

DeAR-GP

(Dementia Assessment & Referral tool)

in community settings: Housing & Community Health Teams

Project Team

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Foreword

The Prime Minister's Challenge on dementia 2020 led to a national effort to increase the proportion of people who are able to access a formal dementia diagnosis (Department of Health, 2012). It is well documented that a timely dementia diagnosis enables access to the right support, care and information.

One of the clinical priorities for the Health Innovation Network (HIN), the Academic Health Science Network for south London, is Healthy Ageing and includes a significant focus on dementia. In 2015, HIN worked with care workers in care homes to co-design **DeAR-GP** (**Dementia Assessment Referral to GP**) which supports care workers in care home settings to identify people who are showing signs of dementia and refer them to their GP for review and a possible diagnosis. Dear-GP now features on [NICE Shared Learning Database](#) and [AHSN Atlas of Solutions](#).

It is estimated that **one third of people with dementia live in care homes** and **two thirds live in community settings**, many of these people living undiagnosed in the community may be receiving support from community health teams or support staff in older adult housing schemes. Recognising this, the HIN worked in partnership with housing providers and community health teams to adapt and pilot DeAR-GP for these settings.

HIN would like to thank the following organisations for their participation and involvement in the project:

[Genesis Housing Association](#) (Staples House, Lawrence Hall, Chadacre Court)

[Metropolitan Care](#) (Homewoods, Ingleton House)

[Royal Borough of Kingston upon Thames](#) (Fountain Court, Older and Vulnerable Persons' Support Service)

[Central London Community Healthcare NHS Trust](#) (CLCH, Case management and care navigator Team)

[Housing Learning and Improvement Network](#) (Housing LIN)

[Alzheimer's Society](#)

Based on the tools and resources designed and tested during the pilot project, this report and accompanying implementation guide have been designed to aid community health and housing providers to implement DeAR-GP.



Dr Farooq Ahmed

Clinical Lead | Healthy Ageing Theme | Health Innovation Network

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“Sheltered, Extra Care and Retirement Living services at Metropolitan are all about supporting people to remain as independent as possible into later life.

It can be a very worrying time for people living with us who feel that their memory is not what it was, or if those closest to them start to see uncharacteristic changes in that person. It is so important to recognise these concerns as early as possible and get help from local NHS services, in order to keep people in control of their own lives and choices, if their memory does start to deteriorate.

The Dear GP tool is a simple tool that helps individuals and those who know them best to articulate any concerns they have about a person’s memory. Because it is so simple it can be completed by people at individual trusts and so takes some of the fear out of this distressing time. The information is very useful to medical professionals because no-one else has a better insight into that person than they and those closest to them do. GPs can use this information to make a diagnosis and get the person any support that may be needed.

Our housing staff feel very reassured to know that there is a tool they can now use with our customers if they are concerned that someone may be at the very early stages of living with dementia.”

- Peter Leach | Metropolitan Care



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“As the GP lead for Dementia in the Kingston CCG, I have been very focused on making sure our care of people in Kingston with Dementia is as good as we can make it, so people in Kingston can live well with dementia.

An important part of living well, includes receiving a diagnosis of dementia in a timely manner. In Kingston we have consistently had a low dementia diagnosis rate compared with other CCGs in London. We want to find out why and to make sure we address any barriers to people receiving a diagnosis in a timely manner. We realise there are a group of patients who do not regularly access GP services, but may be in contact with other services like housing officers etc.

We know that receiving a timely diagnosis means people can be less frightened about the future as they understand the changes that are happening for them and can make plans for the future and access services that will help. We can also make plans to minimise their risk of hospital admissions.

We were very happy to host a pilot to see if this new approach may help find people with concerns about cognitive impairment, and help them receive any referral they needed to access a possible diagnosis of dementia in a timely manner.”

- Dr Nerida Burnie | GP lead for Dementia
| Kingston CCG



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Executive Summary

To address the national agenda to improve dementia diagnosis rates in 2015 the HIN worked with three care homes to co-design the Dementia Assessment Referral to General Practitioners (GP) (DeAR-GP, <http://www.dear-gp.org/>). Following the success of DeAR-GP interest was generated in the housing sector and amongst community health teams. Health Innovation Network conducted this feasibility study to spread and adopt DeAR-GP for both older adults housing providers and community health teams.

