**Human rights implications of the implementation of the Madrid International Plan of Action on Ageing** (MIPAA) **– UK contribution**

**ANNEX 1**

**Information on actions regarding dementia**

The Madrid International Plan of Action acknowledges that “as dementia is a prevalent disease in old age, especially Alzheimer’s, treatment and rehabilitation programmes as well as long-term care are of increasing importance in an ageing world. Strategies to cope with such diseases include diagnosis, medication, psychosocial factors, cognitive training programmes, training for caring family members and caring staff and specific structures of inpatient care. To help dementia patients live at home for as long as possible, it is necessary to respond to their specific needs, for security, adequate social support and home care services. Specific programmes for psychosocial therapy should help to reintegrate patients discharged from hospital.”

Dementia is one of the most significant global health and care challenges of our time. It describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. It is a key priority for this government. In England, it affects around 676, 000 people[[1]](#footnote-1). The number of people living with dementia is expected to double in the next 30 years. It currently affects 47.47m people worldwide, with that number is expected to triple by 2050.

It has been highlighted that people with dementia face issues over variation in care quality, access to support and awareness among health and care staff and in society more generally. An estimated 25 percent of hospital beds are occupied by people with dementia. People admitted to hospital who also have dementia, stay in hospital for longer, are more likely to be readmitted and are more likely to die than patients without dementia who are admitted for the same reason.

People with dementia talk about stigma and social isolation. They report losing friends following their diagnosis, seeing people cross the street to avoid them, feeling lonely, and struggling to use local services. Research with the general public has shown that this is often down to the fear, misunderstanding and helplessness people feel in the face of dementia. This is compounded by common misunderstandings about dementia with the preconception that it is an inevitable part of ageing and that nothing can be done to improve people’s lives.

An estimated one-third of people with dementia live in residential care and two-thirds live at home. Approximately 69 per cent of care home residents are currently estimated to have dementia. People with dementia in care homes are more likely to go into hospital with avoidable conditions.

**Question 2**

Initiatives in place concerning dementia and Alzheimer’s disease

Since 2009, the Department of Health had a number of initiatives to support the care of people with dementia. These include the National Dementia Strategy, launched in 2009, the first Prime Minister’s Challenge on Dementia, which ran between 2012 and 2015, and the Prime Minister’s Challenge on Dementia 2020 which launched in 2015.

National Dementia Strategy 2009

The first National Dementia Strategy was set up in 2009 and ran until 31 March 2014. It provided a strategic framework for local services to deliver quality improvements to dementia services and address health inequalities relating to dementia, provide advice and guidance and support for health and social care commissioners and providers in the planning, development and monitoring of services and provide a guide to the content of high-quality services for dementia.

Prime Minister’s Challenge on Dementia 2012 – 2015

The Prime Minister’s Challenge on Dementia (2012) ran between 2012 to 2015. It built on the National Dementia Strategy and set a number of key commitments to deliver major improvements in research, dementia care and dementia friendly communities.

Prime Minister’s Challenge on Dementia 2020

The Prime Minister’s Challenge on Dementia 2020 was published on 21 February 2015 to coincide with the end of the first Prime Minister’s Dementia Challenge. It builds on the achievements of the Prime Minister’s Challenge on dementia 2012-2015 and aims to identify what needs to be done to make sure that dementia care, support, awareness and research are transformed by 2020.[[2]](#footnote-2)

It sets out what the NHS, along with its partners both locally and nationally will be asked to deliver towards 2020 and has been informed by engagement with a range of stakeholders, including people with dementia and carers who have told us what is important to them.

A major part of the Prime Minister’s Challenge on Dementia 2012-2015 sought to tackle stigma that was associated with dementia and the limited public understanding of the condition.

A key commitment in the Challenge 2012-2015 was to invest in a nationwide campaign to raise awareness of dementia. The national advertising campaign, supported by the ‘Christmas to remember’ website[[3]](#footnote-3), sought to reduce the stigma attached to dementia and to encourage people, worried about a family member if they are having problems with their memory, to have those difficult conversations and to support the family member to visit their GP. It built on the 2010 dementia awareness campaign which showed a positive impact on awareness, recognition of symptoms and attitudes to dementia to effect a change in the dementia journey and foster early diagnosis.

The campaign, delivered at the end of 2012, reached out to over 37 million people. The evaluation findings show that:

* Three quarters of people agreed that the campaign would help people with dementia and their families.
* 86 percent agreed that some people with dementia can still take part in everyday activities.
* 83 percent agreed that they would encourage a relative or friend to visit a GP if they thought they had symptoms of dementia.

The success of the nationwide awareness raising campaign put in place a framework to embed dementia awareness and training across the system. Examples include the support tools developed by the Department of Health and NHS England for GPs, nurses and clinical commissioning groups, and guidance for health and care staff on implementing the new dementia component of the NHS Health Check.

