

Nottinghamshire County Dementia Framework for Action 2016–2020

Contents:

1. Introduction	2
2. The population at risk.....	3
3. Indicators and baseline graphs	3
4. Factors driving the baseline	4
5. Data development.....	5
6. Evidence base for what works to live well with dementia.....	5
7. Recommendations	6
Appendix 1: Key commitments from the Prime Minister’s Challenge on Dementia 2020 and CCG improvement and assessment framework.....	7
Appendix 2: Dementia Services in Nottinghamshire – feedback	10
Appendix 3: The Well Pathway for Dementia	12
Appendix 4: Figure 1: Over 65 population figures.....	13
Appendix 5: Recommendations from the Dementia Stakeholder Event	15

1. INTRODUCTION

Dementia is a priority nationally and in Nottinghamshire. This Framework has been developed following publication of the new Prime Minister's Challenge 2020 and NHS Planning Guidance 2016/17 – 2020/21. The Department of Health has also published a detailed Implementation Plan to support the Challenge which prioritises 18 of the original 50 commitments to be addressed over the next 4 years. A new CCG improvement and assessment framework 2016/2017 CCG Assessment Framework has been developed, aligned to the NHS Planning Guidance, which identifies dementia as a clinical priority. Both sets of commitments are listed in **Appendix 1**.

The Nottinghamshire Plan has also been informed by local discussions in Nottinghamshire, including carers' groups, at Dementia Cafes and a Dementia Stakeholder event held in November 2015. A summary of local views is attached at Appendix 2. The development of the plan will be overseen by the County-wide Dementia and Older People's Mental Health Group.

The aims of the Framework are adopted from NHS England's Well Pathway for Dementia (**Appendix 3**):

- a. Preventing Well - raising awareness, understanding and knowledge about dementia
- b. Diagnosing Well – ensure people get a timely diagnosis
- c. Supporting Well – ensure people get appropriate advice and support
- d. Living Well – enable people with dementia and their carers to live comfortably in their local communities
- e. Dying Well – enable people with dementia to have a good death

The overall outcome of this Framework is to provide services which work together better to support individuals with dementia and their carers

This paper should be considered alongside the Dementia Joint Strategic Needs Assessments (JSNA) for Nottinghamshire, which set out the strategic context, NICE recommendations, current services and gaps in provision ([link below](#)).
[Nottinghamshire Dementia JSNA, 2014](#)

Key points

- 10,246 people live with dementia in Nottinghamshire. This is expected to increase to 11,546 by 2020, an increase of 12.6%
- 30-50% of people in acute hospitals have dementia, delirium or other cognitive impairment
- People live for many years after the onset of symptoms of dementia
- Dementia is overwhelming for carers and they need adequate support
- There are a range of behaviours which can increase our risk of developing dementia, including smoking, obesity and physical inactivity
- People with dementia and their carers need to be involved in formulating plans and services.

2. THE POPULATION AT RISK

The size of the population ages over 65 and predicted prevalence is set out in **Appendix 4. Figure 1** shows that number of people aged over 65 registered in Nottinghamshire CCGs is expected to increase by 11.8%. **Figure 2** shows the resident population by Local Authority and this is expected to increase by 10%. There is a difference between resident and registered populations due to lower increases in some Local Authority areas. The impact of population growth on expected Dementia Prevalence is calculated by CCG and is in **Figure 3**.

The population at risk therefore is people aged over 65, approximately 10,000 of whom may have dementia or mild cognitive impairment. Of these, at least two thirds, 7,126, have a diagnosis recorded on their GP's practice register. Of these:

