DEMENTIA CARE KILBURN PIE

END OF PROJECT REPORT VERSION (V1.0)

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EVALUATION WRITTEN BY DR AUSTEN EL-OSTA

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EXECUTIVE SUMMARY

INTRODUCTION

- The Dementia Care Kilburn (DCK) Partnerships in Innovative Education (PIE) Initiative was established to foster an integrated approach to education and training for professionals and the public.
- Its mission was to reduce the stigma of dementia in local communities particularly amongst black, Asian & minority ethnic (BAME) and faith groups, removing common misconceptions of the disease, raising awareness and understanding, and promoting early diagnosis.
- It also intended to promote Kilburn as a 'Dementia Friendly' ward in Brent by challenging contemporary negative perspectives on dementia, exploring ways jointly with patients, their families and carers, to support people living well with dementia in the community to maintain independence and quality of life for as long as possible.
- The purpose of this report is to present an objective and pragmatic evaluation of the DCK Initiative to inform future direction of travel to commissioners.

AIMS

- DCK aims to address the Prime Minister's Dementia Challenge locally and help to support implementation of the Dementia Strategy in Kilburn through an integrated approach.
- The Initiative has 6 key objectives as itemised below:
    1. Improve Health Literacy: To increase information given about dementia to help inform individuals of the benefits of timely diagnosis and care;
    2. Raise Awareness: To promote the prevention of dementia and raise awareness of risk reducing factors;
    3. Reduce inequalities & promote self-care: To reduce social exclusion and discrimination and promote wellness amongst specific community groups;
    4. Establish Networks: To explore ways of connecting with, supporting and empowering people with memory loss and their carers;
    5. Increase Capacity: To build confidence in general practice to take a lead on the management and care for patients with a diagnosis of dementia;
    6. Improve care planning**:** To develop closer working relationships between primary and secondary care professionals to support joined up pathways of care

METHOD

- 11 General Practices in Kilburn using EMIS system and with a combined list size of 78,500 patients were recruited to participate in the DCK initiative
- The pilot involved a number of interventions & community outreach campaigns delivered over a 10-month period (between November 2016- September 2017).
- Educational and dementia awareness campaigns were targeted at Brent residents and a known cohort of GPs and other primary and community care staff in Kilburn catchment area.
- Interventions included a number of dementia awareness workshops targeted at GPs, and members of the community, including hard to reach BAME groups & faith groups.
- Post-intervention samples of patient referrals from all participating GP practices to the memory clinic were quality assessed using a number of criteria (developed by the Memory Clinic leads).
- Quantitative and qualitative data were collected to inform objective evaluation of specific DCK Project outcomes, resulting in descriptive statistics and narratives highlighting emergent themes.
- Imperial College Department of Primary Care & Public Health was commissioned to evaluate the programme. The method used to inform the evaluation is detailed in the relevant section.

FINDINGS

- The project achieved excellent traction with a wide mix of stakeholders, including members of the public and hard to reach BAME groups in Kilburn.
- A number of high quality educational and community resource leaflets and posters were produced and disseminated in appropriate forums, (including GP practices and public venues such as libraries), and a 2-page exposé of the project in the Brent Magazine which was delivered to 100,000 homes in Brent.
- A total of 5 separate interventions were delivered to over 1,095 participating individuals following engagement with one or more of the following workshops:
    - (1) Dementia Education Online Survey;
    - (2) Dementia Masterclass;
    - (3) Driving with Dementia Workshop;
    - (4) Memory loss dementia workshop;
    - (5) face to face training sessions with Consultant Psychiatrist
- Feedback from participants attending the workshop suggested excellent engagement and improved health literacy with better awareness of the signs of dementia.
- Participating GPs reported significant improvement in their confidence at being able to diagnose, manage and refer patients with dementia.

- There was 83% reduction in the number of patients newly diagnosed with dementia in the primary care setting during the undertaking of the pilot compared to benchmark figures.
- The overall quality of patient referrals to Memory Clinics in secondary care setting appeared to improve overall, but a full analysis could not be conducted as there was no control group.
- A cost benefit analysis using a number of base assumptions suggested that DCK PIE was excellent value for money with a high ROI potential and other intangible benefits
- Objective evaluation of the programme suggests that the DCK Project was largely successful and achieved 20/20 (100%) of targets.

SUMMARY & CONCLUSION

- The project had a number of limitations, including lack of control group, but was successful overall with demonstrable evidence in improving a number of important outcomes including raising awareness and reducing stigma about dementia in Kilburn and upskilling the primary care workforce to improve ability for differential diagnosis of dementia.
- The initiative seemed to have excellent traction with service users, with direct engagement with over 1000 unique individuals and a wide mix of stakeholders with excellent potential for return on investment and various other 'soft' or intangible outcomes.
- As Brent has the widest demography of any catchment area in England, the findings of this project are likely to be representative of other regions in the Capital and in the UK. Generalisations could be made as regards extant barriers and drivers for the timely diagnosis of dementia in primary care, and the root causes of stigma and misconception about mental health and dementia in the community and how to tackle these by working in collaboration with a consortium of partners, including members of the public and patient representatives.
- Project management and clinical leadership for the DCK project was exemplary, helping to deliver this multi-intervention project to time and target, resulting in valuable lessons and findings that could inform the future direction of travel of larger scale implementation programmes in the Kilburn and Brent catchment area.
- The PIE model of healthcare education brings together health care service providers, community groups, patients and education providers focused around enabling the development of learning communities. This high level objective of bringing together different parts of the health and social care workforce, patients and the public to systematically improve services by learning with and from each other about dementia was achieved DCK Project.
- On merit of the findings of the pilot, it is recommended that further investment be considered to scale up the initiative across Kilburn and other catchment areas in Brent to maintain a sustained engagement with residents and the primary care workforce for patient benefit.

1

INTRODUCTION

INTRODUCTION TO SECTION 1

- Brief overview of the Dementia Care Kilburn (DCK) Initiative
    - DCK aim, mission & vision statement
    - DCK main objectives
    - PIE involvement
    - DCK consortium of partners
    - List of participating practices
    - DCK Project management
- Report aims & objectives

THE DEMENTIA CARE KILBURN INITIATIVE

Brief overview of the Dementia Care Kilburn Initiative

The Dementia Care Kilburn (DCK) Initiative was established to foster an integrated approach to education and training for professionals and the public to help reduce the stigma of dementia in local communities particularly amongst black, Asian & minority ethnic (BAME) and faith groups, removing common misconceptions of the disease, raising awareness and understanding, and promoting early diagnosis.

This initiative is also intended to promote Kilburn as a 'Dementia Friendly' ward in Brent by challenging contemporary negative perspectives on dementia, exploring ways jointly with patients, their families and carers, to support people living well with dementia in the community to maintain independence and quality of life for as long as possible.

DCK aims to address the Prime Minister's Dementia Challenge locally and help to support implementation of the Dementia Strategy in Kilburn through an integrated approach. The anticipated benefits of implementing our Kilburn Dementia Care integrated approach are:

- To identify and eliminate stigma associated with dementia;
- To improve the lives of people living with dementia and their families and carers
- To reduce stigma in targeted communities;
- To equip professionals to be able to discuss risk factors associated with dementia for targeted cohorts of patients;
- To help patients, families and carers to maintain dignity in their local communities.

Through our three-stage component programme which was aimed to involve patients, their families and carers in shared learning with health professionals, it also helped to support achievement of Dementia Care Kilburn's overall aim and objectives outlined above.

Specific to the general practice team the DCK project wanted to build **confidence** in GPs so that they felt better equipped and enabled to support patients, their families and carers closer to home. In addition, it helped to improve **capability** by developing skills in the workforce to deliver a consistently high level of quality care across Kilburn, including building **capacity**.

With an increasing aging population the burden on the health service is expected to increase, putting pressure on the system to diagnose and treat more. It will be essential to work together with the voluntary sector and with social care to develop skills in community champions/ peer supporters to help with increasing patient need.

DCK aim and mission statement

Working in partnership, the DCK Initiative has the overall aim of improving the quality of life for people living with dementia, their families and carers by increasing public and professional awareness and understanding of dementia and the stigma associated with it.

The mission of the DCK Initiative is to 'foster an integrated approach to education and training for professionals and the public to help reduce the stigma of dementia in local communities particularly amongst BAME and faith groups, removing common misconceptions of the disease, raising awareness and understanding, and promoting early diagnosis'.

DCK main objectives

The Initiative has a number of key objectives as itemised below:

1. Improve Health Literacy: To increase information given about dementia to help inform individuals of the benefits of timely diagnosis and care;
2. Raise Awareness: To promote the prevention of dementia and raise awareness of risk reducing factors;
3. Reduce inequalities & promote self-care: To reduce social exclusion and discrimination and promote wellness amongst specific community groups;
4. Establish Networks: To explore ways of connecting with, supporting and empowering people with memory loss and their carers;
5. Increase Capacity: To build confidence in general practice to take a lead on the management and care for patients with a diagnosis of dementia;
6. Improve care planning: To develop closer working relationships between primary and secondary care professionals to support joined up pathways of care.

Dementia Care Kilburn realised these objectives by advancing three key components as follows:

1. A local general public information campaign including a road show to complement borough and national strategies targeting BAME and faith communities, run jointly by professionals and community champions/ peers;
2. Targeted campaigns for other specific groups including an integrated series of events delivered by CAD Brent (e.g. cultural and religious organisations, ethnic minority groups, people with disabilities);
3. Structured education sessions aimed a healthcare professionals provided through a variety of workshops, conferences and case based discussions.
4. increase information giving about dementia to help inform individuals of the benefits of timely diagnosis and care
5. promote the prevention of dementia and raise awareness of risk reducing factors
6. reduce social exclusion and discrimination and promote wellness amongst specific community groups
7. explore ways of connecting with, supporting and empowering people with memory loss and their carers
8. build confidence in general practice to take a lead on the management and care for patients with a diagnosis of dementia
9. develop closer working relationships between primary and secondary care professionals to support joined up pathways of care

PIE involvement

Applying learning from previous PIE involvement, the DCK Project Board and Project Team were set up with clearly defined Terms of Reference including accountability, responsibility and remit. The commitment required from each partner in the PIE was agreed prior to the commencement of the project and resources were allocated to the appropriate areas to enable successfully project mobilisation.

Strong clinical leadership was crucial to the successfully delivery of the integrated series and the structured educational programme, therefore the bid included funding for a GP lead and secondary care specialist input. The clinical leads time was used to help design and shape the components of Dementia Care Kilburn as well as support the hands-on delivery.

One of the overall aims of this PIE was to build a sustainable knowledge base and expertise of dementia in primary care and in the local community. We wanted to support the development of Kilburn as a Dementia Friendly community and enable patients to live well.

Relating to the integrated series and developing relationships between primary and secondary care professionals, we have helped to build a network supporting informal channels of communication. This will include easy access to specialist advice and support.

We want to support local community champions/ peers who disseminate information through their local communities and Networks, creating a percolating effect, sharing information from person to person, helping to reduce social isolation and stigma.

Key to this is the delivery of a successful patient information campaign which helps to impart learning to adjust to life to cope with the condition either at the level of the patient, their families, carers and services.

The Dementia Care Kilburn Consortium

The Initiative involves a consortium of partner organisations & groups to realised mutual objectives as listed in **table 1**.

Table 1: DCK PIE Partner Organisations

Partner	Main role / notes
Dementia Care Kilburn	This is the name of the intervention
Health Education England across Northwest London (HEE NWL)	The funder
Kilburn Primary Care Co-op	Lead organisation delivering intervention
Central North West London NHS Foundation Trust	Host organisation of Memory Service.
Age UK Brent	Patient engagement and representation
Ashford Place	Community development hub and acts as a nexus for collaborations and meetings
Community Action on Dementia (CAD) Brent	Facilitates a whole community network and become the leading portal for creative discussion, active partnership and community outcomes.
Brent Carers Centre	Provides information, advice and support to Carers across the borough. Aims to raise awareness of the rights and needs of Carers in Brent.
Brent Multi-Faith forum	BMFF aims to develop shared objectives for discussion to establish key issues for Brent Faith Communities and a plan of action to make strategic interventions.
The Neurology academy	Specialists delivered the 2 half day workshops to GPs at Willesden Library. PIE leaflet advertised on the Neurology academy website.
Brent Council	Local Authority Market Engagement event for care providers in the borough. Project Manager presented and provided an update on the

Partner	Main role / notes
	PIE.
South Kilburn Trust action planning group	Delivers the 'Whole street of support' with the aim of making South Kilburn a dementia friendly area. Seeking to make Mapesbury Ward a pioneer for a dementia friendly ward, where all the community are supporting those residents living with Dementia. Project Manager is a member of the action planning group. Working collaboratively in making Kilburn the first dementia friendly ward in the borough.
Brent CCG Dementia Steering group	In line with the NW London Sustainability Transformation Plan (STP) the purpose of the Brent Dementia Steering Group is to set the strategic direction and design of dementia services in response to patient need and the needs of the families and carers living Brent. The Project Manager is a member of the Steering Group.
Irish Embassy	The Ambassador of Ireland invited the GP Lead and the Project Manager to attend an event on the 18th May at the Irish Embassy. It was dementia week and there were various speakers including Brent Peer project. The room was full of pan London CCG, HWB, Third sector leaders and Irish sector leads.

Participating practices

Brent CCG is made up of all 62 GP practices in the borough who care for approximately 370,000 people registered with GPs in Brent. All practices are part of a network; there are currently three networks/legal entities in Brent - Kilburn Primary Care Co-op Ltd, Harness and K&W Healthcare. Kilburn Primary Care Co-op Limited was established in 2009, to bring a group of local GPs from south Brent together who share a passion to provide excellent primary care services to their patients and families.

Kilburn Primary Care Co-op Limited are a 'not for profit' organisation of dedicated practices throughout the local area. The network is proud to work in partnership with NHS Brent CCG to provide a range of services including GP Extended Access Hub service, Out of hospital services and integrated care.

All the constituent practices of the Kilburn Primary Care Co-op participated in the DCK intiative.

Table 2: The list of practices are below;

No.	Practice Name	Address	List Size	Note
1	**Chichele Road Surgery**	25 Chichele Road, NW23AN	6190	Average
2	**Cricklewood Broadway Surgery**	60 Cricklewood Broadway, NW23ET	2685	Small
3	**Kilburn Park Medical Centre**	12 Cambridge Gardens, NW6 5AY	7935	Average
4	**Lonsdale Medical Centre**	24 Lonsdale Road, NW6 6RR	14656	Large
5	**Park House Medical Centre**	18 Harvist Road, Queens Park, NW66SD	5356	Average
6	**Peel Precinct Surgery**	3 Peel Precinct, Carlton Vale, NW65RE	1650	Small
7	**Staverton Surgery**	51 Staverton Road, NW25HA	8744	Average
8	**The Law Medical Group Practice**	124 Harrow Road, NW105UY	13693	Large
9	**The Windmill Medical Practice**	65 Shoot-Up-Hill, NW23PS	6975	Average
10	**Willesden Green Surgery**	59 Anson Road, NW23UY	3380	Small
11	**Blessing Medical Centre**	307 Kilburn Ln, London W9 3EG	3235	Small

DCK Project Management

The project was implemented using a PRINCE 2 Project Management approach. There were clear lines of governance and accountability with a Project Management Board (**table 3**) who convened monthly with overall accountability and responsibility for the PIE. There was a project group who were responsible for the mobilisation of the PIE who will meet a minimum of fortnightly.

Table 3: DCK PIE Management Board

Team	Name	Designation / role
Project Board	Kate Glass	Kilburn Primary Care Co-Op Ltd (Project Sponsor)
Project Board	Ian Currie	CNWL (Senior Supplier 1)
Project Board	Dr Amanda Craig	Kilburn Primary Care Co-Op Ltd (Senior Supplier 2)
Project Board	Danny Maher	Ashford Place and CAD Brent
Project Board	Anne-Marie Morris	CEO, Brent Carers Centre
Project Board	Aisha Khan	Chair, Brent Multi-Faith forum
Project Board	Jenny Beasley	Brent Council, Commissioning Manager
Project Team	Renata Chavda	Project manager
Project Team	Dr Justin Sacks	Dementia GP lead for Kilburn
Project Team	Clementine Femiola	Peer Support Project Manager, Ashford Place
Project Team	Tara Mullholand	Memory Service, CNWL
Project Team	Dr Claire Hilton	Consultant, Memory Service CNWL
Project Team	Charlotte Curran & Dr Mary Tilki	CAD Brent Project Managers
Project Team	Jasmina Gomez	Brent Council Commissioning & Change Officer
Project Team	Dr Tony Burch	Age UK Chair
Project Team	Hazel Robinson	Person living with dementia

REPORT AIMS AND OBJECTIVES

Supporting the continuous training and development of staff to retain and develop skill mix will be a priority for commissioned health services. It is anticipated that components from Dementia Care for Kilburn will be incorporated to ensure that this work is continued.