A subsequent awareness campaign was jointly launched by the Department of Health and Public Health England in 2014.[[4]](#footnote-4) The Dementia Movement campaign was a collaboration across the voluntary, business and public sectors that aimed to improve public attitudes towards dementia and give more people the confidence to engage with people with dementia. It sought to improve skills so more people know how to help, invited individuals to become a Dementia Friend and communities and businesses to become dementia friendly.[[5]](#footnote-5)

Dementia Friends

Over the course of the Prime Minister’s Challenge 2012- 2015, the Department of Health and the Cabinet Office supported the Dementia Friends programme, developed by the Alzheimer’s Society. The social action movement sought to transform awareness and understanding of dementia across society and to engage with sectors, organisations and communities beyond health and social care.

‘Dementia Friends’ is a community mobilisation initiative that initially aimed to give one million people an understanding of dementia and the small things they can do to make a difference to people living with the condition, achieved via face to face or online awareness sessions.

To support this initiative, Public Health England (PHE) worked with the Alzheimer’s Society on 7 May 2014 to launch a major national multimedia campaign, the Dementia Friends Campaign, which was renewed on December 2014. The campaign aimed to inspire and support a movement of friendship in which everyone played a part and up-skill society so more people developed an understanding of how to engage with people with dementia by recruiting people into the Dementia Friends programme. The campaign also sought to raise awareness of dementia, improve attitudes towards the condition and create a more dementia friendly society by encouraging one million people to become Dementia Friends.

There are currently over 1 million Dementia Friends, achieving the target of reaching one million Dementia Friends by March 2015. This has enabled progress on improving awareness about dementia and on changing public attitudes to reduce stigma and increase understanding.

The Challenge on Dementia to 2020 continues this in setting a vision for a society where the public thinks and feels differently about dementia, reducing fear, stigma and discrimination; and increasing understanding. Through the implementation of the 2020 Challenge, the Alzheimer’s Society has committed to deliver an additional 3 million Dementia Friends in England, with England leading the way in turning Dementia Friends in to a global movement. The 2020 Challenge also called for the support for Dementia Friends Champions to take new opportunities and action, for example through a dedicated volunteering network to maintain and build on the current momentum.

Dementia Friendly Communities

Furthermore, in tackling stigma associated with dementia and providing support to people with the condition, the Department worked closely with the Alzheimer’s Society on the work to create dementia friendly communities across the country.

The aim of creating dementia friendly communities is to ensure that people with dementia, their carers and families can be active citizens with the potential to live well with dementia at every stage of the condition. A dementia-friendly community is one in which people with dementia are empowered to have aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them.

Since the launch of the Challenge 2012-2015, over 105 communities across England, towns, cities and villages, have signed up to Alzheimer’s Society’s foundation-stage recognition process for dementia friendly communities, more than achieving our original ambition to reach up to 20 communities by March 2015. The Dementia Friendly Communities initiative was supported by the actions of groups such as schools and businesses which have allowed the spreading of awareness.

Below are a couple of examples that exemplify the work to create Dementia Friendly Communities.

*Case study - Bernard Gilpin Primary School*

As one of the pioneer schools in the Prime Minister’s Challenge on Dementia, Bernard Gilpin Primary School teaches children to learn about the brain, dementia and its effects. People living with dementia have given talks at the school about how they cope with the disease and how the children can support them to live well. Year 5 held a parliamentary style debate about Dementia Friendly Communities, chaired by the local MP and televised by ITV Tyne Tees. The school has opened “The Living Room – a place to enjoy spending time with others”, an accessible area of the school for the community activities which include: Singing for the Brain, dementia café, dance and an intergenerational choir where children and people with dementia sing together. The primary school has more plans for intergenerational learning in other curriculum areas designed to enhance their dementia-friendly community.[[6]](#footnote-6)

*Case study - Marks and Spencers*

Marks and Spencers (M&S) began its Dementia Friends Campaign with a public press commitment and ran an engagement campaign in May 2014 as part of National Dementia Awareness Week. It gave all of its employees the opportunity to develop a better understanding of dementia through video and online ‘knowledge card’ training focussed on customer scenarios. The campaign was delivered across all employee communications channels and championed by management teams, business reps and Plan A Champions. As a result, teams developed a better understanding and further initiatives ensued. In May 2015, M&S ran a second Dementia Friends Week showcasing employee stories and access to a manager guide on Dementia Friendly workplaces. It also committed to roll out Dementia Friends Champions training across its 550 stores and working with the Dementia Friendly Retail group on a booklet to support other businesses to become Dementia Friendly.[[7]](#footnote-7)

Through the implementation of the 2020 Challenge, we want to build on this progress by seeing

* All businesses encouraged and supported to become dementia friendly, with all industry sectors developing Dementia Friendly Charters and working with business leaders to make individual commitments (especially but not exclusively FTSE 500 companies). All employers with formal induction programmes invited to include dementia awareness training within these programmes.
* All primary and secondary schools being encouraged to include dementia awareness in their work programmes leading to the creation of a dementia-friendly generation and all Further Education Colleges and Universities being encouraged to include dementia awareness in their work programmes.

