

**Project Initiation
Document**

Meeting the
Dementia Challenge

Timely Diagnosis

(Phase 1)



**West Midlands
Strategic Clinical
Network and Senate**

Version 0.4



Project Initiation Document

Meeting the Dementia Challenge – Timely Diagnosis (Phase 1)

Planning Phase: Project Initiation Document (PID)

The PID builds on the Project Brief to fully define the project and form the contract between the Project Board and Project Manager. It provides a baseline against which the Board can assess progress, issues and ask on-going viability questions.

The PID also provides a useful single source of reference for others to quickly and easily find out what the project is about. It answers the following questions:

- What is the project aiming to achieve?
- Why it is important to achieve it?
- Who will be involved and what are their responsibilities?
- How and when will it happen?

Issue Date: 5th June 2014

Document Number: Draft v 0.4

Prepared by: Sharon Adams

Amendment History:

Version	Date	Amendment History
0.1	21.05.14	First draft for comment
0.2	30.05.14	Revisions
0.3	05.06.14	Revisions

Reviewers

This document must be reviewed by the following:

Name	Signature	Title / Responsibility	Date	Version

Approvals

This document must be approved by the following:

Name	Signature	Title / Responsibility	Date	Version
Anna Morton		SCN Associate Director		
Dr Kiran Patel				
Dr Karim Saad		SCN Clinical Director - Dementia		
Ben Parfitt		SCN Network Manager - Dementia		

Related Documents

This document should be read and approved in conjunction with the following:

Name	Owner	Location
Risk and Issue Register	Project Manager – Sharon Adams	H:\Data\NHSCB BBC LAT\Networks and Senates\PMO\Control Documents\Risk Registers
Stakeholder Engagement Strategy / Communications Plan	Project Manager – Sharon Adams	Appendix A
Citizen Participation	Project Manager – Sharon Adams PV&I Lead	Appendix B

Plan	Project Manager – Sharon Adams	Project Delivery Plan to follow
Business Case	Not appropriate/ applicable	
Equality Analysis	Not appropriate/ applicable	

4th DRAFT

Executive Summary

One in three people over the age of 65 will develop dementia. There are 800,000 people in the UK diagnosed with dementia, with 665,000 of this number in England (Alzheimer's Society 2013). Dementia is a progressive condition but people can live with it for 7-12 years after diagnosis if it is diagnosed early enough, however on average less than half the patients with the condition have a diagnosis (DoH 2013; Alzheimer's Society 2013).

Among the over-55s dementia is feared more than any other illness. And at an estimated £19 billion a year, the cost to economy is huge. It is estimated that this is higher than the costs of cancer, heart disease or stroke. There is not only a moral imperative to improve dementia care – there is a strong financial one too.

With an aging population it is predicted that the number of people with dementia in the UK over the next 30 years will double to 1.4 million, with costs trebling to over £50 billion per year. This will place an unsustainable burden on patients, carers and health and social care resources over the long term.

This project will determine what services are currently in place against services that should be available in a quality dementia pathway, from diagnosis to end of life care, whether the system is in a position to deliver what is required of it and how it might utilize existing good practice if it is not. It will also form part of the prevention agenda in primary care that is currently being developed. The West Midlands SCN will also work in collaboration with the East Midlands and East of England SCNs dementia projects as appropriate.

The project will be split in to four phases: Timely diagnosis, Post diagnosis, Living well with dementia and Increasing care & end of life care. The first phase will be achieved through scoping existing services and benchmarking against existing best practice and national guidance, along with the collection, synthesis and analysis of specific qualitative and quantitative dementia metrics to identify variability in primary care. Due to the size and scale of this project, it is likely that further internal and external support will be required, particularly regarding data.

PIDs for subsequent phases and related information will be provided as the project progresses.

Outline deliverables in Phase 1 will be determined against a set of objectives measured at CCG level across the West Midlands, which will form part of a data dashboard used to monitor prevalence and QoF performance across the West Midlands.

Main risks at this stage include the potential for significant overlap with current work nationally, regionally and at CCG level on dementia pathways, CCG/ GP lack of engagement due to conflicting priorities or concerns regarding the dementia ambitions, the availability and measurement of quantitative and qualitative data as well as the complexity and complications involved in cross boundary working as the project moves across the wider health and social care spectrum.

