisations (x2 CWOs)</td>
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<tr>
<td>► Improving confidence of supporting people with dementia</td>
<td>► Supporting partner organisations (e.g. Alzheimer’s Society) to integrate their services into primary care e.g. facilitating market stalls in GP Practices</td>
</tr>
<tr>
<td>► Improving knowledge and awareness of dementia and how it affects people (x3 CWOs)</td>
<td></td>
</tr>
<tr>
<td>► Recognising early symptoms of dementia and making appropriate referral diagnosis</td>
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</tbody>
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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.

• 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:

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52 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 Guidepost Trust was not received until a couple of weeks before the pilot period ended.

• 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 15 below.

Figure 15: 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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