Mild Cognitive Impairment in Bury

A Review

NHS
Bury
Clinical Commissioning Group

Bury
age UK

PJG
Pat
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consultancy & mentoring

ARCC

Contents

About the Authors:

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Executive Summary

1.1 As we get older most of us notice some form of decline in our mental abilities, some of these 'cognitive' skills tend to decline faster than others, such as our memory and attention. Where difficulties are greater than would normally be expected for a healthy person of their age this is defined as Mild Cognitive Impairment (MCI). MCI is not a form of dementia but can, in some cases, lead to dementia. This is particularly pertinent as the stigma associate with dementia and the conflation of the two conditions has led to increased anxiety associated with MCI.

1.2 This report has been compiled utilising academis research, a review of best practice in the field of MCI and extensive engagement, including the views of 17 individuals with a diagnosis of MCI, 14 carers, 11 members of the public and representatives of 16 stakeholder organisations.

1.3 Public and professional awareness of the condition remains relatively low. During the research we raised a query within the national Association of Directors Adult Social Services (ADASS) network around what other local authorities were doing in the field of MCI and there is very little, if any, activity that we could be signposted towards. However, as the British Geriatric Society and Royal College of Psychiatrists articulate in their position statement on loneliness and isolation[i], the early identification of cognitive impairment (amongst other conditions) provides an opportunity to provide interventions and support which left undiagnosed can lead to the progression of frailty. The issue of public awareness was raised repeatedly throughout the engagement, as one respondent to the public consultation stated that "*guidance on how to broach this difficult issue to someone who may be suffering unknowingly*" would be beneficial.

1.4 Data provided by Bury CCG in March 2020 identifies 571 patients with a diagnosis of MCI (1.57% of the 65+ population), research estimates of prevalence vary greatly dependent upon age; however, a conservative estimate of 6.7% prevalence would result in an additional 1823 patients who have the condition (2178 in total).

1.5 Individuals with the condition and their carers who were interviewed broadly expressed a sense of relief in knowing what the problem was and also that this was not a diagnosis of dementia. A future service offering need to be cogniscant of these fears and avoid labels such as dementia.

1.6 A significant proportion of those interviewed stated that they were not offered any support at the point of diagnosis and this was not required due to personal circumstances. The support needs of individuals varied depending upon their support network and interests; however, where to go for information was identified as a recurring issue and interviewees felt it would be beneficial to know that there was somebody that you could talk to and a source of information on how to live with the condition, this was particularly pertinent for carers. The act of being interviewed for the research was the first time that most couples had actively sat down to talk about the condition, as one interviewee stated: "*you just get a diagnosis and you are left on your own so you feel quite alone*".

1.7 It was evident from discussions with both patients and their carers that the condition places considerable strain on relationships. Memory loss can cause tension and anxiety in individuals and couples alike, because the person was self-caring no emotional support was offered to the partner of the individual with MCI on how to deal with the changes; this is something that needs to be reviewed and integrated into any future service offering. Several couples appeared to be struggling and needed mediation/counselling and training on how to live with the condition (anxiety, depression and conflict). This would give the tools to manage the condition daily and also the confidence to access the range of community assets.

1.8 Friendship or support groups were of interest in some cases, especially where there was visible strain on the relationship with the partner; this support would be equally for both parties. Interestingly, none of the carers interviewed had been offered support in their role or provided with a carers assessment, indeed , they were unaware of what financial support and benefits they may be entitled to.

1.9 A review of Bury's online services directory revealed very little provision that directly targets the MCI group with only one entry (the Rainbow Café) identifying as a social opportunity for people with memory problems. However, discussions with the VCFA's new social prescribing service identified that Bury has in excess of 500 community groups and activities. Whilst there is not necessarily a MCI label attached to these community assets, extending beyond the label of MCI to the persons interests and aspirations (rather than their condition) was a key theme which emerged from the engagement. Support, especially social, does not have to be MCI specific.

1.10 Stakeholder interviews conducted raised the need to increase awareness of the condition across organisations in order to lever in their expertise and increase the reach and breadth of support offered. This was particularly pertinent in the BAME community, where language and the stigma associated with mental health conditions act as barriers. Greater awareness in the community, possibly community engagement events or training (train-the-trainer) sessions on memory would help to raise the profile of MCI.

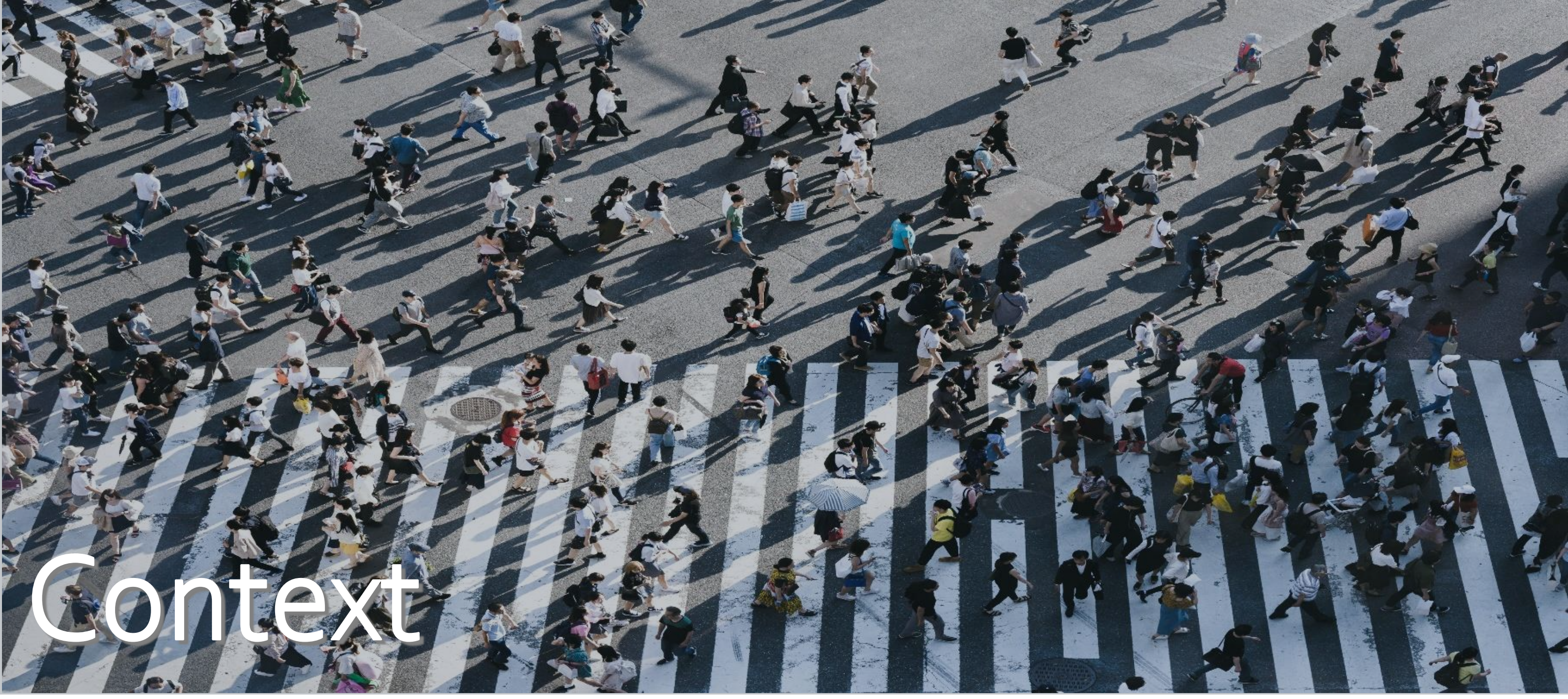
1.11 Due to the current pandemic, engagement with GP's was limited although there was recognition that the impact of social isolation on mental health and subsequently MCI will be significant. Discussions with the GP identified that the introduction of the new clinical pathway has been beneficial in providing structure and also information on support services and signposting. However, there was a concern that raising the profile of MCI could lead to people mis-diagnosing 'forgetfulness' which effects everyone from time-to-time as MCI.

1.12 A 'one size fits all' approach will not help individuals, neither will the assumption that dementia services are appropriate for everyone with MCI. 'Older people' are not a homogenous group and social prescribing will need to offer opportunities for people with MCI that takes account of the age variances, together with minority groups in order to provide meaningful activities. Indeed, the age ranges of patients on the MCI register varied greatly, the eldest being 101 years of age, whilst 3 practices reported patients in their 30's, the youngest being 31 years old.

1.13 Taking into account the feedback on support and also the stigma, coupled with the age and cultural profile of patients and the risk of excluding minority groups, the model proposed in this report is split into 2 phases; these are:

1.14.1 Phase 1: consolidation and enhancement of existing services. Any future service model needs to address the issue of information advice and guidance, strengthening the existing pathway and utilisation of the existing community assets.

1.14.2 Phase 2: redesign current 'dementia' service offer in order to address the gaps in provision which were bespoke to MCI or required significant investment in their own right, this included access to education courses or modules on how to live with the condition and also counselling support for individuals and their partners/carers. The gaps in provision for MCI which appear to offer the greatest impact to people's lives, based on the engagement in this review, could only feasibly be met through the reconfiguration and alignment of existing service offerings.