Contents

- 1 Background7
- 2 Definition8
 - Ambition8
 - NHS England have agreed a national ambition for diagnosis rates that by 2015 two-thirds of the estimated number of people with dementia in England should have a diagnosis, be able to access and are using appropriate post-diagnostic support. This also forms part of NHS England action on parity of esteem.8
 - Aims and Objectives8
 - ‘To improve the diagnosis rates in primary care for people with dementia, including ensuring the availability of appropriate support before and after diagnosis’8
 - 2.3 Scope and Exclusions 11
 - 2.4 Dependencies 11
 - 2.5 Constraints 11
- 3 Approach: 12
 - 3.1 Assumptions 13
 - 3.2 Plan 13
 - 3.3 Deliverables 13
 - 3.5 Stakeholder Engagement & Communications 14
- 4 Business Case 15
 - No business plan has been developed for this project 15
 - 4.1 Cost – Timely Diagnosis (Phase 1) 15
 - 4.3 Equality 16
- 5 Benefits Realisation Plan 17
- 6. Organisation and Capability 18
 - 6.1 Governance 18
 - 6.1 Dementia Project Steering Group 18
 - 6.2 Resource 18
- 7 Management Controls 20
 - 7.1 Reporting 20
 - 7.2 Change Control 20
 - 7.3 Risks and Issues 20
 - 7.4 Quality Management 20
- 8 References 22
- 9 Appendices 23
 - 9.1 Communication Matrix 23
 - 9.2 Citizen Participation Template 24

1 Background

One in three people over the age of 65 will develop dementia. There are 800,000 people in the UK diagnosed with dementia, with 665,000 of this number in England (Alzheimer's Society 2013). Dementia is a progressive condition but people can live with it for 7-12 years after diagnosis if it is diagnosed early enough, timely and accurate diagnosis of dementia improves quality of life by allowing earlier access to treatments and therapies, extends the period of time a person with dementia can be cared for in their own home and reduces the cost to the system by delaying the need for expensive residential care. On average less than half the patients with the condition have a diagnosis (DoH 2013; Alzheimer's Society 2013).

Among the over-55s dementia is feared more than any other illness. And at an estimated £19 billion a year, the cost to economy is huge. It is estimated that this is higher than the costs of cancer, heart disease or stroke. There is not only a moral imperative to improve dementia care – there is a strong financial one too.

Dementia is associated with complex needs, and, especially in the later stages, with a high level of dependency and morbidity. With an aging population it is predicted that the number of people with dementia in the UK over the next 30 years will double to 1.4 million, with costs trebling to over £50 billion per year. This will place an unsustainable burden on patients, carers and health and social care resources over the long term.

In March 2012 the Prime Minister issued his challenge on dementia (DoH 2012) which built on the achievements of the National Dementia Strategy (DoH 2009). This set out an ambitious programme of work designed to accelerate the delivery of major improvements in both dementia care and research by 2015. A key part of this is around improving early diagnosis rates for those with dementia. There is currently a 'gap' between actual prevalence and diagnosis rates which indicates that:

- individuals are not accessing early intervention services and appropriate support at an early enough stage for them to make choices for themselves and their carers.
- Diagnosis is often made at a time of crisis, a crisis that could have been prevented with early diagnosis, and this crisis has both significant emotional and financial implications
- GPs may lack the knowledge, tools and training needed for robust dementia identification, referral and diagnosis
- that health and social care systems, models and planning is predicated on a substantially smaller dementia population than the actuality which raises strategic resource and capacity concerns
- that there is insufficient provision of equitable, appropriate, effective, accessible and systematic post-diagnostic support

Nationally the current average diagnosis rate for dementia in England stands at 48%, which is 2% higher than the rate in 2012, and ranges from 32% to 75%. The average for the Area Teams in the West Midlands region is 49.3% for Arden, Herefordshire & Worcestershire, 50.4% for Birmingham, Solihull & the Black Country and 43.3% for Shropshire and Staffordshire.

The ambition set by the government is for a dementia diagnosis rate of 66% by 2015.

2 Definition

Ambition

NHS England have agreed a national ambition for diagnosis rates that by 2015 two-thirds of the estimated number of people with dementia in England should have a diagnosis, be able to access and are using appropriate post-diagnostic support. This also forms part of NHS England action on parity of esteem.

Aims and Objectives

Specific Measureable Achievable Realistic Time bound

2.1 Aim

‘To improve the diagnosis rates in primary care for people with dementia, including ensuring the availability of appropriate support before and after diagnosis’

It is also anticipated that the data utilized in this project will provide commissioners in the West Midlands with information highlighting areas of low and variable dementia diagnosis and/or poor post-diagnostic support enabling them to focus their attention on specific areas to reduce variation along the pathway.

