# DEMENTIA UNITED

DEMENTIA STRATEGY FOR GREATER MANCHESTER

IMPLEMENTATION PLAN

# Introduction

Health and Social Care Partners have committed to working together over the next five years to make Greater Manchester (GM) the best place to live with dementia.

Over the last 18 months a set of Greater Manchester dementia standards for local care delivery have been produced with people with dementia and their carers and endorsed by the Joint Commissioning Board (JCB).

**This implementation plan outlines the support and development resource for GM to enable localities to embed and meet the GM standards through local leadership and governance, building on their locality plans.**

The deliverables from Dementia United are an integral part of the Greater Manchester Investment Agreement and mark a move from focussing on diagnosis to more broadly the experience of care, post diagnostic support and healthcare utilisation

The September 2016 standards can be seen in Appendix 1.

# The Programme

The Dementia United programme requires deep connections with locality plans and has significant interdependence with mental health and frailty plans which needs to be fully understood.

Co-ordinated regional support through partners, including the Health and Social Care Partnership/Strategic Clinical Network, Haelo and The Alzheimer's Society, will ensure that learning between localities is optimised and variation in service provision is better understood through peer review and knowledge exchange.

This programme will build on the excellent work in localities over the last decade, look to smooth variation and build improvement capability across the region through collaborative improvement which will have high value for future programmes (beyond Dementia United).

# Work Programmes

Dementia United will accelerate the pace of implementation for the GM dementia standards, to improve the lived experience and reduce health and care utilisation.

Four key work programmes are described:

**WORK PROGRAMME ONE**

Describes the delivery system within localities.

**WORK PROGRAMME TWO**

Describes the regional support architecture.

**WORK PROGRAMME THREE**

Describes the infrastructure for intelligence.

**WORK PROGRAMME FOUR**

Focuses on innovation, research and evaluation .

SECTION

# WP1

## Locality Delivery

# Locality Leadership

Each locality will appoint an Executive Lead (EL) for dementia. This individual will have delegated responsibility from the locality partnership to represent the locality in all regional discussions about the strategic direction and performance of dementia services.

They will feedback progress from their locality to the Greater Manchester system and lead the locality peer review and annual dementia review with GM (1.5). The EL will appoint a clinical lead and team from across the 'Well Pathway' to lead DU in the locality. The locality team will be responsible for DU Implementation and cross locality learning in GM.

# Locality Governance

Each locality will agree a system of governance which connects the DU standards into the locality plan. In addition, meetings will be identified where key stakeholders come together to discuss DU implementation within the locality.

As a minimum this will include: public health; primary care; community services; secondary care; mental health services; 3rd sector; care homes, people with dementia and carers. Meetings will be at least monthly, locally co-ordinated and progress shared at regional meetings.

# Improvement Plan

Each locality will use the DU standards, locality profiles and DU dashboard, approved by the JCB, to agree a local system for reconciling the standards with current service delivery across the well pathway.

A strengths analysis will be carried out to identify opportunities for leadership, teaching and learning. Each locality will set their own improvement goals and describe a plan for implementation, identifying resources and how improvement will be measured.

# Peer Review

Each locality will participate in developing the peer review process against an agreed set of design principles. Peer review is an opportunity to bring local stakeholders together for, reflection, learning and team building.

There will be pre visit preparatory work to complete including document collation, data packaging, stakeholder co-ordination and logistics. It is proposed that peer reviews will take at least one day and comprise as a minimum document & data review, site visits, clinical leadership, patients panels and data review. Each locality will be expected to participate in an annual peer review of their own and one other locality.

# Integrating Learning

Each locality will assess its own progress against a matrix to determine the maturity of their team composition, governance systems, aims, measures, compliance with standards and improvement plan.