Context

Mild Cognitive Impairment (MCI)

2.1 From time to time we all struggle with some of our cognitive skills such as our memory, concentration or attention. This can particularly happen when we are very tired or stressed, but it usually becomes more noticeable as we get to retirement age and older. For example, if a person becomes lost in a familiar place or forgets the names of their close family members, it may be a sign that they have 'cognitive impairment' (their ability to 'think'; our brain's ability to process, store and recall information process information, see figure 1). Where difficulties are greater than would normally be expected for a healthy person of their age this is defined as MCI. People with MCI, on the whole, should be able to lead healthy and active lives as MCI is not a type of dementia; however, a person with MCI may go on to develop dementia.

2.2 Generally, there are 2 types of MCI, one that is a pre-dementia condition, the brain has already changed and generally is not treatable and so will lead to dementia (this is referred to as amnestic mild cognitive impairment or aMCI). Whereas, naMCI (all other forms) has a treatable underlying cause, such as depression, stress, vitamin deficiencies, infection and once the underlying cause is treated their symptoms of MCI will stop.

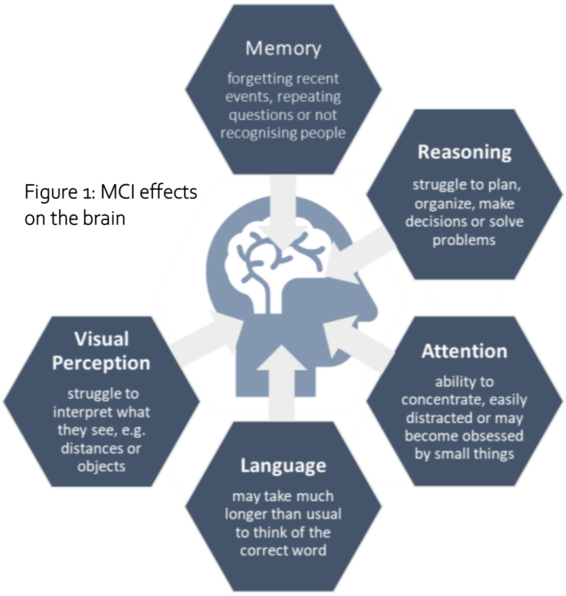


Figure 1: MCI effects on the brain

Causes of MCI

2.3 MCI can have a number of possible causes and can be an early sign that a person has an underlying health problem that may be causing MCI, which can include: depression, anxiety or stress; a physical illness such as an infection or the side effects of medication, to name but a few.

2.4 Unfortunately it isn't always possible to say what is causing MCI, even after a person has had an assessment. It may be necessary to wait several months to see how their symptoms develop. If the cause is treatable and treatment is administered, the person's symptoms may improve over time. For example, if a person has MCI caused by anxiety or depression, it may help if they have treatment such as talking therapies and medication, such as anti-depression drugs[ii]. However for some people, MCI may be the first sign that they have a more serious condition that is affecting their brain and is progressive, this means the person's symptoms will get worse and over time they may eventually develop dementia.

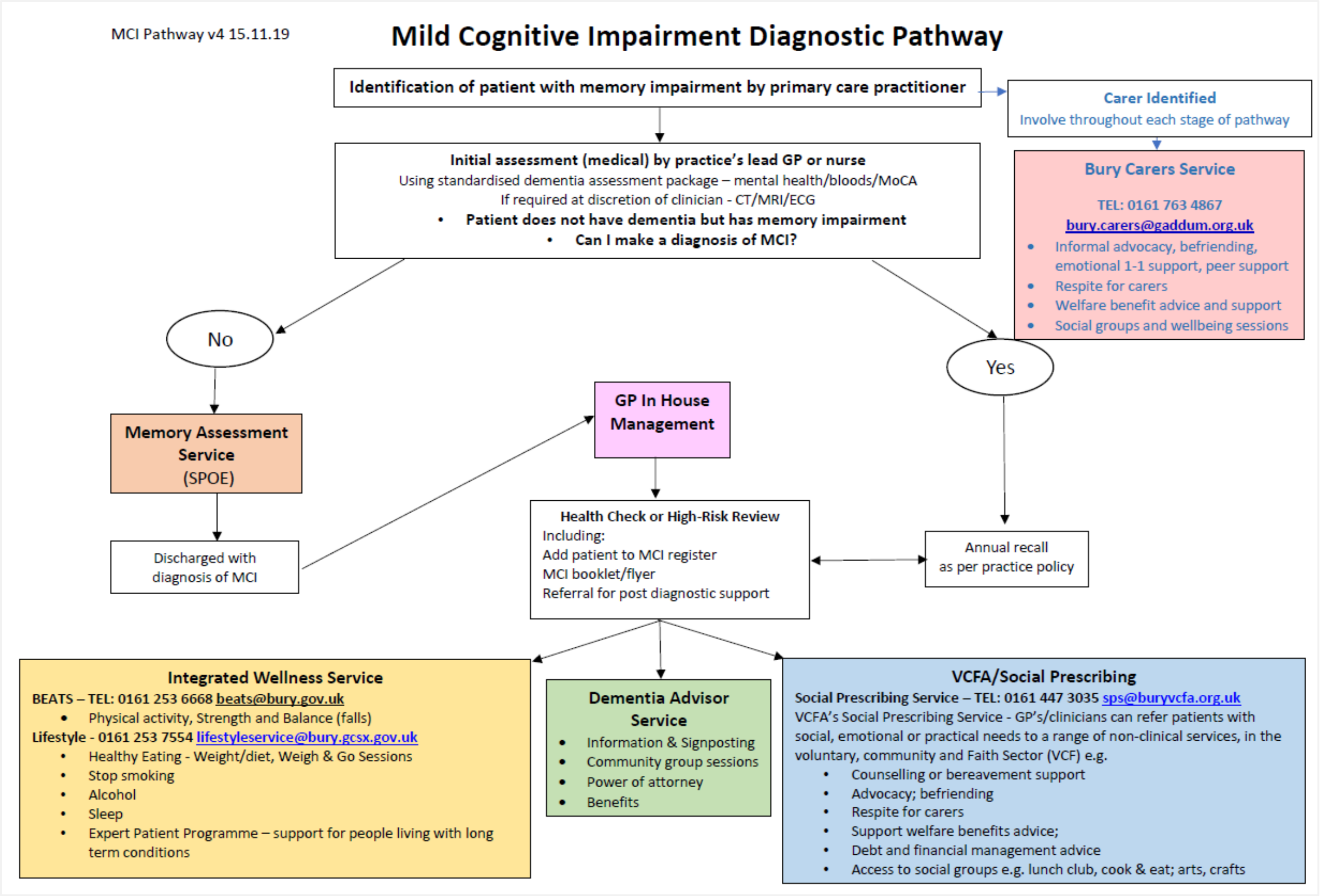
2.5 Age is the biggest risk factor for developing MCI. While some people may develop it during their 50s and 60s, most people with MCI are in their 70s or older, see prevalence section below. A person's health and lifestyle over the course of their lifetime may affect their chances of developing MCI; there is a close link between people having certain medical conditions in mid-life and developing MCI later on. For example, hypertension or high blood pressure has consistently been found to be the most associated health risk factor for MCI[iii] and presence of cardiovascular risk factors is associated with increased likelihood of progression to dementia. Having high cholesterol, diabetes, being overweight in mid-life and having a history of depression may also increase a person's risk. There is evidence that physical injuries or blows to the head (known as 'traumatic brain injuries') may also increase the risk, even if the injuries happened many years ago.

2.6 A person with MCI can keep their risk of dementia as low as possible by managing health conditions well. Therefore, it's important to make sure these kinds of health problems are recognised and managed well. People with MCI should keep their mind as active as possible because this may help to stop them developing dementia. Preliminary evidence has suggested that physical activity[iv] and other leisure activities (e.g., religious services, club membership, gardening, or painting)[v] are positively associated with the preservation of cognitive function. Therefore, it is important that the person should try doing challenging yet enjoyable activities every day and where possible people with MCI should keep doing their hobbies and interests. They should also stay socially active, for example seeing friends and family. While these may not seem like 'thinking' activities, socialising is a great workout for the brain.

Diagnosis

2.7 In November 2019 Bury CCG introduced a standardised clinical pathway (figure 2) for the identification and diagnosis of MCI. Following identification of a patient with memory impairment an initial assessment within the practice will be conducted. The GP or nurse will ask about a person's symptoms including when they started and how they are affecting their daily life. They will also test the person's mental abilities and through the MoCA (Montreal Cognitive Assessment) which is a series of 30 questions, requiring the individual to score 26 or above. If required the standardised dementia screening of bloods, CT/MRI and ECG may be required. At this stage the GP may be able to make a diagnosis of MCI, if this the individual is diagnosed they will be subject to an annual review (following practice policy), a health check and signposted to services (see figure 3). In some cases, the GP may refer the person for a specialist assessment – at the local memory service. The doctor will use clinical guidelines, any test results and their own judgement to make the diagnosis. If the doctor decides that a person has MCI, they will usually refer them back to their GP. What happens post diagnosis varied locally based on the patients we engaged, with only a small number recalling regular (6 or 12 month) reviews of their condition.

2.8 As with dementia, the National Institute for Health and Care Excellence (NICE) recommends that early assessment should take place in order to enable planning for the future[vi]. The main benefit of a person knowing they have MCI is that it can give them a chance to reduce the risk of their condition becoming worse through introducing positive changes to improve their health and wellbeing, the person can also be offered information, advice and support.