2.2 Objectives and measures

The following table outlines the project objectives in more detail. The quantitative measures will form the data dashboard and report to be delivered by the project, and will be measured by at CCG level, grouped by NHS England Area Team localities. The objectives should be seen as the measures by which to determine if the first phase of the projects aim has been met.

2.2 Objectives

Ref	Objective	Measure	Baseline	Target	Source	Target delivery date
OB1	Improve diagnostic rates for people with dementia	DEM001 The practice can produce a register of patients diagnosed with dementia	Will be specific to each CCG	100%	QOF	September 2014
		Prevalence of dementia	Will be specific to each CCG	Will be specific to each CCG/ Practice	Primary Care Web Tool - Dementia	September 2014
		Reduction in dementia gap	Will be specific to each CCG	0	Primary Care Web Tool - Dementia	September 2014
		ANDPR Number of dementia patients in care homes with a dementia diagnosis	Will be specific to each GP practice	66%	Primary Care Web Tool - Dementia	September 2014
		Ensure each General Practice has a named clinical lead, or champion, for dementia	Will be specific to each GP practice	100%	Questionnaire	September 2014
		Number of patients with a diagnosis of dementia who have been appropriately referred to Memory Assessment Services	Will be specific to each GP practice	100%		September 2014
OB2	Improve care of patients with a dementia diagnosis	DEM002 The percentage of patients diagnosed with dementia whose care has been reviewed in a face-to-face review in the preceding 12 months	Will be specific to each CCG	100% (QOF 35-70%)	QOF	September 2014
		DEM003 The percentage of patients with a new diagnosis of dementia recorded in the preceding 1 April to 31 March with a record of FBC, calcium, glucose, renal and liver function, thyroid function tests, serum vitamin B12, and folate levels recorded between 6 months before or after entering on to the register	Will be specific to each CCG	100% (QOF 45-80%)	QOF	September 2014

OB3	Scope awareness and usage of ALCOVE principles (Reference pg 22)	Identify a CCG from each Area Team to baseline current awareness of usage – use this as a basis to develop future actions	Will be specific to each CCG	Baseline report	CCG	October 2014
OB3	Improve access to memory assessment services	Scope and review existing memory assessment services to identify current resources, issues and future needs and benchmark against existing best practice, national guidance and existing quality standards to identify gaps	Will be specific to each CCG/ MH Trust etc	Baseline report	CCG/ Mental Health Trust	October 2014
OB4	Identify current dementia pathways	Scoping exercise with CCGs to identify current pathways and existing work and benchmark against West Midlands Dementia Strategy existing best practice, national guidance and existing quality standards to identify gaps	Will be specific to each CCG/ Mental Health Trust	Baseline report	CCG/ Mental Health Trust	November 2014
OB5	Establish patient and carer forum	Establishment and meeting of patient and carer forum and mapping events to view timely diagnosis process through the eyes of service users		Active forum and report	Service Users	November 2014
OB6	Produce report on identified areas of good practice to support sharing and spread of improvement	Production of report for dissemination to stakeholder organisations		Report		November 2014

2.3 Scope and Exclusions

The project will cover the West Midlands region and will include 22 CCGs (which includes 944 GP practices). The area is divided into three areas

- Arden, Herefordshire and Worcestershire (AHW)
- Birmingham, Black Country and Solihull (BSBC)
- Shropshire and Staffordshire (S&S)

The initial phase also includes scoping memory assessment services which fall under a variety of different organisations (Community Mental Health Trust, Foundation Trusts etc).

It will not cover diagnosis made in Acute Trusts at this stage as it will assume that the diagnosis will be communicated to the appropriate GP practice for inclusion in their dementia register. This may be an area that requires further work in future.

2.4 Dependencies

The project/programme is dependent on the following:

- Provision for timely and appropriate data collection and analysis
- Funding to support stakeholder events
- Further QIL support for subsequent phases of the project

2.5 Constraints

The project has the following constraints:

- Staff resources – due to the scope and scale of the overall project limiting staff resources below those requested will adversely impact on project ambitions, effectiveness and deliverables
- Funding – limited funding is likely to impact on the quality and frequency of stakeholder meetings, workshops, events and any data/ reporting requirements outside the SCN

2.6 Interfaces

The project has the following interfaces

- NHS England Area Teams
- Clinical Commissioning Groups
- Mental Health/ Foundation Trusts
- Alzheimer's Society and other Dementia charities as appropriate
- Patient Groups/ SCN PV&I/ Health and Wellbeing Boards
- Public Health England

3 Approach:

This phase of the project will seek to support CCGs to improve local systems for increasing timely diagnosis rates at GP Practice level across the West Midlands. This will be achieved by using robust data available in the Quality Outcomes Framework to benchmark current practice, identify unwarranted variation against best practice standards, and by highlighting and spreading examples of good practice/ innovative models.