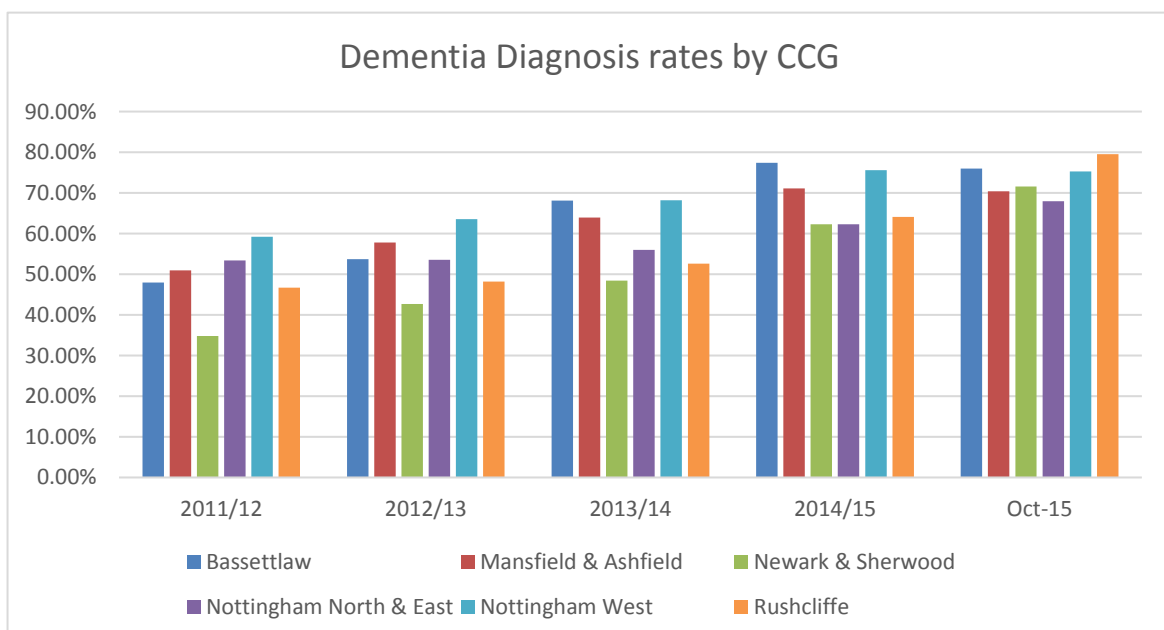
- 55.4% have mild dementia
- 32.1% have moderate dementia
- 12.5% have severe dementia
- 38% of all people with dementia live in care homes, 62% live at home
- Whilst the proportion of all older people residing in care homes has decreased from the early 1990s to the late 2000s (from 5% to 3%), the prevalence of dementia among them seems to have increased, from 56% to 70%.

All from [Dementia UK Update 2014](#)

Estimates of the prevalence of people with dementia under 65 are difficult to confirm as the numbers are low. NHS England notes that 97% of all **diagnoses** are for people aged over 65. If this ratio is applied to prevalence, the estimated number of people under 65 who may have dementia is approximately 340. The Working Age Dementia service however, receive between 400-500 referrals p.a. suggesting that actual numbers may be higher.

3. INDICATORS AND BASELINE GRAPHS

The only reliable and consistent measure giving a baseline performance in dementia is the dementia diagnosis rate which has been monitored for several



years. Diagnosis rates have risen steadily over the last 5 years, as the graph below shows. All 6 CCGs exceed the national target of 66.7%

	Bassetlaw	Mansfield & Ashfield	Newark & Sherwood	Nottingham North East	Nottingham West	Rushcliffe	Total
Prevalence	1499	2270	1601	1840	1455	1581	10246
Diagnosed	1106	1601	1149	1233	975	1060	7126
% rate	73.78%	70.53%	71.8%	67.01%	67.01%	67.05%	69.54%

Public Health England has created a Dementia Profile which provides indicators arranged into six data domains, reflecting the Well Pathway [PHOF Dementia Profile](#):

- Prevalence (measured as % of all ages and over 65)
- Preventing well (performance across a range of risk factors e.g. smoking, weight, CHD)
- Diagnosing well (no indicator yet)
- Living well (social isolation among adult carers)
- Supporting well (rate of admissions to hospital where people also have Alzheimer's)
- Dying well (place of death of people with dementia).

The profile shows that, compared with England, Nottinghamshire has:

- a higher recorded dementia diagnosis
- higher recorded prevalence of smoking, obesity and CHD
- lower % of adult carers who have as much social contact as they would like
- similar or higher rates of hospital admission where people also have dementia
- similar rates of people with dementia dying at home, in a care home or in hospital.

4. FACTORS DRIVING THE BASELINE

The CFASII report shows that later-born populations have a lower risk of prevalent dementia than those born earlier in the past century, that is, a decrease of 1.8% (8.3% compared with 6.5%) in people aged 65 years and older CFASII report. This research has informed the prevalence rates used by NHS England from April 2015.