HIN worked in partnership with three housing providers and one community health team to adapt DeAR-GP for these settings. This project focused on the following key areas

- Improving access to a diagnosis of dementia for those living in community settings
- Recruiting housing and community health partners to adapt DeAR-GP for these settings
- Increased staff awareness and knowledge of signs and symptoms of dementia

A pre-pilot focus group was conducted to gain insight into staff understanding and experience of dementia and what adaptations would be required to make DeAR-GP suitable for these settings. Pilots then took place at eight sites across four London boroughs over a

period of four to ten weeks. Following this post-pilot focus groups were conducted at each site to explore experiences of using the tool. Key findings are listed below.

- DeAR-GP could be adapted for community health teams and older adults housing settings. DeAR-GP was adapted to include Six-Item Cognitive Impairment Test (6-CIT) and Patient Health Questionnaire (PHQ-9) for the community health team and minimal adaptations were required for the housing setting.
- Staff across both settings found the tool accessible and easy to use.
- DeAR-GP acts as a communication aid between front line staff in both settings and GPs.
- Levels of dementia training for front line staff varied across the housing providers. One of the recommendations following this work is that housing providers implement Dementia Friends Training provided by the Alzheimer's Society when implementing DeAR-GP.

This report provides an overview of the methods used over the course of the project, outcomes and recommendations going forward. The tools and implementation guide are available in the [appendices](#).

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Introduction

Health Innovation Network (HIN) is the Academic Health Science Network (AHSN) for south London, one of the 15 AHSNs across England. HIN is a membership organisation connecting academics, NHS commissioners and providers, local authorities, patients and industry in order to accelerate the spread and adoption of evidence based innovations and best practice. HIN, along with the other AHSNs, have four core objectives:

1. Focus on the needs of patients and local populations.
2. Build a culture of partnership and collaboration.
3. Speed up adoption of innovation into practice to improve clinical outcomes and patient experience.
4. Create wealth through co-development, testing, evaluation and early adoption and spread of new products and services.

The HIN has a number of clinical priorities, one of which is Healthy Ageing.



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It is well recognised that everyone has a right to a dementia diagnosis as it enables access to information, advice and support and pathways of effective treatment and care (Prince et al., 2011). An earlier diagnosis enables more appropriate care and support and it may provide an opportunity for individuals to plan for the future and access specific treatments or interventions depending on the type and stage of dementia (Burns, 2014; Prince et al., 2011).

Recognising this, in recent years the government and NHS England have placed a focus on improving dementia diagnosis rates (Department of Health, 2012; Prince et al., 2011). In 2014, the Five Year Forward View stated that **‘The NHS is making a national effort to increase the proportion of people with dementia who are able to get a formal diagnosis from under half, to two thirds of people affected or more. Timely diagnosis can prevent crises, while treatments are available that may slow progression of the disease’** (NHS England, 2014).

In response to this in 2015 and in recognition of the low diagnosis in residential and nursing homes the HIN worked with three care homes to co-design the Dementia Assessment Referral to GP (DeAR-GP). DeAR-GP supports care workers in care home settings to identify people who are showing signs of dementia and refer them to their GP for review. It incorporates a set of observations along with the 4-item Abbreviated Mental Test (AMT-4) cognitive scale to be completed by the care worker. Supported by the Alzheimer’s Society, since its launch there has been uptake nationally and it is recognised as a **‘low cost, high impact intervention’** (NHS England, 2016). DeAR-GP also supports NICE quality statement 1 ‘Dementia: support in health and

social care’ and quality statement 2 ‘People with suspected dementia are referred to a memory assessment service specializing in the diagnosis and initial management of dementia’ (NICE, 2017). DeAR-GP now features on [NICE Shared Learning Database](#) and [AHSN Atlas of Solutions](#).

Improving access to a dementia diagnosis continues to be a national priority as reflected in the recent Government’s Mandate to NHS England for 2017 -2018 (Department of Health, 2017). There is a continuing agenda to achieve and maintain the agreed national ambition for diagnosis rates that two thirds of the estimated number of people with dementia should have a diagnosis and appropriate post-diagnostic support (NHS England, 2016). At the outset of this project, **in September 2016 71.2% of people over 65 suspected of living with dementia were diagnosed with dementia in south London compared to the national average of 67.5%** (NHS Digital, 2016). This means that **approximately 27,500 people in south London have undiagnosed dementia** and as a result are not receiving the information and support they need (NHS Digital, 2016). Four south London boroughs were not meeting the national target of a dementia diagnosis rate of two thirds.