To this end, the DCK initiative requires an objective evaluation to inform next steps, and to determine how best to commission dementia services locally. It is acknowledged that adopting a qualitative and quantitative approach to evaluation of this PIE will be crucial to gauging the impact of the interventions and understanding the extent to which the aims and objectives have been achieved.

Primary Aim

Objectively evaluate the Dementia Care Kilburn Programme using available quantitative, qualitative and contextual data to inform future direction of travel for policy makers and commissioners.

Secondary aims:

1. Understand the Knowledge, Attitude & Perception (KAP) of professionals, patients and carers in relation to DCK Initiative

2. Comparative analysis of DCK achievements against targets

3. Understand how the Programme posits within the wider health economy of Kilburn and NWL

4. Quantitative analysis to assess impact of the programme on early diagnosis, referral numbers, congruence of referrals to secondary care, response rates to participate in the programme and subsequent DNA rates and other objective measures and level of engagement of patients and their demography (in narrative form)

2
EVALUATION METHOD

2.0 Evaluation method

A mixed methods approach was used to drive objective evaluation of the DCK initiative, to include analysis of quantitative results, as well as qualitative and contextual findings as described in the sections below.

As there is no validated framework for formative evaluation of similar interventions, a pragmatic evaluation framework was developed by considering number of elements, including the widely used Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist.

The following sections describe the methods used for:

- Data scoping
- Analysis of quantitative data
- Analysis of qualitative and contextual data
- Developing pragmatic framework for evaluation of DCK based on PRISMA checklist statement, and a configuration matrix to illustrate whether DCK aims and strategic objectives were met
- Cost benefit analysis & economic modelling to determine if DCK is cost effective from the user perspective in the context of the wider health economy and asset based use of resources in Brent/Kilburn.

Data provenance

All relevant documents regarding DCK Initiative were collected from Renata Chavda, Project Manager & Dr Justin Sacks, GP Lead of the Project Team. This included quantitative datasets describing programme activity (i.e. user engagement and participation, workshops, demographic profiling etc.) were collected for analysis.

Information governance

Where applicable, DCK Project team pseudonomised the data set prior to passing on to the Evaluation Team. At no point did the Project Evaluation Team at Imperial College have access to patient identifiable data. However, the names of those individuals who delivered masterclasses and workshops were recorded and communicated to the Project Evaluation Team.

Scope & timeline of analysis

The pilot intervention extended for 10 months (from November 2016-September 2017). For the purposes of this report, we limited our analysis interim data received prior to 29 September 2017

Analysis of quantitative data

Basic demographic information was captured from participating practices and general practitioners/participants, including age, sex, ethnicity, designation and various other measures. Pre and post intervention data describing number and type/appropriateness of referrals to the Memory Service, as well as number of missed appointments and various other measures were analysed. Where applicable, quantitative data was analysed using routine statistical methods and presented in figures and tables, illustrating demographic profiling and descriptive statistics.

We were also able to perform some basic statistical analysis of the outcome measures based on the responses to questionnaires administered before and after various interventions coordinated by the DCK initiative

Analysis of qualitative and contextual data

Semi-quantitative, qualitative and contextual data to glean perspectives from wide mix of stakeholders were collected from the DCK Project team, which in turn collated the data from partner organisations.

Contextual analysis of qualitative data

Notes were recorded of salient responses and the contextual data was analysed to detect emergent themes. Emergent themes were categorised and presented in summary format in tables for reference. Where relevant, ad verbatim quotations were cited for inclusion in the report.

Measuring success of DCK PIE

The success of the Dementia Care Kilburn Programme will be measured by assessing 20 criteria (**table 4**) and satisfying a number of parameters illustrated in **table 5**.

Table 4: table showing 20 assessment criteria for DCK PIE initiative

OBJECTIVES
1. **Improve Health Literacy:** To increase information giving about dementia to help inform individuals of the benefits of timely diagnosis and care
2. **Raise Awareness:** To promote the prevention of dementia and raise awareness of risk reducing factors
3. **Reduce inequalities & promote self-care:** To reduce social exclusion and discrimination and promote wellness amongst specific community groups
4. **Establish Networks:** To explore ways of connecting with, supporting and empowering people with memory loss and their carers;
5. **Increase Capacity:** To build confidence in general practice to take a lead on the management and care for patients with a diagnosis of dementia
6. **Improve care planning:** To develop closer working relationships between primary and secondary care professionals to support joined up pathways of care.
COMPONENTS
7. A **local general public information campaign** including a road show to complement borough and national strategies targeting BAME and faith communities, run jointly by professionals and community champions/ peers
8. **Targeted campaigns for other specific groups including an integrated series of events delivered by CAD Brent** (e.g. cultural and religious organisations, ethnic minority groups, people with disabilities)
9. **Structured education sessions aimed a healthcare professionals** provided through a variety of workshops, conferences and case based discussions.
ADDRESSING THE PRIME MINISTER'S CHALLENGE ON DEMENTIA
10. **increase information giving** about dementia to help inform individuals of the benefits of timely diagnosis and care
11. **promote the prevention of dementia** and raise awareness of risk reducing factors
12. **reduce social exclusion and discrimination** and promote wellness amongst specific community groups
13. **explore ways of connecting with, supporting and empowering people** with memory loss and their carers
14. **build confidence in general practice** to take a lead on the management and care for patients with a diagnosis of dementia
15. **develop closer working relationships** between primary and secondary care professionals to support joined up pathways of care
ANTICIPATED BENEFITS
16. To **identify and eliminate stigma associated with dementia**;
17. To **improve the lives of people** living with dementia and their families and carers
18. To **reduce stigma in targeted communities**;
19. To **equip professionals to be able to discuss risk factors** associated with dementia for targeted cohorts of patients;
20. To **help patients, families and carers to maintain dignity** in their local communities.

Table 5: Questions and Parameters required to inform success of DCK PIE

Category	Questions / Parameter
Demography	1. Demographic profile of participating GP/practices
Referral rates	2. Did Programme have on patient/overall referral rates?
Early diagnosis	3. Did the Programme impact early diagnosis?
Stigma	4. No. of appointments declined (aiming to measure impact on stigma)
Missed appointments	5. Does the programme impact number of missed appointments (DNA)?
Cost analysis	6. We can do a cost calculation on that
Patient & Public Involvement	7. Demonstrable engagement with particular patient groups with & representation from wide mix/segments of society?
Engagement	8. Number of attendees/Register/several events/demographic profiling (CAD)
Competency	9. The GP does not always diagnose. Is this due lack competence/training or lack of time?
Confidence check	10. Do GPs feel more confident to diagnose & manage patients? What are the thresholds/fears?
Appropriate referrals	11. Did the programme result in referrals that are more appropriate?
Barriers to PPI	12. Investigate if there are any languages/barriers to patient involvement & engagement

Pragmatic method for evaluation of DCK

It was acknowledged that there is not currently a validated or recommended framework specifically intended for the evaluation of complex, multi-intervention initiatives directed at upskilling of the medical workforce.

For the purpose of this evaluation, the DCK initiative was evaluated using a bespoke, fit for purpose pragmatic framework by taking into consideration the following elements:

1- Assessment based on whether or not the programme satisfied the targets illustrated in DCK objectives document
2- A configuration matrix (i.e. a dashboard style type table) illustrating the level of apparent success of different aspects of the DCK initiative with BRAG reporting (where Black= not reported; Red= not achieved; Amber = Partly achieved; Green = achieved)
3- Basic mathematical modelling/cost benefit analysis illustrating whether DCK was:
    a. cost effective from service user perspective
    b. cost effective from the perspective of Partner Organisation/s
    c. value for money in the context of asset based use of resources in Brent
    d. return on investment (ROI) potential

A short narrative describing the basic methodology used to evaluate each of the 3 categories illustrated above is presented in the relevant section of results.

3
RESULTS

3.0 RESULTS

This section describes the results of the quantitative and qualitative evaluation of DCK Initiative

A description of the informational and educational materials ads communications is first presented.

The results of the analysis pertaining to demographic data/information of GPs participating in the DCK initiative and data relevant to service referrals to Memory Service is then presented in a series of graphs, followed by tables and graphs to show the outcomes of the interventions based on responses to pre- and post-intervention questionnaires.

This is followed by itemising qualitative data and findings gleaned from surveys, roundtable discussions and various face-to-face meeting with key stakeholders is presented.

This Section concludes by illustrating the results of a basic health economic exercise to determine the potential scope for the return in investment (ROI) of DCK initiative.

For reasons of pragmatism, the findings are presented in the following sub-sections:

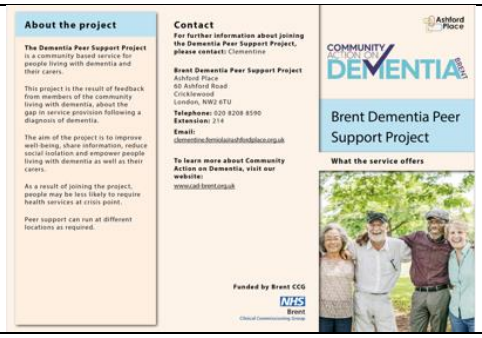
4.1 Description of informational material and media mentions
4.2 Qualitative findings
4.3 Quantitative findings
4.4 Comparative analysis of DCK achievements against targets
4.5 Results of basic health economic exercise
4.6 Summary of results

3.1 INFORMATIONAL MATERIAL

A series of informational leaflets, posters & brochures were developed and disseminated to raise awareness about dementia and the DCK initiative. Salient examples are included for reference in **table 6** below illustrating:

a) Poster: Reduce your risk of dementia
b) Leaflet: What is dementia?
c) Leaflet: Worried about loss or Dementia
d) Leaflet: Striving to make Kilburn dementia friendly- The Dementia Care Project
e) Leaflet: Brent Dementia Peer Support Project Leaflet

Table 6: informational and educational material

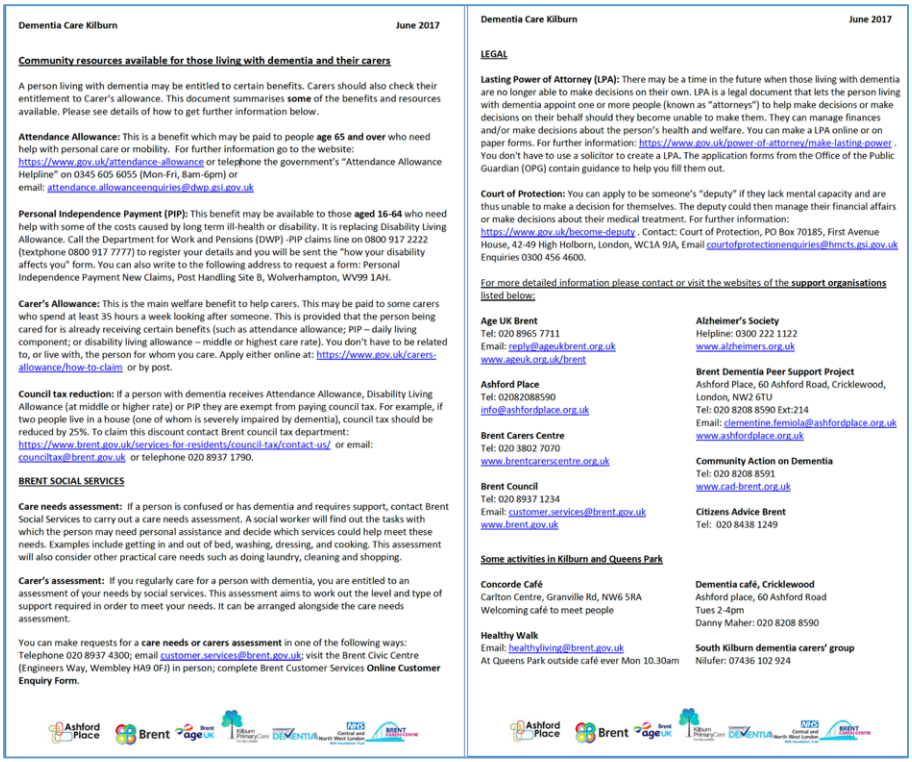
Descriptor	Item
(a) **POSTER** **Reduce your risk of dementia**	
(b) **LEAFLET** **What is dementia?**	
(c) **LEAFLET** **Worried about loss or Dementia?**	
(d) **LEAFLET** **Striving to make Kilburn dementia friendly- The Dementia Care Project**	
(e) **LEAFLET** **Brent Dementia Peer Support Project Leaflet**	

Community resources available for those living with dementia and their carers

A two-page document itemising the recourses available for people living with dementia and their carers was produced and disseminated in the locality. The document **(figure 1)** has information about various aspects and services including:

- Attendance allowance
- Personal Independence payment (PP)
- Care's allowance
- Council tax reduction
- Care needs assessment
- Care's assessment
- Lasting Power of Attorney (LPA)
- Court of Protection
- Useful contact details

Figure 1: snapshot of 'Community Recourses available for people living with dementia and their carers' document



Dementia Care Kilburn June 2017

Community resources available for those living with dementia and their carers

A person living with dementia may be entitled to certain benefits. Carers should also check their entitlement to Carer's allowance. This document summarises **some** of the benefits and resources available. Please see details of how to get further information below.

Attendance Allowance: This is a benefit which may be paid to people **age 65 and over** who need help with personal care or mobility. For further information go to the website: https://www.gov.uk/attendance-allowance or telephone the government's "Attendance Allowance Helpline" on 0345 605 6055 (Mon-Fri, 8am-6pm) or email: attendance.allowanceenquiries@dwp.gsi.gov.uk

Personal Independence Payment (PIP): This benefit may be available to those **aged 16-64** who need help with some of the costs caused by long term ill-health or disability. It is replacing Disability Living Allowance. Call the Department for Work and Pensions (DWP) -PIP claims line on 0800 917 2222 (textphone 0800 917 7777) to register your details and you will be sent the "how your disability affects you" form. You can also write to the following address to request a form: Personal Independence Payment New Claims, Post Handling Site B, Wolverhampton, WV99 1AH.

Carer's Allowance: This is the main welfare benefit to help carers. This may be paid to some carers who spend at least 35 hours a week looking after someone. This is provided that the person being cared for is already receiving certain benefits (such as attendance allowance; PIP – daily living component; or disability living allowance – middle or highest care rate). You don't have to be related to, or live with, the person for whom you care. Apply either online at: https://www.gov.uk/carers-allowance/how-to-claim or by post.

Council tax reduction: If a person with dementia receives Attendance Allowance, Disability Living Allowance (at middle or higher rate) or PIP they are exempt from paying council tax. For example, if two people live in a house (one of whom is severely impaired by dementia), council tax should be reduced by 25%. To claim this discount contact Brent council tax department: https://www.brent.gov.uk/services-for-residents/council-tax/contact-us/ or email: counciltax@brent.gov.uk or telephone 020 8937 1790.

BRENT SOCIAL SERVICES

Care needs assessment: If a person is confused or has dementia and requires support, contact Brent Social Services to carry out a care needs assessment. A social worker will find out the tasks with which the person may need personal assistance and decide which services could help meet these needs. Examples include getting in and out of bed, washing, dressing, and cooking. This assessment will also consider other practical care needs such as doing laundry, cleaning and shopping.

Carer's assessment: If you regularly care for a person with dementia, you are entitled to an assessment of your needs by social services. This assessment aims to work out the level and type of support required in order to meet your needs. It can be arranged alongside the care needs assessment.

You can make requests for a **care needs or carers assessment** in one of the following ways: Telephone 020 8937 4300; email customer.services@brent.gov.uk; visit the Brent Civic Centre (Engineers Way, Wembley HA9 0FJ) in person; complete Brent Customer Services **Online Customer Enquiry Form.**

Dementia Care Kilburn June 2017

LEGAL

Lasting Power of Attorney (LPA): There may be a time in the future when those living with dementia are no longer able to make decisions on their own. LPA is a legal document that lets the person living with dementia appoint one or more people (known as "attorneys") to help make decisions or make decisions on their behalf should they become unable to make them. They can manage finances and/or make decisions about the person's health and welfare. You can make a LPA online or on paper forms. For further information: https://www.gov.uk/power-of-attorney/make-lasting-power . You don't have to use a solicitor to create a LPA. The application forms from the Office of the Public Guardian (OPG) contain guidance to help you fill them out.

Court of Protection: You can apply to be someone's "deputy" if they lack mental capacity and are thus unable to make a decision for themselves. The deputy could then manage their financial affairs or make decisions about their medical treatment. For further information: https://www.gov.uk/become-deputy . Contact: Court of Protection, PO Box 70185, First Avenue House, 42-49 High Holborn, London, WC1A 9JA, Email courtofprotectionenquiries@hmcts.gsi.gov.uk Enquiries 0300 456 4600.