Nevertheless the numbers of people with dementia will continue to rise because of our increasing older population, specifically:

- Numbers of older people and as a percentage of total population
- Numbers of people aged over 80
- Numbers of frail older people with multiple co-morbidities.

The single biggest risk factor for dementia is age.

5. DATA DEVELOPMENT

Additional local information that would contribute to this plan is:

- Activity information available for dementia services, specifically, number of people diagnosed by the memory assessment service (compared to number of referrals) and including the Working Age Dementia services
- Equalities information for the local population, specifically referrals and diagnoses of people from BAME groups.

6. EVIDENCE BASE FOR WHAT WORKS TO LIVE WELL WITH DEMENTIA

- a) Prevention - the single biggest modifiable risk factor is in relation to vascular dementia and this risk can be reduced by adopting a healthy lifestyle in mid-life. Specifically this means not smoking, eating healthily, being physically active and reducing alcohol consumption. These changes could prevent between 3-20% of new cases over 20 years. [Blackfriars Consensus](#)
- b) Diagnosing Well – good practice in assessment and diagnosis, has identified 3 successful models [Models of Dementia Assessment & Diagnosis](#)
 - (i) A primary care managed service with specialist care outreach
 - (ii) A specialist care managed service with primary care delivery
 - (iii) An entirely specialist led service.

The Nottinghamshire model most closely resembles “b”, with the capacity for GP diagnosis where appropriate e.g. for patients in care homes.

There is no evidence to support population screening, however, evidence suggests most people prefer to know if they have dementia in order to access appropriate support and treatment and to plan for the future <http://www.bmj.com/bmj/section-pdf/898705/12>

The way in which the diagnosis is given is also important to people.

Culturally appropriate assessment screening tools and cognitive stimulation therapy are needed.

- c) Supporting and Living Well - access to post-diagnostic treatment, advice and support is important but insufficient. More research is also needed to identify what are the most effective components of care that enable a person with dementia and their carer to live well and maintain independence . Key components include:
 - (i) Information and advice
 - (ii) Personal care
 - (iii) NHS and hospital care
 - (iv) Care homes
 - (v) Treatments for symptoms or behaviour
 - (vi) Living Well including:
 - support for carers

- feeling included in society
- activity and spirituality

The [Prime Minister's Challenge 2020](#) calls for the development of a solid evidence base for most of these components.

- d) [Dying Well](#) – people with dementia are more likely to be admitted to hospital or at care home towards end of life. They may also receive poor care because they are unable to communicate their needs and wishes. Advance care planning and staff training are therefore important. [SCIE Dementia: End of Life Care Evidence](#)

7. RECOMMENDATIONS

Recommendations attached at **Appendix 5**. Recommendations are intended to follow through into local plans for member organisations where indicated. The plan will continue to develop over the period of the Challenge.

Appendix 1

1. 18 Key commitments from the Prime Minister's Challenge on Dementia 2020 linked to 5 themes:

a) Continuing the UK's Global Leadership Role

Commitment 1: An international dementia institute established in England.

b) Risk Reduction

Commitment 2: Improved public awareness and understanding of the factors, which increase the risk of developing dementia and how people can reduce their risk by living more healthily. This should include a new healthy ageing campaign and access to tools such as a personalised risk assessment calculator as part of the NHS Health Check.

c) Health & Care

Commitment 3: In every part of the country people with dementia having equal access to diagnosis as for other conditions, with an expectation that the national average for an initial assessment should be 6 weeks following a referral from a GP (where clinically appropriate), and that no one should be waiting several months for an initial assessment of dementia.

Commitment 4: Every person diagnosed with dementia having meaningful care following their diagnosis, which supports them and those around them, with meaningful care being in accordance with published National Institute for Health and Care Excellence (NICE) Quality Standards. Effective metrics across the health and care system, including feedback from people with dementia and carers, will enable progress against the standards to be tracked and for information to be made publicly available.

Commitment 5: GPs playing a leading role in ensuring coordination and continuity of care for people with dementia, as part of the existing commitment that from 1 April 2015 everyone will have access to a named GP with overall responsibility and oversight for their care.