MCI Pathway v4 15.11.19

Mild Cognitive Impairment Diagnostic Pathway

Identification of patient with memory impairment by primary care practitioner

Carer Identified
Involve throughout each stage of pathway

Bury Carers Service
TEL: 0161 763 4867
bury.carers@gaddum.org.uk
- Informal advocacy, befriending, emotional 1-1 support, peer support
- Respite for carers
- Welfare benefit advice and support
- Social groups and wellbeing sessions

Initial assessment (medical) by practice's lead GP or nurse
Using standardised dementia assessment package – mental health/bloods/MoCA
If required at discretion of clinician - CT/MRI/ECG
- **Patient does not have dementia but has memory impairment**
- **Can I make a diagnosis of MCI?**

No

Memory Assessment Service
(SPOE)

Discharged with diagnosis of MCI

Yes

GP In House Management

Health Check or High-Risk Review
Including:
Add patient to MCI register
MCI booklet/flyer
Referral for post diagnostic support

Annual recall
as per practice policy

Integrated Wellness Service
BEATS – TEL: 0161 253 6668 beats@bury.gov.uk
- Physical activity, Strength and Balance (falls)

Lifestyle - 0161 253 7554 lifestyleservice@bury.gcsx.gov.uk
- Healthy Eating - Weight/diet, Weigh & Go Sessions
- Stop smoking
- Alcohol
- Sleep
- Expert Patient Programme – support for people living with long term conditions

Dementia Advisor Service
- Information & Signposting
- Community group sessions
- Power of attorney
- Benefits

VCFA/Social Prescribing
Social Prescribing Service – TEL: 0161 447 3035 sps@buryvcfa.org.uk
VCFA's Social Prescribing Service - GP's/clinicians can refer patients with social, emotional or practical needs to a range of non-clinical services, in the voluntary, community and Faith Sector (VCF) e.g.
- Counselling or bereavement support
- Advocacy; befriending
- Respite for carers
- Support welfare benefits advice;
- Debt and financial management advice
- Access to social groups e.g. lunch club, cook & eat; arts, crafts

Figure 2: Bury CCG MCI clinical pathway

Bury COUNCIL

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NHS Bury Clinical Commissioning Group

Memory Loss Support Services

Have you recently been diagnosed with a memory loss condition? Wondering what happens next or where to go for advice, help, practical and emotional support? There is a range of support available locally.

BURY LIVE WELL SERVICE

Lifestyle Health Trainers
For details contact
0161 253 7554
- ✓ Healthy Eating - weight/diet and Weigh & Go Sessions
- ✓ Stop smoking
- ✓ Alcohol
- ✓ Sleep
- ✓ Expert Patient Programme – support for people living with long term conditions

BEATS exercise referral scheme
For people with long term health conditions
For details contact
0161 253 6668
Contact your GP and healthcare professional for a referral
- ✓ Physical activity, strength and balance

SOCIAL PRESCRIBING SCHEME

For details contact 0161 447 3035
- ✓ Counselling and bereavement support
- ✓ Advocacy; befriending
- ✓ Respite for carers
- ✓ Support welfare; benefits advice
- ✓ Debt and financial management advice
- ✓ Access to social groups; lunch club, cook and eat, arts and crafts

DEMENTIA ADVISOR SERVICE

Contact your GP for a referral
- ✓ Information and Signposting
- ✓ Community group sessions
- ✓ Power of attorney advice
- ✓ Benefits advice

Greater Manchester Health and Social Care Partnership

Information for patients diagnosed with

MILD COGNITIVE IMPAIRMENT (MCI) in Greater Manchester

Taking care of our health.

GMCA
NHS in Greater Manchester
Dementia United
NHS Greater Manchester and Eastern Cheshire

Figure 3: Bury CCG MCI information leaflet

Prevalence

2.9 MCI is a heterogeneous concept, therefore making it difficult to obtain accurate prevalence figures, as not everyone with decline of memory will present with symptoms. The Alzheimer's Society estimate between 5–20% of people aged over 65 have MCI. However, this estimate should be treated with caution as a meta-analysis of research conducted in the field identified prevalence and incidence rates differ greatly with age, type of MCI, severity of impairment. Research estimates of MCI incidence per 1000 person-years were 22.5 for ages 75–79y, 40.9 for ages 80–84y, and 60.1 for ages 85+y[vii]. Conversely, MCI prevalence was 6.7% for ages 60–64, 8.4% for 65–69, 10.1% for 70–74, 14.8% for 75–79, and 25.2% for 80–84[viii]. Cumulative dementia incidence was 14.9% in individuals with MCI older than age 65 years followed for 2 years. One review found the prevalence of MCI in adults aged 65 years and older to be 10-20%, risk increasing with age and with men appearing to be at higher risk than women.[ix]

2.11 Currently, there is no clear tool to assess which people with MCI will go on to develop dementia (current research suggests about 5 – 15% of MCI patients will develop dementia every year), most research focus on Alzheimer's; however, very little research has been undertaken on other forms of dementia. A random-effects meta-analysis demonstrated that the cumulative incidence for the development of dementia in individuals with MCI older than age 65 followed for 2 years was 14.9%[x].

2.12 Data provided by Bury CCG in March 2020 identifies **571 patients with a diagnosis of MCI** (1.57% of the 65+ population) this is a significant increase from the data provided in June 2019 (355 patients; 0.98% of 65+ population and may reflect the new clinical pathway. If we use the lower range estimate of prevalence (6.7% for 60-64 years of age), this could potentially give an **additional 1823 patients** who have the condition (2178 in total). Conversely, the higher range estimate of 20% proposed by the Alzheimer's Society would represent an additional 6904 patients (7259 in total). In reality the number of people with the condition is likely to be somewhere between the two estimates.

2.13 A breakdown of the patient numbers by the five townships (figure 4 and appendix 1 provides a detailed breakdown by practice) reveals Radcliffe (2.15%) and Bury East (1.77%) identified the largest proportion of patients based on population size, of which Radcliffe Medical Centre (3.53%), Walmersely Road (3.43%) and Townside (3.32%) had the largest rates of diagnosis across the 26 practices. At the other end of the spectrum, Huntley Mount had no patients on the MCI register and 6 identified less than 1%. This is important as there are clearly outliers where lessons can be learned.

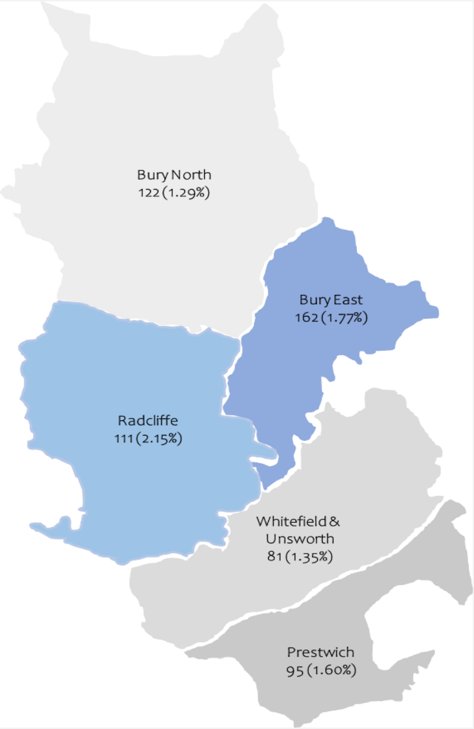

Figure 4: geographic distribution of MCI patients

2.14 In order to shape future services it is important to understand the profile of these patients. Data on gender was not available; however, from the sample interviews together with the academic research, it would appear to be **more prevalent in males**. Analysis of ethnic profile was limited as 35% of patient's ethnicities were unknown, what we were able to ascertain from the 65% was that they **predominately identify as White or Mixed British**. Only 5% were recorded as having an ethnicity of 'other and this was mainly Asian, Indian, Caribbean and 'other' while background. This is broadly in line with the 5.8% estimate of people born outside the United Kingdom (2011 census). The **average age across all practices was 77 years old**, with the minimum and maximum ages revealing a large discrepancy in the profile of patients. The **eldest was 101 years of age**, whilst 3 practices reported patients in their 30's, the **youngest being 31 years old**. Clearly, there is not a homogenous profile of patients and any future model needs to be flexible to both age and ethnicity or run the risk of excluding minority groups.

Review of Support Offers

Current service offers in Bury

3.1 A review of Bury’s online services directory[xi] revealed very little provision that directly targets the MCI group, of note was one group, the Rainbow Café which offerers support for families living with memory problems and is based in BL9 area, although this does not directly signify MCI as the target audience. There is also various generic carer support groups, such as coffee mornings at the carers centre.

3.2 What people use sevices for can differ so we widened the search to consider: (1) ‘dementia services’ that do or could support people with a diagnosis of MCI and their carers; (2) groups/services that provide face to face support to Bury residents that can indiectly support people with MCI (linked to themes emerging from our engagment); and (3) national support and information services. The services below have been aligned to 4 support service types in appendix 2: support service gap analysis. It is important to note that whilst these services could be used by people with a diagnosis of MCI there remains a gap in the specific knowledge and experience of the condition.

3.3 A review of the Bury Support Directory revealed the below **dementia services that do or could support people with a diagnosis of MCI and their carers**. It is important to note that utilising dementia services is not free from its challenges, as alluded to in the engagement with patieints and carers.

- **Beautiful Memories** is a mobile support service for people with or effected by dementia offering a range of venues and activities based on what the people want.

- **Peace of Mind DEEP group** is held at St Peter's Church St Peter's Rd Bury on the second Thursday of every month 1:30-3pm. This group is for people living with dementia share their experiences of what it may be like to live with dementia in the community.

- Alzheimer's Society **Dementia Adviser service** provides information to people with dementia and their families to help make the right decisions. Dementia Advisors provide Information, advice and signposting to people with dementia and their carers. This is provided at the point of diagnosis and throughout the dementia journey. People accessing this service must have a diagnosis of dementia received either through their GP or via the Memory Assessment Service. The Alzheimer’s Society also run **Singing for the Brain** sessions in several locations across the borough.