For more detailed information please contact or visit the websites of the **support organisations** listed below:

Age UK Brent
Tel: 020 8965 7711
Email: reply@ageukbrent.org.uk
www.ageuk.org.uk/brent

Ashford Place
Tel: 02082088590
info@ashfordplace.org.uk

Brent Carers Centre
Tel: 020 3802 7070
www.brentcarerscentre.org.uk

Brent Council
Tel: 020 8937 1234
Email: customer.services@brent.gov.uk
www.brent.gov.uk

Alzheimer's Society
Helpline: 0300 222 1122
www.alzheimers.org.uk

Brent Dementia Peer Support Project
Ashford Place, 60 Ashford Road, Cricklewood, London, NW2 6TU
Tel: 020 8208 8590 Ext:214
Email: clementine.femiola@ashfordplace.org.uk
www.ashfordplace.org.uk

Community Action on Dementia
Tel: 020 8208 8591
www.cad-brent.org.uk

Citizens Advice Brent
Tel: 020 8438 1249

Some activities in Kilburn and Queens Park

Concorde Café
Carlton Centre, Granville Rd, NW6 5RA
Welcoming café to meet people

Healthy Walk
Email: healthyliving@brent.gov.uk
At Queens Park outside café ever Mon 10.30am

Dementia café, Cricklewood
Ashford place, 60 Ashford Road
Tues 2-4pm
Danny Maher: 020 8208 8590

South Kilburn dementia carers' group
Nilufer: 07436 102 924

Development of Community Action on Dementia (CAD) Brent Strategy

A slide deck outlining version 1 of CAD Brent strategy was produced. A snapshot of slide number 10 of the slide deck outlining summary of the DCK PIE as illustrated in **figure 2** below. Briefly, the outline CAD Brent strategy is to:

1. **Promote our work –** Display posters or leaflets for CAD Brent and/or our partner organisations.
2. **Sponsor a Project or Fundraise –** If you can support a project financially (directly or through fundraising) or in kind (e.g. people's time) we would be delighted to hear from you.
3. **Become Dementia Friendly** – Ensure your business or organisation is operating in a Dementia friendly way. This could include Dementia Friends Information Sessions, which cover five key messages that we want everyone to know about dementia, and help people to think what they could do to help.
4. **Become part of CAD Brent** – Join with us as a partner organisation e.g. becoming involved in one or more of our projects.

Figure 2: Snapshot of slide 10 and nested PPT file.

Snapshot of Slide 10

Brent Community Action on Dementia

Annex A: Dementia Care Kilburn PIE Project

Project Purpose

Our Partnerships in Innovative Education (PIE) project aims to:

- Improve the quality of life for people living with dementia, their families and carers by increasing public and professional awareness and understanding of dementia.
- Promote an integrated approach to education and training, spanning primary and secondary care, Community Action Dementia Bren and involving patients and local communities.
- Support the development of Kilburn as a 'Dementia Friendly' ward.

How will we know it has Succeeded?

Will be evaluated by Imperial College London in September. Grand finale event at Queens Park Fayre. Outputs will include:

- Raising awareness and improving knowledge of dementia locally via a series of events within communities especially amongst BAME communities, faith groups and healthcare staff.
- A leaflet and poster produced to be displayed at GP practices and public venues.
- Workshops delivered to GPs within Kilburn to further improve confidence in recognising and managing dementia.
- Face-to-face educational sessions with GPs in Kilburn.

Project Lead and Team

Who is the lead and who are the other key people involved?

Renata Chavda – Project Manager, Dr Justin Sacks – GP Lead

Project Resources

Project is funded by Health Education England across North West London (HEE NWL) and is a collaboration with Kilburn Primary Care Co-op Limited, CAD, Brent Dementia Peer Support Project, CNWL, Brent Council, Age UK Brent and Ashford place.

Project Interdependencies

- A Whole Street of Support
- Peer Support project

If evaluation positive, will look to roll out to other main GP federations in Brent (subject to available funding).

"A Dementia Friendly Borough of Brent" 10

Media mentions

A joint article was prepared and appeared on double page spread on pp38 – 39 (Issue 152-Summer 2017) of The Brent Magazine[1] as evidenced from the following link: https://www.brent.gov.uk/council-news/the-brent-magazine/

The Magazine is published quarterly and delivered to over 100,000 homes in Brent. A hard copy of the article was delivered via post to mail boxes in Brent 1st week of July 2017 (**figure 3)**

Figure 3: Screenshot of joint article appearing in The Brent Magazine & disseminated to residents via mail



HAPPY & HEALTHY

Helping to make Brent dementia-friendly

With more of us living longer, Brent's bid to become a 'dementia friendly' borough is of growing importance to more and more local people

The number of Brent residents aged 65 and over living with dementia is expected to rise by around 1,500 to just under 4,000 by 2030.

Dementia describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. These changes are often small to start with, but for someone with dementia they have become severe enough to affect daily life. A person with dementia may also experience changes in their mood or behaviour.

Community Action on Dementia

Brent Council is working with Community Action on Dementia (CAD Brent) to make Brent dementia friendly. CAD Brent supports local people living with dementia in a number of ways including a peer support project which offers one-to-one and group peer-to-peer support. The aim is for people with dementia to meet others, pursue interests and hobbies, share information and reduce social isolation.

Residents can join by referring themselves or be referred by a carer, family member or health professional.

Having recently been diagnosed with dementia, Hazel Robinson wanted to find local activities to keep active and connected and so she walked us round her neighbourhood. It was disappointing to see how few services there were for people living with dementia. The Brent Dementia Peer Support service has helped to overcome this.

Hazel explains, "The depression being associated with dementia was what brought me down. Now being involved in this project has brought me back to life."

"The wonderful art class at the Brent Dementia Peer Support Project, Ashford Place, has given me a new lease of life after being diagnosed with Alzheimer's disease. It has been such a relief to come back to my love of drawing, especially in the company of others in the same boat."

> 'The depression associated with dementia was what brought me down. Now being involved in this project has brought me back to life.'

Support and advice

Dementia Care Kilburn aims to make Kilburn a 'dementia friendly' area by raising awareness and understanding of dementia, bust some myths associated and help to improve access to support and advice. "We are running a local public information campaign, free community workshops, as well as a public event to be held in the summer of 2017. This is a fantastic opportunity for health, social care and the community to come together to make a difference for families affected by dementia. It is important to raise awareness and improve understanding of the condition so that everyone can play their part to support people and their families," says Dr Amanda Craig, Local GP and Chair of Kilburn Primary Care Co-op Limited. For more information, please email kilburn.admin@nhs.net or visit www.kilburnprimarycare.co.uk

Brent also has a number of dementia cafes where people with dementia or their carers and relatives can drop in and get involved in a range of activities such as singing, dancing, arts and crafts and exercise classes.

Cllr Krupesh Hirani, Cabinet Member for Community Wellbeing, said, "I'm delighted to see how much we have progressed in Brent in such a short space of time in developing a whole community response to Dementia. Dementia is a condition that blurs the boundaries between physical, mental and social needs. It is crucial that we address this important issue with wider engagement. As part of our Brent Health and Care Plan we have committed to making Brent a Dementia Friendly Borough by 2021 and we will work with CAD Brent to make our commitment a reality."

For more information about Brent Dementia Peer Support Project, visit www.cad-brent.org.uk and www.ashfordplace.org.uk or telephone 020 8208 8590.

For further information about dementia cafes visit www.brent.gov.uk/events and click on 'Dementia' in the category box.

QUEENS PARK DAY, 17 SEPTEMBER

There will be information and a quiet space for people living with dementia, their carers and relatives at Queens Park Day on Sunday 17 September 2017 from 12 noon to 5.30pm in Queens Park, NW6 6SG.

38 Brent SUMMER 2017

[1] The Brent Magazine is the locality's award-winning publication of news and what's on in Brent.

3.2

SEMI-QUALITATIVE FINDINGS

- **INTERVENTION 1:** Dementia Education Online Survey
- **INTERVENTION 2:** Dementia Masterclass
- **INTERVENTION 3**:Driving with Dementia Workshop
- **INTERVENTION 4:** Memory loss/dementia workshop
- **INTERVENTION 5:** Face to face sessions with Consultant Psychiatrist

INTERVENTION 1:
Dementia Education Online Survey

Results from the online questionnaire aimed at GPs and some clinical staff prior to participating in the training workshops are shown in **table 6 & 7** below. The survey helped inform the programme for the clinician training workshops.

- 22 participants total; Male: Female ration was 48:52 ; Vast majority (76%) were principal GPs, 8% Salaried GP and 14% of other designation.
- **Dementia Education – Clinicians**
- **N = 22; 58% M: 52% F**
- 78% Principle GP; 8% salaried GP; 14% other designation

Table 6: Confidence check for GPs

How confident are you about?	VERY	SOMEWHAT	A LITTLE	NOT AT ALL	TOTAL
Understanding risk factors for the development of dementia	27.27% 6	54.55% 12	13.64% 3	4.55% 1	22
Identifying possible cases of dementia	22.73% 5	68.18% 15	4.55% 1	4.55% 1	22
Use of screening tools for identifying possible dementia	18.18% 4	63.64% 14	13.64% 3	4.55% 1	22
Investigations used in the recognition of dementia	45.45% 10	40.91% 9	9.09% 2	4.55% 1	22
Differentiating between dementia and other conditions eg delirium, depression	31.82% 7	45.45% 10	18.18% 4	4.55% 1	22
Differentiating between types of dementia	13.64% 3	40.91% 9	27.27% 6	18.18% 4	22
Understanding the process followed in a memory clinic	0.00% 0	27.27% 6	45.45% 10	27.27% 6	22
Understanding the role of drugs in managing dementia	0.00% 0	57.14% 12	28.57% 6	14.29% 3	21
Discussing the probable diagnosis with your patients	19.05% 4	71.43% 15	4.76% 1	4.76% 1	21
Discussing the probable diagnosis with their family	22.73% 5	68.18% 15	4.55% 1	4.55% 1	22
Responding to behavioural or psychological symptoms	9.09% 2	59.09% 13	13.64% 3	18.18% 4	22
Legal aspects of dementia including advanced care planning	9.09% 2	45.45% 10	36.36% 8	9.09% 2	22
When to involve the palliative care team	13.64% 3	45.45% 10	22.73% 5	18.18% 4	22

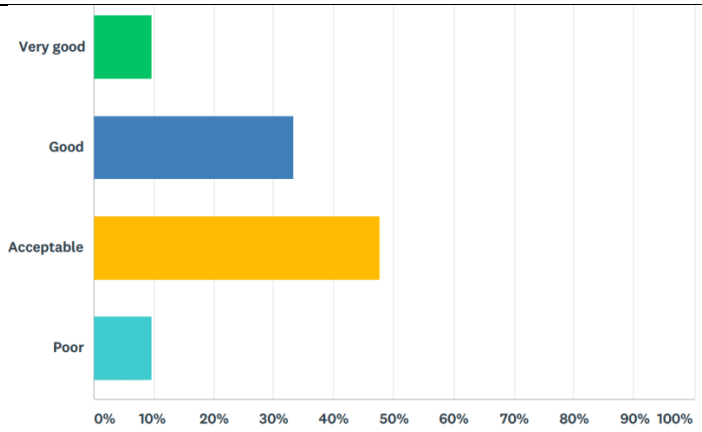
Table 7: showing (a) rating awareness of services and (b)current care provided by GPs for patients with dementia; (c) coordination of support services for people with dementia, and (d) usefulness of resources

(a) Rating awareness of services available in the community (e.g. dementia cafes, support groups, advocacy services).

	VERY GOOD	GOOD	ACCEPTABLE	POOR	TOTAL	WEIGHTED AVERAGE
For those living with dementia	0.00% 0	18.18% 4	54.55% 12	27.27% 6	22	3.09
For carers of those living with dementia	4.55% 1	9.09% 2	45.45% 10	40.91% 9	22	3.23

#	WHY DID YOU COME TO THAT JUDGEMENT?	DATE
1	Based on patient experience which they have reporte to me.	6/22/2017 10:09 AM
2	I've only just started working in this area of London	5/3/2017 8:31 PM
3	There is no work shop or training for carers of those living with Dementia	5/3/2017 6:07 PM
4	The services I feel are not utilsed effectively.	5/3/2017 12:17 PM
5	as i have been actively involved in care of dementia patients in community	3/13/2017 2:32 PM
6	involved with patients with dementia, carers and dementia nurse.	2/15/2017 6:37 PM
7	have used the service often	2/7/2017 2:27 PM
8	my understanding is that there are very few of these services available.	1/25/2017 5:03 PM
9	The services provided by the memory service are not that good so I have had to learn this myself.	1/25/2017 12:59 PM
10	Over the years- everything keeps changing so I have given up	1/25/2017 12:40 PM

(b) Rating current care provided by GP practice for patients living with dementia.



#	WHY DID YOU COME TO THAT JUDGEMENT?	DATE
1	But I feel with better knowledge I can make it even better	6/22/2017 10:09 AM
2	regular home visits for our dementia patients in line with Qof requirement	5/4/2017 8:26 AM
3	Acrually I can't comment as I only started working there recently but I imagine good or very good	5/3/2017 8:31 PM
4	There is evidence of improvement in Dementia assessment	5/3/2017 12:17 PM
5	we have a register,refer ,sign post and follow up	3/31/2017 12:17 PM
6	as i am new here at practice and not aware of what has been done in the past	3/13/2017 2:32 PM
7	not enough resources to make it very good.	2/15/2017 6:37 PM
8	using ICP for patient with dementia , regular reviews	2/7/2017 2:27 PM
9	terrible support services for people with dementia.	1/25/2017 5:03 PM
10	Over the years. Three boroughs, three different sets up community services, cannot keep up	1/25/2017 12:40 PM
11	I think it gets medicalised when most of the needs are social.	1/25/2017 11:21 AM

(c) How easy do you find coordinating support services for people with dementia

	VERY	SOMEWHAT	A LITTLE	NOT AT ALL
Coordinating support services for people with dementia	5.00% 1	10.00% 2	45.00% 9	40.00% 8
Getting specialist advice by telephone	0.00% 0	15.00% 3	30.00% 6	55.00% 11

(d) How useful would you find the following resources?

	VERY	SOMEWHAT	A LITTLE	NOT AT ALL	DON'T KNOW
Written information for clinicians on services in the community and benefits available to patients with dementia	63.64% 14	22.73% 5	13.64% 3	0.00% 0	0.00% 0
Written information to provide to your patients with details of services in the community and benefits available	77.27% 17	13.64% 3	9.09% 2	0.00% 0	0.00% 0
An EMIS template providing more guidance of the process to follow	54.55% 12	13.64% 3	13.64% 3	13.64% 3	4.55% 1
An online pathway providing information on the dementia pathway and services	52.38% 11	23.81% 5	19.05% 4	4.76% 1	0.00% 0
Meeting with providers of support services in the community for those suffering with dementia	63.64% 14	22.73% 5	9.09% 2	4.55% 1	0.00% 0

INTERVENTION 2:
Dementia Masterclass

Evaluation summary and comments pertaining to 2 Dementia Masterclasses delivered at Willesden Library on 4 May (Day 1) & 22 June (Day 2) are shown **tables 8 & 9** below.

Table 8: attendance characteristics and result of evaluation of Day 1 Dementia Masterclass (on 4 May 2017)

Agenda & format	Details of meetings
 Dementia Academy GP Dementia MasterClass 4 May 2017 – Willesden Library, London Session 1: Afternoon 13:00 Welcome & background: Introduction to dementia – an overview Dr Iracema Leroi 13:20 What is dementia? An introduction to the clinical syndrome & underlying disease sub-types – Practical understanding for GPs Dr Ross Dunne 14:00 Practical assessment of dementia – which questions to ask and why? Including a case Dr Ross Dunne 14:40 Interactive Dementia Pathway during refreshments Sue Thomas 15:00 Differentiating between types of dementia Dr Iracema Leroi 15:45 Refreshments – continue pathway building 16:00 Behavioural and psychological symptoms in dementia: recognition and management Dr Ross Overshott When to involve palliative care Dr Ross Overshott 17:00 Closing remarks and depart	**Day 1- Dementia Masterclass** **(4 May 2017)** **Attendees** (n=13) (4 Male : 9 Female) (44% Male : 56 % Female) Principal GP x 7 (35%) Salaried GP x 3 (23%) Nurse practitioner x 1 (<10%) Pharmacist x 1 (<10%) District Nurse x 1 (<10%)

OVERALL ASSESSMENT	**Low**	**Poor**	**Average**	**good**	**High**
Overall relevance to your educational needs				42%	50%
Overall quality of the education offered				50%	50%
Effectiveness of the meeting for CPD purposes				58%	42%
Extent to which you will modify your practice			15%	31%	54%

CONFIDENCE CHECK **Following this workshop, how <u>confident</u> are you about?**	**Very**	**Some-what**	**A little**	**Not at all**
Understanding risk factors for the development of dementia	91%	9%		
Identifying possible cases of dementia	73%	27%		
Investigations used in the diagnosis of dementia	55%	45%		
Reaching a diagnosis of dementia	55%	45%		
Differentiating between types of dementia	91%	9%		
Understanding the process followed in a memory clinic	55%	45%		
Discussing the probable diagnosis with your patients	55%	45%		
Discussing the probable diagnosis with their family	55%	45%		
Responding to behavioural or psychological symptoms	45%	55%		
When to involve palliative care	27%	73%		

SPEAKER ASSESSMENT

Delegates attending were asked to rate and comment about each of the 6 sessions.