Building on the progress already made, the Department worked with Alzheimer’s Society and the British Standards Institute (BSI) to develop a Publically Available Specification (PAS) for dementia friendly communities. This was launched on 9 July 2015. The PAS provides more detailed guidance to communities working to become dementia friendly. It covers what areas of a community to consider, areas for action, promoting and sharing information and over what changes to expect as a result of developing a dementia friendly community.[[8]](#footnote-8)

Through the implementation of the Prime Minister’s Challenge on Dementia 2020, we want to see over half of people living in areas that have been recognised as Dementia Friendly Communities, according to the guidance. We also want to see that each area should be working towards the highest level of achievement under these standards, with a clear national recognition process to reward their progress when they achieve this. The recognition process will be supported by a solid national evidence base promoting the benefits of becoming dementia friendly.

The workstream also involves organisations from a wide range of sectors. A number of sectors have developed led their own charters and toolkits to become dementia friendly. There have also been a range of Task and Finish Groups which were taking action in individual sectors. These include: Assistive Technology, Dementia Friendly Retail, Dementia Friendly Employers, Rural Communities, Power of Attorney and Data Protection, Civil Society and Voluntary Sector, Sport and Leisure, Arts Sector, Transport Sector and Maintaining Personal Wellbeing.

A partner in the delivery of both of the Challenges, Alzheimer’s Society has also been working in partnership to support churches to be more dementia-friendly and contribute to the creation of dementia-friendly communities. They have for example, developed an online resource pack which can be used by local churches.

*Case study - Livability*

The Alzheimer’s Society have provided their expertise in dementia research and support with the context of Christian belief and teachings provided by Livability. The pack provides information, resources and advice to support churches to effectively engage with people living with dementia. It is suitable for church leaders, clergy, lay preachers, worship leaders, bible study or small group facilitators and anyone interested in church based activities for people with dementia. The Department of Health welcomed the use of this pack by other faith groups and non-faith based organisations. Alzheimer’s Society has developed targeted programmes across London through its Connecting Communities[[9]](#footnote-9)

Through the implementation of the Challenge 2020, we want to see greater involvement of people with dementia and carers in the development of dementia friendly communities and increasing involvement of voluntary and civil society organisations in local Dementia Action Alliances to support communities at a local level.

Human rights

Through the 2020 Challenge, we also want to see a greater understanding and protection of the human rights of those living with dementia around the world through global collaboration and work with the Independent Expert for Human Rights of Older People.

On 11th September 2013, the Declaration agreed during the G8, (now G7), Dementia Summit in London, set out a number of commitments with national, subnational and local responsibilities:

* Commitment 10 - Supporting improvements in care and services
* Commitment 11 – Through Civil Society, reduce stigma, exclusion and fear and “Call upon the UN Independent Expert on the enjoyment of human rights by older persons to integrate the perspective of older people affected by dementia into their work.”

The UK Government committed to tackling dementia domestically and internationally and has been working closely with the UN Independent Expert on the enjoyment of all human rights by older persons since her appointment in 2014. Rosa Kornfield-Matte has demonstrated her commitment to the GAAD programme on many occasions, stressing the importance of States adopting a human rights-based approach when addressing the concerns of older people with dementia.

Solutions to tackling dementia lie in global collaborative efforts, and shared information and experiences. We must continue to ensure dementia is embedded within existing mechanisms such as the UN Independent Expert on the enjoyment of all human rights by older persons work, or WHO programmes to address non-communicable diseases.

**Question 3**

People’s experience of living with dementia or caring is significantly determined by characteristics such as their ethnicity, age, pre-existing disabilities or whether they have a carer living with them.

An important component of the Prime Minister’s Challenge on Dementia 2020 is the work conducted to tackle inequalities that groups shaped by these characteristics.

The Prime Minister’s Challenge on Dementia 2020 set a vision to create a society by 2020 where every person with dementia, and their carers and families, from all backgrounds, walks of life and in all parts of the country receive high quality, compassionate care from diagnosis through to end of life care. Its vision considers and makes equal the needs of people in groups of different ages, gender, sexual orientation, ability or ethnicity and in different localities. These include for example Black, Asian and Minority Ethnic (BAME) groups and the Lesbian, Gay, Bisexual and Transgender (LGBT) communities.