- Dignifying Dementia run a series of social activities throughout the borough, these include: **carers night out**, **merrie melodies** and **social group meetings** at various community settings (pubs and shops). Sessions are primarily aimed at people with dementia, but open to people with MCI, although we understand that uptake has been low due to the challenges associated with conflating the two conditions. The sessions incorporate use mental arithmetic and reading out loud of poems in order to provide cognitive stimulation and are based on the research of Dr Kawashima and his 'Japanese Memory groups'.

- **Storybox Creative Café** held at Bury Art Museum for people with dementia and their carers.

- **Purple Café** at the Fed which is for carers from Jewish community.

3.4 The following **groups/services that provide face to face support to Bury residents that can indiectly support people with MCI** were identified.

- **Age UK Bury** offers the Jubilee Centre, an active ageing centre that provides 30 social and recreational activities per week; four Friends Together support groups aimed at people who need extra support to access social activity, and a free Information & Advice service, that supports people to claim for pension age welfare benefit; and a new befriending service.

- Bury Council's **Living Well Service** offer a broad range of support services to help keep people well, in the best possible health, physically, mentally, socially and emotionally. The service offers support to: get active, eat wll, cope with long term conditions, manage stress/anxiety, improve health and wellbeing. Alongside the service is **BEATS**, a free physical wellbeing scheme for people with long term conditions. The service can help with anything health related and all their activities are dementia friendly. The **Expert Patient Programme** provides support to help an individual live with a long term condition through a structured self management programme. Facilitation is delivered by people with experience of living with conditions. Relevant content includes: managing low mood, stress, anxiety and depression; relaxation techniques and better sleep; healthy eating, weight management and physical activity; decision making, problem solving and planning and how to communicate more effectively with family, friends and healthcare teams.

- **Incredible Edible Brandlesholme** is a group of people who love gardening and growing fresh fruit and vegetables for the community, providing participants with recreation and exercise in the garden and the surrounding environment.

- The **Creative Living Centre** provides a wide range of courses, activities and 1:1 support (including counselling) to help people better understand and manage their mental wellbeing. Supporting people with issues such as low mood, anxiety and stress, as well as diagnosed conditions such as depression, schizophrenia and OCD, and people can self-refer. Support includes access to a range of courses, creative activities (singing, art, crafts), group and 1:1 therapies (art therapy, music therapy, counselling, massage, reiki, acupuncture), exercise and relaxation (yoga; mindfulness; meditation) and social activities.

- **Forever Friends** is a community cafe set up to tackle loneliness and social isolation amongst older people.

- **BIG Anxiety & Depression Group** is a support group for people who are feeling anxious or depressed. The group is a safe space for people to come together to share their experiences and listen and learn from others in a non judgemental environment.

- CAST (**Community Advice and Support Team**) at The Fed provides a carer's advice worker offering support to individuals who are responsible for looking after a loved one. They assess what can be done to help people cope with their caring situation and advice on a variety of topics, such as claiming benefits, setting up respite care or accessing practical support. Our carers' groups provide opportunities for carers to meet people in similar circumstances for mutual, peer-led support.

- **Rethink Mental Illness** is a national charity that run services and support groups in relation to mental illness. Rethink's website provides access to further information including the contact details of services or groups in the area. Practical advice and information on issues that affect the lives of people living with mental illness is available through the charity's National Advice Service.

- At **Nurture Counselling & Therapies** offers face to face, individual counselling.

- The **Healthy Minds service** is for people over the age of 16 years, who are registered with a GP in Bury. The service offers support and treatment for those who are experiencing symptoms such as difficulty sleeping, low mood, stress, worry or anxiety, feelings of hopelessness or panic attacks. It can also help those dealing with the effects of a long-term health problem or chronic pain, Post Natal Depression, Obsessive Compulsive Disorder, phobias, or eating difficulties. The service is delivered by a range of professionals including therapists and counsellors, who will find a level of treatment for the individual, this could be a group workshop, an online or telephone based course of self-help treatment, or an individual therapy session.

- The **Jinnah Centre** has a wide range of activities which aim at improving the health and wellbeing of older people. These activities include: yoga; exercise sessions; arts and crafts; Healthy Mind sessions; a Dementia Café; coffee mornings, regular workshops on mental health, cancer and diabetes. Through these activities the Jinnah Centre aims to relieve social isolation and loneliness.

3.5 The following **national support and information services** which offer remote support (via telephone and the internet) were identified.

- **National Age UK** offers a 7 day a week (8AM to 7PM) telephone/online information and advice service, covering money, wellbeing, health and lifestyle. The charity also operate a 'Call in Time' telephone befriending service where a volunteer befriender will phone an older person at an agreed time for a chat.

- **Independent Age** offer confidential advice over the telephone for older people, their families and carers on issues such as getting help at home, adaptations, care assessments, paying for care, staying in touch with other people and welfare benefits. The service operates weekdays and Saturdays.

- **Silverline** is a free confidential helpline providing information, friendship and advice to older people, open 24 hours a day, every day of the year.

- **Samaritans** offer a 24 hour 'listening' service for anyone who has concerns, worries or stresses such as: relationship and family problems, bereavement, financial worries, job-related stress, loneliness, depression and thoughts of suicide

- **Mind** is a mental health charity which provide advice and support to empower anyone experiencing a mental health problem, alongside a range of online resources Mind offers two confidential mental health information services, the Mind Infoline and the Legal Line, the latter offering guidance on mental capacity and legislation. Both helplines are open weekday office hours.

Other areas of best practice

3.6 Greater Manchester Mental Health NHS Foundation Trust (GMMH). GMMH's Memory Skills Group is for people who experience memory problems. The five week course aims to teach people strategies to help them cope with their memory problems. People may attend with a friend or relative to support them and help put the strategies into practice. The following topics are covered: what is memory; external aids to help memory; internal strategies to help memory; memory and mood; goal setting and thinking about the future. The group involves a mixture of learning and practising new strategies to help memory, as well as sharing ideas with others. The group is run by Psychology and Occupational Therapy professionals who work in Memory Services in Manchester and referral is through the individuals health practitioner, for example their GP.

3.7 Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust. Alongside offering a comprehensive assessment and diagnosis service, CNTW's Memory Protection Service provides support and advice to people and their families about coping with a memory difficulty, access to information given as a Personal Information Pack and a range of non-pharmacological interventions such as support groups. More information on the programme and impact can be found by clicking here

Neighbouring Age UK Services

3.8 Wirral Age UK, under their 'Stepping Stones' programme, partly funded by the local CCG offer **Maintenance Cognitive Stimulation Therapy (MCST)** groups and **Reminder Finders sessions**, which are a 12 week programme for up to 12 participants who have memory problems (MCI and mild/moderate dementia), and is predominately accessed by 65 to 80 year old's. Working alongside Admiral Nurses, the team provide activities which include: discussions, word games, quizzes, physical activities and creative and musical activities, assisting participants to maintain skills and memory for longer and improve general wellbeing and happiness, as well as the opportunity to interact socially, have fun and make new friends. The service utilizes the MoCA to test baseline and review score to assess impact; more information on the programme and impact can be found by clicking here. Alongside MCST and Reminder Finder Sessions, Age UK Wirral also offer a range of **carer support services** (emotional support, information and advice resources and legal surgeries) in recognition of the active role carers play in supporting people with memory loss conditions. The service also offers access to counselling which people can be referred to internally and a befriender scheme which has 100+ befriender volunteers.

3.9 At the time of compiling this report and undertaking stakeholder engagement, Age UK Trafford were unavailable to be interviewed due to the pandemic; however, the service they operate locally had been identified as local area of good practice in the field of MCI. The local **Memory Loss Advice Service** has two dementia advisers and an MCI Community Connector to support people with dementia and MCI and their family carers. In recognition of the diversity of the people effected by dementia and MCI the service has developed different avenues for people to access support, including drop-in services, a helpline, newsletter, twitter and memory awareness events. Examples of support provided include helping people complete attendance allowance forms, advising what to say to a GP when addressing symptom concerns, referral to and liaison with social services and care providers to enable access to care, advice and support around lasting power or attorney and advance care planning, equipment and community transport to improve quality of life, information events, social gatherings and emotional support. There is a dedicated programme of support for people diagnosed with Mild Cognitive Impairment (MCI) including a weekly support group called "Blossom Out", the service has also helpfully produced two videos, one for professionals and the second one for members of the public which provide insight into MCI as a condition, the videos can be accessed by clicking here. A central tenant of the service is to "*enable the person with dementia or MCI to live as full a life as possible, to maintain their skills, family roles and social opportunities*".

3.10 Salford Age UK's **Dementia Support Service** provides community-based advice, guidance and support to individuals, their families and carers with memory loss or a dementia diagnosis and is funded by the local CCG. The service is open referral and following an initial assessment, due to delays in the diagnosis process the service was opened to anybody who had memory loss or who was concerned about their memory. Individuals are offered one to one and group-based support across Salford, including a **6 week training programme aimed at supporting carers** to develop a better understanding of cognitive impairment (including legal and finance matters). Support groups allow carers to meet other carers and to share advice and experiences and to support each other in their everyday lives. The team also run an intergenerational project (' Mr Alzheimer's') in which a volunteer with a diagnosis of cognitive impairment works with the local schools.