It will also look to identify current practice and support CCG/ Trust on-going work on improving MAS access and dementia pathways across the West Midlands. This will be carried out using a combination of meetings, discussions, mapping events, patient and carer input and evaluations to produce a report identifying key issues to support commissioners.

It is anticipated that this will run coterminous across the West Midlands region, and will be supported by an internal SCN project team, though engagement and support from external stakeholders will also be essential.

It will also seek to support key operational stakeholders in other NHS and external organisations to apply some of the learning from other effective models of care, innovation or their own ideas, utilising standard Quality Improvement (QI) methodology such as Plan, Do, Study, Act (PDSA) cycles, the NHS Change Model and/ or other QI tools and techniques as appropriate. It is essential to ensure that this is embedded into working practice to develop a culture of continuous improvement within participating organisations.

Subsequent phases of the project (Phase 2 – Post diagnosis, Phase 3 – Living well with dementia and Phase 4 – Increasing care and end of life care) will all entail a level of scoping to establish existing provision to benchmark against best practice recommendations.

Further information on these phases is recorded in the Dementia Service Review Project Brief located at <H:\Data\NHSCB BBC LAT\Networks and Senates\Theme 1 - Pathways\Dementia\Brief Theme 1 - Dementia Pathway v0.03 250414.docx>

The project will adhere to the following guidelines

- NICE Quality Standard QS1 (2010) - Dementia
- NICE Quality Standard QS30 (2013) – Supporting people to live well with dementia
- NICE Clinical Guideline CG42 (2006) – Supporting people with dementia and their carers in health and social care
- National Dementia Strategy and National Dementia Challenge ambitions

3.1 Assumptions

The project approach has been defined with the following assumptions in mind:

- That key stakeholders across the health and social care spectrum will be willing to engage
- That a realistic level of staff and funding resources are available to ensure successful delivery
- Data support will be available to assist in collection, synthesis and presentation of data

3.2 Plan

This section should be read in conjunction with 'Related Documents' (see page 3).

3.3 Deliverables

Deliverable or product	Owner	Start date	End date
Stage 1			
Develop <ul style="list-style-type: none"> • PID • Risk Register • Communication Plan • Stakeholder Analysis 	Sharon Adams	May 2014	June 2014
Sign off all project documentation	Dementia Sub Group	June 2014	June 2014
Stage 2			
Analysis of QOF data at Regional/ AT/ CCG/ GP practice level	Sharon Adams	June 2014	August 2014
Identify and meet with key CCG/ Trust stakeholders to identify dementia priorities	Sharon Adams	June 2014	October 2014
Baseline ALCOVE principles usage in a designated CCG in each Area Team – PDSA approach to inform further work	Sharon Adams	July 2014	October 2014
Support Patient & Carer dementia pathway mapping events/ workshops on timely diagnosis (their experiences)	Sharon Adams	July 2014	October 2014
Develop CCG Dementia Reports (data dashboard) to monitor region wide progress	Sharon Adams	July 2014	September 2014
Analysis of current demand and capacity of Memory Assessment Services – Report to	Sharon	July	September

support commissioners	Adams		2014
Report on identified areas of good practice models to support sharing and spread of improvement	Sharon Adams	August 2014	October 2014
Establishment of Dementia patient/ carer forum	Sharon Adams	July 2014	August 2014
Deliver one Dementia stakeholder event	Sharon Adams	October 2014	November 2014
Complete End of Phase 1 Project Report	Sharon Adams	October 2014	November 2014
Prepare options for Phase 2 of project (Post Diagnosis)	Sharon Adams		

3.4 Outcomes

Outcome	Indicator it has been delivered	Target date
Increase in the proportion of dementia patients with a dementia diagnosis recorded on GP registers – 66% in line with Dementia Challenge ambition	Increase in numbers	March 2016
Increase in the number of GPs utilizing the four ALCOVE principles to ensure a baseline standard of quality care in dementia diagnosis and post dementia diagnosis	Increase in numbers	March 2016
Increase in the proportion of patients with suspected or confirmed dementia, having a full diagnostic assessment	Increase in numbers	March 2016
Dementia diagnosis data dashboard produced	Report	August 2014
Report on current Memory Assessment Services	Report	September . 2014
Report on West Midlands dementia pathway mapping (early diagnosis)	Report	November 2014

3.5 Stakeholder Engagement & Communications

This section should be read in conjunction with 'Related Documents' (see page 3), but will include, as appropriate:

- Dementia Sub Group
- Project team
- Locality teams

- CCG's
- Acute Trusts
- Patients and Carers
- Clinicians
- Health and Wellbeing Boards
- Public Health England
- Local Authorities
- Alzheimer's Society, Dementia UK, Age Concern and other relevant charities/ third sector organisations
- AHSN
- West Midlands Partnership Forum
- Dementia Intelligence Network

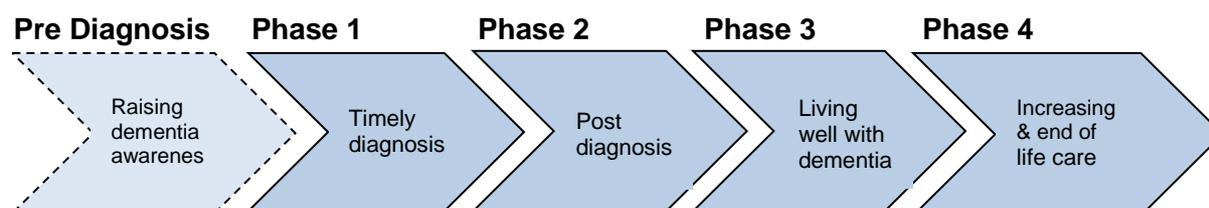
Names of representatives are not as yet known

4 Business Case

No business plan has been developed for this project

4.1 Cost – Timely Diagnosis (Phase 1)

	SCN	Costs £
Revenue including staff costs		For Phase 1 (approx. 6 months)
Data Analysis	External	£10 K per Phase 1
Mapping events across W Mids		£10K per Phase 1
Stakeholder engagement event		£3K per Phase 1
Independent evaluation of patient/ carer feedback	External	£5K (estimated if required)
Specialist backfill for meetings/ events etc as required	External	£1K (estimated if required)
Media costs – development of video collating dementia patient and carer experiences	External	£10K (estimated)
Total project costs		£39K



Phase 1 – Timely diagnosis

- Measure and compare specific quantitative and qualitative dementia metrics in primary care across the West Midlands and identify variability (diagnosis rates, coding issues, ACI medication)
- Scoping exercise with CCGs to identify current pathways, issues, ambitions, existing work
- Map existing services and benchmark against West Midlands Regional Dementia Strategy, existing best practice, national guidance and existing quality standards to identify gaps
- Produce a report on identified areas of good practice to support sharing and spread of improvement
- Establish patient and carer forum to identify what worked well within this phase and where need to improve

4.2 Project income

Income source	Income £
Total Project Income	Nil

4.3 Equality

This project will help to promote equality in line with the Equality Act 2012 and the Health & Social Care Act 2012 by ensuring services are available to the entire West Midlands population who may not currently have access to appropriate dementia diagnosis and management

5 Benefits Realisation Plan

Benefit description (outcomes perceived as positive)	How will this be realised	How will this be measured	Baseline measure	Key date for benefit realisation
Better informed commissioning of dementia pathway(s)	Report produced will be acted upon by CCGs	Against national best practice and through patient/ carer evaluation	Current mapping	Report due October 2014
Improved quality around timely diagnosis and patient support utilizing the ALCOVE principles	Baseline for engaged CCGs	Numbers of GPs using	To be determined following scoping	Report due October 2014
Identification of unwarranted variation in timely diagnosis rates across the West Midlands	Report produced will be acted upon by CCGs to address variation	Against national current timely diagnosis ambition of 66%	Current diagnosis rate yet to be determined	Report due October 2014
Identification of best/ good practice to share	Scoping of good practice models to produce a report/ run an event	Improved services – lower waiting times etc	Current scoping	Report due October 2014 Throughout project