An annual dementia update (quality account) will be produced by the locality and will describe the local partnership, engagement in the DU programme and improvement breakthroughs. The report will also describe learning from the peer review and local plan for the coming year including measurable aims, improvement programmes and methodology. The report will be structured using the Well Pathway and will describe the ambition across the pathway and, importantly, the role of each of the partners in delivery.

# DU Quality Mark

During years 1&2 the regional team will co-ordinate the development of a DU Quality Mark system.

Every locality will be asked to participate in a working group to develop the Quality Mark system for dementia services. Task and finish workgroups will be established to determine the process of application and award; ensure information is easily stored / retrieved and incentives (for participation) are attractive to localities and GM.

# Data Collection

Localities will set up data collection systems to determine the 'lived experience' for people living with dementia and those who care for them by participating in the development of the Dementia Barometer.

This will include surveying all people living with dementia (being treated by a healthcare professional) on 1 day per month, submitting the data to a GM portal, analysis of qualitative data, sharing intelligence with other localities and using thematic analysis to influence improvement plans.

# Collaborative Participation

Each locality will participate in up to three improvement collaboratives (2.7). Localities will be able to select which collaboratives they participate in based on their local performance data.

Each collaborative will run for between 6-12 months and will bring teams from all participating localities together on three occasions to work on improvement in the focus areas of one to one care, post diagnostic support and improving carer support and / or end of life care.

SECTION

# WP2

## Regional Support

# Governance & Regional Partnership


The DU programme will report to GM through the Mental Health Work programme. An independent Chair will be appointed to lead a DU Executive which will represent key stakeholder groups.

Terms of reference will be agreed. The Executive will ensure the programme is delivered and risks are managed and mitigated. A Programme Director will be appointed who will report to the DU Executive Chair and provide leadership to the system on behalf of GM. The Programme Director will also oversee operational delivery and be the primary point of liaison with key stakeholders.

# Programme Management

A DU programme management office (PMO) will be established to provide central co-ordination (programme management), measurement and improvement support.

In addition, with key partners, the PMO will bring together work programmes of key partners including Haelo and The Strategic Clinical Network to manage operational delivery of DU, including stakeholder engagement and supply chain management. The PMO will surface any new opportunities for innovation or barriers to implementation for consideration by the Executive via monthly operational updates.

# Hardwiring evidence into DU practice


The current DU programme is built on a set of evidence based standards that have been developed in conjunction with people living with dementia.

They represent a minimum set of expectations for people living with dementia in GM. Each locality will be asked to review and supplement these where necessary to align them with local priorities. There will be a joint responsibility to review and update the standards (both in GM and in localities), this will be done in partnership.

A lead provider will be appointed to co-ordinate this process and provide assurance that the standards are robust and updated in a timely way at agreed intervals.

# Locality Support

Three locality co-ordinators (LC) will be appointed or seconded (from localities or stakeholder partners) to provide support to localities.

Each LC will support three or four localities, ensuring that stakeholders are engaged, milestone reviews are organised, Key Performance Indicators (KPI's) delivered and partners co-ordinated.

The LC's will support a standardised locality assessment on a six monthly basis which will inform the peer review process, and the development of the DU quality mark (1.6).

# Improvement Coaching

In year one, the PMO will support an improvement capability assessment with each of the ten localities to determine improvement strengths and training needs.

A tailored programme of support including improvement clinics and training programmes will be offered to each locality from a menu of providers. The provider, intensity and type of support will be agreed through the strengths assessment and improvement plans developed in year one and may include the utilisation of local improvement teams wherever possible.

# Stakeholder Engagement

GM has a significant number of regional partners involved in making our region a great place to live.

The DU PMO will proactively manage stakeholder engagement including linking with national charity and policy leaders ensuring the brand is 'inclusive' and permissive. Stakeholder relations in each locality will be supported by the regional team to gain traction in the system. A cross sector coalition of partners will participate in a social movement campaign to make GM the best place to live with dementia.

The campaign platform and brand is already established, this will be developed into a change platform. Goals for reach will be ambitious. Each year, two 1 day stakeholder events will be organised.