3.11 In an interview with Age UK's Salford we explored the profile of MCI as a condition and the challenge of bringing together MCI and dementia patients was explored, specifically: *"I do think we throw MCI in with those with dementia which can be a bit intimidating at times, the reason I say that is we have got quite a few people with MCI who actually are great and don't have any issues but initially there is that they go to a group where some people can be quite advanced and it can be frightening. I think it would be good in some areas to give people an option, and there isn't anything like that in Salford currently apart from the research there aren't any groups specifically for people with MCI"*.

3.12 In the case of Wirral and Salford Age UK services, it is interesting to observe the variation in funding and resources across the Age UK Providers. It would be interesting to further understand what money is spent in Bury on MCI and Dementia.

Stakeholder Insight

Patients and Carers Interviews

4.1 Interviews were conducted, either jointly or individually, with 17 individuals living with a diagnosis of MCI and 13 carers, the key observations are provided below.

Identifying the condition

4.2 In most instances the patient recognised they were forgetting things and partners actively noticed this and began to worry. *"I was worried about telling him that I thought he was losing his memory"* the MoCA test was a way of both parties addressing these underlying concerns. Where there was denial this tended to be due to a fear that the presenting condition could be dementia. A future service offering need to be cogniscant of these fears and **avoid labels such as dementia.**

> *"…its one of those things that you don't want to admit you have got"* Patient

Obtaining a diagnosis

4.3 Patients on the whole were positive in regards to the engagement with health professionals and the diagnosis process. For example, one patient and carer identified that they took us both in together and then separately and then together again in order to explain the condition. There was a **sense of relief** in knowing what the problem is: *"…quite relieved really at last somebody had told me what it was and you know they weren't sort of sending me away as if I was a bit daft".* The relief that the issue was not dementia was also very prominent: *"when I started forgetting I really thought I had got Alzheimer's or dementia and it really panics you".*

4.4 Only half of those engaged reported ongoing engagement with health staff in relation to the condition; such as practice nurses repeating the assessment; follow up post-diagnosis was not consistent and explanation of the condition as well as support available was an area that could be improved.

> *"For me I've worked with care of the elderly so I sort of have an idea, it's that final diagnosis that gets to you, my GP said well you know you have worked with it and you will know all about it, but no you don't, its different when it's your own and when people come into homes with it and have got it slightly; so taking it from the beginning it was a bit scary for us"* Carer

4.5 One patient did identify a potential limitation with the assessment process, they had received 3 tests to date and as the questions are the same (and assessed out of 30), he felt that he could try to 'revise' and subsequently received the highest score on the last assessment. The CCG may want to consider this feedback and review the current assessment process.

4.6 Despite the introduction of the MCI clinical pathway, patients and carers recounted different approaches to the assessment process; this may be a reflection of the process pre-introduction of the pathway but should be considered in any future review or engagement to ensure that the pathway is being applied consistently.

Support

4.7 Interviewees were asked whether they needed and offered support at the point of diagnosis, **only a quarter said they felt they needed support at this point** with the remainder either unsure or not requiring support. This reflected either their family circumstances and support network were deemed to be adequate or a lack of awareness of what would have been available to support them. In the case of the latter, the significant portion of interviewees (90%), did not recall being offered support. Unless individuals are technologically savvy, we need to be cautious about relying on the internet and online directories as sources of information, people are more likely to engage with an individual, such as a GP or social prescriber, to obtain information.

> *"I think it's not so much that you want the support now but you would like to know if it moved fast and you really did start to lose your memory you would like to know what's available and what you are entitled to".* Patient

4.8 The support needs of individuals varied depending upon their support network and interests; however, where to go for information was identified as a recurring issue and interviewees felt it would be beneficial to know that there was somebody that you could talk to, this was particularly pertinent as most individuals interviewed had worries about what the future holds. Day-to-day activities, such as driving, and money also came up on several occasions.

4.9 On the whole, most people kept busy with physical activity such as walking, attending gyms and mental stimulation such as cross words, painting and reading. Some interviewees accessed local community groups or had existing hobbies and groups which provided a form of support and assisted in reducing social isolation. This is not to say that people did not feel socially isolated in some instances, which was probably further exacerbated by the current pandemic and social distancing.

4.10 The role of the carer in supporting the individual with MCI on a daily basis cannot be understated; however, **none of the carers interviewed had been offered support in their role or provided with a carers assessment**, indeed , they were unaware of what financial support and benefits they may be entitled to, as one couple stated: *"we don't think he would qualify for any help".* This is particularly pertinent given financial concerns which were identified.

4.11 Friendship or support groups were of interest in some cases[xii], especially where there was visible strain on the relationship with the partner; this support would be equally for both parties. In response to befriending opportunities one carer stated: *"actually it would be good for X as he doesn't get out that much, we have got some friends but we don't go out as we should do, well I do but X doesn't and I have often talked to him about joining one of these men in sheds clubs because he loves working with woodwork I have found in the last 12 months he can't be bothered to do things or he gets a little bit frustrated".* It is important to consider the mental health and anxiety of people as this could be compounding the condition.

> *"I think the conversation now with you really brings it home for X as well what is happening to us both and it is obviously making him more aware and understanding about how it affects me, it does affect me because sometimes he doesn't believe me or he will say it didn't happen but I know it has so it brings it home so he is aware of this without shouting at me or saying no it's wrong".".* Carer

4.12 It was evident from discussions with both patients and their carers that the **condition places considerable strain on relationships**. There were particularly insightful comments that exposed the potential strain on couples. Memory loss can cause tension and anxiety in individuals and couples alike, similarly, dementia is a very lonely occupation for a carer because the person they have always done the socialising with is gradually drifting away from them.

4.13 When you had both the carer and the person diagnosed together it gave a real insight to what support both people needed as a result of this diagnosis and how the partner/carer were dealing with that diagnosis and helping to support the other. No emotional support was offered to the partners of the individuals with MCI on how to deal with the changes; this is something that needs to be reviewed and integrated into any future service offering. Several couples appeared to be struggling and needed mediation/counselling and training on how to live with the condition (anxiety, depression and conflict). This would give the tools to manage the condition daily and also the confidence to access the range of community assets.

4.14 Support needs identified through the interviews can be grouped into the following areas:

- **Access to counselling and expert advice on the condition** when they get a diagnosis. Aside from tensions and frustrations within the relationship due to the incidents of 'forgetfulness' there was also several couples interviewed where it was apparent that the individual with MCI would not discuss the condition with their partner even though they are their main carer and supporting the individual to remain independent. Anxiety was a big issue for both of these people, so it's what's available to help them to deal with their anxiety levels. Anxiety was about finance and whether he would be stopped from driving. This could be characterised as 'needing someone to talk to who understands'.

- **Information and knowing where to go to and what are on offer.** Whilst some interviewees were self-sufficient people felt it would be beneficial to access activities and groups to build relationships and reduce isolation. It was not directly inferred that this had to be people with similar conditions, as point 3 addresses the condition specific information people required, it was more a case of meeting people to socialize and stimulate their minds. Interestingly, most people had access to physical activity opportunities (gyms or walking).

- **Access to financial support and assessment for the carer** (where required). It's a wider diagnosis than just the MCI, if a person is in a partnership/marriage that also has to be taken into consideration.

Awareness of the condition

4.15 Less than a quarter of those people interviewed felt that there was enough awareness of the condition and the context of their awareness was attributed to their own life experience or personal knowledge. There was a sense that memory issues were associated with dementia and the subsequent fear and stigma. Clearly more awareness raising of the condition, symptoms and actions people can take to reduce the impact/intervene should be undertaken – both locally and nationally. MCI as a condition is where dementia was 20 years ago.

"...don't think there's much about anything really think it's at the bottom of the list medical wise, don't think it's a priority until you may be causing harm to yourself..." Patient

Public Consultation

4.16 Twelve responses were received from the online consultation[xiii], of which eleven identified as someone interested in MCI and one was a carer of a person with the condition. A summary of the consultation results is provided below.

- All respondents felt there was insufficient public and professional awareness of the condition. There was also perceived stigma associated with MCI (82%), with the remainder being unsure if this was the case. As one respondent stated: *"I hadn't heard of it until we were concerned about my wife. She has a diagnosis of Frontotemporal Dementia (FTD). Lack of knowledge about these illnesses causes many difficulties and misunderstandings for all involved".*

- Two-thirds (64%) of respondents were unsure who to speak to in order to obtain advice, a diagnosis or support if they suspected they, or someone who they knew, had the condition. The GP was cited as the point of contact for the remaining 36%.

- When asked what support they (or someone they cared for) would look for, respondents **overwhelmingly chose information advice and guidance** (11 of the 12), followed closely by **practical support to assist with memory** (8 out of 12) and **peer/emotional support** (7 out of 12). Interestingly, some of the comments received indicated that there are some groups in the area who offer activity and support relevant to this group of people, but not badged as diagnosis specific. For example: *"The voluntary sector is a good resource, the support does not necessarily need to be diagnosis specific, it can be provided from organisations that offer activity relevant for this group".*

- The carer response correlated with the interviews undertaken (above); namely, they were unaware of what support was available and were not offered a carers assessment.

Stakeholder Engagement

Ethnic Minorities

4.17 The **Jinnah Centre, ADAB** and the **Asians Women's Centre** identified several attendees where memory loss was a concern, but it was unclear whether these conditions had formally been identified and diagnosed. In cases such as these, the Asian Women's Centre rely on expertise from external partners such as Healthy Minds as experience and knowledge in this area is limited, although some work has been done to raise the awareness of dementia with their clients. Knowledge of the referral pathway, where to go for help and what support may be available was very limited, as stated: *"...they don't know that there is something available for them, they don't even know that they could do some mental exercises that could help them to jog their memory they don't even know that because they expect going to their GP and the GP will work miracles and tell them what they have to do..."* Greater awareness in the community, possibly some community engagement events or training (train-the-trainer) sessions on memory would help to raise the profile of MCI, this could be incorporated into the Laugh and Lunch sessions the centre holds. Frustration, anger and confusion were cited as challenges for both the individual experiencing memory loss and their family and sessions (alluded to above) may help to reduce the impact. Communication and language barriers can be overcome through commissioners utilising resources such as the centre and their established relationships.