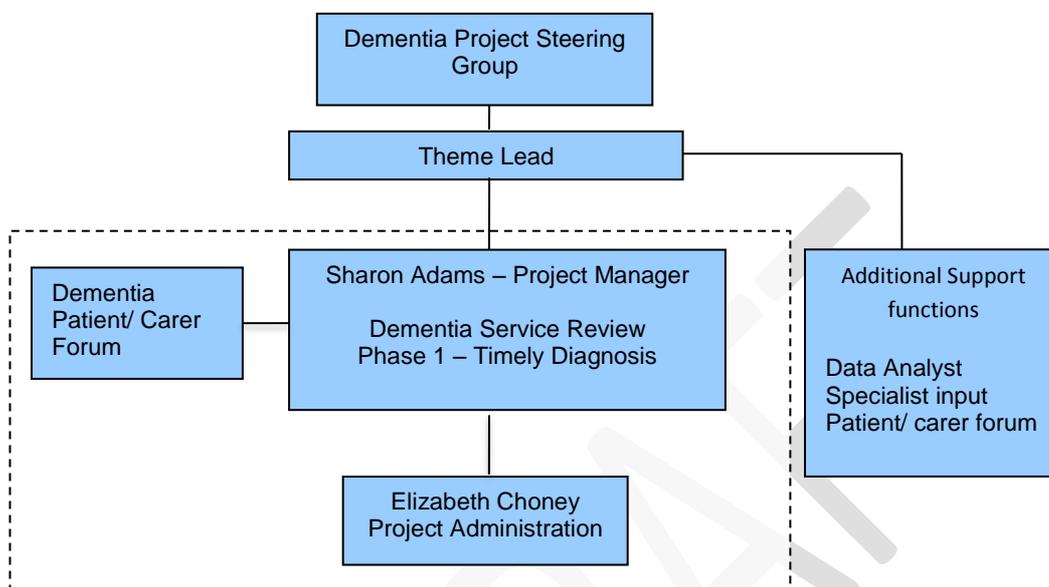
Dis-benefits (outcomes perceived as negative) could also impact on the project. These could include:

- GP resistance to the ambitions around increasing dementia diagnosis rates within their practice
- Greater capacity issues for services following potential increases in patients diagnosed with dementia

6. Organisation and Capability

6.1 Governance

To be confirmed but draft structure below



6.1 Dementia Project Steering Group

For further development

6.2 Resource

<i>Resource</i>	<i>Time</i>	<i>Role</i>
Core Project Management		
Dementia Sub Group – Theme Lead SCN Dementia Clinical Director SCN Dementia Network Manager	Monthly	Responsible for the overall direction and management of the project and should provide guidance and support to the Project Manager
Senior Responsible Owner – SCN Dementia Network Manager	Weekly	Ultimate responsibility for delivery of the project lies with SCN Dementia Network Manager

<p>Project Manager – 1 FTE</p>	<p>5 Days (equivalent of 37.5 hours per week) [May 14 – March 16]</p>	<p>The Project Manager has the overall responsibility for the successful planning and execution of the project. He/she will manage the overall schedule to ensure work is assigned and completed on time, within budget and that all deliverables adhere to acceptable quality levels. He/she must identify, track, manage and resolve project issues risks and lessons learned and ensure that mitigating actions are implemented. The Project Manager will have project management responsibility for the technical and business change team members and will report to the IMG on a monthly basis and at key decision points in the lifecycle.</p>
<p>Project Support 2 x Band 7 QILs</p>	<p>3 days per week</p>	<p>To provide support across Area Team regions to enable project objectives to be delivered (scoping, meetings, data, etc as required)</p>
<p>Project Admin Support –</p>	<p>1 Day/Week [May 14 - March 16]</p>	<p>To provide administration support to the project as required, Team including the organising of meetings, taking minutes and distributing documents</p>
<p>Communication</p>	<p>1 Day/ Fortnight</p>	<p>To provide communication skills support to project team as required</p>
<p>Additional support functions (specialists, including patients and carers)</p>	<p>As required</p>	<p>It will be necessary to occasionally draw in stakeholders with specialist knowledge for time limited support. It is expected that this will include, but will not be limited to, data analysis expertise</p>
<p>Working group (task & finish group) Membership determined by task</p>	<p>As required</p>	<p>Time limited groups set up to perform a specific task. Might be region wide or locality focused groups</p>

7 Management Controls

7.1 Reporting

Report	Frequency	Audience
Highlight / Status Report	Fortnightly initially	Project Board
Exception Report	As needed	Project Board
Risk / Issues	Monthly	Project Board
Lessons Learnt	Project close	Project Board
End of project Report	Project close	Project Board Area Teams/ CCGs

7.2 Change Control

Changes to the content of this PID following approval can only be authorised by the Project Board.

7.3 Risks and Issues

Risks and issues will be tracked and managed in accordance with the NHS England risk and issue management strategy.