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It is estimated that one third of people with dementia live in care homes, and two thirds live in the community (Alzheimer's Society, 2017). Many of these people may be receiving support from district nurses or support staff in older adult housing schemes. There is a growing recognition that training front line housing staff to identify the signs of dementia and seek support for early diagnosis is a key priority (Alzheimer's Society, 2017). Additionally, focusing on primary and community nursing supports the Health Education England (HEE) London priority to up skill primary care nursing encouraging closer working and learning between primary and community-based nursing teams (Health Education England, 2016). Recognising this and following the success of DeAR-GP, the HIN identified an opportunity to consider adapting DeAR-GP for these settings.

This project aims to increase identification of individuals living with undiagnosed dementia by staff in older adult housing schemes and community health teams by adapting DeAR-GP, for use by staff in these settings.



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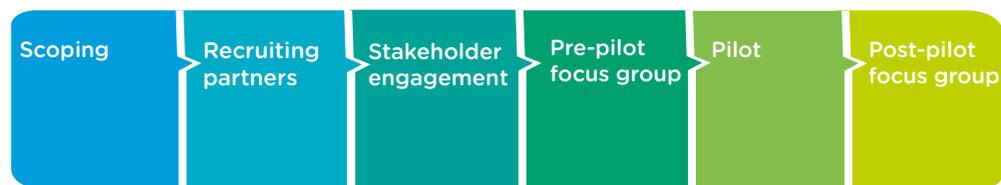


Figure 1: Summary of Methodology

1 | Scoping

The purpose of the scoping exercise was to determine the interest, capacity and motivation of the following community sectors

- Housing schemes
- Community pharmacies
- GP practice nursing
- District nursing.

Through conversations with potential stakeholders in each sector HIN determined that dementia case finding was relevant to in each of these sectors. The stakeholder interview questions (appendix 1) were developed based on the **Implementation Science Learning and Development Tool** and was used to support the options appraisal below (Table 1) (CLAHRC, 2016).



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Table 1 | Options Appraisal

Community Sector	Comments
Housing	<p>During conversations extra care housing scheme managers identified that staff were able to recognise changes in cognition and welcomed the thought of a tool to aid referral and communication with GPs. Further conversations revealed that the original DeAR-GP tool would need little adaptation for the extra care house setting. Support staff were in constant contact with their scheme residents, so they were well placed to make observations over three-month period. The following challenges in implementing the DeAR-GP tool in extra care housing were identified:</p> <ul style="list-style-type: none"> • Forging a relationship with extra care housing schemes and local GPs, Memory Service and Social Services where limited working relationships exist previously. • Not all extra care housing schemes provide dementia training to front line support staff so this would need to be considered when looking for partners to pilot the tool in this setting.
Community Pharmacists	<p>There was much interest regarding dementia case finding in community pharmacies from various stakeholders due to the fact that medication could be reviewed immediately for contraindications or harm. Dementia case finding is not something that has been done in pharmacies in south London previously.</p> <p>Despite the interest in this innovative idea, the project team decided not to pursue this avenue mainly due to lack of funding to support community pharmacists to carry out this work. There were also concerns that all individuals may not access the same community pharmacies over a period of time, in which case community pharmacists may not be well placed to observe changes in cognition over a period of time.</p>
GP Practice Nursing	<p>Based on discussion with practice nurses it was determined that there is large variation in the responsibilities held by practice nurses. Further there is variation in the support they receive for additional training. This was identified as a barrier as spreading and adopting a dementia case finding tool may be difficult in the presence of variation between GP practices..</p>
District Nursing	<p>With regards to district nurses, it was identified that nurses in some boroughs are already using cognitive scores where there is a concern about an individual's memory. However, there is no formal process for a referral to be made to GPs or directly to the memory service.</p>

The options appraisal clearly indicates that, at this point in time, both housing providers and district nursing teams were interested, motivated and had capacity to adapt DeAR-GP. **After presenting and discussing the options appraisal at the Healthy Ageing Advisory Board, the project team decided to work with housing providers and a community health provider for the purpose of this project.**

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2 | Recruiting partners

Expressions of interest were invited from community health teams using existing contacts within the Healthy Ageing Theme. Prior to this project, HIN had limited experience working with the housing sector, so a call of interest was included in the Housing Learning and Improvement Network (Housing LIN) weekly newsletter which reaches housing providers across the country.