Commitment 6: All hospitals and care homes meeting agreed criteria to becoming a dementia-friendly health and care setting.

Commitment 7: All NHS staff having received training on dementia appropriate to their role. Newly appointed healthcare assistants and social care support workers, including those providing care and support to people with dementia and their carers, having undergone training as part of the national implementation of the Care Certificate, with the Care Quality Commission asking for evidence of compliance with the Care Certificate as part of their inspection regime. An expectation that social care providers provide appropriate training to all other relevant staff.

d) Dementia Awareness and Social Action

Commitment 8: Alzheimer's Society delivering an additional 3 million Dementia Friends in England, with England leading the way in turning Dementia Friends in to a global movement including sharing its learning across the world and learning from others.

Commitment 9: Over half of people living in areas that have been recognised as Dementia Friendly Communities, according to the guidance developed by Alzheimer's Society working with the British Standards Institute. Each area should be working towards the highest level of achievement under these standards, with a clear national recognition process to reward their progress when they achieve this. The recognition process will be supported by a solid national evidence base promoting the benefits of becoming dementia friendly.

Commitment 10: All businesses encouraged and supported to become dementia friendly, with all industry sectors developing Dementia Friendly Charters and working with business leaders to make individual commitments (especially but not exclusively FTSE 500 companies). All employers with formal induction programmes invited to include dementia awareness training within these programmes.

Commitment 11: National and local government taking a leadership role with all government departments and public sector organisations becoming dementia friendly and all tiers of local government being part of a local Dementia Action Alliance.

e) Research

Commitment 12: Funding for dementia research on track to be doubled by 2025.

Commitment 13: Increased investment in dementia research from the pharmaceutical, biotech devices and diagnostics sectors, including from small and medium enterprises (SMEs), supported by new partnerships between universities, research charities, NHS and the private sector. This would bring world class facilities, infrastructure, drive capacity building and speed up discovery and implementation

Commitment 14: Dementia research as a career opportunity of choice, with the UK being the best place for Dementia Research through a partnership between patients, researchers, funders and society.

Commitment 15: Increased numbers of people with dementia participating in research, with 25 per cent of people diagnosed with dementia registered on Join Dementia Research and 10 per cent participating in research, up from the current baseline of 4.5 per cent.

Commitment 16: Cures or disease-modifying therapies on track to exist by 2025, their development accelerated by an international framework for dementia research, enabling closer collaboration and cooperation between researchers on the use of research resources – including cohorts and databases around the world.

Commitment 17: Open access to all public funded research publications, with other research funders being encouraged to do the same.

Commitment 18: More research made readily available to inform effective service models and the development of an effective pathway to enable interventions to be implemented across the health and care sectors.

2. CCG improvement and assessment framework 2016/17

- Estimated diagnosis rate for people with dementia
- Dementia care planning and post-diagnostic support

Appendix 2

Dementia Services in Nottinghamshire – feedback from people with dementia and carers

Throughout October and November 2015 discussions were held with carers' groups, and Dementia Cafes and key themes were presented at the Health & Wellbeing Board Dementia Stakeholder event. About 100 people were invited to contribute their views in face to face meetings. A request was also made on-line via <http://www.dementiacarer.net/>

The briefing and questions are set out below:

Consultation with carers

Dementia is a key priority within Nottinghamshire's Health and Wellbeing Strategy and is a condition that crosses health, social care, voluntary sector and other boundaries. It is particularly relevant for the population of Nottinghamshire which has an increasing proportion of older people who may be at risk. It is also important to acknowledge the immense and invaluable role that carers play in supporting people with dementia.

The Health & Well-being Board is planning a stakeholder event which will focus on dementia. This will aim to inform a Nottinghamshire-wide plan for the Health & Wellbeing Board and its partners. This will provide a local focus to address the recommendations in the Prime Minister's Challenge 2020 (link below) which sets out new recommendations for improving care for people with dementia and carers:

<https://www.gov.uk/government/publications/prime-ministers-challenge>

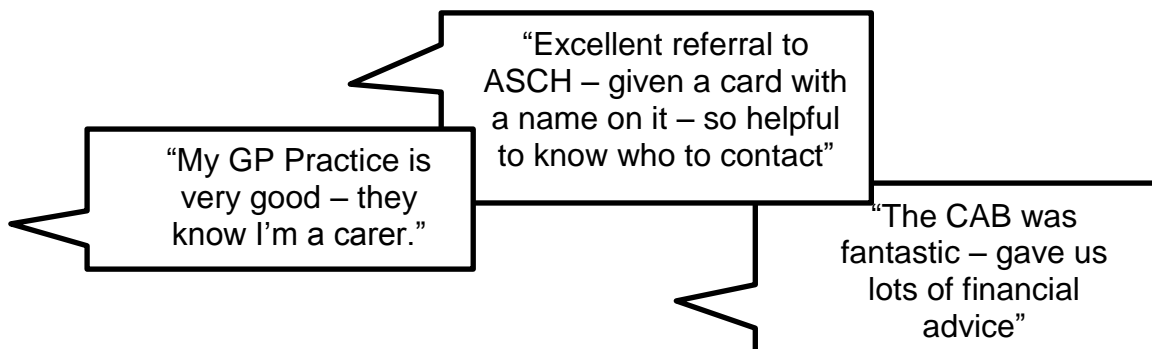
We are seeking the views of resident carers to inform and influence the work of the Council, the local NHS and 3rd sector, which will be discussed at the stakeholder event in the autumn.

Questions

What's working well?
What isn't working well?
How can we improve it?

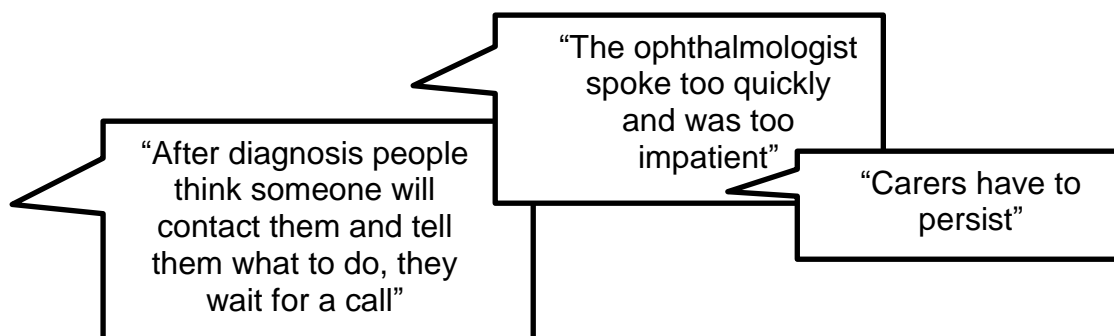
Meetings were held in:

Worksop
Newark
Stapleford
Mansfield








Summary of Carers' Consultation meetings

<p>What's working well</p>	<ul style="list-style-type: none"> • Individual services, once accessed, very good <ul style="list-style-type: none"> - Red Cross equipment service - Day care/Care home/Social worker - GP Practice/ Sheila Gibson clinic - CRISP/PRISM • Access to information - CAB • Self-help groups <ul style="list-style-type: none"> - Worksop group - Crossroads - Forget-me-not • Carer seen separately in clinic
<p>What isn't working well?</p>	<ul style="list-style-type: none"> • Lack of accessible local services • Lack of co-operation and co-ordination between health & social care • Lack of understanding about dementia among health and social care staff • Day care mix of clients • Layout of GP practice • Very trying to have to visit so many people with a person with dementia • Word 'carer' is off-putting • Dealing with changes to day care fees • Lack of services for people with Working Age Dementia
<p>How can we improve it?</p>	<ul style="list-style-type: none"> • Having someone to follow you through rather than time-limited services • Not having to repeat yourself many times • For assessments HCP needs to come more than once • Help for isolated carers (who do not attend groups) • Delivering the diagnosis 'kindly' • Occupational therapy advice about aids and adaptations • Annual review • More men working in care homes • Financial advice – confusion around different allowances