Please refer to Risk Register folder at <H:\Data\NHSCB BBC LAT\Networks and Senates\PMO\Control Documents\Risk Registers>

7.4 Quality Management

This project will be guided by the following quality standards and guidelines:

- West Midlands Dementia Strategy
- NICE Quality Standard QS1 (2010) - Dementia
- NICE Quality Standard QS30 (2013) – Supporting people to live well with dementia
- NICE Clinical Guideline CG42 (2006) – Supporting people with dementia and their carers in health and social care
- National Dementia Strategy and National Dementia Challenge ambitions
- Locally determined guidelines as appropriate.
-

8 References

ALCOVE **AL**zheimer **CO**operative Valuation in **E**urope

Further information regarding the ALCOVE project can be found at:

<H:\Data\NHSCB BBC LAT\Networks and Senates\Theme 1 - Pathways\Dementia\ALCOVE> Information from Dr Karim Saad, SCN Clinical Director for Mental Health, Dementia & Neurological Conditions and UK Chair, Alzheimer Cooperative Valuation in Europe (ALCOVE)

<http://www.alcove-project.eu/>

[http://www.alcove-project.eu/images/synthesis-report/ALCOVE SYNTHESIS REPORT WP5.pdf](http://www.alcove-project.eu/images/synthesis-report/ALCOVE_SYNTHESIS_REPORT_WP5.pdf)

Healthy life expectancy has dramatically increased in Europe over the past 50 years. At the same time, there has been a corresponding increase in diseases linked to aging, particularly dementia. Alzheimer's disease and related dementias are an EU public health priority given their high prevalence and cost as well as the profound impact they have on society. The ALCOVE project was co-financed by the European Commission and over the past two years it has built a sustainable network which includes 30 partners from 19 EU Member States. Through its work, ALCOVE has aimed to improve knowledge and to promote the exchange of information on dementia in order to preserve the health, quality of life, autonomy, and dignity of people living with dementia and their carers in EU Member States

Strategy for timely detection:

1. Timely and accessible
2. Decrease fear and stigma
3. Rights and wishes of the patient and their carer
4. Diagnosis as a key intervention for the patient and their family

9 Appendices

9.1 Appendix A Communication Plan

This communication plan describes the approach for communicating and collaborating on the Dementia Service Review – Timely Diagnosis (Phase 1) project. The plan identifies the audiences for the project, the information to communicate, and the communication methods to use. This plan can help facilitate effective and coordinated communication between all project audiences.

Project Audiences

List here the project audiences

- The *Project team* includes the stakeholders and all people assigned to work on the project.
- Dementia Sub Group
- Area Teams in the West Midlands region
- CCGs in the West Midlands region
- Acute Trusts
- Dementia Patients and Carers
- Local Authorities
- Clinicians as appropriate
- Alzheimer's Society, Dementia UK, Age UK and other appropriate charities (eg Young Onset of Dementia Forum)
- Other appropriate organisations as identified (eg LETB/ LETC/ HAWB etc)

For this project, we have created six categories of information to simplify project communication:

- *Approval* information represents documents, change requests, budget requests, or project deliverables that require stakeholder approval.
- *Stakeholder project status* includes high-level summaries of completed milestones, major accomplishments, current schedule and budget performance, and any issues or risks that have occurred.
- *Detailed project status* includes completed and in progress work packages, team accomplishments, issues that need resolution, and lessons learned.
- *Project reference* represents all project documents and document-based deliverables.
- *Collaboration* information includes change requests, issues, risks, and lessons learned.
- *Publicity* represents high-level overviews and status.

Communication Methods

We will use the following methods of communication:

- *Email* is the preferred method for sending information that people are supposed to act on, whether they are to approve documents or begin work on an assignment.
- *Voice mail* is a secondary method for requesting action.
- *Meetings* will be kept to a minimum.
- *The SharePoint Web site contains project reference information.*

The Communication Matrix

The communication matrix shows how we plan to communicate information to the project audiences. The matrix also includes the frequency of communication for different types of information and the method of communication.

Given the small size of the team on this project, communication is relatively simple. Team members will copy all e-mail to the entire team. The project manager will document telephone calls and meetings and post notes to a shared workspace. The project manager will maintain a folder in Microsoft Office Outlook® for all e-mail correspondence.

In addition to the project deliverables, the project manager will distribute biweekly status reports to the project team. The status reports will cover the previous two weeks and include tasks completed, tasks in progress, upcoming tasks, and copies of the current issues list, risks and issues and other information as appropriate.