# Digital DU

Building on the existing website and social media activity, the PMO will operationalise digital communications and knowledge capture.

They will provide real time updates on progress (including case studies) through film and digital media. The web portal will be the 'go to' place for DU and link to the GM Health and Social Care Partnership (HSC) & locality communications. The development of the DU brand will be owned by the PMO. They will have responsibility for reaching networks outside GM and harvesting information back into the GM system.

# Delivery of Collaboratives

The PMO will be responsible for co-ordinating the delivery (with partners) of three regional collaboratives (to run years 1-3) to:

i. Improve 1-2-1 care in in-patient settings (implementing John's campaign in every ward)

ii. Post diagnostic support

iii. Improving carer support and / or end of life care

Each collaborative will run for one year and will bring teams from all participating localities together on three occasions to work collaboratively on improvement in the focus areas.

# Fellowships & Capability Building

## 2.9

High quality dementia services depend on high quality leadership with skills in improvement.

Over three years we will recruit up to 60 GM DU Fellows (20 per year). As leaders of services they will commit to: improve dementia services in their ward, team, service or organisation.

They will participate in six 2 day training events over 12 months, graduating with a presentation to the GM HSC leadership team. The programme will be run jointly with academic partners in GM.

SECTION

# WP3

## Intelligence

# Dementia Barometer

## The PMO will co-ordinate the development of the barometer.

Working with localities to test operational definitions, establish data collection systems, agree data presentation, build a prototype web platform for online data collection and review how localities are using the data – optimising the support systems to provide effective support.

The Dementia Barometer will be the primary mechanism through which the GM system will establish its 'big conversation' with the citizens of GM. Throughout this process the PMO will partner with people with dementia, those who care for them and localities in driving this work programme.

3.1

# Improvement Dashboard

DU has a triple challenge to improve the lived experience (tested through the barometer), measure system improvement and contain costs.

The PMO will support the development of a regional dashboard which will include measures from along the well pathway including: health checks, diagnosis rates, time to diagnosis, post diagnostic support, dementia friends, A&E attendances, hospital admissions, length of stay, readmissions and end of life care.

Initially the dashboard will be issued quarterly, however the PMO will work with GM to ensure incorporation into regional 'real time' dashboards.

3.2

# Locality Profiles

DU has developed an innovative infographic to display data in a way which makes it useable and useful to all.

The PMO will develop the locality profiles, gaining feedback from the localities about their format and utility. The locality profiles will be produced for each locality twice yearly and used to inform the discussion at the peer review. Themed profiles will be produced to support the delivery of improvement collaboratives (2.7).

3.3

# Integration & Delivery Partnerships

## Measurement of dementia services requires access to data from multiple sources.

The DU PMO will support co-ordination to ensure the data permissions and source data systems are accessible to all. They will be responsible for ensuring governance systems are in place and for working with the GM data experts and Datawell to ensure the emergent dementia metrics are incorporated into data systems in Manchester.

3.4

SECTION

# WP4

## Innovation, Research & Evaluation

4.1

# Digital Innovation

## DU is working with partners to develop the digital ‘place’ for people living with dementia

This includes wearable devices for monitoring individuals, sensor technologies for monitoring environments and new social connection systems (Project Time Box). Most of this work is being done by partners in universities and the private sector (The Landing, MediaCityUK).

DU provides an essential connection to the community and to health and social care professionals, acting as a connector and providing support to access grant funding. The DU PMO will accelerate this work, increasing the partnerships to deliver the aims of DU.

# 4.2

# Housing Partnerships

DU has started working with Social Housing to determine the potential for partnerships to support healthy independent living for people with dementia living in social housing.

Our intelligence suggests that a first step in this process is to identify people (via a registry system) living with dementia in social housing. Housing Associations have a number of innovative solutions to post diagnostic care and are already working with GM Fire and Rescue Service  on periodic health checks.