Speaker 1: Dr Iracema Leroi; Welcome & Background: Introduction to Dementia – An overview

	Low	Poor	Av.	good	High
Session relevance			10%	40%	50%
Session delivery				40%	60%

Comments: Not applicable ; Missed it; Neuropsychological Assessment ; N/a – arrived late; Good introduction; Very clear; Missed it I'm afraid

Speaker 2: Dr Ross Dunne; What is Dementia? An Introduction to the Clinical Syndrome & Underlying Disease Sub-types – Practical Understanding for GP's

	Low	Poor	Av.	good	High
Session relevance			8%	38%	54%
Session delivery			7%	31%	62%

Comments: Very good; Very useful session; Nicely presented with real life examples; Very good delivery; I didn't always follow the train of ideas but some really good points, effectively conveyed, thanks.

Speaker 3: Dr Ross Dunne; Practical Assessment of Dementia – Which Questions to Ask and Why. Including a case

	Low	Poor	Av.	good	High
Session relevance				31%	69%
Session delivery				31%	69%

Comments: Very good; Assessment tools used in secondary care are difficult to relay into primary care due to time restrictions

Speaker 4: Sue Thomas; Interactive Dementia Pathway During Refreshments

	Low	Poor	Av.	good	High
Session relevance			18%	55%	27%
Session delivery			18%	82%	

Comments: Didn't get enough time; Would like to see how relevant to our locality; Very knowledgeable but short time; Good idea and development of posters, unfortunately not enough time to put post-it notes on; I couldn't look at the charts properly as there by the coffee table and was too crowded

Speaker 5: Dr Iracema Leroi; Differentiating Between Types of Dementia

	Low	Poor	Av.	good	High
Session relevance				45%	55%
Session delivery				55%	45%

Comments: Short time – had to skip areas; Improved my understanding and I can apply this to my consultations and management

Speaker 6: Dr Ross Overshott; Behavioural and Psychological Symptoms in Dementia: Recognition and Management

	Low	Poor	Av.	good	High
Session relevance				15%	85%
Session delivery				23%	77%

Comments: Very good; Very good and useful session; Again too much info in a short period of time

Speaker 7: Dr Ross Overshott; When to Involve Palliative Care

	Low	Poor	Av.	good	High
Session relevance				15%	85%
Session delivery				23%	77%

Comments: I would like to learn more about advance care planning in a practical sense and how to advise patients and relatives

VENUE ASSESSMENT

	Low	Poor	Av.	good	High
Meeting venue				67%	33%
Refreshments			8%	67%	25%
Organisation of the meeting				75%	25%

Comments: The overall session was informative and very educative

Table 9: attendance characteristics and result of evaluation of Day 2 of Dementia Masterclass (on 22 June 2017)

Agenda & format	Details of meetings
Dementia Academy **GP Dementia MasterClass** 22 June 2017 – Willesden Library, London **Session 2: Afternoon** **13:00 Welcome & introduction** Dr Tony Burch **13:05 Recap on differential diagnosis** Prof Iracema Leroi **13:15 Prescribing relevant to general practice** Prof Iracema Leroi **13:45 Group work – 30 mins per mini workshop (rotate around all)** • Driving and dementia – Local community partner, Dr Claire Hilton • Legal aspects – Local community partner, Dr Clare Smith **14:45 When & how to refer to your local Memory Service & what happens there** Dr Claire Hilton **15:15 Refreshment break** **15:30 Will broccoli prevent dementia?** Dr Tony Burch **15:50 Screening tools (including GPCOG / 6 item CIT test, practical assessment)** Prof Iracema Leroi **16:30 Community resources (10 mins each)** • What written information is available for patients and clinicians? • Meeting providers of support services: ○ Danny Maher, CEO, Ashford Place ○ Hazel Robinson, person living with dementia ○ Phillip O'Dwyer, carer of person living with dementia ○ Clementine Femiola, Brent Dementia Peer Support Project **16:50 Closing remarks** Prof Iracema Leroi **17:00 Depart**	**Day 2- Dementia Masterclass** **(22 June 2017)** **Attendees** (n=13) (4 Male : 9 Female) (44% Male : 56 % Female) Principal GP x 8 Salaried GP x 3 GP Registrar x 1 Pharmacist x 1

OVERALL ASSESSMENT	**Low**	**Poor**	**Average**	**good**	**High**
Overall relevance to your educational needs			8%	15%	77%
Overall quality of the education offered			8%	15%	77%
Effectiveness of the meeting for CPD purposes			8%	15%	77%
Extent to which you will modify your practice			8%	8%	54%

CONFIDENCE CHECK **Following this workshop, how <u>confident</u> are you about?**	**Very**	**Some-what**	**A little**	**Not at all**
Understanding risk factors for the development of dementia	62%	38%		
Identifying possible cases of dementia	62%	38%		
Investigations used in the diagnosis of dementia	64%	54%		
Reaching a diagnosis of dementia	31%	69%		
Differentiating between types of dementia	58%	33%	8%	
Understanding the process followed in a memory clinic	50%	42%	8%	
Discussing the probable diagnosis with your patients	42%	58%		
Discussing the probable diagnosis with their family	42%	58%		
Responding to behavioural or psychological symptoms	25%	75%		
When to involve palliative care	25%	58%	17%	

SPEAKER ASSESSMENT					
Speaker 1: Prof Iracema Leroi: Recap on differential diagnosis					
	Low	**Poor**	**Av.**	**good**	**High**
Session relevance					94%
Session delivery					94%
Comments: Being aware of diagnosis and to screen. The Alzheimer's society assessment was great					
Speaker 2: Prof Iracema Leroi: Prescribing relevant to general practice					
	Low	**Poor**	**Av.**	**good**	**High**
Session relevance					98%
Session delivery					98%
Comments: Could have done with a little more time; Learned something new; Think this was the best session about dementia management; Could be a bit longer; Very useful; More time on this please; Useful to recap the different type of dementia and help to refocus the mind on the topic					
Speaker 3: Dr Claire Hilton, Local community partner (Group work): Driving and dementia					
	Low	**Poor**	**Av.**	**good**	**High**
Session relevance					95%
Session delivery					95%
Comments: Very important session; Good session, unfortunately short comings in service provisions which we are well aware of were apparent; Good session especially on aspects and DVLA; Thanks; Very useful overview, bit too long more case based better; Very useful update and helpful guide					
Speaker 4: Dr Clare Smith, Local community partner (Group work): Legal aspects					
	Low	**Poor**	**Av.**	**good**	**High**
Session relevance					95%
Session delivery					95%
Comments: Very useful; Lots of info in short time; Maybe case studies would be useful; Very comprehensive overview; Very practical; Very useful; Very good but rather too long.					
Speaker 5: Dr Claire Hilton: When & how to refer to your local Memory Service & what happens there					
	Low	**Poor**	**Av.**	**good**	**High**
Session relevance					76%
Session delivery					85%
Comments: Was a bit negative at the end but can understand frustration; Hope to improve referrals; More specific on local pathways					
Speaker 6: Dr Tony Burch: Will broccoli prevent dementia?					
	Low	**Poor**	**Av.**	**good**	**High**
Session relevance					92%
Session delivery					96%
Comments: Good advice and presentation for adult disorders; Good session on risk factor; Useful overview					
Speaker 7: Prof Iracema Leroi: Screening tools (including GPCOG / 6 item CIT test, practical assessment)					
	Low	**Poor**	**Av.**	**good**	**High**
Session relevance					98%
Session delivery					98%
Comments: Good session on meds and different indications usage					
Session 8: Community resources					
	Low	**Poor**	**Av.**	**good**	**High**
Session relevance					98%
Session delivery					98%
Comments: Invested awareness of community resources from service users.					
VENUE ASSESSMENT	**Low**	**Poor**	**Av.**	**good**	**High**
Meeting venue					76%
Refreshments					80%
Organisation of the meeting					93%
Comments: Acoustics not great but ok; Thank you					

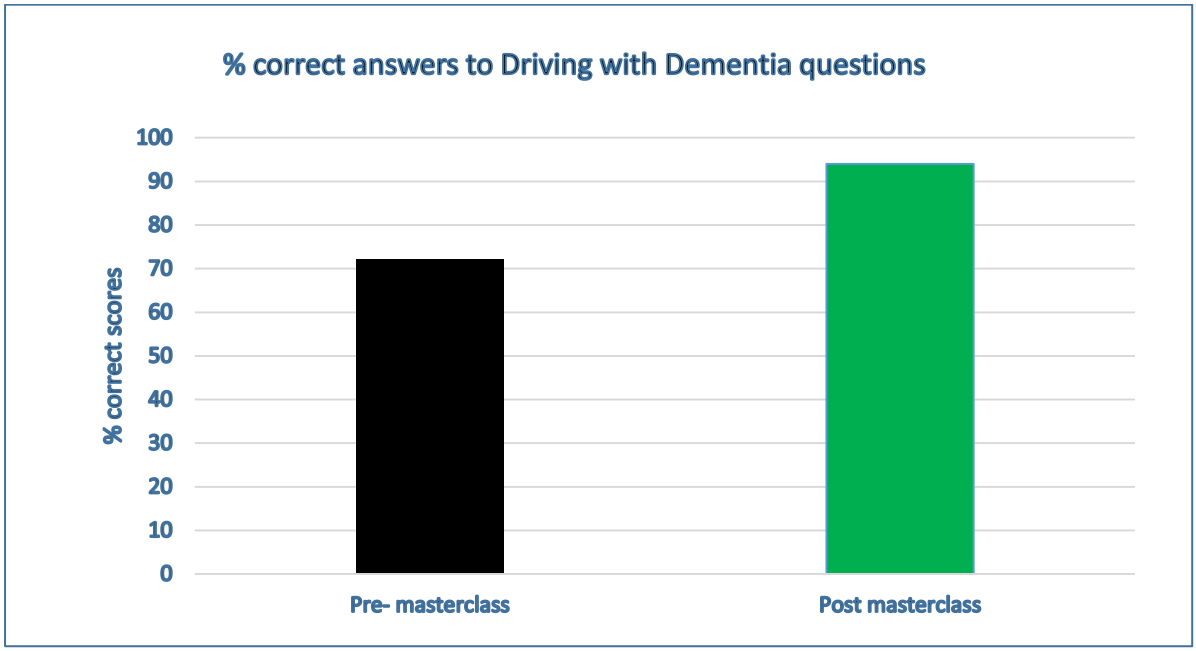
INTERVENTION 3:
Driving with Dementia Workshop

The following 6 questions were used to evaluate the Driving with Dementia workshop delivered by Dr Claire Hilton, Consultant Old Age Psychiatrist, Brent Memory Service, CNWL.

1. A diagnosis of 'dementia' means a patient must stop driving
2. A diagnosis of Mild Cognitive Impairment means a patient must stop driving
3. A MMSE score of 25 is appropriate cut-off for deciding if someone is safe to drive
4. It may be best for the doctor to inform the DVLA, rather than the patient's partner, if the patient will not do it
5. It is useful question to the middle generation is 'Would you let your mother/father drive your son/daughter?
6. Any person with dementia told to stop driving must be given information about alternatives

The workshop resulted in a significant increase in baseline (pre-workshop) test score, rising from 72% to 94% following delivery of masterclass (**Figure 4)**

Figure 4: Effect on Driving with Dementia workshop on overall score



INTERVENTION 4

Memory loss/dementia awareness workshops

CAD Brent delivered a series of face to face (F2F) dementia workshops to: (A) client facing staff in GP practices; (B) community organisations; and, (C) the wider community as follows:

1. Workshop (A) for reception and administrative staff in GP practices
2. Workshop (B) to members of the public & volunteers
3. Workshop (C) to community/faith/ethnic organisations

Aims of the workshops (a & b) were to:

1. Challenge misconceptions about people with dementia, understand the "person" behind the dementia, acknowledging their biography, strengths and abilities
2. Understand the experience of dementia for patients and their family carers
3. Explore the barriers faced by people with dementia using the GP surgery, identifying how receptionists or client facing staff can anticipate or help overcome them
4. Consider the principles of effective communication with people who have memory problems /dementia
5. Explore the reasons why a person with dementia might be agitated or displaying unusual behaviour and consider how this might be avoided and/or dealt with
6. Identify factors in the physical environment which might make access to the practice difficult

The aims of Community/faith/ethnic organisations workshop (c) were to :

1. Outline key facts about dementia, risk factors and importance of early diagnosis
2. Explore the experience of living with dementia and/or being a carer
3. Understand the value of having an early diagnosis in enabling the person to cope, plan their life and take measures to slow the progress of dementia
4. Explore communication with people living with dementia and how to minimise distress and anxiety
5. Highlight the importance of social interaction, cognitive stimulation and ways of maintaining continuity while adapting to and coping with dementia.

The following tables illustrate attendance characteristics of the 3 workshops:

- **Table 10:** (Workshop A) Evaluation summary from Dementia Care Kilburn working group meeting 3.10.17, 2-4pm, Ashford place
- **Table 11**: (Workshop B) Evaluation summary from Community (public) awareness events
- **Table 12:** (Workshop C) Evaluation summary from Community /faith organisations

A narrative section describing important evaluation outcomes of each workshop is presented in that same order.

Table 10: Evaluation summary from Dementia Care Kilburn working group meeting 3.10.17, 2-4pm, Ashford place

GP Practice	Date	Facilitator	Participants	Evaluations	Comments
1. Windmill	17/07/17	MT	11	11	Considering way of flagging up dementia on patient records Also considering setting up dementia support group
2. Blessing	21/07/17	MT	4	4	Already flag up people with dementia on their records but will consider keeping an eye on people with cardiovascular disease, diabetes
3. Willesden Green	24/07/17	MT	6	6	Considering ways of flagging up dementia diagnosis on records. Will arrange an environmental audit. Thinking about setting up a dementia service (suggest calling it a memory service)
4. Park House	04/09/17	MT	7	7	Already flag up dementia diagnosis and telephone reminders sent to people with dementia. Arranging a mini audit by DPSP
5. Peel Precinct	25/07/17	CF	4	4	Explored flag up systems, how staff could be more helpful, signage, flooring, lighting
6. Kilburn Park	15/08/17	CF	10	10	Discussion about signage, reasonable adjustments that could be made to improve the experience of people living with dementia and a flag up system on dementia patients records.
7. Staverton Surgery	11/08/17	CF	12	12	Arranged mini-audit by DPSP. Noted suggestions about signage, lighting and changed voicemail message to make it shorter and easier for people with dementia to understand.
8. Cricklewood Body	18/09/17	CF	-	-	Completed
9. Lonsdale Medical Centre	29/09/17	MT	-	-	Completed
10.Law Medical Practice	28/09/17	CF	-	-	Completed
10. Chichele Rd	-	-	-	-	Not able to arrange
TOTAL	**-**	**-**	**53**	**53**	

Table 11: Evaluation summary from Community (public) awareness events

Organisation	Date	Facilitator	Participants	Evaluations	Comments
APDA	08/05/17	MT	30	Verbal	Half day event aimed broadly at Asian community
Brahma Kumaris	03/07/17	MT/CC	65 +52 on webcast	57	Two hour session for BK and wider community. Webcast live to international audience
Ashford Place	05/06/17	MT	5	5	Open session but poor attendance
Brent Carers	23/06/17	MT	13	13	Organised by Brent Carers at Ashford Place
Brent Housing Partnership	12/09/17	MT	8	6	Invited by BHP for Resident representatives often advocating on behalf of vulnerable tenants -increasingly people with dementia. Considerable potential to establish groups for isolated people to reduce risk of dementia.
TOTAL	**-**	**-**	**173**	**81 + verbal**	

Table 12: Evaluation summary from Community /faith organisations

Organisation	Date	Facilitator	Participants	Evaluations	Comments
APDA	10/05/17	MT/CC	5	Verbal	Half day targeted at staff/volunteers working with people who may have dementia . Keen to establish a memory café subject to funding
Brahma Kumaris	03/06/17	MT	19	17	Whole day event as BK interested in establishing local support group
Neasden Temple	16/08/17	DM/CF	132		Successful event with follow up events requested from the Temple
Cricklewood Mosque	18/8/17	DM/CF	150	10	Clem presented to the women and Danny to the men. Good interest in the topic and a plan to develop dementia support services
Pakistani Community Centre	23/08/17	DM/CF	20	-	Follow up events requested e.g. development of a dementia café. Low levels of confidence in approaching GPs therefore more work required
South Kilburn Trust	-	-	-	-	Planned for mid-September
TOTAL	**-**	**-**	**326**	**27 + Verbal**	

(A)

Memory loss/dementia awareness Workshop to GP practice staff

Dementia awareness workshops were delivered to ten GP practices in the South Kilburn area by Dr Mary Tilki and Clementine Femiola (CAD Brent), from July to end of September 2017.

