Dementia United

GM DRAFT STANDARDS – PRODUCT 1

Dementia United seeks to improve the lived experience for people living with dementia and their carers, making GM the best place to live.

This set of standards is intended as a tool for making progress on Dementia United pledges and offer GM an opportunity to collectively, as well as locally, make improvements for people with dementia and their carers. Itis not a comprehensive list of everything that is happening to deliver or improve dementia care.

To date, there is no established holistic measure of the lived experience, which asks people what it is like for them to live with dementia. GM has a unique opportunity to develop a measure which will monitor the lived experience and use the findings to co-produce and redesign the system in a way which is meaningful and required. Dementia United aims to develop a Lived experience Barometer, which will be developed, tested and piloted within the Financial Year 2017-2018.

Whilst some of the GM Standards will require an agreed measure, within year one (Financial Year 2017-2018) we suggest the use of 5 measures, one from each domain of the Living well pathway, which could constitute a dashboard to monitor progress.

The proposed standards will be regularly monitored and reviewed, initially every twelve (12) months. The purpose of this is to ensure that the Standards are reflective of current practice and include the most up to date national guidance.

Further information about the rationale, consultation process and evidence base of the GM Draft Standards please see below;

Living Well Pathway Domain	**Standard***	**Potential Year 1 Measure**
PREVENTING WELL	1. 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* • Health Checks Offered • Health Checks Uptake *Source* Public Health England, Quarterly (http://fingertips.phe.org.uk/profile/nhs-health-check-detailed/data)
DIAGNOSING WELL	2. Each locality will achieve dementia diagnosis rates comparable with the top 20% nationally 3. People receiving an initial assessment and diagnosis will feel this is timely 4. People will receive a comprehensive assessment of mental and physical health issues as part of the diagnostic process and at regular intervals subsequently 5. People will be offered medication in line with	*Measure* Dementia Diagnosis *Source* NHS England, Monthly (https://www.england.nhs.uk/mentalhealth/dementia/monthly-workbook/)

	NICE guidelines	
LIVING WELL	6. People living with a diagnosis of dementia and their carers will be surveyed on one day per month to determine their 'lived experience' 7. 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. 8. 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* Dementia Living Experience Barometer *Source* To be developed within Financial Year 2017-2018
SUPPORTING WELL	9. People with dementia will receive information and signposting to peer support group(s) and networks that are appropriate to their needs and preferences 10. 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 11. 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. 12. Carers of people with dementia will be offered signposting and information to peer support groups that are appropriate to their needs and preferences 13. 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)*. 14. 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* Percentage of Patients who have had their care reviewed in last 12 months (dementia) *Source* HSCIC (Quality & Outcomes Framework), Annual (http://www.hscic.gov.uk/catalogue/PUB18887)

DYING WELL	15. All people with a diagnosis of dementia will have a preferred place of death recorded in their care record	*Measure* Preferred place of death recorded in care record *Source* HSCIC (Primary Care Mortality Dataset)

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

IMPLEMENTATION

IMPROVING WELL	1. All localities will publish a local dementia improvement plan and co-design this with people with dementia and carers 2. Improvement updates will be included in hospital quality accounts and locality updates to the Health and Social Care partnership by Financial Year 2017-2018 3. All localities will track an agreed dashboard of measures and commit to working on reducing variation in outcomes in particular hospital admission, re-admission and length of stay 4. Increase the proportion of people living with dementia's involvement in research trials
DELIVERING WELL	5. All hospitals will commit to improving the experience of people living with dementia and their carers during a hospital stay e.g. becoming dementia friendly environments by Financial Year 2017-2018 6. All hospitals will adopt John's Campaign and allow open visiting for people living with dementia and their carers during periods of acute hospitalisation by Financial Year 2017-2018

These standards do not attempt to duplicate the much more detailed best-practice guidance and ambitions that are available elsewhere including:

- Nationally: NICE guidance, the National Dementia Strategy, recommendations from the
  National Audit of Dementia Care, the CQUIN measures, RCPsych advice, the PMs Challenge on Dementia
- Locally: the GM mental health strategy, local commissioning arrangements which include performance standards for mental health and acute trusts on dementia, the community based care standards.

INTERDEPENDENCIES

- Plans for delivering effective support and services will require local development and should pay particular attention to the interface between mental and physical health, older people and frailty services.
- Dementia United Standards will be included in the locality plans of each CCG / Locality. To this end a named executive lead from each locality will be required to

lead the work. This individual will act as the accountable officer for the locality reporting into the Dementia United Board.

- For localities that chose to implement or already have in place a case management or post diagnostic support system for people with dementia we would expect implementing these standards to be a core aim for that service.
- Each Locality will supplement their local plan with an assistive technology plan which will highlight how technology is currently being used for people living with dementia and carers, and the local plans for expanding digital services using the foci of: monitor my health, enrich my world and connect me.