This is in light that the number of people with dementia from BAME groups in the UK is expected to rise significantly as the BAME population ages. It is estimated that there are nearly 25,000 people living with dementia from BAME backgrounds in England and Wales. This number is expected to grow to nearly 50,000 by 2026 and over 172,000 by 2051. [[10]](#footnote-10)

Moreover, people with learning disabilities have an increased risk of developing dementia than other people and usually develop the condition at a younger age. In particular, one in three people with Down’s syndrome will develop dementia in their 50s.[[11]](#footnote-11)

Some LGBT also people do not feel that support services were able or willing to meet or understand their specific needs. Many feel that they would be uncomfortable with care home staff or paid carers knowing their sexual orientation. This is often for fear of hostility and prejudice as they may have experienced discrimination in the past. [[12]](#footnote-12)

Under the Equality Act 2010, it is unlawful to treat people unfairly because of their sexual orientation. Therefore, service providers have a duty to ensure that their services and their staff do not discriminate against people on the grounds of their sexual orientation. [[13]](#footnote-13)

To tackle these inequalities through the 2020 Challenge, we want to see an increase in the numbers of people of Black, Asian and Minority Ethnic origin and other seldom heard groups who receive a diagnosis of dementia, enabled through greater use by health professionals of diagnostic tools that are linguistically or culturally appropriate.

The 2020 Challenge also called for local commissioners and providers need to continue to improve their understanding of the best ways to tailor post-diagnosis support services to diverse needs. For example there is evidence that shows that BAME communities in particular have lower rates of access to these services.

It also called for the encouragement of greater personalisation in the provision of post-diagnosis services; building support around the individual with dementia, their carer and family and providing them with more choice, control and flexibility in the way they receive care and support – regardless of the setting in which they receive it.

This builds on work conducted to raise awareness about dementia within harder to reach communities as exemplified by the Meri Yaadain project.

*Case study - Meri Yaadain*

In West Yorkshire, the Meri Yaadain project, reaches out to the South Asian community to raise awareness of dementia and the services and support available to families and carers of people with dementia. It is a south Asian community outreach project led by Bradford City Council, in partnership with the NHS, Age Concern and the Alzheimer’s Society.

The team undertake a range of activities to reach out and engage with older people and their families and carers, from South Asian communities, to raise awareness of the condition and services and support available to them.

The team deliver home visits, host support groups, provide telephone advice, hold community roadshows, produce a quarterly newsletter and appear on local radio programmes.

The success of the project has led to it being established as a long-term initiative.

As part of the process in developing a dementia friendly community, the PAS Code of Practice for Dementia friendly communities called for those developing the community to be inclusive of people with dementia irrespective of characteristics such as age, race, gender, sexual orientation, socio-economic status, seldom heard/vulnerable groups and those with long term or acute medical conditions when engaging with stakeholders.

The guide also emphasised that the stakeholder groups should pay particular attention to BAME, LGBT and other populations that may traditionally be more likely to be excluded from support and service and consider factors sensitive to their culture and backgrounds.

**Question 6**

Since the launch of the Prime Ministers’ Challenge on Dementia 2012-2015, significant progress has been made in improving health and care for people with dementia and their carers, creating dementia friendly communities and boosting dementia research.

Diagnosis

The Prime Minister’s Challenge 2012-2015 set the first ever national ambition on dementia diagnosis rate. It aimed for two thirds of the estimated number of people with dementia to receive a diagnosis and appropriate post-diagnosis support; an ambition that NHS England are maintaining. This has led to major progress in how many people receive a diagnosis.

The Prime Minister’s Challenge 2020 builds on this by setting the commitment that in every part of the country people with dementia having equal access to diagnosis as for other conditions, with an expectation that the national average for an initial assessment should be 6 weeks following a referral from a GP.

A timely diagnosis of dementia is vital to ensuring that a person with dementia can access the advice, information, care and support that can help them to live well with the condition and remain independent for as long as possible. It facilitates access to post diagnosis support which can include a very wide range of interventions including provision of an accountable clinician for people with Dementia, provision of a Dementia Adviser for people with Dementia, support for Carers and medication for those diagnosed.

There are initiatives in place to support people after diagnosis. For example, NHS England is working with Age UK, the Alzheimer’s Society and others to ensure that the Improving Access to Psychological Therapies (IAPT) programme is able to meet the psychological therapy needs of older people with depression and anxiety disorders. Work to underpin this ambition includes the review and update of an Older People’s training module, introduced in 2013/14, to support therapists to work with older people beginning to experience cognitive impairment and with the carers of those suffering from dementia

To facilitate timely diagnosis and support for people with dementia, the Dementia Directed Enhanced Service (DES) and Commissioning for Quality and Innovation (CQUIN) are in place to reward GP practices and hospital settings respectively. To help GPs make a more timely diagnosis and facilitate support, NHS England published a Dementia Toolkit. With the help of these schemes, more people now receive a diagnosis of dementia than ever before.