> *"Organisations need to be empowered to talk about MCI and then resources in terms of leaflets/social media, needs to happen. Secondly things around therapies, when we do therapies, we don't class as mental health, dementia, we do therapies around arts and crafts things , and other forms around massage, stress relief, a lot of people come to that because these therapies are things that people like to attend. I feel if there were therapies that are not clinical based where you are diagnosing people, the therapies that help people to remember things, that maybe music or other things, I think there would be a lot of take up on that, not only by organisations but also by people who might be suffering of this. Also think GP' should have a better pathway for people to refer into...".* Stakeholder

4.18 The stigma associated with dementia and mental health conditions within the culture prevents people engaging with assessment processes, as MCI is associated with dementia this is likely to contribute to under-representation in the statistics from the BAME community. In this regard, counselling services would be beneficial to help support individuals and families, whilst ensuring also that the labels provided to services (such as 'dementia' or 'mental health') do not inadvertently exclude minority groups.

4.19 Discussions with a retired Psychiatrist from the **Orthodox Jewish community** identified three organisations offering support to this cohort. These were The Fed and Ezra-Care and Neshomo, the latter recruit, train and supervise volunteers, for people who have serious mental health issues, which helps to sustain people and is an early warning system for if the person or the carer are not coping. The organisation advertises for befrienders and clients and at present have around 20 or 30 pairings. Counselling and support the carer through potentially stressful situations was identified as a gap in provision and would be beneficial for the community. **The Fed** offer services which indirectly may support people in the Jewish community who experience MCI, for example community services provide access to assisted technology, family support, support to keep people living well at home; support needs to be considered alongside how the condition effects daily life. This was an interesting concept which we can lose sight of when considering what support people require; it is central that we **maximise a person's independence**. Salford CVS was identified as an area of good practice for social prescribing and community groups which may be worth further consideration as to the model, they have currently deployed and how this links with Age UK Salford (as referenced above).

Health and Social Care Professionals

4.20 Due to the current pandemic, **engagement with GP's** was limited although there was recognition that the impact of social isolation on mental health and subsequently MCI will be significant. Discussions with one GP identified that the introduction of the new clinical pathway has been beneficial in providing structure and also information on support services and signposting. The Bury Directory was the key source of information and encouraged those diagnosed to go to groups that interest them.

4.21 The GP felt that training for the patient and carer on the condition and how to manage would be beneficial as there was an acknowledgement that there is little awareness of the condition in the public arena, although there was some caution around raising the profile: *"Personally, I would not do an ad campaign about MCI, it's too specific, a bit niche. You would then get a lot people saying oh I have got mild cognitive impairment… In my opinion the best thing is encouraging people to socially interact, talk and not be afraid of talking and not be embarrassed about it and not embarrassed to say I feel rubbish and you know I feel anxious… I like to use the phrase mental physiotherapy… I would be wary of doing anything at the moment because there is too much information out there".*

4.22 A representative of the **Staying Well Service** was interviewed and identified that awareness of the condition could be improved both publicly and professionally. The service uses the quality of life tool as the conversational tool so staff would be able to pull information from the Bury Directory if they came across someone with MCI. The service also has a key part in intervening early as the member of staff succinctly stated: *"We get over 100 referrals a month so if we could include that where we are getting people early so we could be making people think about it, we are an early intervention service, so we can be planting little seeds that its ok and so they could be getting help earlier. So yes, coaching would definitely be good to raise awareness".*

4.23 Discussions with **adult social care** managers stressed the importance of "people being treated as equals" and not making assumptions about the person based on the condition, especially given the lack of awareness of what MCI is. A 'one size fits all' approach will not help individuals, neither will the assumption that dementia services are appropriate for everyone with MCI. There was a sense that we should be doing more not just with statutory services, but fundamentally at a real grass route level in the community as this is where people live and exist. If a future service/pathway model could build on community networks so individuals are supported within the community and not potentially ending up in day centres (where it may not be appropriate). The formation of the new Integrated Neighbourhood Teams (INT's) has aligned social workers a social prescriber and staff from the staying well team; furthermore: *"We now have access to a wealth of knowledge which is also being shared with GP Practices so what we are finding is they are sharing information and finding hidden gems in their communities where families can be signposted to when they come into the surgery"*.

"We have a lot of men in reablement who have lost their wives and you have to retrain them how to use a microwave or do the washing as their wives have always done it for them and it's like stress they are forgetting things but once you have been with them for a week and they get the confidence doing it; they feel like they have forgotten but they haven't it is about getting the confidence back. I think it is different from the start of being diagnosed with memory loss and it's too easy to put them on that pathway but if they did more at the start to find out why it might be, they have had a bereavement or there is an underlying condition". Stakeholder

Bury VCFA

4.24 A representative of **Healthwatch Bury** was consulted on MCI and awareness of the referral pathway and support available was raised as an area of improvement. The strength of a person's relationship with their GP (and willingness to 'open up' about concerns) was cited as a potential determining factor for the assessment process. An individual's willingness to accept they have MCI may result in low uptake of services (in part due to stigma and denial) which in-turn effects the viability of service offerings, outside of those required by statute, e.g. assessment.

4.25 **Dementia Connect** raised the importance of co-designing so that people feel they have stake in it and being listened to, which is particularly pertinent "*given there is so little work being done on MCI*". The introduction of the pathway was seen as a positive addition and whilst there may be an absence of services directly aimed at people with MCI, there was a suspicion that it was: *"probably going to be a lot of the smaller groups that will end up supporting this which is great".* At present the service offers telephone and email advice service (as part of a national programme) to people with dementia and have given information on MCI, but this is limited due to capacity. Post-diagnostic education was cited as an example of good practice from other areas, through which people can understand what the condition is, what it means to their lives and how to manage the condition through the use of experts by experience – **social prescribing has to be underpinned by education**. The service would be keen to link in with any future service offering that emerge from this research.

"…quite happy if they could go to some sort of awareness session if they knew what support was available most people would want to know what things they could be doing to improve their memory and what strategies that they can take, we do strategies for people with a visual impairment so there must the same kind of thing I am sure we could put something together for people to help them". Stakeholder

4.26 Discussions with the **Social Prescribing** service queried whether it mattered if someone had a diagnosis of MCI as to whether they could or could not access activities; this would very much be dependent upon the individuals capabilities and also level of interest/comfort of the individual. As a new service (launched in January 2020) there has not been any (known) incidents of people with MCI passing through the social-prescribing service. However, irrespective of the condition the services central principal is to undertake a person-centred approach to consider their needs and where it is appropriate to refer them to. At present this would likely be one of the Dignifying Dementia sessions or Age UK Bury; however greater work is needed in terms of solidifying the offer as the VCFA represents **over 500 voluntary groups so** there is significant support out in the community it is just that a 'label' of MCI may not apply.

Observations for a Future Support Model

5.1 The future support model we propose below takes account of the research and engagement identified throughout this report and we would propose that prior to any action taken further engagement is undertaken with patients to ensure the model is fully co-produced.

5.2 Prior to commencement of the research there was an preliminary set of outcomes which we have tested throughout the course of this research; these were:

Option 1: No specialist group but increased support to signpost people into existing generic services
Option 2: Informal coffee morning, meeting monthly, bi-weekly or weekly
Option 3: Peer-led support group, meeting monthly, bi-weekly or weekly
Option 4: Self-help peer-led support group, with help from a development worker at the start (frequency TBC)
Option 5: Facilitated support group (frequency TBC)
Option 6: Structured health and well-being sessions (frequency TBC)

5.3 Interestingly, whilst there are some parallels in the research undertaken within this project and also the 'Evaluation of Dementia Friendly Community Support Services in Bury' undertaken by Social Research Partners in March 2020, it is important to note that considering the two conditions the two conditions (MCI and dementia) alongside each other when reviewing the social support interventions[xiv] may not be entirely beneficial. As identified in the engagement, individuals greatest anxiety about their episodes of forgetfulness was that the condition may be dementia and conversely, the relief that this was the case is likely to dissuade people from accessing services that are overtly labelled as dementia services. This coupled with the age and cultural profile of patients and the risk of excluding minority groups indicates that a support service with a MCI label may not be beneficial.

5.4 To this extent, we would initially discount 2-6 (above) in favour of consolidating existing offers and raising awareness of the condition (option 1); as the stigma associated with the condition (and dementia) and also the flexibility to meet individual needs (and profile of patients) may result in low uptake of services. This is not to suggest that options 2 and 3 could be piloted as extensions of existing community services to see if there is proof of concept. However, it is our judgement that the proposed service model (below), offers the potential for the greatest impact within existing resources.