Based on this, the HIN worked with three housing providers (Genesis Housing Association, Royal Borough of Kingston upon Thames, and Metropolitan Housing Association) and one community health provider (Central London Community Healthcare NHS Trust).

Housing

In total there were six housing pilot sites across three boroughs (Newham, Lambeth, Kingston). Three of these sites were extra care housing schemes and three of the sites were sheltered housing schemes. The tool was also piloted in Kingston with the Older and Vulnerable Peoples Support Service (OVPSS).

The pilot sites represented some of the many variations of housing available. Variations include level of care and services provided and design and layout. Sheltered housing describes independent, self-contained homes within in a block of flats where all other residents are over 55 years. Extra care housing is similar to sheltered housing in that the homes are self-contained, however residents also require varying levels of care and support (Housing LIN, 2017). The OVPSS is a part of Kingston Council Housing department and is funded by Adult

Social Services to also support anyone aged over 55 years in a holistic manner to maintain their accommodation and independence within the community.

There was the option to work with two different sets of staff groups housing support or carers.

Early on, partners identified that housing staff (i.e. support staff, housing officers) would be best suited to pilot the tool as they maintain regular contact with the residents of the housing schemes whereas the carers are often employed through agencies and therefore may not be in a position to make observations over a consistent period of time.

Community Health Team

HIN partnered with one community health provider, Central and London Community Healthcare (CLCH) with the aim of piloting the tool with the district nursing team. CLCH reviewed which staff team were best placed to refer using DeAR-GP and the role of the case management team became apparent. A decision was made to pilot the tool with this team with a view to apply to learning to district nursing teams. The case management team consists of case managers and care navigators and together they manage an identified group of patients with complex needs.

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3 | Stakeholder engagement

Once the partners were recruited, HIN arranged face-to-face meetings within each borough with the housing provider or representative of the community health provider, commissioner, GP dementia lead and secondary mental health trusts. This meeting provided an opportunity to collaborate and agree an effective communication pathway across the system from the front line staff to the GPs through to the memory service in each Borough.

Following the initial stakeholder meeting, a project brief was disseminated to the GPs associated with each pilot site in one of many ways that was deemed most suitable by the stakeholder group. Examples of communication methods include: emailing or posting project brief, communicating through internal communications such as borough wide GP newsletter or briefing at a GP teaching session. Where possible, the initial communication was followed up with a telephone phone call to the GP.



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4 | Pre-pilot Focus Group

A pre-pilot focus group and training session were conducted with a total of forty front line staff across participating organisations. Each session had between two to thirteen people, all of whom provided consent to discussions being recorded and transcribed. Participants included a range of housing support staff and managers in housing schemes, and care navigators and case managers in the community health team. The questions were standardised across four focus groups and adapted from feedback from the focus groups conducted with care home staff during the development of the original DeAR-GP tool. The purpose of the focus group was threefold:

- To understand the feelings, knowledge, understanding and experience of dementia.
- To understand thoughts on the original DeAR-GP tool and how it would be need to be adapted for the setting.
- To understand thoughts on case-finding in the settings.

During the focus group staff provided feedback on the DeAR-GP tool and its applicability to their roles. Staff from the housing sector and community health team had the opportunity to contribute to the co-design on the tool for their respective settings. The general consensus amongst the pilot groups was to maintain the ease of use and simplicity of the original DeAR-GP tool. Minimal adaptations of the original DeAR-GP tool were agreed with the housing partners ([appendix 2](#)).

The community health team requested to include the Six-Item Cognitive

Impairment Test (6-CIT) in place of the Abbreviated Mental Test (AMT-4) ([appendix 3](#)). Patient Health Questionnaire (PHQ-9), a depression scale was added acknowledging the link between depression and dementia and the incidence of depression in older adults. Each staff member had the opportunity to provide feedback on at least one iteration of the tool through the design process.