Health and Care

A key strand of the 2012-2015 Challenge was improving health and care in supporting people with dementia. Through the implementation of the 2020 Challenge, we want to see every person diagnosed with dementia having meaningful care following their diagnosis, which supports them and those around them.

We also want to see effective metrics across the health and care system, including feedback from people with dementia and carers, will enable progress against the standards to be tracked and for information to made publicly available. This care may include for example:

* receiving information on what post-diagnosis services are available locally and how these can be accessed, through for example an annual ‘information prescription’.
* access to relevant advice and support to help and advise on what happens after a diagnosis and the support available through the journey.
* carers of people with dementia being made aware of and offered the opportunity for respite, education, training, emotional and psychological support so that they feel able to cope with their caring responsibilities and to have a life alongside caring.

This builds on the implementation of the Care Act. The Act creates a ‘well-being principle’ to underpin the care and support system. The impact is that people’s well-being, and the outcomes which matter to them will be at the heart of every decision that is made.

The Act provides a duty for local authorities to ensure that information and advice services are available to all people, including carers in their area regardless of whether or not they have care needs. It also places carers’ rights on the same footing as the people they care for and extends their rights to an assessment. This is based on the appearance of a need for support and consideration of the impact of caring on the carer and the outcomes they wish to achieve. On 1st July 2015, the Secretary of State announced that we will develop a new carers’ strategy that looks at the best of international practice and examines what more we can do to support existing and new carers.

Since the launch of the first Challenge, measures to make health and care settings including hospitals and care homes more dementia friendly have taken place. These included making developments in the physical environment, training of health and care staff and delivering improved care and support.

In 2013/14, as part of the ‘Improving the Environment of Care’ programme, £50 million funding was provided to support capital projects in health and social care settings designed to improve the environment of care for people with dementia with £25m each going to health and social care projects. An evaluation of the programme and a building note of best practice in creating dementia friendly environments in both health and social care was published on 25 March 2015. It provides a positive picture of the impact of the capital works on the quality of life of people with dementia. The best practice building note sets out design principles and features for a dementia friendly environment.

The Department of Health supported the Dementia Action Alliance (DAA) in its work to develop a Dementia Friendly Hospitals Charter. This supports hospitals to become more dementia friendly. To continue the encouragement of making hospitals dementia friendly, the Department and NHS England wrote to encourage hospitals to sign up to the Charter in March 2013. It sought to encourage every hospital to commit to becoming dementia friendly with the aim of delivering better outcomes for patients and carers by enabling them to experience high quality care and leave hospital sooner. A further letter that the Department and NHS England wrote in 2015, asked hospitals to consider how they might facilitate requests of some carers of patients with dementia to continue their caring role in hospital outside of normal visiting hours. Since then, we have seen hospitals signing up to the Charter and making arrangements to allow carers to visit outside of normal visiting hours.

Furthermore, Dementia champions, who promote the wellbeing of people with dementia are in place in most hospitals and following the introduction of the Commissioning for Quality and Innovation (CQUIN) goal for dementia, the impact is that health needs of people with dementia are better assessed. To build on this through the implementation of the Challenge on Dementia 2020, we want to see all hospitals and care homes meeting agreed criteria to becoming a dementia friendly health and care setting.

We recognise the importance of making sure that education and training on dementia is high quality and effective and improves the quality of care provided for people with dementia. With the support of Health Education England (HEE), there has been good progress in the education and training of NHS staff about dementia. The result is that 515,967 NHS staff have received Tier 1 (foundation level) training on dementia, more than achieving the aim of 350,000 set out in the Government’s Mandate to HEE. We recognise the importance of making sure that education and training on dementia is high quality and effective and improves the quality of care provided for people with dementia.

Through the 2020 Challenge, we want to see a clear evidence base for what works in training on dementia for health and social care staff, which can be used to develop smarter education and training programmes and all NHS staff having received training on dementia appropriate to their role. By the end of 2018, Tier 1 tools and training opportunities will be made available to all NHS staff.

With regard to social care staff, the Department of Health has worked with Skills for Care and other organisations to provide high quality training on dementia for social care staff. Over 100,000 social care workers have received dementia awareness training.

Through the implementation of the Challenge on Dementia 2020, we want to see newly appointed healthcare assistants and social care support workers, including those providing care and support to people with dementia and their carers, having undergone training as part of the national implementation of the Care Certificate and an expectation that social care providers provide appropriate training to all other relevant staff.

The impact of the delivery of appropriate education, training and support is that it promotes the provision of dignity and compassion in caring for people with dementia and in working in partnership with carers.