5.5 Phase 1: consolidation and enhancement of existing services (aligned to option 1). First and foremost, any future service model needs to address the issue of information advice and guidance, strengthening the existing pathway (figure 5) and utilisation of the existing community assets. As one stakeholder succinctly stated, this is: *"a lot could be simple things we could do, cost effective ways of doing stuff, making sure everybody is linked up".*

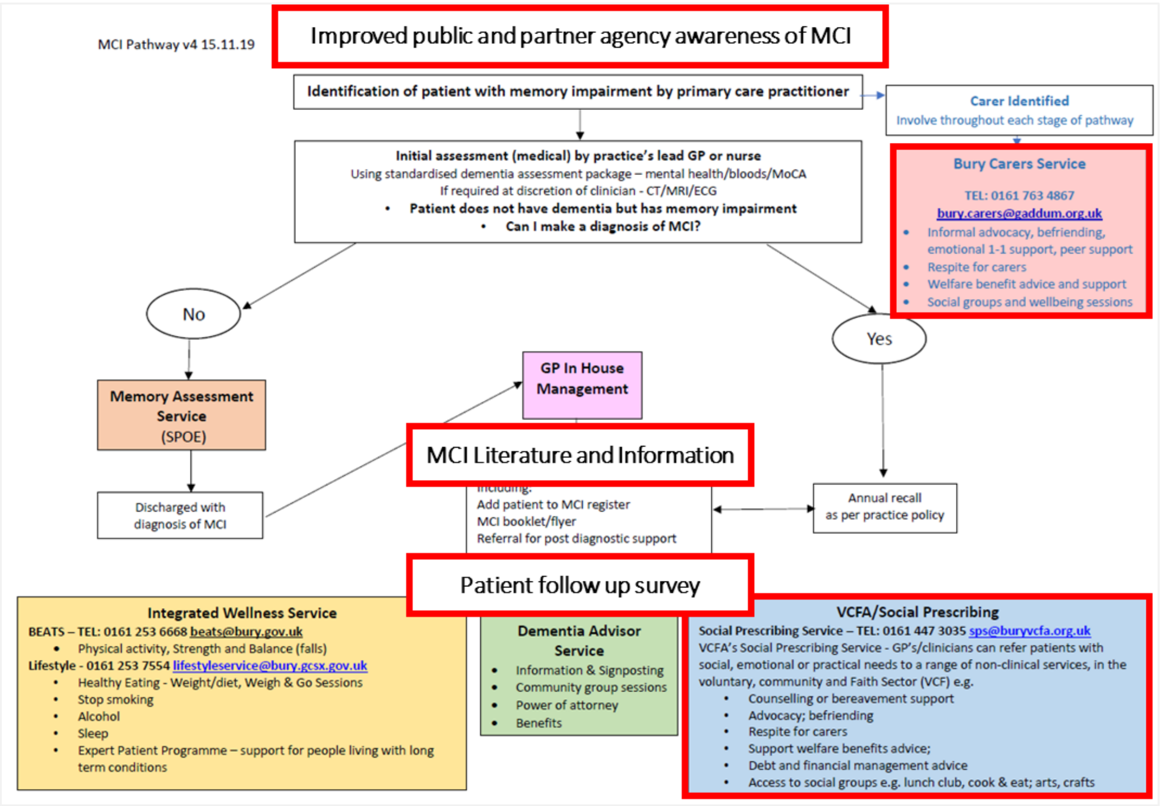

Figure 5: Bury CCG MCI clinical pathway with improvement areas

5.6 Within phase 1 and, utilising existing partner resources, we would propose the following steps are taken:

- **Increasing awareness of MCI** through existing communication forums, such as Healthwatch Bury and roadshows run by the CCG and key stakeholders.

- Improved links and up-skilling of the **social prescribing service** on the condition and the benefit of people accessing existing social activities; broadening the scope beyond services labelled as dementia and 'memory loss' (as alluded to above). Activities should include: social opportunities (such as befriending), cognitive stimulation (choirs, reading clubs etc.) and healthy lifestyle. Key to the offer is flexibility of activities so that it can meet the 'personalised' interest of people, for example: one patient used to be a tailor, so he loved to sew, he used to like cooking and he loved DIY. A lesson from dementia could be applied in this approach; utilising Tom Kitwood's person-centred model, the discussion regarding support for the person with MCI and their carer could focus on the six psychological needs: love, comfort, identity, occupation, inclusion, and attachment[xv].

- **Improving access to information**, ensuring all patients are provided with the 'information for patients diagnosed with MCI in Greater Manchester' leaflet (figure 3), which provides a brief overview on how to keep the brain active, key daily living considerations (such as driving and tips for prompting) and also updating the Bury specific information leaflet to direct people towards social prescribing, thus increasing the breadth of services offered. It is important to note that during the review some queries were raised in relation to the accuracy of the clinical pathway and the access to services. It would be prudent for the CCG to review the following areas to ensure that people receiving a diagnosis are receiving the most accurate information:

    - As of the 1st June 2020 Bury Carers services will be run by n-compass;
    - The social prescribing pathway omits the Stay Well Team; and
    - It is understood that the Dementia Advisor Service signpost to benefits and power of attorney guidance /support.

- Utilising Healthwatch to **ensure the pathway is consistently being applied** and that people are being provided with the above information and carers are being signposted for a carers assessment and existing information and guidance; this could be achieved through follow up patient surveys.

5.7 Phase 2: redesign current 'dementia' service offer (incorporating elements of options 4, 5 and 6). Through the engagement and review of current support services there was several gaps in provision which were bespoke to MCI or required significant investment in their own right (see appendix 2). This included access to education courses or modules on how to live with the condition and also counselling support for individuals and their partners/carers to help support them through the anxiety and strain that they are experiencing. In recognition of the ageing population and the potential for increased numbers (up to 7000 individuals with the condition) counterbalanced with resource and financial pressures public services find themselves in, we cannot assume that new monies are available to commission additional services. For instance, if we assumed that 10% of the potential cohort of people with the condition required counselling, the estimated cost for a 12 week programme could exceed £336,000[xvi]. Therefore, the gaps in provision for MCI which appear to offer the greatest impact to people's lives, based on the engagement in this review, could only feasibly be met through the reconfiguration and alignment of existing service offerings. One such area is the current contract for provision of Dementia Advisors.

5.8 A revised service should help to build the infrastructure that may be required to meet future demand and tackle the gaps in service provision. Alongside delivering core services (relating to dementia; whilst avoiding use of the label) activities of a new 'Memory Service' could include:

- There can be a period of uncertainty after a person is diagnosed with MCI. This can be hard for the person and those around them, the person could be given information and advice, and internal counselling if needed. They may also be offered more support to help them live as well as possible through establishing and facilitating peer support, possibly aligned to practices, as people expressed a desire to have 'someone to talk to'.

- Development of support modules, potentially utilising experts by experience or creation of 'day-in-the-life' video blogs to provide and idea of what it is like to live with the condition and hits and tips on how to live a full and active life with the condition (patient and carer specific). The social prescribing alluded to in phase 1 will need to be underpinned by education and awareness of the condition, particularly those diagnosed and their carers, in order to ensure there is the confidence to access and participate fully in activities.

- Support the development and integration of cognitive stimulation activities and programmes such as the one in operation in Age UK Wirral. To maximise reach a syllabus/programme could be developed and rolled out through a train the trainer model to wider community groups, alongside awareness raising activity, to allow organisations such as the BAME community to deliver locally and at their own discretion.

5.9 Engagement with community groups did not articulate a particularly strong relationship with commissioners in order to affect future planning; therefore, phase 2 would provide an opportunity to co-produce the new service structure with community groups and also people living with the condition. There was significant interest from all stakeholders in being involved in any future planning of services.

Appendix 1: MCI diagnosis data table

gp_practice_desc	Neighbourhood	(A) MCI register (Aged 65+)	(B) MCI register ethnic data (Aged 65+)	Variance	Patients aged 65y or over	% BASED ON A	% BASED ON B	Patient prevalence at 6.01%(1)	Increase on current register	Patient prevalence at 20% (2)	Increase on current register
FAIRFAX GROUP PRACTICE	Prestwich	21	29	8	1752	1.20%	1.66%	105	84	350	329
THE UPLANDS MEDICAL PRACTICE	Whitefield & Unsw	13	17	4	1400	0.93%	1.21%	84	71	280	267
TOWNSIDE SURGERY	Bury East	25	37	12	1113	2.25%	3.32%	67	42	223	198
RAMSBOTTOM MEDICAL PRACTICE	Bury North	10	14	4	1469	0.68%	0.95%	88	78	294	284
RADCLIFFE MEDICAL PRACTICE	Radcliffe	23	50	27	1415	1.63%	3.53%	85	62	283	260
BLACKFORD HOUSE MEDICAL CENTRE	Whitefield & Unsw	8	19	11	1867	0.43%	1.02%	112	104	373	365
MONARCH MEDICAL CENTRE	Radcliffe	3	10	7	504	0.60%	1.98%	30	27	101	98
UNSWORTH MEDICAL CENTRE	Whitefield & Unsw	11	30	19	1487	0.74%	2.02%	89	78	297	286
TOWER FAMILY HEALTHCARE	Bury North	59	76	17	5931	0.99%	1.28%	356	297	1,186	1,127
RIBBLESDALE MEDICAL PRACTICE	Bury East	24	30	6	1828	1.31%	1.64%	110	86	366	342
WOODBANK SURGERY	Bury North	6	9	3	868	0.69%	1.04%	52	46	174	168
MINDEN FAMILY PRACTICES - DR SAXENA	Bury East	38	53	15	3325	1.14%	1.59%	200	162	665	627
PEEL GPS	Bury East	6	12	6	1479	0.41%	0.81%	89	83	296	290
KNOWSLEY MEDICAL CENTRE	Bury East	13	17	4	729	1.78%	2.33%	44	31	146	133
ST GABRIEL'S MEDICAL CENTRE	Prestwich	6	11	5	1139	0.53%	0.97%	68	62	228	222
GREYLAND MEDICAL CENTRE	Prestwich	3	4	1	460	0.65%	0.87%	28	25	92	89
RED BANK GROUP PRACTICE	Radcliffe	28	38	10	2319	1.21%	1.64%	139	111	464	436
WHITTAKER LANE MED CENTRE	Prestwich	10	19	9	1154	0.87%	1.65%	69	59	231	221
THE ELMS MEDICAL CENTRE	Whitefield & Unsw	2	15	13	1234	0.16%	1.22%	74	72	247	245
THE BIRCHES MEDICAL CENTRE	Prestwich	8	14	6	610	1.31%	2.30%	37	29	122	114
WALMERSLEY ROAD MEDICAL PRACTICE	Bury East	8	8	0	233	3.43%	3.43%	14	6	47	39
MILE LANE HEALTH CENTRE	Radcliffe	9	13	4	929	0.97%	1.40%	56	47	186	177
GARDEN CITY MEDICAL CENTRE	Bury North	9	23	14	1191	0.76%	1.93%	71	62	238	229
HUNTLEY MOUNT MEDICAL CENTRE	Bury East	0	0	0	458	0.00%	0.00%	27	27	92	92
LONGFIELD MEDICAL PRACTICE	Prestwich	9	18	9	835	1.08%	2.16%	50	41	167	158
ROCK HEALTHCARE LIMITED	Bury East	3	5	2	567	0.53%	0.88%	34	31	113	110
		355	**571**	**216**	**36296**	**0.98%**	**1.57%**	**2178**	**1823**	**7259**	**6904**