Releasing staff for training was difficult and workshops were held during lunchtimes or as part of regular practice meetings. A total of 77 staff who were mostly in reception, administrative or health care assistant roles participated. Most practice managers and a small number of GPs and practice nurses also participated. A total of 75 evaluation forms were completed and summary outcome is shown in **table 13** below.

Table 13: Evaluation outcomes of Dementia awareness workshops for reception and administrative staff in GP practices

Practice staff n=75 total	Strongly Disagree	Disagree	Ambi-valent	Agree	Strongly Agree
I have a better knowledge of dementia than I had before			3 (4%)	30 (40%)	42 (56%)
I have a better understanding or what it feels like to have dementia			4 (5%)	33 (44%)	38 (51%)
I understand the barriers faced by people with dementia in my department			3 (4%)	31 (41%)	41 (54%)
I feel more confident to talk to and support a person living with dementia		1 (1%)	2 (2%)	32 (42%)	40 (53%)
I understanding why a person with dementia might be agitated			1 (1%)	30 (40%)	44 (59%)
I understand that people with dementia are still people and retain many skills and abilities			1 (1%)	24 (24%)	50 (75%)
I would like to learn more about dementia			10 (13%)	29 (39%)	36 (48%)

Additional verbatim comments from delegates attending

- *informative and interesting*
- *The facilitator was friendly. Informative. Answered questions*
- *Very informative and interesting*
- *After this training I feel more confident to support people with dementia"*
- *very good training, it opened my eyes*
- *Excellent trainee; Great training & Very good presentation*
- *Greater understanding of dementia. Hopefully more training*
- *This service was wonderful to be part of. Very informative, useful information which can be passed on*
- *Very interesting talk, very useful for a medical student as we only focus on the clinical side.*

Dr Mary Tilki's reflections on the workshops are included in **table 14** below.

Table 14: Reflections form public GP practice staff awareness workshop

Reflective Feedback Summary (by Dr Mary Tilki)
Releasing staff for training was difficult and workshops were held during lunchtimes or as part of regular practice meetings. A total of 77 staff who were mostly in reception, administrative or health care assistant roles participated. Most practice managers and a small number of GPs and practice nurses also participated. A total of 75 evaluation forms were completed. Although participation aim was a minimum of 90 minutes, this was only possible in a small number of practices. However the facilitators were made to feel welcome and there was a general thirst to understand more about dementia and work towards making the practices dementia friendly. Although intended for reception and administrative staff, a number of GPs and practice nurses also participated in these sessions and reported that the training had been thought provoking, throwing a different light on the barriers faced by people with dementia. Participants drew upon experiences with patients who either had a dementia diagnosis or they suspected might have the condition. They also talked about family members they were currently concerned about or caring for. Some expressed anxiety about their own memory or that of a relative. Most groups asked about ways of preventing dementia, although the time to address this was very minimal. The workshops were invariably rushed, but facilitators got the impression that staff underestimated the capacity of people with dementia to understand what was happening to them, be independent or have a reasonable quality of life albeit with support. Many had not thought about environmental barriers such as automated phones, poor signage, lighting or the inadequacy of ten minute appointments. Some were already aware that people who had spoken English as a second language for decades might lose this ability when they got dementia. Participants were somewhat surprised that people with dementia were aware of their memory problems although not necessarily able to communicate clearly and had not considered how the fear anxiety and embarrassment this caused often led them to isolate themselves from uncomfortable situations. Participants were generally conscious of patients with memory loss, but had not considered other symptoms, such as communication problems, changes in behaviour, neglect of appearance, poor judgement etc. They were interested to understand more about behavior as a form of communication in order to minimize the underlying causes of agitation or aggression . While many

appeared to keep an eye on patients with dementia, they had not considered that people attending practice for other conditions such as cardiovascular disease, hypertension, diabetes might also have dementia.

What was evident was that all participants were concerned to help and support people and make the service dementia friendly. One practice was hoping to establish a specialist service for people with dementia and sought advice about breaking down the reluctance of people to engage. Another practice hoped to have a carer's group. Going forward practices who did not already do so, planned to discuss secure ways of flagging up dementia diagnosis on medical records. They would endeavour to ensure patients were given written appointments and information about treatments. Telephone or text reminders would be sent to ensure people remembered check-ups or follow-up appointments. Automatic telephone systems and voice mail messages would be reviewed to ensure they were easier to understand or operate by people with dementia and/or older people. Participants were keen to review signage, lighting, colour schemes and general ease of navigating around the surgery. Some practices have already arranged for people living with dementia from the Dementia Peer Support Project to undertake an environmental audit to help them make the physical environment more accessible.

A simple Likert scale evaluation form was completed by all except two participants. Evaluations were completed very quickly as staff had to re-open surgery so few written comments were included. However the staff, were very grateful for the sessions, felt more time was needed, and asked questions as they got ready to open doors again. A small number of staff spoke to the facilitators confidentially because they were worried about their own memory or that of a relative. Had time been available the participants felt that sessions would have benefitted from more information about dementia, especially about how to prevent it.

(B)

Memory loss/dementia awareness Workshop to members of the public & volunteers

Two sessions were provided by Asian Peoples Disability Alliance (APDA) as follows:

1. The first session on 08/05/17 was a public awareness session held at APDA centre and organised by APDA staff.
2. The second session on 10/05/17 was intended predominantly for staff/ volunteers to build on the general awareness session using case study examples to explore communication and barriers and how to minimise agitation and increase an understanding of the person and the barriers they face.

APDA's reflections on the workshops are included in **table 15** below.

Table 15: Reflections form public awareness session

Reflective Feedback Summary from Public awareness session held at APDA centre and organised by APDA staff
• The audience comprised of 17 service users/carers / members of the public and 13 members of staff/volunteers all from diverse Asian backgrounds, with a range of physical, psychological and learning disabilities within the group. To address language barriers for the service users, the content was simultaneously translated into the commonest used language, Gujurati by a member of staff. This took a lot of time but was valuable for participants as staff debated different terms, meanings, words and concepts in other Asian languages. • Although intended as a community awareness session, staff engaged more readily, asking questions, relating content to clients they supported in home care or APDA settings and attitudes to dementia in their own communities. The experience of dementia and approaches to communication were discussed, as well as the importance of assessment and diagnosis. Family carers needs were also discussed and staff reported that the training provided them with further insight into understanding how family carers can experience isolation and need more understanding and support within their communities. • Staff engagement in the training demonstrated a real desire to learn about dementia and sought advice on how they can improve their own practice both professionally and within their personal lives. They spoke about the lack of awareness and stigma within their own communities and suggested that more direct community work is required to bring effective change with leaflets translated into various languages to

be made available. It was believed that families within the Asian community will not present for assessment until crisis occurs.

- Staff were keen to have more information and requested simple written information which could be used in places of worship to improve awareness and change attitudes. Because the staff represent different faiths, cultures and generations, they could be a conduit to the wider community and faith groups. Although most of the service users appeared engaged, it is difficult to know to what extent some had the capacity to understand even in a familiar language. Because of literacy, language, level of disability and time it was not feasible to undertake a written evaluation.

Reflective Feedback Summary from session held for staff/ volunteers to build on the general awareness session using case study examples

- This session was intended predominantly to explore communication and barriers and how to minimise agitation and increase an understanding of the person and the barriers they face
- The session provided the opportunity to explore what can be done to help a person with dementia in specific situations. Disappointingly only five staff members and one volunteer were available to attend this second session due to the number of service users in the centre on the day and the need for staff to be present. The session was conducted in English with occasional words translated and the meaning debated in different languages . Although all participated and contributed, the lack of basic information was a problem for some of the participants. They directly expressed their disappointment and requested that the second session be repeated. Only one person who attended the first session was released to participate however this staff member did offer to share their learning by using the case studies to share with other staff.

(C)
Memory loss/dementia awareness Workshop to community/faith/ethnic organisations

A number of awareness raising workshops were organised in collaboration with voluntary, community and faith groups with the following aims:

1. Outline key facts about dementia, risk factors and importance of early diagnosis
2. Explore the experience of living with dementia and/or being a carer
3. Understand the value of having an early diagnosis in enabling the person to cope, plan their life and take measures to slow the progress of dementia
4. Explore communication with people living with dementia and how to minimise distress and anxiety
5. Highlight the importance of social interaction, cognitive stimulation and ways of maintaining continuity while adapting to and coping with dementia.

The Dementia Awareness workshops

Ten workshops were delivered by Dr Mary Tilki, Charlotte Curran, Danny Maher, Clementine Femiola of CAD Brent and took place between July and September 2017 in various venues across the borough (**table 16** below).. Although the aims were common to all, the information was tailored to the needs of different constituencies and responsive to their questions or concerns.

In total, dementia awareness was provided to over 450 people. Further workshops were requested by Cricklewood Mosque, Pakistani Community Centre, Neasden Temple and Brent Housing Partnership

Table 16: list of community/faith and ethnic organisations hosting dementia awareness workshops

Organisation	Event description
Asian Peoples Disability Alliance (APDA)	facilitated a workshop geared to people from different Asian communities and was attended by 30 people including APDA staff and volunteers. The session was delivered in English with translation provided by staff and volunteers.
Brent Carers Centre	organised a workshops at Ashford Place which provided information and opportunities to ask questions. It was attended by 13 people caring for relatives with dementia from Caribbean, African, Asian, Arabic, Irish and Mediterranean communities.
Neasden Temple	organised an event attended by 132 people of Hindu origin from different parts of the world. The session was delivered in English with translation of terms provided by volunteers
Ashford Place	organised an open public workshop attended by six people

Organisation	Event description
Cricklewood Mosque	organised a Friday Midday event, attended by 150 people with men and women participating in different sessions. The session was delivered in English with translation provided by participants
The Pakistani Community Centre	organised a workshop attended by 20 people. The session was delivered in English with translation provided by participants
Brahma Kumaris	(also known as World Spiritual University) facilitated a session attended by 65 people with 50 more participating in the live webcast.
Brent Housing Partnership	workshop was attended by eight tenant representatives from different parts of Brent, who were interested to learn how they could help the growing numbers of people with dementia and others who were isolated and at risk of dementia. BHP have since arranged conversations with Ashford Place about the design and development of community led dementia support services.
Brahma Kumaris and APDA	interested in setting up memory cafes. A further whole day workshop at Brahma Kumaris was attended by 19 people. A second half day workshop was delivered to six people at APDA. These events provided more detailed information about dementia and used case studies to explore communication, behaviour and the meaning of dementia friendly environments for people of different cultures.

Evaluation of workshops (narrative by Dr Mary Tilki)

Where language, literacy and time permitted, participants completed a simple Likert scale evaluation form. Brent Carers Centre and Brent Housing Partnership, asked participants to complete their own evaluation forms which were different to that of CAD Brent, but sought views on what had been learnt.

Written Evaluations

The written evaluations demonstrated very clearly that participants felt they had increased their knowledge of dementia and they had a greater understanding of how a person with dementia or a family carer might feel. They were better able to appreciate the value of early diagnosis in helping people plan their lives and learn to cope with the changes brought by the disorder. They felt more confident to talk to and support and person with dementia , because they understood the importance of seeing the person as a person rather than a product of their disease. They appreciated the value of social interaction, stimulation and keeping in touch with family and community. Participants who added comments, generally thanked the facilitators for their time, the information provided and many mentioned the need for further workshops and/or more time.

Verbal evaluations

However, for the majority, written evaluation proved too difficult. Instead, audiences were given the opportunity to say how much they had learned, whether they had a better understanding of dementia, or how confident they felt to talk with somebody living with dementia. In particular participants reflected on how they had tended to underestimate

how much people with dementia understood. They now realised that people with dementia could continue to function and live well with support from family, businesses, services or members of the public. There were many discussions about the tendency to overprotect which could result in people with dementia losing their identity, confidence or becoming deskilled. Participants said they now had more empathy with those who had dementia and had learned how they might communicate or act to minimise anxiety, distress or agitation. Those who had not been carers were mostly unaware of how demanding informal care was and how unsatisfactory social care services could be. Participants had begun to see the value of a diagnosis, although many had struggled to get a family member (or sometimes the wider family) to agree to see a doctor. Some had negative experiences of getting a doctor to make a diagnosis. Several participants commented that they wish they had access to this type of information when their relative was diagnosed.

Reflective evaluation from the facilitators

While the different approaches to evaluation demonstrate the learning participants have gained, the facilitation process highlighted a number of issues which should influence and shape how we go forward. Although it was not possible to remember or record every interaction, a number of themes were evident across all the community/faith groups which should inform the ongoing direction of Kilburn PIE and CAD Brent. The themes are summarised in **table 17** as follows.

Table 17: reflections on 9 themes arising from community/faith/ethnic workshop interaction

1. Great thirst to know more about dementia
Facilitators were invariably welcomed, invited back and participants were happy to ask questions, to know more about dementia and particularly about the causes, risk factors and how to prevent it. People often drew on their experiences as carers, seeking help to cope with a relative or being worried about their own memory. Although some were happy to ask about themselves in the groups, facilitators were approached confidentially on several occasions after the workshop by participants concerned about their memory. Several participants commented that the information was presented in an accessible, light-hearted manner and was easy to understand. ○ *Great workshop. More workshops like this would be great, Strokes, heart attacks (Participant - Brent Carers Centre workshop)* ○ *"It has brought a lot of clarity and made me more comfortable to help out. Also insights on preventive measures to take" (Participant Brahma Kumaris workshop)*
2. Knowledge of dementia
Workshops generally included a question about images of and assumptions about dementia and these generally highlighted negative stereotypes of people with dementia, exaggerating the prevalence of violence and aggression and presuming almost total loss of capacity. There was fairly widespread belief that dementia was a normal and almost inevitable part of ageing. Discussions highlighted the low level of knowledge (even stereotypical) in different Asian communities and either the lack of a word or use of

degrading words to describe dementia in various Asian languages. Participants in one Asian group highlighted the need for accessible information about dementia, where to go for help and how to help somebody with the condition in different languages. Because of high levels of illiteracy in some communities printed information is not useful and audio or visual formats are needed.

- *"Thank you for thinking of us and helping us to understand. We need more of this" (Participant Neasden Temple workshop)*
- *"Learned a lot today on this subject which will be very helpful for me in the future" (Participant Brent Carers Centre workshop)*

3. Underestimating the ability of people with dementia

Participants had generally not thought that people with dementia were aware of the problems they had with memory or speech. They tended to perceive people with dementia as helpless and hopeless rather than able to be reasonably independent (especially in the early stages) providing they had some support from those around them. Few had thought about how frightening loss of memory or not being able to communicate efficiently was for people with dementia and planned to be more patient and helpful. Participants understood that shame and embarrassment caused people to isolate themselves or adopt strategies to avoid meeting people they might not recognise or be able to talk to. They were pleased to learn how to communicate with somebody who had dementia and many pledged to be more proactive in helping a person who looked confused, lost or who appeared unable to work out how much to pay in a supermarket

4. Dementia in families

Participants in all workshops had experience of dementia in their families, were caring for or had cared for a relative with dementia. This clearly reflects the demographic of a diverse and increasingly ageing multicultural population with many risk factors associated with dementia. Those who spoke, invariably talked about the demands of caring, the impact on their health and isolation experienced because friends and family did not understand dementia. Asian participants appeared particularly isolated and felt neglected by their own communities. Many were unaware of the help available to them in the community or health and social care sector but several participants talked about difficulty in negotiating the different services. There were particular concerns about the quality of social care especially for people from minority ethnic groups . A few participants, were reluctant to seek help for a relative with dementia either because they or the person concerned feared being taken away and being placed in a home.

- "*Our community are suffering and we need your help" (Participant - Neasden Temple workshop)*

5. Struggling to cope

Apart from having difficulty accessing services carers were struggling to care for somebody, whose personality had changed and whose behaviour they did not understand. Carers seemed to be willing to talk about difficulties they were experiencing and appreciated learning simple strategies which might make life easier. While

participants were mainly aware of memory problems, they had little understanding of the communication, behaviour or cognitive difficulties which occur in dementia. Several participants sought advice about dealing with repetitive questioning, whether to correct the person with dementia when they believed something wrong, how to prevent agitation. They did not understand behaviour as a form of communication and were keen to explore ways of identifying the causes of agitation, so as to minimise or avoid them.
Some carers who spoke (some confidentially) would consider external help such as day care or home care but believed their family or community would not approve. A few had considered or tried local day care but it did not feel right for people from other cultures. Participants had not thought about the exacting demands on carers and vowed to be more proactively supportive of people they knew were caring for a relative.