Dementia Friendly Communities

A key component of the Dementia Challenge 2012-2015 was the Dementia Friendly Communities workstream. The aim of this workstream was to challenge issues around stigma, misunderstanding and isolation that people with dementia face and to provide support to people with the condition.

Dementia friendly communities are helping to support people with dementia to live more independent and fulfilling lives in their own communities, for longer.

With the establishment of dementia friendly communities programme, there is now a far greater awareness and understanding of dementia. The creation of dementia friendly communities has helped to support people with dementia to live more independent and fulfilling lives in their own communities, for longer.

Since the launch of the 2012-2015 Challenge, over 105 dementia friendly communities across England, including towns, cities and villages, have signed up to Alzheimer’s Society’s foundation-stage recognition process for dementia friendly communities. Becoming dementia friendly is a continual process and these communities have committed to shape their communities around the needs of people with dementia.

Building on the foundation stage recognition process, Alzheimer’s Society worked with the British Standards Institute (BSI) to develop a Publically Available Specification (PAS) for dementia friendly communities. This provides more detailed guidance to communities working to become dementia friendly. Through the implementation of the 2020 Challenge, we want to see over half of people living in areas that have been recognised as Dementia Friendly Communities, according to the guidance. Each area should be working towards the highest level of achievement under these standards, with a clear national recognition process to reward their progress when they achieve this. The recognition process will be supported by a solid national evidence base promoting the benefits of becoming dementia friendly.

A central component of the Dementia Friendly Communities strand is Dementia Friends. Dementia Friends is a social action movement. It aims to give people a greater understanding of dementia and the small things that can be done to make a difference to people living with the condition. There are already over 1 million people in England who have become Dementia Friends. By 2020, the Alzheimer’s Society has committed to deliver an additional three million Dementia Friends.

Over the course of the first Challenge on Dementia and the 2020 Challenge, the impact is that there is a greater awareness and understanding of dementia. The emergence of dementia friendly settings including dementia cafés, social and care settings has enabled the improvement of quality of life for people with dementia through means such as better support.

Building on the Dementia Friendly Communities programme is the Dementia Action Alliance. There are 151 local Dementia Action Alliances (DAAs) in place bringing together organisations and individuals to support people with dementia and their carers. DAA membership includes local authorities, NHS and social care organisations, businesses, voluntary sector organisations and people with dementia and carers.

Members of the Dementia Action Alliance have signed up to a National Dementia Declaration. Created in partnership with people with dementia and their carers, the Declaration explains the huge challenges presented to our society by dementia and some of the outcomes we are seeking to achieve for people with dementia and their carers. Signatories to the Declaration have published their own Action Plans setting out outcomes.[[14]](#footnote-14)

By 2020, we want to see all businesses encouraged and supported to become dementia friendly, with all industry sectors developing Dementia Friendly Charters and working with business leaders to make individual commitments (especially but not exclusively FTSE 500 companies). All employers with formal induction programmes invited to include dementia awareness training within these programmes.

Research

A third component of the Prime Minister’s Challenge 2012-2015 which continues in the 2020 Challenge was research into dementia. This workstream sought and continues to help discover what causes dementia, how to delay its onset and slow the course of the condition. The research sought to know who is at greatest risk of developing dementia, to understand how to reduce this risk and to know how best to care for and support people with dementia and their carers.

Over the course of the Prime Minister’s Challenge 2012-2015, Government spending on dementia research has doubled since 2009/10 from £28.2m to £60.2m in 2013/14 and on track to achieve the target of over £66 million for 2014/15. This was boosted by the Dementia Discovery Fund, of $100 million of which £15 million is public funding. It brings together the combined expertise of government, financial, industry and charity partners, which will finance pre-clinical research to find new drugs to treat dementia.

Since the launch of the first Challenge, initiatives in dementia research arose which included Dementias Platform UK (DPUK), a £53 million public private partnership led by the Medical Research Council. The DPUK’s aims are early detection, improved treatment and ultimately, prevention, of dementias. A key element of DPUK is the UK Biobank. £9.6 million has been provided to expand this study which will ultimately scan the brains of 100,000 participants. £36 million funding was also provided for a National Institute for Health Research (NIHR) translational research collaboration in dementia. Through the collaboration, there is ongoing research into better treatments, care and understanding of the condition. Another initiative is the Join Dementia Research programme launched on 24 February 2015. It enables more people to sign up to take part in research.

Over the course of the 2020 Challenge, we want to see funding for dementia research on track to be doubled by 2025, cures or disease-modifying therapies on track to exist by 2025, their development accelerated by an international framework for dementia research and increased numbers of people with dementia participating in research.

Risk Reduction

Smoking, excessive drinking, high blood pressure, lack of physical activity, depression and diabetes all contribute to a higher risk of an individual getting dementia later in life. The impact of tackling these causes of ill health will not only reduce someone’s risk of dementia, but can also mean they live a longer, healthier life , as these conditions are also major contributors to long term illness and early death.