Notes:

(A) MCI diagnosis data provided June 2019

(B) MCI diagnosis data provided March 2020 to analyse ethnicity and identified a further 221 patients.

1.Meta-analysis estimates (95% CI) of MCI incidence per 1000 person-years were 22.5 (5.1–51.4) for ages 75–79y, 40.9 (7.7–97.5) for ages 80–84y, and 60.1 (6.7–159.0) for ages 85+y. Reference: Gillis C, Mirzaei F, Potashman M, Ikram MA, Maserejian N. The incidence of mild cognitive impairment: A systematic review and data synthesis. Alzheimer's Dement (Amst). 2019;11:248–256. Published 2019 Mar 8

2. Alzheimer's estimated prevalence range of 5 to 20%

gp_practice_desc	Neighbourhood	Av.Age	Max Age	Min Age	Ethnicity White British	Ethnicity British or mixed British	Ethnicity Other	Unknown	Dementia register (Aged 65+) (Jan 2020)	Patients aged 65y or over (Jan 2020)	%
FAIRFAX GROUP PRACTICE	Prestwich	80	90	55	17.24%	31.03%	10.34%	41.38%	127	1,785	7.11%
THE UPLANDS MEDICAL PRACTICE	Whitefield & Unsw	77	94	61	47.06%	17.65%	5.88%	29.41%	51	1,335	3.82%
TOWNSIDE SURGERY	Bury East	79	98	52	45.95%	10.81%	8.11%	35.14%	66	1,124	5.87%
RAMSBOTTOM MEDICAL PRACTICE	Bury North	78	92	53	50.00%	28.57%	7.14%	14.29%	67	1,489	4.50%
RADCLIFFE MEDICAL PRACTICE	Radcliffe	70	94	31	36.00%	24.00%	4.00%	36.00%	58	1,425	4.07%
BLACKFORD HOUSE MEDICAL CENTRE	Whitefield & Unsw	80	94	68	57.89%	15.79%	15.79%	10.53%	68	1,903	3.57%
MONARCH MEDICAL CENTRE	Radcliffe	71	83	54	70.00%	20.00%	0.00%	10.00%	20	507	3.94%
UNSWORTH MEDICAL CENTRE	Whitefield & Unsw	76	92	45	6.67%	50.00%	3.33%	40.00%	55	1,499	3.67%
TOWER FAMILY HEALTHCARE	Bury North	77	94	49	26.32%	26.32%	2.63%	44.74%	324	6,023	5.38%
RIBBLESDALE MEDICAL PRACTICE	Bury East	81	96	39	23.33%	26.67%	6.67%	43.33%	111	1,827	6.08%
WOODBANK SURGERY	Bury North	72	100	33	11.11%	44.44%	0.00%	44.44%	40	878	4.56%
MINDEN FAMILY PRACTICES - DR SAXENA	Bury East	73	99	51	11.32%	43.40%	5.66%	39.62%	158	3,330	4.74%
PEEL GPS	Bury East	73	95	56	25.00%	50.00%	8.33%	16.67%	67	1,486	4.51%
KNOWSLEY MEDICAL CENTRE	Bury East	76	95	66	23.53%	11.76%	17.65%	47.06%	33	752	4.39%
ST GABRIEL'S MEDICAL CENTRE	Prestwich	83	96	57	0.00%	9.09%	0.00%	90.91%	61	1,155	5.28%
GREYLAND MEDICAL CENTRE	Prestwich	76	82	68	75.00%	0.00%	25.00%	0.00%	12	455	2.64%
RED BANK GROUP PRACTICE	Radcliffe	81	99	52	10.53%	5.26%	0.00%	84.21%	152	2,309	6.58%
WHITTAKER LANE MED CENTRE	Prestwich	82	94	63	57.89%	10.53%	0.00%	31.58%	82	1,141	7.19%
THE ELMS MEDICAL CENTRE	Whitefield & Unsw	80	101	56	20.00%	13.33%	6.67%	60.00%	45	1,217	3.70%
THE BIRCHES MEDICAL CENTRE	Prestwich	71	85	55	50.00%	35.71%	7.14%	7.14%	31	615	5.04%
WALMERSLEY ROAD MEDICAL PRACTICE	Bury East	87	100	80	0.00%	0.00%	0.00%	100.00%	14	268	5.22%
MILE LANE HEALTH CENTRE	Radcliffe	79	96	55	15.38%	69.23%	0.00%	15.38%	47	974	4.83%
GARDEN CITY MEDICAL CENTRE	Bury North	76	96	56	38.46%	61.54%	0.00%	43.48%	49	1,212	4.04%
HUNTLEY MOUNT MEDICAL CENTRE	Bury East								10	475	2.11%
LONGFIELD MEDICAL PRACTICE	Prestwich	77	93	50	33.33%	61.11%	0.00%	5.56%	71	838	8.47%
ROCK HEALTHCARE LIMITED	Bury East	78	88	65	40.00%	60.00%	0.00%	0.00%	47	554	8.48%
		77			**31%**	**29%**	**5%**	**35%**	**1866**	**36576**	**5.10%**

Appendix 2: Support service gap analysis

	Lifestyle Risk Factors	Emotional Support & Social Connection	Memory Intervention	Info, Advice & Guidance
Rainbow Café		○		
Beautiful Memories		○		
Peace of Mind DEEP group		○		
Dementia Adviser service			○	○
Singing for the Brain		○	○	
Dignifying Dementia social activities		○	○	
Storybox Creative Cafe		○		
Purple Cafe		○		
Age UK Bury social activities and IAG		○		○
Living Well Service	○			
BEATS	○			
Expert Patient Programme	○			
Incredible Edible Brandlesholme		○		
Creative Living Centre		○	○	
Forever Friends		○		
BIG Anxiety & Depression Group		○		
Community Advice & Support Team		○		
Rethink Mental Illness		○		
Nurture Counselling & Therapies		○	○	
Healthy Minds service		○	○	
Jinnah Centre		○		
National Age UK		○		○
Independent Age				○
Silverline		○		○
Samaritans		○		
Mind				○

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[i] https://www.rcpsych.ac.uk/docs/default-source/members/faculties/old-age/position-statement-on-loneliness-and-isolation-dec-2019-(3).pdf?sfvrsn=52a394f0_2

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[iv] Carvalho A, Rea IM, Parimon T, Cusack BJ. Physical activity and cognitive function in individuals over 60 years of age: a systematic review. 2014;9:661–682. Published 2014 Apr 12

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[viii] Petersen RC, Lopez O, Armstrong MJ, et al. Practice guideline update summary: Mild cognitive impairment: Report of the Guideline Development, Dissemination, and Implementation Subcommittee of the American Academy of Neurology. Neurology. 2018;90(3):126–135

[ix] Langa KM, Levine DA; The diagnosis and management of mild cognitive impairment: a clinical review. JAMA. 2014 Dec 17312(23):2551-61. doi: 10.1001/jama.2014.13806.

[x] Petersen RC, Lopez O, Armstrong MJ, et al. Practice guideline update summary: Mild cognitive impairment: Report of the Guideline Development, Dissemination, and Implementation Subcommittee of the American Academy of Neurology. Neurology. 2018;90(3):126–135

[xi] https://www.theburydirectory.co.uk/kb5/bury/directory/home.page

[xii] Cultural sensitivities need to be considered in this area, whilst the majority of individual interviewed could be classified as White British, one couple interviewed identified as Jewish and struggled to engage with community activities possibly due to faith; however, they did not access The Fed.

[xiii] https://www.onecommunitybury.co.uk/mild-cognitive-impairment-mci-survey

[xiv] Phuong Leung, Martin Orrell and Vasiliki Orgeta; Social support group interventions in people with dementia and mild cognitive impairment: a systematic review of the literature, International Journal of Geriatric Psychiatry · July 2014

[xv] https://www.verywellhealth.com/what-is-person-centered-care-in-dementia-97737

[xvi] Assumed the median of the NHS guidance range see: https://www.nhs.uk/conditions/Counselling/
The calculation is £40 per hour x 12 x 700 (10% of the maximum prevalence) = £336,000