Once the design was finalised forty staff across both housing and community health were trained on the appropriate use of DeAR-GP in their setting by a facilitator from the HIN. A lead nurse facilitated a training session for the community health team to on the scoring of the 6-CIT and PHQ-9 scale.

5 | Pilot

Once the tool and guidance were adapted the pilots took place over a four to six week period in the housing schemes and a 10-week period with the community health team in Merton. The HIN project lead supported staff at each pilot site for the duration of the pilots by contacting each pilot site on a once weekly basis. If required, a site visit also took place midway through the pilot period.

6 | Post-pilot focus groups

Post-pilot focus groups were facilitated at each pilot site in order to explore how the pilot went from the perspective of the front line staff. Where possible, individual interviews were conducted with staff who used the tool and residents referred using DeAR-GP.

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Outcomes

1 | Pre-Pilot Focus Group Outcomes

Pre-pilot focus groups and training sessions were conducted with front line staff from each participating organisation. Generally all participants across the participating organisations were engaged and expressed enthusiasm for being involved in this work. During these sessions staff had an opportunity to provide feedback on the original DeAR-GP tool in order to influence its design for their setting. The first impressions of staff were that DeAR-GP seems **“accessible and easy to use”**. Staff felt that the referral letter would formalise and speed up communication to GPs, where a referral was made.

Housing

There was one incident during a focus group where staff in one extra care housing scheme felt that dementia case finding did not fall under their remit and declined to continue with the focus group. For all other participating housing schemes, findings are listed below.

There was considerable variation in training levels. Many staff had not received any formal training surrounding dementia whereas in some schemes, staff had received Dementia Friends Training or some form of internally developed dementia awareness training.

All staff had experience and awareness of some of the signs and symptoms of dementia. Staff were also able to recognise the benefits of receiving a dementia diagnosis such as **“ruling out other organic**

causes for the symptoms such as UTI [urinary tract infection] or vitamin B12 deficiency”, “a formal diagnosis can help put things in place” and it also provides an opportunity to **“educate and look after carers”**.

There was a consensus that even though working with dementia was challenging, it was also rewarding and **“provided a sense of purpose”**. In terms of the applicability of the tool, housing staff determined that minimal adaptations were required of the original DeAR-GP tool.

Community Health Team

Similar to the housing staff, all members of the community health team had experience with dementia. The team also thought that dementia case-finding fell under the remit of their role.

In contrast to the housing staff, all of the community health team had received some type formal dementia training and for some this included Dementia Friends Training. Unlike the housing staff, the community health team amended the original DeAR-GP tool to include the Six-Item Cognitive Impairment Test (6-CIT) in place of the AMT-4. The Patient Health Questionnaire (PHQ-9), a depression scale was added acknowledging the link between depression and dementia and the incidence of depression in older adults.

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1 | Pre-Pilot Focus Group Outcomes

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Housing

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- There was considerable variation in training levels. Many staff had not received any formal training surrounding dementia whereas in some schemes, staff had received Dementia Friends Training or some form of internally developed dementia awareness training.
- All staff had experience and awareness of some of the signs and symptoms of dementia. Staff were also able to recognise the benefits of receiving a dementia diagnosis such as **“ruling out other organic causes for the symptoms such as UTI [urinary tract**

infection] or vitamin B12 deficiency”, “a formal diagnosis can help put things in place” and it also provides an opportunity to **“educate and look after carers”**.

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2 | Pilot outcomes

The number of referrals using DeAR-GP per partner organisation are listed below.

Housing

Borough	Number of Referrals using DeAR-GP
Genesis Housing Association	1
Royal Borough of Kingston upon Thames	1
Metropolitan Care	0

Community Health Team

Borough	Number of Referrals using DeAR-GP
CLCH Case Management Team	10*

*4 of the referrals made by the community health team were for both low mood as well as symptoms of cognitive impairment.



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3 | Post-Pilot Focus Groups Outcomes

Post pilot focus groups were conducted at each pilot site by a facilitator from the HIN. There were a total of 23 participants in the post pilot focus groups consisting of front line staff and managers. Where possible, individual interviews were conducted with staff who referred using the tool. The emerging themes are listed here.