- *" I wish I'd known all this when I was a carer for my mother" (Participant Brent Carers Centre workshop)*

6. Stigma

The cultural/religious organisations collaborating with CAD Brent to arrange the workshops, were keen to encourage dialogue about dementia, improve knowledge and reduce misunderstanding and stigma associated with it. Although people from a range of different ethnic /religious groups were happy to talk about dementia in the workshops, they invariably talked about stigma in their own communities. Participants believed a lot of work was needed with BME communities to improve their knowledge of dementia and the services available to support people with the condition and their families. Several Asian people mentioned concerns about arranged marriage which might prevent families being open about a relative with dementia. Caribbean, Asian and Irish people mentioned shame attached to seeking external help, almost a derogation of their duty as family members. There is still stigma attached to claiming "benefits" –several participants claimed proudly they had never asked for benefits. Clearly any allowances are the entitlements that people have already paid for.

7. Dementia diagnosis

Participants could see the value of having a diagnosis and having one as early as possible, but many did not know how or where to get one. Many complained about the difficulty of getting appointments with GPs and several were dissatisfied with the experience of seeking help for a relative with dementia. Some felt that doctors did not have enough time to do an adequate assessment but others felt GPs did not listen to relatives and dismissed signs and symptoms that were happening frequently but denied by the patient. Those whose relatives had been diagnosed, felt they had not been given adequate information and although some did their own online research they needed information which made sense to them which was relevant to their relative and their culture.

- *"Can my GP diagnose dementia?" (Participant -Neasden Temple workshop)*

8. Preventing dementia

A recurrent theme across all the workshops was how to prevent dementia. Several participants expressed concern about their own memory or that of a close relative. Because of time constraints this could only be dealt with very superficially but there is an appetite for information about prevention, especially targeted at different communities. Participants were particularly interested in diet, sleep and the impact of stress on

dementia.

- *I am worried that I have dementia. When watching a film with my children, they were worried because I didn't recognize the same character who had appeared in the film earlier on" (Participant Cricklewood Mosque Workshop)*

9. Dementia friendly environment

Participants from community faith /ethnic organisations were keen know more about making their environments more dementia friendly and accessible to people with memory problems. These groups saw the valuable role they could play in enabling people with dementia and carers remain connected to their communities, practice their faith, navigate their localities and retain their cultural identity.

- *"I would like to know more how to develop the memory to prevent dementia. What sort of food should be taken?"(Participant Brahma Kumaris workshop)*

Ongoing development

Neasden Temple, Cricklewood Mosque, and the Pakistani Community Centre all expressed an interest in making their venues and services more accessible and inclusive of people with dementia and their carers.

Brent Housing Partnerships have expressed an interest in developing support for people with dementia, as well as for isolated people who may be at risk of dementia and have already been in contact with CAD Brent for advice.

Recommendations

1. There is interest and concern which should be harnessed, working collaboratively with community, faith and ethnic community groups, but expanding these across the borough
2. The workshop format was successful. There is a need to create dialogue which challenges the negativity and hopelessness of current dementia discourse and focus what can be done to enable people with dementia have a decent quality of life
3. Information and training must focus on the strengths, abilities and personhood of the person with dementia while recognising the challenges dementia imposes and the rights of the individual.
4. There is a need to reach out urgently and with cultural sensitivity to people who are already caring for somebody with dementia. There are opportunities to invest in cultural, faith and ethnic groups who already provide or have the potential to provide accessible, acceptable support for people with dementia and their family carers.
5. Family carers urgently need information and training to help them cope, avoid or minimise crises and maintain their own health. There is an urgent need for culturally sensitive support for family carers and respite for people with dementia.
6. There is a need to address stigma across all communities but particularly in BAME groups who appear to have assimilated public discourses about benefits, dependence as well as dementia. There is a need to challenge negative messages about seeking external help within some BAME communities.
7. GPs and their practices need to consider the barriers for people with dementia and carers and to signpost them to NHS or resources in the community as appropriate

INTERVENTION 5
Face to face sessions with Dr Warner, Consultant Psychiatrist

Consultant Psychiatrist evaluation

Dr James Warner, a well-known and respected Consultant Psychiatrist in Brent visited individual practices and delivered a 1 hour session on dementia, before recording feedback on the evaluation form . Results of the feedback are summarised in **figure 5 & table 18.**

Figure 5: Configuration matrix showing delegate feedback following face-to-face sessions with Dr James Warner.

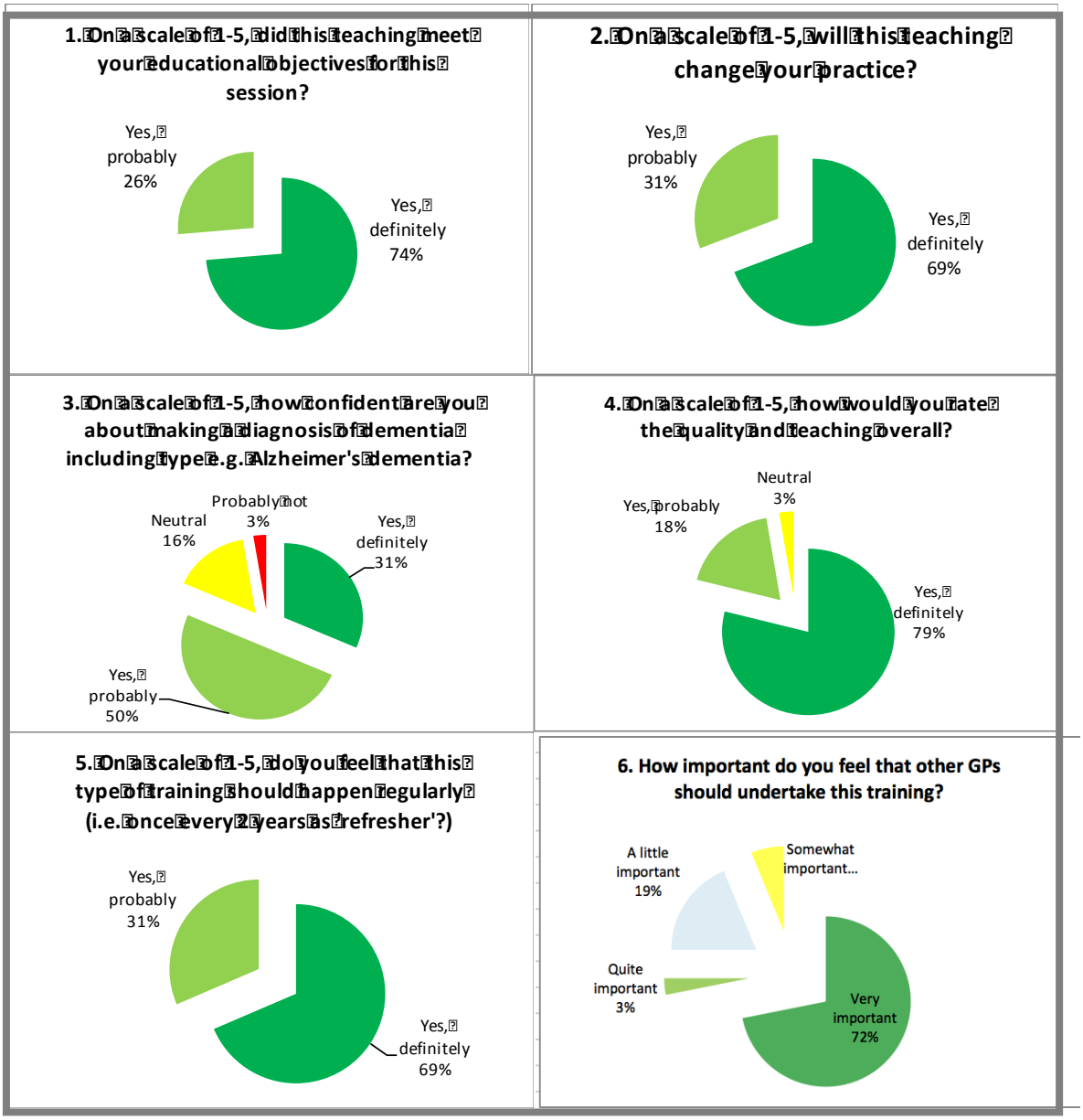


Table 18: participant feedback and comments following face to face sessions with Dr James Warner

Question	Participant feedback/comments (highlights, abridged)
How did this teaching meet your educational objectives for this session?	• Addressed key issues in Dementia and Memory service • Good coverage of diagnosing dementia and challenges faced • Relevant and interactive; Clarified queries I had about early diagnosis benefit and my position as GP Interactive session would be helpful • useful practical info on diagnosing and prescribing • Excellent discussion cover the diagnosis and treatment • Discussed management plan, I learnt many new things about dementia e.g. Montreal cognitive assessment • All points were covered and explained clearly, covered main types of dementia • Very informative but big topic • It was focused more to our needs as GPs • Good balance of GP led discussions and learning bits from consultant • Very concise, informative and helpful • Good recap on dementia signs and symptoms, treatment options, good one to one teaching, interactive • Case based discussion, Q&A session • Lucid interactive presentation, brilliant talk • covered multiple topics, very approachable • Understanding the evidence base for antipsychotic/anti-depressants, understanding when to use referral pathways - Would have like some more info aimed toward nurses/HCAs - session was a little bit short
2. How will this teaching change your practice?	• Consider initiating treatment for patients and seeking second opinions if needed • Confidence in making diagnosis &prescribing • Importance of engaging patient/family in early diagnosis even if patient still functioning • Feel more confident to Diagnose and treat • will commence medication/treatment • I am more clear about diagnosing dementia than I was before the meeting • crib sheet provided, to go back to and reflect on • review treatment, social care • Use awareness of cog decline in clinics • Learnt more about suitable drugs to initiate elderly patients with dementia • very useful tips/practical points; My understanding has improved • I have a few patients in nursing homes who would be suitable for audit re. change of meds • revealed that dementia is a condition for GP diagnosis and management • More awareness of dementia, will use a better screening test opt help diagnosis • lots of learning points; Informative, very clearly explained • more confident in treating and diagnosing Alzheimer's disease • very good summary of medical treatment options • Good update on medication and management of night time distress • more confident making clinical diagnosis at the outset • use of Anticholinesterases inhibitors and when to make this decision, decision to use antidepressants - extensive guidance and discussion
3. What determines your confidence are you	• Occasionally cases-certain, are more difficult to diagnose clearly • is type important? When more repeat prescription (although we discussed different medications according to symptoms • Info on tools

about making a diagnosis of dementia including type e.g. Alzheimer's dementia?	• Need to do it and practice • observations/clock test • I need more experience to diagnose dementia with confidence • more confident and have more guidance • educate managing further • need more training • I have special interest in mental health, todays training has given me moral boost • I need more training • it's very refreshing and useful session • From 2 study afternoons and today's meeting • Year of experience • clear explanation • improved knowledge • Well, improving confidence • lack of practice/experience • I still need some help with initial diagnosis and type of dementia • confident but usual exposure required from myself • especially with regards to scans • increase confident in making the diagnosis at GP level
Additional (generic) comments	• Would benefit from regular (yearly) sessions like this and a phone advice line if necessary in between (?GPSI) • Thank you Dr Warner • Excellent update • Thank you Dr Warner • Please further teaching session • Very interesting talk and participation • Very good way to access relevant CPD • Very well presented and informative, thank you • Dr Warner was very nice and gave me a one to one tutorial. I am a single handed GP, however a group session with other GPs could have also been very effective • Extremely helpful, much better than the large group workshops • It would also be important to know about local services • Please further teaching session • Very interesting talk and participation, and a good way to access relevant CPD • Dr Warner was very nice and gave me a one to one tutorial. I am a single handed GP, however a group session with other GPs could have also been very effective • Extremely helpful, much better than the large group workshops • It would also be important to know about local services
Post evaluation comment from Board Member	One of the best evaluations if have seen for a while. Goes to show why this PIE was so important. Great to hear the enthusiasm coming through from GPs and they have obviously been impressed, so let's have more? We need to change the 19 people saying 'yes, probably' to the question of whether or not you feel more confident of making a dementia diagnosis to them saying 'Yes, definitely'. Excellent.

DCK Working Group Survey for project

DCK Working Group Survey for the project used the CLAHRC long term success survey tool (LTST) (http://bmjopen.bmj.com/content/7/9/e014417). The survey provides an indication

of the Working Group believe the project was progressing and will form part of the final evaluation. Figures 6 & 7 below show results of LTST from 22 respondents.

Figure 6: Configuration matrix showing responses to questions 1-7 from CLAHRC long term success survey tool

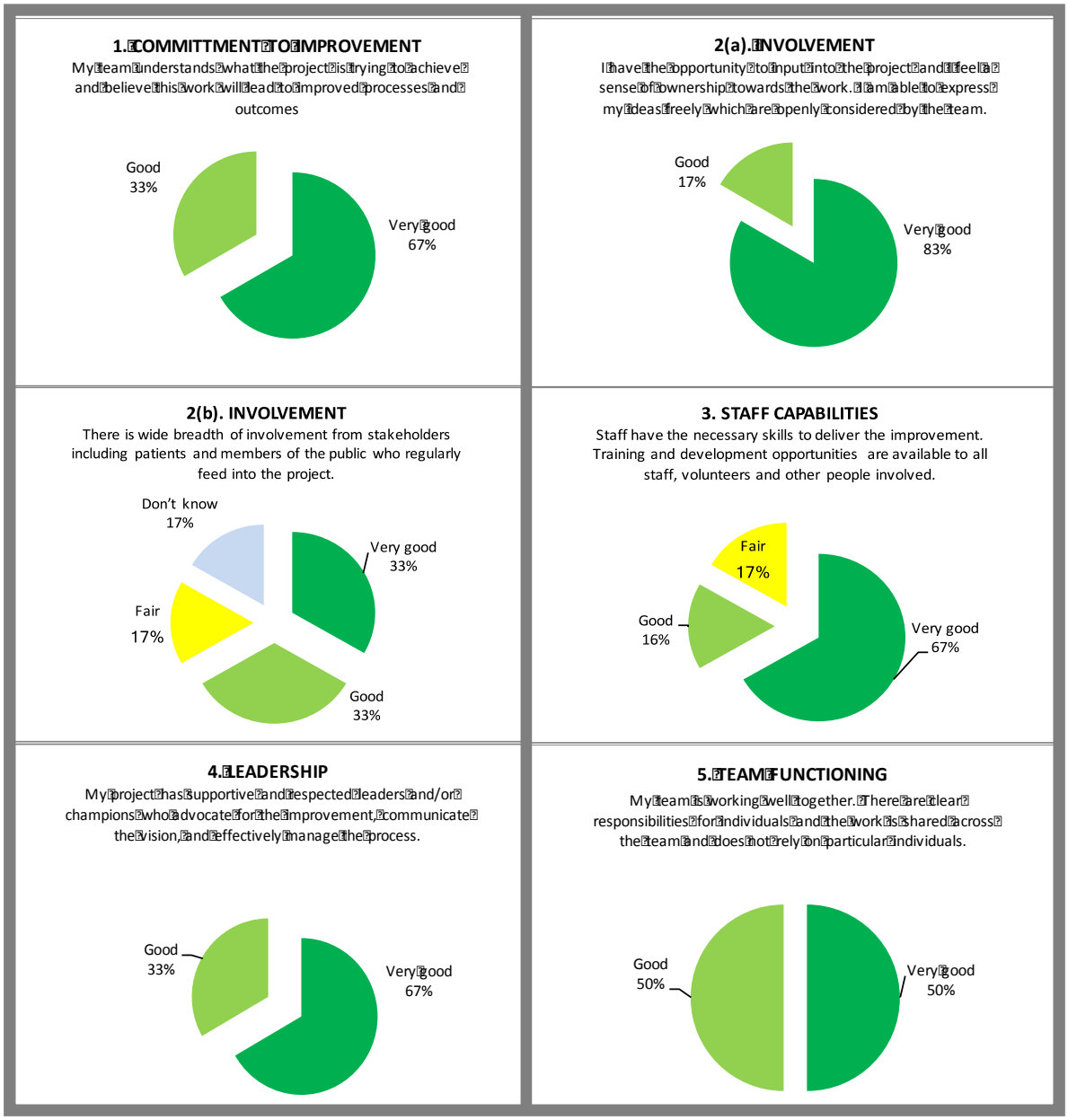
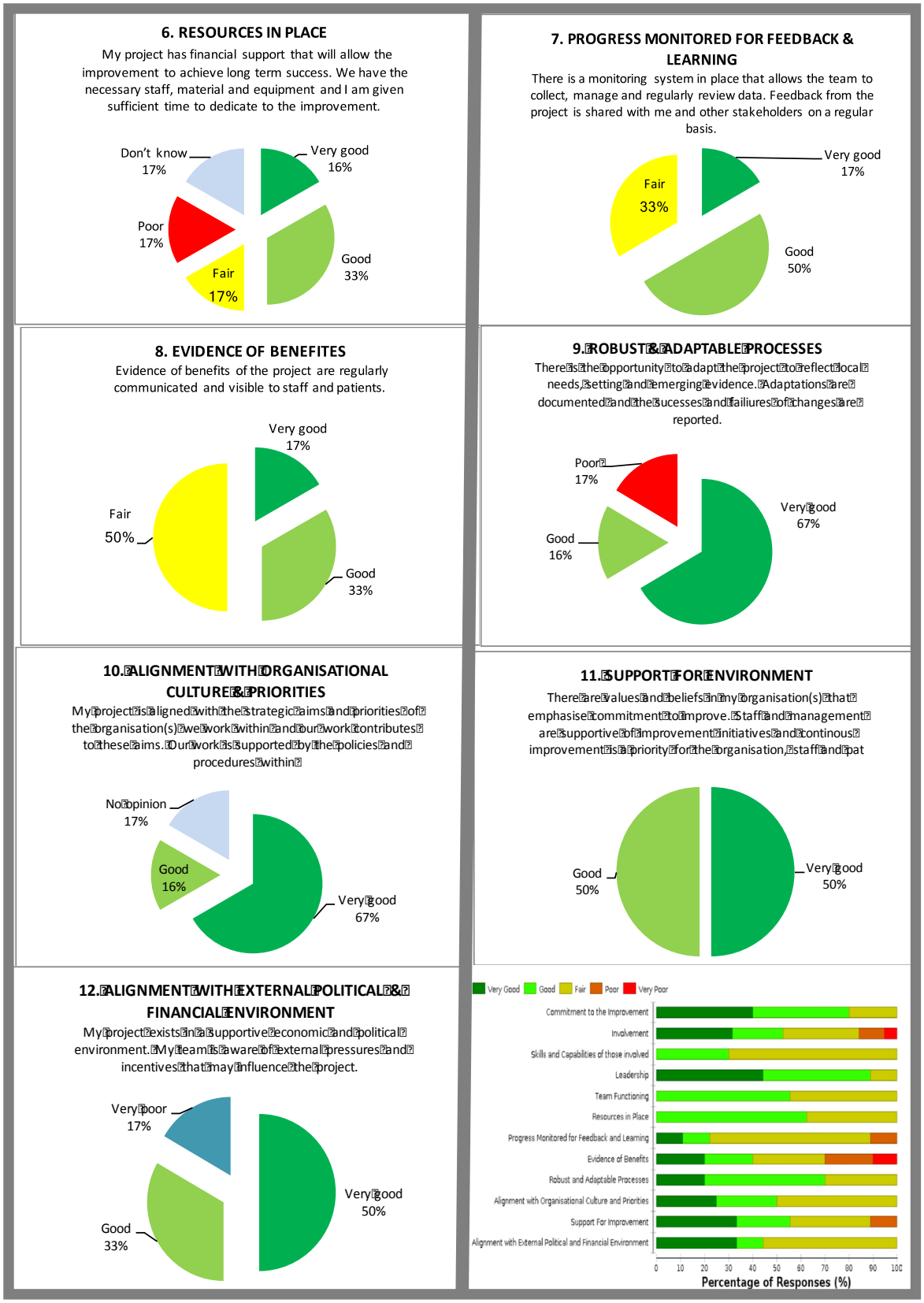