The PMO will support the scoping of a programme of work that collaborates with social housing across GM – led by housing and working in partnership with citizens which will operationalise in years 2-4.  The PMO will align this with the wider housing work across GM.

4.3

# Programme Evaluation

The PMO will be responsible for co-ordinating a programme evaluation.

This will align with the evaluation model for GM (being set up for the Integrated care programmes) and will be largely low cost and rapid cycle, informing the programme delivery in ‘real time’.

The PMO will work with academic partners to produce a protocol for a summative evaluation. The funding for the full summative evaluation will be sought through external funding sources (NIHR, charity etc). This will be supported by the PMO.

4.4

# Research Partnerships

## Greater Manchester has world class research and researchers in dementia in its universities.

The programmes / research they deliver often require close collaboration with the health and social care system however results from the outputs of research are often unknown to the system.

DU will continue to work with an established research community who seek to use DU to support a more coherent strategy for dementia research/trials. The DU PMO will continue to support the interaction between research and care delivery to improve interaction, generate new ideas and bring inward investment into GM through research.

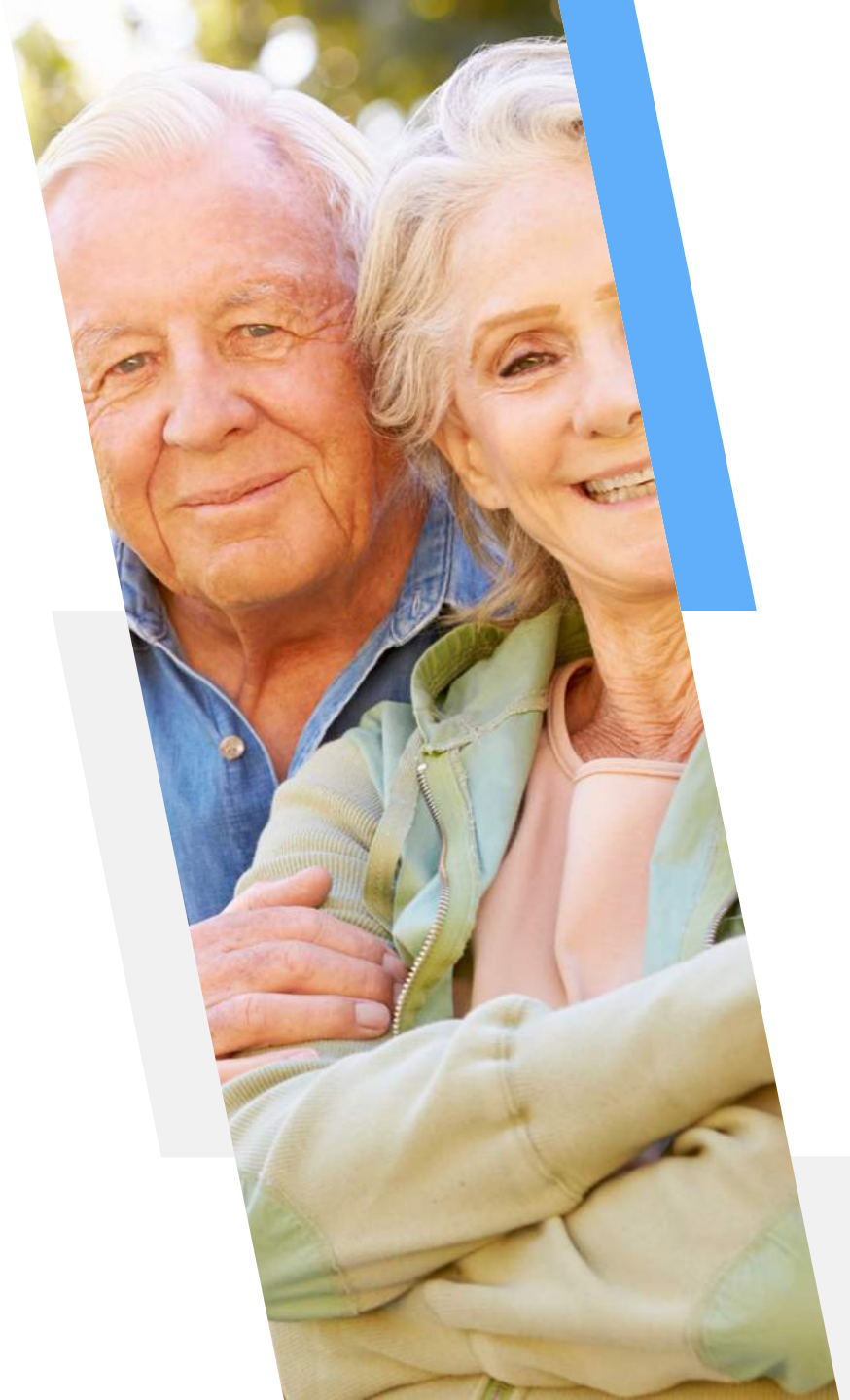
# Development Focai

**Post Diagnostic Support**

**Social Finance**

During feedback from our preliminary papers (Jan – Apr 2016) it was clear that each locality was developing plans to address post diagnostic support for people living with dementia. In some cases localities were using a key worker/case management model, however, the terminology, approach and local implementation varied considerably from one locality to the next.

Given our commitment to local delivery within GM we agreed to defer the pledge to 'have a key worker for every person with dementia' and will be working with localities to determine how this can be met within their local planning. This does not reflect a movement away from a DU commitment to post diagnostic support, but more a commitment to work in partnership with the localities on this.  We therefore have deferred this and will be working through it more in year one.