Audience	Information	Method	Frequency	Who Is Responsible
Project team/ Dementia Sub Group	Detailed project status	Email	Weekly	Team leads
Project team/ Dementia Sub Group	Collaboration	Email	As required	Team leads
Project team	Collaboration	Meeting	Every other week	Project manager
Project team/ Dementia Sub Group	Approval	Email/ meeting	As required	Project manager
Project team/ Dementia Sub Group	Stakeholder project status	Meeting	Monthly	Project manager
Area Teams CCGs	Publicity	Email	As required	Project manager
Patient and Carer Forum	Publicity	Email/ meetings	As required	Project manager
Alzheimer's Society/ other appropriate charities	Publicity	Email	As required	Project manager

Other project audiences as required	Depending on level of engagement/ involvement	As required	As required	Project Manager
-------------------------------------	---	-------------	-------------	-----------------

9.2 Appendix B Citizens Participation Template

<p>Type of citizen participation needed: Identify the role required by individual members of the public and/or patients e.g. attend meetings / review documentation / surveys / research / focus group / other etc.</p>
<p>The role would involve active participation in mapping events across the West Midlands region to gain an understanding of the Dementia pathways from the patient and carer perspective.</p> <p>As such there would need to be attendance at meetings and mapping events, as well as taking part in surveys and</p> <p>The Alzheimer's Society, and other dementia charities, have existing and active patient and carer groups and forums that this SCN project can engage with.</p>
<p>Reason for citizen participation: Why is citizen participation required?</p>
<p>There is a need to understand the patient's perspective and experiences of existing dementia services to identify areas where improvements could, and should, be made. This information should help inform commissioners of dementia services.</p>
<p>Does the person(s) you are seeking need any specific skills and/or interests: e.g. interviewing / minute taking / experience of a particular service area (mental health etc?)</p>
<p>Experience of dementia services is essential, both as a service user and a carer of a person with dementia</p>
<p>Time commitment required: e.g. number of meetings to attend over a period of time</p>
<p>The plan for this phase of the project is that there will be at least one half day mapping event per Area Team region, possibly two, with different people involved in each session.</p> <p>There will also be one large full day stakeholder meeting for this project during</p>

2014/15 with regular update emails for review and comment.

It is also hoped that we may video some patients and carers discussing their experiences to encourage clinicians and commissioners to understand the

Supporting Documents and Links: How does this contribute to existing priorities and policy – local / regional / national)

Dementia is a key priority in all CCG plans.

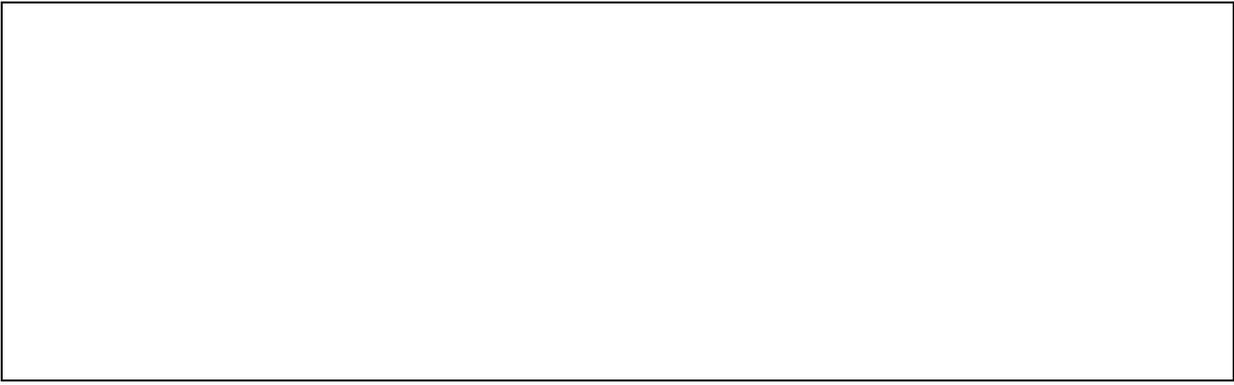
NHS England have agreed a national ambition for diagnosis rates that by 2015 two-thirds of the estimated number of people with dementia in England should have a diagnosis, be able to access and are using appropriate post-diagnostic support. This also forms part of NHS England action on parity of esteem.

Key documents informing policy are:

- 'Living Well with Dementia: A National Dementia Strategy' (2009)
- 'Prime Ministers Challenge on Dementia – Delivery major improvements in dementia care and research by 2015' (2012)
- NICE Guidelines, Pathways, Quality Outcome Framework and Quality Standards
- West Midlands Dementia Strategy
- NHS and Social Care Outcomes Frameworks

Outcomes: How will this work benefit patients / carers / staff / organisations / Network & Senate

- Earlier diagnosis and appropriate management of patients with dementia, allowing access to appropriate help and support to help them live well with dementia
- Improved awareness of quality around timely diagnosis and patient support utilizing the ALCOVE principles
- Identification of unwarranted variation in timely diagnosis rates across the West Midlands
- Better informed commissioning of dementia pathway(s), which would include patient perspective and input
- Identification of best/ good practice to share
- As per section 3.4 (page 14)



4th DRAFT