RATIONALE, CONSULTATION PROCESS AND EVIDENCE BASE

We briefly summarise below the rationale behind some of the standards listed below;

1. Each locality will achieve uptake of NHS health checks comparable with the top 20% nationally and dementia screening will be documented in these checks

Accurate and timely diagnosis is a key driver of other performance standards, with extensive work already going on around Greater Manchester to achieve this.

3. People receiving an initial assessment and outcome feel this was timely and appropriate

Initially this standard set a specific target for the waiting time for initial assessment and then again for the time to receive diagnosis. Feedback from the expert group of people with dementia and carers felt that this was arbitrary and that it would be better to measure whether people were satisfied with the service. Many localities already set maximum time targets in addition and this will clearly continue.

4. Receive screening for mental and physical health issues

NICE guidance recommends that, at the time of diagnosis, medical co-morbidities and key psychiatric features associated with Dementia should be assessed to ensure optimal management of the co-existing conditions.

A recent literature review[1] found that the prevalence of co-morbidities for people with Dementia is significant (up to 29% for cerebrovascular disease, up to 39% for diabetes). There is some evidence that people with Dementia do not have the same access to treatment and monitoring for these conditions.

Consideration could be given to emerging initiatives such as personalised treatments based on people's genetic code and predisposition as is already being done for people with Diabetes.

[1] *Comorbidity and dementia: a scoping review of the literature*, F. Bunn, 2014

5. Be offered medication in line with NICE guidelines

NICE guidance supports the prescription of acetylcholinesterase inhibitors for managing mild to moderate Alzheimer's disease. There are also clear recommendations around the use of anti-psychotics. There is evidence nationally that prescribing guidelines are not being fully implemented. It is likely to the case that this is true in Greater Manchester as well but we are not aware of any data.

A recent literature review[2] found that the prevalence of co-morbidities for people with Dementia is significant (up to 29% for cerebrovascular disease, up to 39% for diabetes). There is some evidence that people with Dementia do not have the same access to treatment and monitoring for these conditions.

7. People with dementia should have the same access to community health and care services as others including but not limited to vaccinations, screening rates and help with housing

This was included on the advice of the Task and Finish group, as both an important matter of principle that people with dementia should treated equally but also as means of avoiding duplication of existing community care standards.

Potential opportunity here to be innovative in GM is to make a common sense reasonable adjustment in the way we communicate e.g. find a better way to remind people of appointments so that they don't DNA; so rather than contacting people by letter/telephone which may be forgotten/not be able to be read or understood try using a unique approach to this via telecare perhaps or working with relatives to alert them.

8. 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

NICE guidance refers to assistive technology, adaptive aid (including low-level technology) and telecare for people with Dementia without specifying particular interventions.
There is some evidence in the literature that telecare and assistive technology can signal potential health changes or dangers such as falls supporting people to stay in the community longer, thereby delaying moves to higher dependency care. A recent telecare programme evaluation in Scotland found that for the 325 people with Dementia who received the telecare package, an estimated 114 hospital admissions and 88 care homes placements were avoided.

9. Receive information and signposting to peer support group(s) that are appropriate to their needs and preferences

This was included at the request of the expert group of people with dementia and carers. The benefits of peer support groups are also highlighted by a number of key third sector partners and professional groups/networks.

[2] *Comorbidity and dementia: a scoping review of the literature*, F. Bunn, 2014

11. Be offered a structured group cognitive stimulation programme provided by a range of health and social care workers with training and supervision and delivered irrespective of any anti-dementia drug received

Cognitive Stimulation Therapy (CST), by example, is a form of behavioural therapy provided in structured group sessions aimed at stimulating cognitive function. It is recommended for people with mild to moderate Dementia of all types by NICE.

12. All carers should be offered signposting and information to peer support groups that are appropriate to their needs and preferences

This was included at the request of the expert group of people with dementia and carers. The benefits of peer support groups are also highlighted by the Alzheimer's Society and others.

13. All carers should be offered evidenced based and multicomponent interventions suited to the differing circumstances of dementia carers and assessed as helpful, such as Strategies for Relatives

Strategies for Relatives (START) is a manual based coping intervention comprising eight sessions and delivered by supervised psychology graduates to carers for people with Dementia. The programme consists of psychoeducation about Dementia, addresses carers' stress levels, and information on where to get emotional support (which prioritise relaxation techniques, education about dementia, strategies to help manage the behavior of a person with dementia, contact with therapists and changing unhelpful thoughts). It has been evaluated in an RCT as being effective and was also identified as being cost effective in a recent LSE review.