# Case for Change

## Health and Social Care Spending

National statistics suggest an average cost of £32,250 for each person living with dementia each year. 16.3% of this is spent on healthcare and 39.1% on social care. The remaining 44.6% is spent by people with dementia (and their families) to pay for help with everyday tasks that are provided by professional care workers - such as washing, dressing and eating[1]. From these data we can estimate that the cost to the taxpayer for health and social care currently provided for people with dementia across Greater Manchester is £270m per year.

## Hospital and Care Activity

There are an estimated 26,841[2] people living with dementia in GM. Each year there are 26,000 hospital admissions for people living with dementia (in any diagnostic position). Patients with dementia stay in hospital longer than their age matched peers (12.7 days on average[3]) and of those discharged 18% will return within 30 days[4]. The experience for people living with dementia in hospital is poor. There is also significant variation between the best and worst localities on all these activity measures[5] (see Dementia United July 2016 data report).

## Improvement Goals

The programme will seek to support localities to reduce avoidable hospital admissions, non-elective patient bed days and re-admissions each year in GM by getting each locality to match the performance of the current best in class (FY16-17) on each of the measures **by 2022**. The improvements in these areas we predict to take 5 years with a particular focus of working with the localities that are furthest from the 'best in class'.

# Financials & Investment

## Investment Opportunities

In preparation for this work Dementia United have already secured inward investment in kind up to £250k and would see this accelerating with the programme development  to circa £500k seeking to attract investment from other third sector organisations, industry, social finance and other funding sources. As such, the investment by the devolution team would be leveraged as capital against which we would seek to attract inward investment into the region to support the work.

## Programme Costs

Due to the complexity of the DU programme and work that is already within locality plans, a detailed piece of financial modelling work is being undertaken, led by members of the Task and Finish Group. This will outline the funding envelope required to deliver the plan and where/how much of this is available within current resource in the GM system or could be sourced through match and 'in kind' funding.  This work will provide the foundations for a full Cost Benefit Analysis (CBA) and Health Economics (HE) piece of work that clearly articulates the costs, benefits and outcomes from the DU programme over and above those being released and realised from locality plans.