Figure 7: Configuration matrix showing responses to questions 8-12 from CLAHRC long term success survey tool



Other outcomes

The pilot had a number of unexpected outcomes including advocacy, outreach and other unexpected outcomes as summarised in **table 19** below.

Table 19: Invite and example feedback following proposal to carry out dementia friendly audit across participating GP Practices.

Item	Description
(ADVOCACY) Primary Care Led Dementia & Psychosis Service	Currently, Brent CCG are commissioning a Primary Care led Dementia and Psychosis service for Brent. Kilburn have had the opportunity to lead on the provider side as a result of the learning from the PIE. The Project Manager sits on the task and finish group for the service and the Dementia Steering group.
(ADVOCACY) Brent Side Dementia Steering Group	The Project Manager now sits on the Brent Side Dementia Steering Group. Her membership in the Steering Group supports advocacy and information sharing between both groups.
(OUTREACH) Queens Park Day	Working with Brent Dementia Peer Support and a 'Whole Street of Support', the DCK PIE initiative commissioned a stall at Queens Park Day on Sunday 17th September. The invitation to GP practices was well received and this community engagement activity was a good example of Brent Dementia projects working collaboratively. It was the first time that the collaboration had presence in Queens Park Fair in the form of a stall. The event helped to raise awareness of dementia and sharing experience of/interest in dementia. It was also an opportunity to reduce stigma in the community, to make new connections and supported the vision to making Kilburn dementia friendly. The event also included stall and YURT! with posters and dissemination of leaflets and informational material.
(UNEXPECTED OUTCOME) **Mini Dementia Friendly Audits**	A peer and volunteer organised to walk through a number of practices with the aim of assessing suitably of signage and any other elements of the building that may need modification that would help towards a dementia friendly place. The invitation to participate in this 'mini dementia friendly audit' was well received by practices. <u>Excerpt from response email following completion of audit (at Staverton Surgery):</u> "The visit went extremely well. The points I noted are as follows: Signage:- Reception, Way Out (Yellow Background), Disabled Toilet (Yellow Background, Sign for upstairs toilet, Cleaning cupboard needs a No Entry sign. Sensor Light in toilets (I will be looking into getting quotes for this). It was mentioned that you have some signage posters. I wonder if you would be kind enough to email them to me so that we can print them off in colour and laminate them. Diane and Hazel also helped me with the voicemail message to make it simpler and easy to understand, this will be updated by 1st October."

3.2 QUANTITATVIVE FINDINGS

- Dementia diagnosis and outpatient referral data
- Audit of quality of the referrals to the Brent Memory Service

Quantitative evaluation to assess the effect of the DCK PIE interventions following benchmarking exercise

Two EMIS searches were conducted centrally across the General Practices participating in DCK PIE to support the evaluation as follows:

1. the number of referrals for all Kilburn practices to the memory service – Pre- project from November 2016 and then again end of September 201 (Benchmark timeline)
2. Number of patients diagnosed with dementia – between November 2016 and end of September 2017 (i.e. Intervention timeline)

Although 11 General practices were involve, data relating to practice list size, dementia diagnosis and subsequent secondary care referrals to memory clinic were only forthcoming from 10 practices (**table 20**).

The 10 General Practices had a combined list size of 72,849 patients, with 323 dementia diagnoses in the 10 month pre-intervention (i.e. bench-mark) period, compared to only 54 new diagnosis during the pilot intervention with the same time span (**tables 20-21; figure 8**). This equates to 83% reduction in dementia diagnosis during the intervention timeline when compared to benchmark figures across a similar time span.

Referrals to memory clinic were also significantly (26%) lower during the intervention when compared to benchmark figures (71 referrals during vs. 96 referrals prior); **figure 8**. The number of patients on the dementia Register across all practices increased from 323 at baseline to 379 (i.e. 14% increase in 10 months).

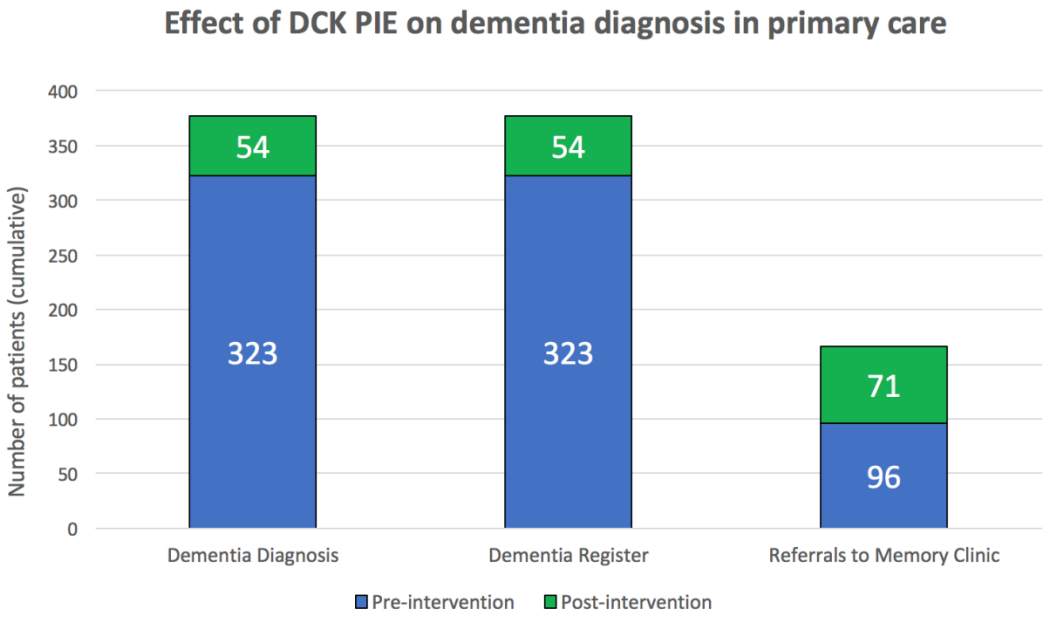


Figure 8: the effect of DCK PIE interventions on improved dementia referrals in primary care and subsequent referrals to memory clinic

Table 20: Dementia diagnosis and patient referral data from 11 participating DCK practices over 20 month period (10 months prior to intervention, and during 10 months intervention timeline)

	Blessing Medical Centre	Chichele Road Surgery	Cricklewood Broadway	Kilburn Park Medical Centre	Park House Medical Centre	Peel Precinct Surgery	Staverton Surgery	The Law Medical Group Practice	The Lonsdale Medical Centre	The Windmill Medical Practice	Willesden Green Surgery	TOTAL
	BMC	**CRS**	**CB**	**KPM**	**PHMC**	**PPS**	**SS**	**TLMGP**	**TLMC**	**TWMP**	**WGS**	
All Currently Registered Patients	3235	6190	2685	7935	5356	-	8744	13693	14656	6975	3380	**72849**
DEMENTIA DIAGNOSED (OVER 10 MONTH (PRE- & POST) INTERVENTION) PERIOD)												
Before Nov 2016 (Baseline)	8	8	7	45	31	-	36	102	52	22	12	**323**
Between Nov 2016 and Sept 2017 (during pilot intervention)	3	0	1	11	2	-	7	13	9	6	2	**54**
DEMENTIA REGISTER												
In Sept 2017 (post-intervention)	11	8	8	56	33	-	43	116	62	28	14	**379**
Dementia Register Over 65y	11	8	7	44	33	-	40	114	61	27	13	**358**
Dementia Register Under 65y	0	0	1	12	0	-	3	2	1	1	1	**21**
REFERRED TO MEMORY CLINIC												
Jan 2016 to Nov 2016 (Baseline 10m Period)	2	7	7	11	6	-	12	19	19	7	6	**96**
Nov 2016 to Sept 2017 (Project 10m Period)	3	7	2	5	4	-	7	18	9	13	3	**71**

Table 21: Descriptive statistics of dementia diagnosis and patient referrals from 10 participating DCK practices

Currently Registered Patients from 10 participating practices (combined list sixe = 72,849 patients)		**TOTAL**	**Percent % (analyses)**	**Comment**	
% patients who are diagnosed with dementia (over 10 month period from combi med list size)	**Before Nov 2016 (Baseline)**	323	0.44%	Prevalence of dementia is 0.44% (when compared to total/combined list size of 72849 patients from 10 participating practices)	
Dementia Diagnosed	**Between Nov 2016 and Sept 2017 (during 10 month intervention)**	54	-	Average = 5.4 diagnoses/month during intervention	
	Post-intervention (cumulative) total	379	-	Cannot make further assumptions regarding this variable as timeline of baseline is unknown.	
Dementia Register	**Dementia Register Over 65y**	358	94.5%	Vast majority of patients on Dementia register are >65 as expected.	
	Dementia Register Under 65y	21	5.5%	A small minority of patients are <65yr.	
Referrals to memory clinic	**Jan 2016 to Nov 2016 (BASELINE 10 month period)**	96	100%	Average = 9.6 referrals/month (115 referrals /year)	27% less referrals per unit time following intervention
	Nov 2016 to Sept 2017 (INTERVENTION 10 month period)	71	73%	Average = 7.1 referrals/month (85 referrals/year)	

Assessing quality of the referrals to the Brent Memory Service

The Brent Memory Service conducted a quality of referrals audit for Brent Memory Service for referrals received from October 2016 to October 2017. A total of 10 referrals were selected randomly- one from each participating General Practice- within Brent. The quality of the referral received by Brent Memory Service was based on the following criteria with equal weighing function (**table 22**).

Table 22: assessment criteria used to measure quality of referrals to memory clinic

Category	Criteria
(1) Administrative details	• Patient telephone number • Ethnicity • Employment status: • Name and telephone number of NOK or carer: • Is patient aware and have they consented to referral? YES / NO • Has patient given permission for us to speak with NOK / carer about referral? YES / NO
(2) Clinical History	• Onset, course, duration and severity of cognitive dysfunction, impact on everyday functioning and assessment of risk • Copy of cognitive screening test • Past medical history • Current medications
(3) Investigations	• Dementia screening blood tests completed within past month (FBC, U&E, ESR, CRP, TFT, LFT, B12, Folate, Calcium, HbA1c / Glucose) • Mid-stream urine sample and results • Brain scan report (if completed) • ECG (if completed)

4

DISCUSSION

General discussion

The DCK PIE initiative was established to foster an integrated approach to education and training for professionals and the public to help reduce the stigma of dementia in local communities particularly amongst BAME and faith groups, removing common misconceptions of the disease, raising awareness and understanding, and promoting early diagnosis.

Secondary aims of the pilot were to improve confidence of GPs in being able to detect and appropriately diagnose & manage patients with dementia whilst improving the quality of referrals made to secondary care memory clinic. Crucially, the initiative also intended to promote Kilburn as a 'Dementia Friendly' ward in Brent by challenging contemporary negative perspectives on dementia, exploring ways jointly with patients, their families and carers, to support people living well with dementia in the community to maintain independence and quality of life for as long as possible.

The multi-stakeholder project was conducted over a 10-month period between November 2016 & September 2017, and involved 11 General Practices, 14 partner organisations, 10 community, voluntary and faith organisations and engaged directly with several hundred individuals including health professionals, patients, carers and members of the public. Informational material about the project, including an exposé in Brent Magazine delivered by post to over 100,000 homes in Bent, maximised awareness and outreach potential of the project.

This section will consider the limitations and successes of DCK PIE in context, with a list of recommendations to inform the design, implementation and evaluation of future like interventions.

Success of DCK PIE

The programme delivered a series of suitable information materials including a Community Resources Leaflet for people living in dementia and their carers, and a media mention earmarked to several thousand individuals in Brent. The initiative also informed and supported the development of the Community Action on Dementia Brent Strategy.

The main thrust of the programme was upskilling the primary care workforce, with a focus on improving the confidence and skills of GPs in diagnosing early dementia and in improving the quality of subsequent referrals to memory clinics. The results of the evaluation show that these aims were largely satisfied, with many GPs reporting a significant improvement in their confidence and ability to appropriately diagnose patients. However, although most practices increased their diagnoses of dementia during the pilot, it was not clear whether this was related to DCK PIE interventions. It was also difficult to make sense of the referral

rates as the benchmark figures for dementia diagnosis were significantly higher. Further study over at least one year cycle and with a control group of practices is required to determine if reduced referral rates during the pilot reflect greater confidence in diagnosing other causes of memory problems or that increased referral rates reflect greater awareness of dementia.

A second important component of the project was to increase awareness and reduce stigma and misconceptions about dementia in Brent overall. The DCK PIE consortium verified direct engagement with over 1000 unique individuals in Brent from all walks of life, including engagement with community, third sector and faith organisations and service users. Whilst it is difficult to objectively measure the levels of patient activation or improvements in health literacy of members in the community following the intervention, the pilot raised awareness about dementia using a variety of informal materials and events, with provision to deliver some health messaging in other languages 'at scale' in unique settings, such as mosques and temples for example where language may be a barrier.

The excellent evaluation notes from Dr Tilki and her team (**tables 14-17)** illustrated the level and breadth of engagement and lessons learnt from these workshops, highlighting also the clear need, requirement and willingness of various segments of society to learn more about dementia and mental health in general.

Indeed, health literacy levels are likely to be poor in some communities, especially where there are language barriers, or in hard to reach communities and residents who may be socially isolated. Initiatives like DCK PIE and the Bent-based Dementia Peer Support Project that foster collaboration between multiple stakeholders (including community interest groups, the CCG, the Council, third-sector organisations and faith communities) demonstrate that abilities and skills could be retained by people living with dementia who wish to help others to contribute and to remain connected with their communities. Future initiatives should ideally build on this capacity and harness the power of individuals, communities and local assets in Kilburn and Brent.