Housing

- For the housing staff taking part in the pilot, awareness of the signs and symptoms of dementia increased and also improved staff confidence when making referrals. One housing staff member explained that the tool helped her **“gain a better understanding of what to look for”** in terms of the signs and symptoms of dementia.
- Minimal training was required and when used, the tool was deemed to be **“accessible and user friendly”** by staff across both settings. One housing staff member explained that **“having the tool to refer to was useful not only when making observations but also when completing risk assessments and periodic welfare checks”**.
- Housing staff indicated that they understood that DeAR-GP was only to be used where a resident was showing signs and symptoms of dementia rather than as a blanket screening tool.
- Staff were enthused with the tool even after the end of the pilot period. Staff across all sites wanted to know whether they could continue using the tool. One of the staff explained that having the tool to use if necessary **“shows that we care and that we are passionate about helping people as well”**.

Community Health Team

- In contrast to the housing staff, the community health team expressed that they were already well aware of the signs and symptoms of dementia as they’d been working with people with dementia. They did agree however; that having the tool increased their confidence levels when making referrals to the GP.
- The community health team required additional training for the scoring of the 6-CIT and PHQ-9 scale.

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Challenges

The shared challenges across both settings are listed below.

- Despite engagement with GPs prior to the pilot, staff across both settings expressed they were unsure of whether GPs were aware of the pilot and connected with the individual for further assessments.
- A facilitator from HIN, alongside a housing scheme staff member attempted to interview one of the residents referred from a housing scheme. However, it was not possible because the individual appeared to be confused and unable to engage in a conversation at the time of the interview. No other residents or patients were identified to be interviewed.

The challenges that were unique to the housing setting are listed below.

- There were minimal number of referrals in the housing schemes. When explored with the staff, they explained that majority of residents come into the schemes through adult social care which means they often already have a thorough assessment complete before entering the scheme. Although data is limited in this realm, people who move into extra care were much less physically and cognitively impaired than those who moved into care homes (Callaghan, 2009).
- Housing staff had reservations obtaining consent to complete the cognitive scale, AMT-4 whereas this was not the case

for the community health team. Housing staff explained that although the observations were a part of their everyday role, obtaining consent to complete a brief cognitive assessment was new for them. There were concerns from the housing staff about whether completing the referral removed the sense of independence that sets housing apart from care homes.

- Completing the observations in sheltered housing might be difficult because there is limited staff on site – for example a once weekly visit to the site.
- Discussion with the housing staff highlighted that, unlike in settings such as care homes, housing staff who participated in this pilot did not have access to a resident’s medical information and care plan.

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- DeAR –GP facilitated collaboration between front line staff of both housing and community health providers with memory service leads (i.e. secondary mental health trusts), GPs and commissioners.
- Adding PHQ-9 for the community health team helped to raise both the awareness of depression amongst staff and in this patient group and facilitated four referrals.
- Prior to this project a dementia case finding tool did not exist for the housing sector or community health teams.
- Stakeholder engagement and good communication are key to implementing DeAR-GP in both sectors.
- Adapting DeAR-GP for older adult housing enabled the HIN to form relationships with national housing providers and strengthen those with a large community health provider.
- The successful adaptation of DeAR-GP for community health and housing indicates the applicability of DeAR-GP for other settings.
- DeAR-GP added to the skill base of community-based nursing teams and front line housing staff. DeAR- GP provides an opportunity to improve knowledge and understanding of dementia. Dementia awareness can be further solidified by providing [Dementia Friends Training](#) provided by the Alzheimer’s Society (appendix 4).
- Although there was limited opportunity for staff (particularly in housing sites) to test the tool, feedback from the staff remained overwhelmingly positive.

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The pilot has demonstrated that DeAR-GP can be adapted for housing schemes and community health teams to support staff in these settings identify people displaying signs and symptoms of dementia in order to refer them to their GP for review.

Staff across both settings provided feedback that DeAR-GP is accessible and easy to use. DeAR-GP supports the Dementia Friendly Housing Charter by promoting awareness of dementia and contributing towards developing and maintaining dementia friendly communities (Alzheimer's society, 2017). The tools for both settings are available in appendix (2 and 3). Please follow the link for the implementation guide.

1 | Next Steps

The HIN is committed to share the project report and implementation guide through the AHSN network, the London Clinical Network and the Housing LIN. The project has been accepted as a poster submission at the UK Dementia Congress October 2017 and is due to be a published article in the [Pharmaceutical Journal](#).