The programme would commit to delivering the CBA and HE in Quarter 1 of the programme through WP1 and WP2. *(A small amount of funding maybe required to complete this).*

# 05

# PROGRAMME DELIVERY

# Current Arrangement

DU has been co-ordinated by GM partners through an Executive group chaired jointly by Sir David Dalton (Salford Royal NHS Foundation Trust) and Pat Jones–Greenhalgh (Bury Council) and including Professor Alistair Burns (National Clinical Director for Dementia) . Over the last six months a supplementary Task and Finish group, led by Anthony Hassall (Salford Clinical Commissioning Group (CCG), with members including Ann Barnes (Stockport NHS Foundation Trust), Mike Burrows (GM AHSN), Bev Humphreys (Greater Manchester West Mental Health Trust) and Sandy Bering (Strategic Lead Commissioner, Trafford CCG), have provided support to the Executive in developing standards and the implementation plan.

The Task and Finish Group were supported further by four expert groups which included people with dementia, representatives from the strategic clinical network, CCG's, acute sector, local authorities, 3rd / voluntary sector and academia. Localities have participated in regional delivery workshops on a regular basis; these have been supported by the Strategic Clinical Network. Haelo (Salford's Innovation and Improvement Science Centre) was commissioned as the delivery partner during the scoping and development phase of the programme. They have provided a director, programme management and improvement expertise.

GM oversight and strategic alignment has been provided by Warren Heppolette. The programme has been funded by the GM Health and Social Care Partnership on a quarterly non-recurrent basis (June 2015 – June 2016). Salford CCG are the accountable officers for the financial governance of the programme with money transferred from the GM to Salford and onto Haelo as the delivery partner.

# Proposed Arrangement & Delivery Partners

This proposal builds on the commitment to use expertise in Greater Manchester to support local delivery. There is a coalition of partners who have committed to supporting the delivery of DU and have already participated in the work to date including Haelo, the Alzheimer's Society and the Strategic Clinical Networks. The breadth and detail of the implementation plan also invites consideration of the contributions of additional improvement partners such as Health Innovation Manchester, AQuA, and the I-Network. It is our intention to work with these partners, and potentially others, to establish a unique delivery partnership which draws the best of Greater Manchester's improvement and innovation capability together in direct support of one of the Greater Manchester's Health & Social Care Partnership's confirmed priority programmes.

These relationships will require robust contract management and governance and this document lays down a clear set of milestones and deliverables which can be reported back to the Greater Manchester Senior Management Team (funders) which will provide flexibility to refine the offer (at 3 monthly review points) over the contract period to meet the requirements of the emergent programme.

# Timeline

| High level timeline | FY17-18 | | | | FY 18-19 | | | | FY 19-20 | | | | FY20-21 | | | | FY21-22 | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Leadership, Governance & Programme Management Support set up | ■ | | | | | | | | | | | | | | | | | | | |
| Leadership, Governance & Programme Management Support in place | | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ |
| Locality support – strength's analysis undertaken & improvement plans developed | | ■ | ■ | ■ | | | | | | | | | | | | | | | | |
| Locality support | | | | | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ |
| Kite Mark programme developed | | ■ | ■ | ■ | | | | | | | | | | | | | | | | |
| Peer review process developed | | ■ | ■ | ■ | | | | | | | | | | | | | | | | |
| Peer Review process active | | | | | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ |
| Improvement Coaching | | | | | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ |
| Innovation products | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | | | | | | | | | | | | |
| Collaborative [1] | ■ | ■ | ■ | ■ | | | | | | | | | | | | | | | | |
| Collaborative [2] | | | | | ■ | ■ | ■ | ■ | | | | | | | | | | | | |
| Collaborative [3] | | | | | | | | | ■ | ■ | ■ | ■ | | | | | | | | |
| Fellowship cohort [1] | ■ | ■ | ■ | ■ | | | | | | | | | | | | | | | | |
| Fellowship cohort [2] | | | | | ■ | ■ | ■ | ■ | | | | | | | | | | | | |
| Fellowship cohort [3] | | | | | | | | | ■ | ■ | ■ | ■ | | | | | | | | |
| Dementia Barometer – development & testing | ■ | ■ | ■ | ■ | | | | | | | | | | | | | | | | |
| Dementia Barometer – roll out | | | | | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ |
| Dashboard & Locality Profiles | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ |
| Evaluation | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ | ■ |