Success of the DCK Pie initiative depended on a number of factors and in delivering a number of outcome measures. The configuration matrix shown in **table 23** overleaf summarises achievements against agreed targets of DCK PIE, suggesting that all 20 listed targets (100%) were achieved at end of pilot.

Objective evaluation also necessitated the collection and analysis of quantitative and qualitative data to answer a number of generic and dementia service specific question. Pilot data was sufficient to make reasonable and largely favourable conclusions about the overall impact of DCK PIE in context (**table 24**).

Table 23: table showing RAG reporting matrix of DCK PIE achievements against targets.

ACHIEVEMENT TARGET	RAG Rating
OBJECTIVES	
1. **Improve Health Literacy:** To increase information giving about dementia to help inform individuals of the benefits of timely diagnosis and care	Satisfied
2. **Raise Awareness:** To promote the prevention of dementia and raise awareness of risk reducing factors	Satisfied
3. **Reduce inequalities & promote self-care:** To reduce social exclusion and discrimination and promote wellness amongst specific community groups	Satisfied
4. **Establish Networks:** To explore ways of connecting with, supporting and empowering people with memory loss and their carers;	Satisfied
5. **Increase Capacity:** To build confidence in general practice to take a lead on the management and care for patients with a diagnosis of dementia	Satisfied
6. **Improve care planning:** To develop closer working relationships between primary and secondary care professionals to support joined up pathways of care.	Satisfied
COMPONENTS	
1. A **local general public information campaign** including a road show to complement borough and national strategies targeting BAME and faith communities, run jointly by professionals and community champions/ peers	Satisfied
2. **Targeted campaigns for other specific groups including an integrated series of events delivered by CAD Brent** (e.g. cultural and religious organisations, ethnic minority groups, people with disabilities)	Satisfied
3. **Structured education sessions aimed a healthcare professionals** provided through a variety of workshops, conferences and case based discussions.	Satisfied
ADDRESSING THE PRIME MINISTER'S CHALLENGE ON DEMENTIA	
1. **increase information giving** about dementia to help inform individuals of the benefits of timely diagnosis and care	Satisfied
2. **promote the prevention of dementia** and raise awareness of risk reducing factors	Satisfied
3. **reduce social exclusion and discrimination** and promote wellness amongst specific community groups	Satisfied
4. **explore ways of connecting with, supporting and empowering people** with memory loss and their carers	Satisfied
5. **build confidence in general practice** to take a lead on the management and care for patients with a diagnosis of dementia	Satisfied
6. **develop closer working relationships** between primary and secondary care professionals to support joined up pathways of care	Satisfied
ANTICIPATED BENEFITS	
1. To **identify and eliminate stigma associated with dementia**;	Satisfied
2. To **improve the lives of people** living with dementia and their families and carers	Satisfied
3. To **reduce stigma in targeted communities**;	Satisfied
4. To **equip professionals to be able to discuss risk factors** associated with dementia for targeted cohorts of patients;	Satisfied
5. To **help patients, families and carers to maintain dignity** in their local communities.	Satisfied

Table 24: Assessment of DCK Project in addressing a number of knowledge gaps

Category	Question/ Parameter	Achieved? Summary of finding / narrative	RAG
Demography	• Demographic profile of participating GP/practices	• Yes. Basic descriptive/demographic data was provided. However, more data would be needed to calculate prevalence of dementia in participating practices.	
Referral rates	• Did Programme have on patient/overall referral rates?	• Yes. However, although the data is indicative of success, it does not account for seasonality and the improvement seen is inconclusive.	
Early diagnosis	• Did the Programme impact early diagnosis?	• Yes. The number of new dementia diagnosis decreased significantly by end of intervention when compared to benchmark figures (**figure 8)** -presumably because GPs reported being more confident/aware about dementia- and the number of referrals to memory clinic also decreased.	
Stigma	• Number of appointments declined (aiming to measure impact on stigma)	• No data was forthcoming form GP practice/Memory clinics so this could not be assessed. • However, even if data was available, the results will be inconclusive given short timeline of pilot and relatively small number of patients referred to memory clinic	
Missed appointments	• Does the programme impact number of missed appointments (DNA)?		
Cost analysis	• Does DCK PIE have good ROI?	• Yes. Basic cost benefit analysis demonstrated that the programme has excellent ROI potential, with £79K envelope resulting in coherent and impactful engagement with healthcare professionals, members of the public, patients and their careers. • It was also recognised that the initiative delivered a number of intangible benefits. • **(a simplistic cost-benefit calculation included in table 25 below)**	
Patient & Public Involvement	• Demonstrable engagement with particular patient groups with & representation from wide mix/segments of society?	• The imitative delivered excellent engagement and traction with a wide mix of stakeholders, healthcare professionals, members of the public, patients and their careers, including hard to reach segments of society.	
Engagement	• Number of attendees/Register/several	• Attendance log verified engagement with at least 1000 individuals **(tables 6-19)**	

Category	Question/ Parameter	Achieved? Summary of finding / narrative	RAG
	events/demographic profiling		
Competency	• The GP does not always diagnose. Is this due lack competence/training or lack of time?	• Results confirmed this is due to low confidence levels (in some GPs) in identifying early dementia, coupled to lack of sustained training. The initiative seemed to address this by delivering bespoke training to GPs resulting in improved confidence and congruent referrals. The short duration of routine consultation time was cited as one factor that did not allow GPs to identify early signs of dementia.	
Confidence check	• Do GPs feel more confident to diagnose & manage patients? • What are the thresholds/fears?	• GPs reported feeling significantly more confident in diagnosing and managing patients with dementia. Those GPs that felt somewhat confident would welcome the support of a GPSI or consultant psychiatrist advice/support while making a diagnosis. • GPs mostly reported their fears as centring largely around (1) lack of confidence, knowledge and experience in diagnosing dementia, (2) an over-reliance on imaging to make definitive diagnosis of dementia and (3) uncertainty about what medication could be prescribed to manage patients with dementia.	
Appropriate referrals	• Did the programme result in referrals that are more appropriate?	• Yes. 9/10 referrals audited by the Memory Clinic met all quality criteria, with the remaining 2/10 referrals meeting 80% of the criteria. However, the audit did not contact a control sample of non-participating GP practices referring patients to the Memory Clinic during the same time span. Whereas the findings of the audit are encouraging, a larger audit including a control sample is indicated.	
Barriers to PPI	• Investigate if there are any languages/barriers to patient involvement & engagement	• Brent has the widest demography of any catchment area in England. Language barriers are expected to be a problem but this was overcome largely by engaging with community, third sector and faith organisations. On some occasions, health literacy information was delivered in other (non-English) languages.	

Cost benefit analysis of CDK PIE in the context of the wider health economy

The Alzheimer's Society UK estimates that there are 850,000 people living with dementia, with social care and NHS costs totalling £26bn /year (REF). It is difficult to model this costing as there was a mix of professional education and community groups.

The HEE NWL funded DCK PIE project had an operating budget of £79K and delivered a wide programme of activity concerned with capacity and capability building in the primary and community care settings, including direct engagement with at least 1,096 individuals.

The DCK Project is excellent value for money enabling engagement with over 1000 individual users. Such initiatives could in the future result in real (direct) savings to NHS if stigma and misconceptions about dementia are reduced, resulting in timely presentation and early diagnosis of patients with dementia, or interlocution with members of the community who want to learn more about mental health in general.

Timely diagnosis could delay the onset of advanced dementia and therefore reduce pressure on NHS resources in the long-run whilst also maintaining the quality of life of the patient where possible. Further, the DCK Project has arguably excellent ROI potential for a variety of reasons including:

1. It has the potential to reduce unnecessary GP appointments[2]
2. It upskilled primary care workforce to ensure timely diagnosis of dementia
3. It has the potential to improve quality of referral rates to Memory service (which have a cost attached to them)
4. It enabled engagement with a wide mix of stakeholders including hard to reach BAME groups and members of the community who may have a language barrier.

DCK PIE aligns with another high level objective concerned with empowering individuals to take more interest in their own health and wellbeing. For example, the NWL Self Care STP October 2016 submission documents outline a vision in which residents are empowered with tools for self-management and self-care, enabling them to take an active role in their

[2] According to the 2013 Units Health and Social Care report from the Personal Social Services Research, a single 11.7-minute consultation with the GP costs the NHS £45 (PSSRU Government Data). The costs for 2015-16 are likely to be significantly higher (circa £50/visit). The same report highlights the following relevant information:

- It costs £27 for a 7.1-minute telephone consultation with a GP.
- Home visits from a GP lasting 23.4 minutes are £114
- One prescription from your GP costs £41.35. This includes the cost of the medication
- A 15-minute appointment with your nurse in a GP practice costs £13

own care for common conditions[3]. There is also strong evidence that involving individuals and communities in defining problems and solutions result in better outcomes, and often at a lower cost [23][39].

Whereas it is not in the scope of this evaluation to propose a health economic analysis illustrating the of cost-effectiveness of DCK PIE from the NHS perspective, the programme resulted in significant improvement in health literacy and awareness of the signs of dementia in a significant number of GPs, primary healthcare staff, carers, patients and residents in Brent. It also helped to reduce stigma and misconceptions about mental health in general , suggesting a high ROI potential.

Intangible benefits of DCK PIE as a networking hub to promote social awareness for mental health wellbeing

With many people suffering from mental health it is vital to tackle the problem at scale via direct engagement with the community, including the provision of useful information to reduce social stigma and raise overall awareness about the different types of mental health conditions including dementia. This is particularly important in BAME groups where social isolation, stigma and general misconceptions about mental health are likely to be more common.

In addition to satisfying the outcome measures descried earlier, other intangible benefits of DCK PIE include:

- Reduction in sense of social isolation, particularly in BAME population, faith groups and hard to reach communities
- Improved engagement with government and local councillors on important matters
- Improvements in health literacy and improvements in patient/person activation in relation to awareness, assisted self-care, early diagnosis and management of dementia.
- Possible spill out of useable health and lifestyle information to children, family and extended network of participating service user

[3] A King's Fund report in 2010 suggests that self-care is thought to save an hour per day of GP time which is currently spent on minor ailment consultations. For every £1 invested in self-care for long-term conditions, £3 is saved in reducing avoidable hospital admissions and improving participants' quality of life. The same report outlines that if social value is included, the ROI goes up to £6.50 for every £1 spent (King's Fund, 2010). The impact of self-care approaches is estimated to reduce A&E attendances by 17,568 across NW London, with a financial impact of £2.4 m (NWL STP submission document).

- Possible increased uptake in public health screening and public health intervention programmes
- Possible reduction in unnecessary visits to GP or practice nurse following timely diagnosis of dementia and/or appropriate referral to memory clinic
- Increased awareness and participation in local schemes, activities and community resources
- Improved health outcomes following participation in health literacy setting and lifestyle interventions resulting in improved overall quality of life of residents in Brent
- Better use of local assets – skills, knowledge and physical resources
- Capacity building of individuals and organisations

The value of these types of activities, although not necessarily audited or acknowledge by the NHS at large, is paramount in helping to foster a more cohesive and progressive social matrix supporting the integration of BAME groups in Brent, and in reducing stigma and misconceptions about dementia overall.

Limitations of the evaluation

The current evaluation of had a number of limitations itemised in **table 26** below. In spite of these limitations, the evaluation was largely objective and captured salient aspects resulting in descriptive statistics and qualitative themes that are largely representative.

Table 26: limitations of the evaluation

Category	Description
Pilot Timeline	• Evaluation of based on 10 month intervention did not include cycle of one year and cannot account for variations related to seasonality. • The evaluation is limited to Brent/Kilburn/participating practices, and the findings may not be representative or scalable
Lack of control group	• The pilot involved 11 General Practices but did not include a control group of practices. • Benchmarking data for number of (new) dementia diagnosis and referral to memory clinic was conducted retrospectively whereby a prospective audit would be more suitable.
Multi-Intervention	• The project delivered a number of interventions. Although all interventions are related (i.e. dementia awareness workshop, upskilling of GPs, improving health literacy of patients and public etc.), it is not possible to distinguish which interventions had the most impact.
No validated questionnaires	• The pilot did not use validated questionnaires to assess improvements in health literacy and other important measures used to assess success of outcome measures.
Data provenance	• Quantitative and qualitative data were gathered, summarised and processed by various partner organisations, often received in different format and style. This made collating and analysing data difficult. • The data cut-off point exceeded proposed timeline, with some data received 2 days before evaluation report as due.
Analysis of qualitative data	• A pragmatic (rather than systematic and technology driven) analysis of contextual, thematic or qualitative data was undertaken to identify and categorise emergent themes.
Evaluation framework	• There is no validated or published framework recommended for the evaluation of multi-intervention initiatives such as DCK PIE • This necessitated the evaluation to be conducted in a pragmatic yet objective way using a mixed method approach. As such, it would be difficult to benchmark DCK project against other PIE programmes.

The case for DCK PIE as flagship initiative intended to tackle mental health inequalities in Brent

The NHS Five Year Forward View makes clear that harnessing the 'renewable energy' of patients and communities is no longer a 'discretionary extra' but instead is key to the sustainability of health and care services[40], and the Health and Social Care Act 2012 proposes commissioners champion a more local approach to address health issues in the community.

In order to challenge the issue of health inequalities, policy makers, public health commissioners and the NHS need to prioritise targeting people who may be socially isolated, who have a language barrier, in lower socio-economic groups and in BAME groups to reduce extant large gap in health inequality. These ambitions align with DCK PIE's main strategic aim to provide localised and more efficient services for the people who need them and will benefit most from them, including the upskilling of the primary care workforce so that it is empowered to recognise early signs of dementia for patient benefit.

In the contemporary setting, policy makers argue that people have a right to define what health means to them, and to be given the opportunity to act in the interest of their own health whilst having control over the decision making processes that affect their health [15]. This also applies to specific communities and BAME groups who may have different priorities and needs. A social model of health suggest that an "upstream" approach to health improvement is essential [15]. Such a model proposes that wider determinants – rather than the presence or absence of disease and individual health behaviours- have an impact on people's health and conditioned health behaviours. These determinants operate and interact at many different levels and differently in different contexts and settings. Those who experience disadvantage and poor health outcomes know most about their own conditions, and their involvement is crucial in both identifying and understanding the causes of health issues and problems and who should be involved in addressing them.

People in the late stages of dementia receive most of their healthcare from GPs or emergency services rather than from specialist health care professionals, despite them having complex needs. While those with advanced dementia often suffered chronic pain and psychiatric symptoms, they had little contact with specialist services such as palliative care, geriatrics or mental health (REF). This suggests that healthcare services are not currently tailored to the complex needs and symptoms of people with advanced dementia. Given that dementia is now the leading cause of death, there is urgent need to ensure an adequate standard of comfort and quality of life for patients. This makes interventions like DCK PIE that aim to improve health literacy, whilst reducing misconceptions and stigma about dementia and upskilling of the primary care workforce to support early diagnosis

crucial.

There is a policy drive to ensure assessments for dementia are moved from secondary to primary care, However, this comes at a time when 64 CCGs in England have reduced the proportion of their budget that they spend on mental health in 2017/18 (REF). Strengthening the Workforce is a cardinal aim of the Five Year Forward View for Mental Health white paper. The DCK programme is a flagship example of a mental themed partnership in innovative education in Brent and a suitable vehicle to support the adoption and diffusion of evidence based culturally adapted interventions for service users, carers, community members and health professionals.

Summary & conclusion

The DCK Project was a successful initiative delivered over a 10 month timeline with demonstrable evidence in improving a number of important outcomes including raising awareness and reducing stigma about dementia in Kilburn and upskilling the primary care workforce to improve ability for differential diagnosis of dementia.

The pilot had a number of limitations, but the initiative seemed to have excellent traction with service users and a wide mix of stakeholders with excellent potential for return on investment and various other 'soft' or intangible outcomes.

Project management and clinical leadership for the DCK project was exemplary, helping to deliver this multi-intervention project to time and target resulting in valuable lessons and findings that could inform the future direction of travel of larger scale implementation programmes in the Kilburn and Brent catchment area.

The PIE model of healthcare education brings together health care service providers, community groups, patients and education providers focused around enabling the development of learning communities. This high level objective of bringing together of different parts of the health and social care workforce, patients and the public to systematically improve services by learning with and from each other about dementia was achieved DCK Project.

As Brent has the widest demography of any catchment area in England, the findings of this project are likely to be representative of other regions in the Capital and in the UK. Generalisations could be made as regards extant barriers and drivers for the timely diagnosis of dementia in primary care, and the root causes of stigma and misconception of mental health and dementia in the community and how to tackle these by working in collaborate with a consortium of partners, including members of the public and patient representatives.

On merit of the findings of the pilot it is recommended that further investment be considered to scale up the initiative across Kilburn and other catchment areas in Brent to maintain a sustained engagement with residents and the primary care workforce for patient benefit.

END.