[View the Implementation Guide for DeAR-GP 2](#)

[View references for this report.](#)

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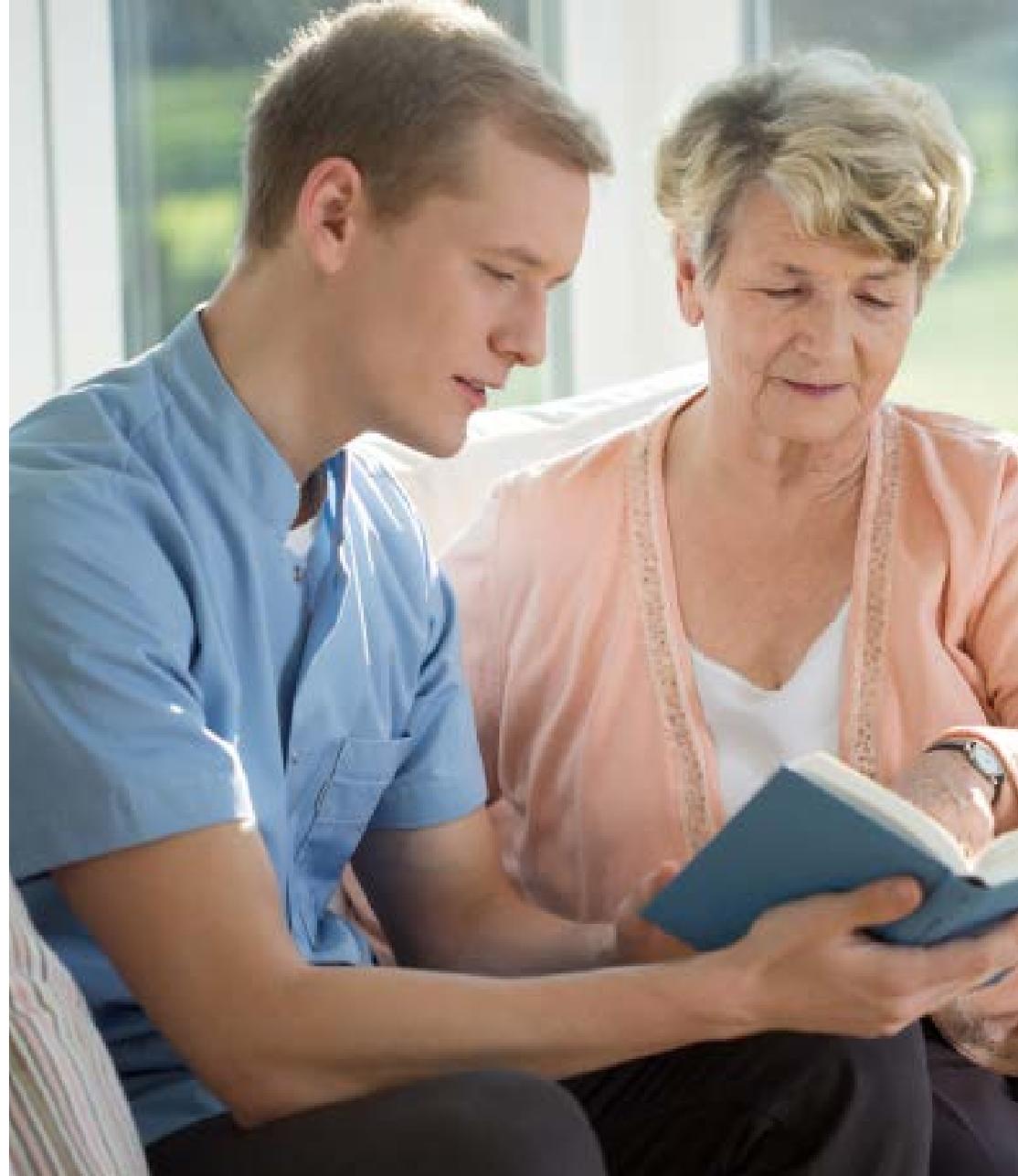
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Appendix 1:

Questions for stakeholder interviews

Appendix 2:

Tool for Housing Schemes

Appendix 3:

Tool for Case Management Team

Appendix 4:

Dementia Friends Training



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