Appendix 3

The Well Pathway for Dementia

NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA				
PREVENTING WELL	DIAGNOSING WELL	SUPPORTING WELL	LIVING WELL	DYING WELL
 <p>Risk of people developing dementia is minimised</p>	 <p>Timely diagnosis, integrated care plan, and review within first year</p>	 <p>Access to safe high quality health & social care for people with dementia and carers</p>	 <p>People with dementia can live normally in safe and accepting communities</p>	 <p>People living with dementia die with dignity in the place of their choosing</p>
<p>“I was given information about reducing my personal risk of getting dementia”</p>	<p>“I was diagnosed in a timely way”</p> <p>“I am able to make decisions and know what to do to help myself and who else can help”</p>	<p>“I am treated with dignity & respect”</p> <p>“I get treatment and support, which are best for my dementia and my life”</p>	<p>“Those around me and looking after me are supported”</p> <p>“I feel included as part of society”</p>	<p>“I am confident my end of life wishes will be respected”</p> <p>“I can expect a good death”</p>
<p>STANDARDS:</p> <p>Prevention⁽¹⁾ Risk Reduction⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Diagnosis⁽¹⁾⁽⁵⁾ Memory Assessment⁽¹⁾⁽²⁾ Concerns Discussed⁽³⁾ Investigation⁽⁴⁾ Provide Information⁽⁴⁾ Care Plan⁽²⁾</p>	<p>STANDARDS:</p> <p>Choice⁽²⁾⁽³⁾⁽⁴⁾ BPSD⁽⁶⁾⁽²⁾ Liaison⁽²⁾ Advocates⁽³⁾ Housing⁽³⁾ Hospital Treatments⁽⁴⁾ Technology⁽⁵⁾ Health & Social Services⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Integrated Services⁽¹⁾⁽³⁾⁽⁵⁾ Supporting Carers⁽²⁾⁽⁴⁾⁽⁵⁾ Carers Respite⁽²⁾ Co-ordinated Care⁽¹⁾⁽⁵⁾ Promote independence⁽¹⁾⁽⁴⁾ Relationships⁽³⁾ Leisure⁽³⁾ Safe Communities⁽³⁾⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Palliative care and pain⁽¹⁾⁽²⁾ End of Life⁽⁴⁾ Preferred Place of Death⁽⁵⁾</p>
<p>COMMISSIONING GUIDANCE:</p> <ul style="list-style-type: none"> Develop commissioning guidance based on NICE guidelines, standards and evidence-based best-practice. Agree minimum standard service specifications, set business plans, mandate and resources. Work with ADASS, PHE & other ALBs on co-commissioning strategies to provide an integrated service. 				
<p>MEASUREMENT:</p> <ul style="list-style-type: none"> Develop Quality, Access and Prevention metrics to form the basis of the CCG scorecard. Identify data sources and agree with HSCIC, et al on the extraction processes. Set ‘profiled’ ambitions for each metric, to form the basis of the transformation plan. 				
<p>TRANSFORMATION, RESEARCH, INNOVATION, TECHNOLOGY, PATIENT ENGAGEMENT AND BEST-PRACTICE:</p> <ul style="list-style-type: none"> Transformation: using CCG scorecard to set & achieve a national standard for Dementia services. Intervention: Intensive Support Team to provide ‘deep-dive’ support and assistance for CCGs that fall short. Innovation: Intel from Research, Patient involvement, best-practice and technology to influence change. 				
<p>References: (1) NICE Guideline. (2) NICE Quality Standard 2010. (3) NICE Quality Standard 2013. (4) NICE Pathway. (5) Organisation for Economic Co-operation and Development (OECD) Dementia Pathway. (6) BPSD – Behavioural and Psychological Symptoms of dementia.</p>				

Appendix 4: Population figures and dementia prevalence

Figure 1 shows that number of people aged over 65 registered in Nottinghamshire CCGs is expected to increase by 11.8%.

Figure 2 shows the resident population by Local Authority and this is expected to increase by 10%. There is a difference between resident and registered populations due to lower increases in some Local Authority areas. The impact of population growth on expected Dementia Prevalence is calculated by CCG and is in **Figure 3**.