To allow older persons to have an adequate quality of life, the government supports the Blackfriars Consensus statement, published by PHE and the UK Health Forum. It stated that “the scientific evidence is sufficient to justify action on dementia prevention and risk reduction”. Effective public health policies to tackle the major chronic disease risk factors of smoking, physical inactivity, excess alcohol and poor diet across the population will help reduce the risk of dementia in later life.

PHE has made dementia risk reduction one of its key public health priorities for the next five years with the aim to “transform a generation’s risk of dementia”. PHE’s priority focus is on reducing prevalence and incidence of dementia among 65-74 year olds, so that more people can enjoy a healthy and independent life for longer.

**Question 8**

Attitudes

While attitudes towards and understanding of dementia has improved amongst health and social care staff, many staff still do not recognise the importance of improving their understanding of dementia. For example, some GPs and hospital doctors are not convinced of the value of diagnosing someone with dementia, with the belief that there is little that can be done to help the individual and their carer in the early stages of the disease. The 2020 Challenge recognises that more needs to done therefore to continue to change the understanding, attitudes and behaviours of everyone working in health and social care.

Impaired mental capacity

The impairment in mental capacity caused by dementia can make people with dementia particularly vulnerable to discrimination and infringements of their rights. For example, they may be excluded from discussions about their care because their views and preferences are not seen to be valid or perceived to be a result of their condition, rather than a legitimate preference. When this occurs, the person with dementia may also be less able to object, or to challenge decisions that have been made on their behalf. Under the Mental Capacity Act 2005, a person must be presumed to be able to make their own decisions "unless all practical steps to help him (or her) to make a decision have been taken without success". [[15]](#footnote-15)The 2020 Challenge calls for more to done to continue to change the understanding, attitudes and behaviours of everyone working in health and social care.

Barriers to care

A poll of over a thousand GPs commissioned by the Alzheimer’s Society in 2015 stated that many GPs believe patients do not get enough help, care or provision from health and social care services, are forced to rely on informal carers and face barriers to support due to a lack of cooperation between NHS and social care. Moreover, over a quarter of GPs admit they would be less likely to refer people with suspected dementia for diagnosis if support services were not in place. [[16]](#footnote-16)

In recognising these issues, the Prime Minister’s Challenge on Dementia 2020 set its vision of everyone diagnosed with dementia having meaningful care following their diagnosis, supporting them and those around them, of a reduction in unwarranted variation of post diagnosis support and of better dissemination of best practice and what works, including effectiveness of different types of post diagnosis support. The Department is working closely with health and care stakeholders in implementing the Dementia Challenge to ensure real and sustainable improvements are delivered for people with dementia and their carers.

This builds on ongoing work for example, the Department also supported initiatives including the Dementia Toolkit and Dementia Roadmap, legislated to give carers new rights under the Care Act and will develop a new Carers’ strategy. The Better Care Fund is bringing together local authority and NHS budgets, allowing joined-up services that better fit people’s needs.

Minority groups

People with dementia from specific groups face barriers that prevent them from having appropriate support. These barriers include the lack of research and negative experiences people have encountered.

A report led by Public Health England centred on a literature review that looked into the prevalence of dementia and protected characteristics. These characteristics include Black, Asian and Minority Ethnic (BAME) groups and the Lesbian, Gay, Bisexual and Transgender (LGBT) communities. The review identified that qualitative research was needed to be conducted into the differential access of health services by different groups mediated by different cultural beliefs. This research needed includes the identification of barriers and enablers for those communities.[[17]](#footnote-17)

A report conducted by the All Party Parliamentary Group Service[[18]](#footnote-18) found that people from BAME communities were under-represented in services and faced low levels of awareness of dementia, late diagnosis and lack of access to culturally sensitive services.

A summary report in 2015 conducted by the University of Worcester and the Dementia Engagement and Empowerment Project[[19]](#footnote-19) over LGBT people with dementia highlighted prejudices and heteronormative assumptions from health and care staff and adverse impacts on social, cognitive and communicative functioning from if service provision was not LGBT friendly. The report also highlighted the need to challenge assumptions and homophobia, be actively inclusive of all members and for training and recognition of LGBT people for care home staff.

A roundtable discussion held by the National Care Forum highlighted similar concerns. From the discussion, a written report that would disseminate good practice through case studies based in a range of settings would be produced. This publication would help staff, families and people themselves envisage more appropriate care. A practical ‘toolkit’ for commissioners would also be drafted; raising awareness and supporting them to commission care that supports the specific needs and concerns of older LGBT people.[[20]](#footnote-20)

In recognising these issues, the Prime Minister’s Challenge on Dementia 2020 set its vision for people with dementia having equal access to diagnosis as for other conditions, in every part of the country, and an increase in the numbers of people of Black, Asian and Minority Ethnic origin and other seldom heard groups who receive a diagnosis of dementia, enabled through greater use by health professionals of diagnostic tools that are linguistically or culturally appropriate.