# References


1. https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=418
2. Data source:  2015 Office National Statistics data (ONS)
3. Data source:  Hospital Episode Statistics (HES)
4. Data source:  Hospital Episode Statistics (HES)
5. Dementia United July 2016 data report (based on HES and ONS data)

# Appendix 1:

| LIVING WELL PATHWAY DOMAIN | STANDARD* | POTENTIAL YEAR 1 MEASURE |
|---|---|---|
| PREVENTING WELL | Each locality will achieve uptake of NHS health checks comparable with the top 20% nationally and dementia screening will be specifically documented in these checks | **Measure**<br>- Health Checks Offered<br>- Health Checks Uptake<br>**Source**<br>*Public Health England, Quarterly (http://fingertips.phe.org.uk/profile/nhs-health-check-detailed/data)* |
| DIAGNOSING WELL | Each locality will achieve dementia diagnosis rates comparable with the top 20% nationally<br>People receiving an initial assessment and diagnosis will feel this is timely<br><br>People will receive a comprehensive assessment of mental and physical health issues as part of the diagnostic process and at regular intervals subsequently<br>People will be offered medication in line with NICE guidelines | **Measure**<br>- Dementia Diagnosis<br>**Source**<br>*NHS England, Monthly (https://www.england.nhs.uk/mentalhealth/dementia/monthly-workbook/)* |
| LIVING WELL | People living with a diagnosis of dementia and their carers will be surveyed on one day per month to determine their 'lived experience'<br>People with dementia should have the same access to community health and care services as others with complex support needs. Each locality will commit to monitoring a subset of community based care standards to track and evidence this.<br><br>People with dementia will receive an assessment for evidence based assistive technology and/or necessary personal 'reasonable adjustments' shortly after diagnosis and on request by carers at other times | **Measure**<br>- Dementia Living Experience Barometer<br>**Source**<br>*To be developed within Financial Year 2017-2018* |

| | | |
|---|---|---|
| SUPPORTING WELL | People with dementia will receive information and signposting to peer support group(s) and networks that are appropriate to their needs and preferences<br>People with dementia will have their living well plan reviewed at least annually (or when circumstances change) including a review of medication in line with NICE guidelines<br><br>People with dementia will be offered access to a structured group cognitive stimulation programme commissioned and provided by a range of health and social care workers with training and supervision, and delivered irrespective of any anti-dementia drug received.<br><br>Carers of people with dementia will be offered signposting and information to peer support groups that are appropriate to their needs and preferences<br>Carers of people with dementia will be offered evidenced-based therapy's and multicomponent interventions suited to the differing circumstances of dementia carers and assessed as helpful, such as Strategies for Relatives (START).<br><br>Carers and people with dementia will be able to access appropriate multi-disciplinary support at times of crisis through a clear, single point of contact | **Measure**<br>- Percentage of Patients who have had their care reviewed in last 12 months (dementia)<br>**Source**<br>*HSCIC (Quality & Outcomes Framework), Annual (http://www.hscic.gov.uk/catalogue/PUB18887)* |
| DYING WELL | All people with a diagnosis of dementia will have a preferred place of death recorded in their care record | **Measure**<br>- Preferred place of death recorded in care record<br>**Source**<br>*HSCIC (Primary Care Mortality Dataset)* |

**Each of the standards will be measured using one or more indicators and a measurement strategy developed.*