Figure 1: Over 65 population by CCG 2015 and 2020 (registered)

CCG	Bassetlaw	Mansfield & Ashfield	Newark & Sherwood	Nottingham North and East	Nottingham West	Rushcliffe	Nottinghamshire
2015	23,143	34,549	26,827	29,473	19,186	25,211	158,391
2020	26,138	38,565	30,113	32,664	21,090	28,554	177,123
Diff	2,995	4,016	3,286	3,191	1,904	3,343	18,732
% incr.	12.9%	11.6%	12.2%	10.8%	9.9%	13.2%	11.8%

Source: PH Info

Figure 2: Over 65 population by Local Authority 2015 and 2020 (resident)

LA	Bassetlaw	Ashfield	Mansfield	Newark & Sherwood	Gedling	Broxtowe	Rushcliffe
2015	24,073	22,858	19,798	24,989	23,570	22,764	23,656
2020	26,787	25,148	21,688	27,615	25,743	24,565	26,412
Diff	2,714	2,290	1,890	2,626	2,173	1,801	2,756
%	11.2%	10.0%	9.5%	10.5%	9.2%	7.9%	11.7%

Source: PH Info

Figure 3: Over 65 dementia prevalence by CCG 2015

CCG	Bassetlaw	Mansfield & Ashfield	Newark & Sherwood	Nottingham North and East	Nottingham West	Rushcliffe	Nottinghamshire
2015	1,499	2,270	1,601	1,840	1,455	1,581	10,246
2020	1,692	2,633	1,796	2,038	1,599	1,788	11,546

Source: NHS England planning Trajectory 2015/16 adjusted for CFASII

Appendix 5

Recommendations for Action from the Dementia Stakeholder Event

Action	Lead Responsibility
<p>1. Raising awareness and Reducing the risk of dementia</p> <p>1.1 Preventing Well</p> <ul style="list-style-type: none"> a. Public Health to promote awareness of the risk of dementia to adults through lifestyle services: smoking , obesity & weight management, alcohol and substance misuse and Health Checks b. Raising awareness of the symptoms of dementia through Health Checks so that relatives and carers can identify onset c. Tackle stigma and shame about dementia in BaME communities 	Public Health
<p>2. Primary Care/General Practice</p> <p>2.1 Diagnosing Well</p> <ul style="list-style-type: none"> a. Maintain diagnosis rates at least two thirds prevalence b. Review Nottinghamshire Dementia Referral Guidelines (autumn 2017) <p>2.2 Supporting Well</p> <ul style="list-style-type: none"> a. Develop local plans to improve the quality of post-diagnostic treatment and support including Annual b. Reviews (Links to 3. Below) b. Consider dementia friendly GP practices: c. Identify a Dementia Champion d. Dementia Friends for all staff e. Consider dementia friendly layout in new build/refurbishment schemes <p>2.3 Dying Well</p> <ul style="list-style-type: none"> a. Preparation for families 	Nottinghamshire CCGs
<p>3. Meaningful Care after Diagnosis</p> <p>3.1 Supporting Well</p> <ul style="list-style-type: none"> 3.1.1 Provision of a care plan and appropriate information on what services are available locally and how these can be accessed e.g. DASS 3.1.2 Quality of annual reviews in Primary care 3.1.3 Better integration of health and social care; mental and physical healthcare 3.1.4 NHS & social care staff training in the community, hospital, care homes and home care 3.1.5 Housing options e.g. Extracare 3.1.6 Use of technology 	<p>Nottinghamshire CCGs</p> <p>HWBB CCGs & ASCHPP Provider organisations ASCHPP & DCs</p>

<p>3.2 Living Well</p> <p>a. Ensuring access to information, advice and a social care assessment</p>	<p>ASHPP</p>
<p>4 Carers</p> <p>4.1 Living Well</p> <p>a. Carers of people with dementia being made aware of and offered:</p> <p>i. Information, education and training</p> <p>ii. Emotional and psychological support</p> <p>iii. Home care/respite</p> <p>iv. Compass workers</p>	<p>ASCHPP</p>
<p>5 Dementia Friendly Communities (DFCs)</p> <p>5.1 Living Well</p> <p>a. Work with the local Dementia Action Alliance to promote DFC's in local areas</p> <p>b. Promote awareness in specific groups: BaME groups, deaf people, police schools</p> <p>c. Promote dementia awareness in NHS contracted services: dentists, pharmacists, opticians</p> <p>d. Promote dementia awareness in the workplaces (links to risk reduction)</p>	<p>All</p> <p>HWBB</p> <p>NHSE</p> <p>HWBB</p>

Abbreviations

AHSCPP Adult Social Care, Health and Public Protection

HWBB Health & Wellbeing Board

DC District Council