Financial

Financially, dementia costs UK society an estimated £26 billion a year, more than the costs of cancer, heart disease or stroke.

It is estimated that if there was a disease-modifying treatment from 2020 that delayed the onset of Alzheimer’s disease by 5 years, by 2035 there would be 425,000 fewer people with dementia, with accumulated savings from 2020 of around £100 billion.

A study by the Centre for Economic and Business Research estimated that by 2030, dementia will cost companies more than £3 billion, with the numbers of people who will have left employment to care for people with dementia set to rise from 50,000 in 2014 to 83,100 in 2030. Yet if companies increased their employment rate of dementia carers by just 2 per cent over the years to 2030, for example by offering more flexible terms of employment, the retention of these skilled and experienced staff would deliver a saving of £415 million. [[21]](#footnote-21)

Businesses have started to recognise this issue, with one in twelve companies (8 per cent) having made attempts to accommodate the needs of a member of staff with dementia, and more than half (52.1 per cent) considering taking such action in the future.

Through the implementation of the 2020 Challenge, we want to build on this see more employers having carer friendly policies and practice enabling more carers to continue working and caring.

1. Department of Health (2015) Prime Minister’s Challenge on Dementia 2020 [↑](#footnote-ref-1)
2. Department of Health (2015) *Prime Minister’s Challenge on Dementia 2020* <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf> [↑](#footnote-ref-2)
3. The Christmas to Remember (2012) <http://xmas-to-remember.tumblr.com/?utm_campaign=xmas2remember&utm_source=dh&utm_medium=website> [↑](#footnote-ref-3)
4. Department of Health (2014) Mid-year report 2014-15; For the period 1 April to 30 September 2014 [↑](#footnote-ref-4)
5. <https://publichealthmatters.blog.gov.uk/2014/02/17/living-well-with-dementia/> [↑](#footnote-ref-5)
6. Alzheimer’s Society and British Standards Institute (2015); PAS 1365:2015 Code of Practice for the recognition of dementia-friendly communities in England [↑](#footnote-ref-6)
7. Further information can be found here: <http://corporate.marksandspencer.com/blog/stories/dementia-friends> [↑](#footnote-ref-7)
8. Alzheimer’s Society and British Standards Institute (2015); PAS 1365:2015 Code of Practice for the recognition of dementia-friendly communities in England [↑](#footnote-ref-8)
9. Further information can be found here: <http://www.livability.org.uk/church/dementia-friendly-churches/> [↑](#footnote-ref-9)
10. All Party Parliamentary Group on Dementia (2013) *Dementia does not discriminate* [↑](#footnote-ref-10)
11. Alzheimer’s Society (2011) Learning disabilities and dementia: http://www.alzheimers.org.uk/site/scripts/documents\_info.php?documentID=103 [↑](#footnote-ref-11)
12. Alzheimer’s Society (2013) *Supporting lesbian, gay and bisexual people with dementia* [↑](#footnote-ref-12)
13. Alzheimer’s Society (2013) *Supporting lesbian, gay and bisexual people with dementia* [↑](#footnote-ref-13)
14. Further information about the Dementia Action Alliance can be found here: http://www.dementiaaction.org.uk/ [↑](#footnote-ref-14)
15. Alzheimer’s Society (2012) Equality, discrimination and human rights: http://www.alzheimers.org.uk/site/scripts/documents\_info.php?documentID=1674 [↑](#footnote-ref-15)
16. Alzheimer’s Society (2015) *Dementia 2015: Aiming higher to transform lives* [↑](#footnote-ref-16)
17. Public Health England (2015) *Prevalence of dementia in population groups by protected characteristics: a systematic review of the literature* [↑](#footnote-ref-17)
18. All-Party Parliamentary Group on Dementia (2013) *Dementia does not discriminate: The experiences of black, Asian and minority ethnic communities* [↑](#footnote-ref-18)
19. Peel, E. and McDaid, S. (2015) “Over the Rainbow” Lesbian, Gay, Bisexual and Trans People and Dementia Project; Summary Report [↑](#footnote-ref-19)
20. The National Care Forum (2015); *The Dementia Challenge for LGBT Communities: a paper based on a roundtable discussion, 2 December 2014*: link: http://www.nationalcareforum.org.uk/documentLibraryDownload.asp?documentID=772 [↑](#footnote-ref-20)
21. Centre for Economic and Business Research (May 2014); *Cost of dementia to business* [↑](#footnote-ref-21)