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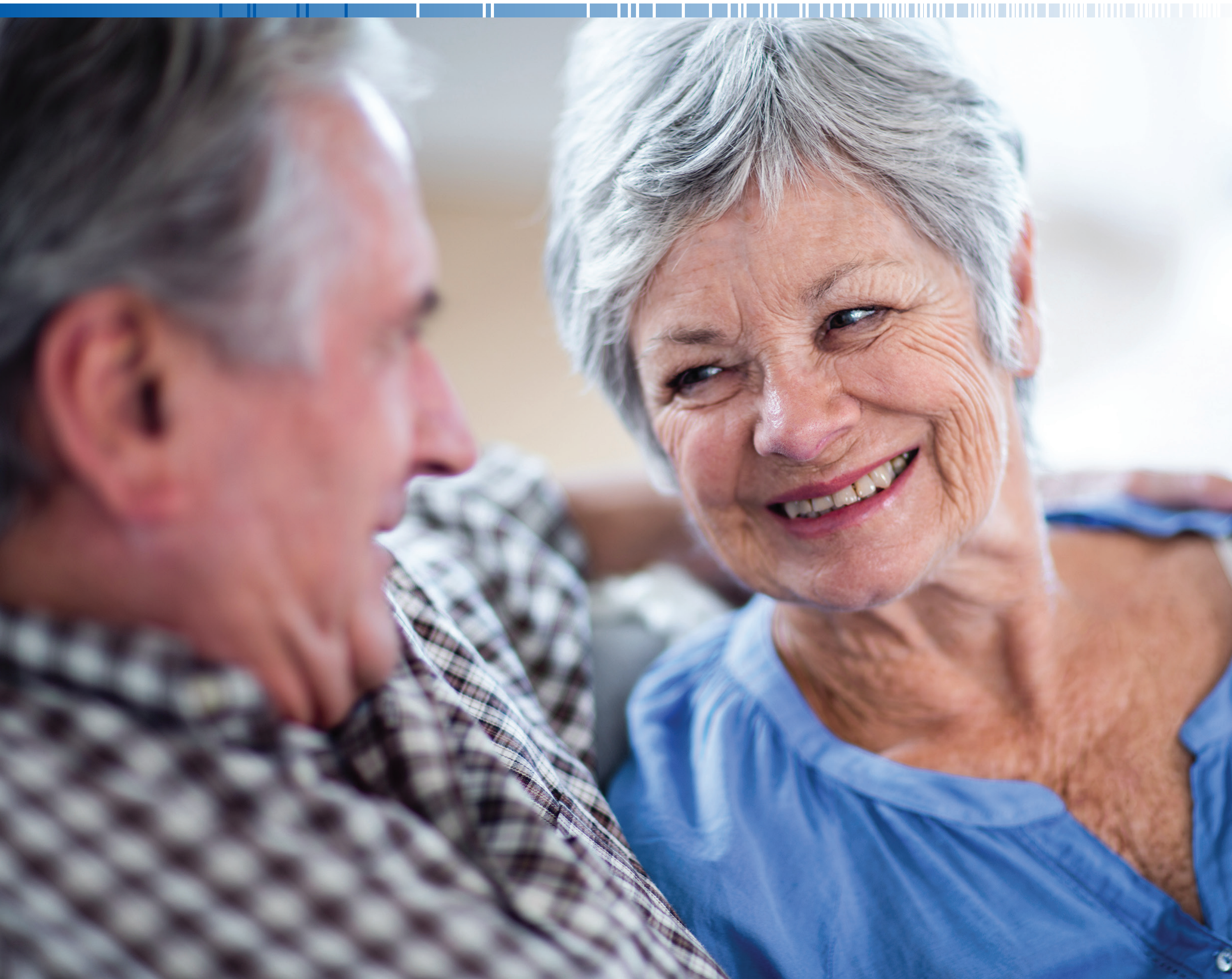
Roche

Creating a fairer future for people living with Alzheimer's disease



Alzheimer's disease and dementia have a devastating impact on people and their families. In the UK in 2019, there were 850,000 people living with Alzheimer's disease and dementia – every one of whom will need different levels of dedicated care and support.[1]

Foreword from the Co-Chairs

The nature of the health and social care system in the UK means that the services that strive to provide this care are divided between and within the NHS and social care systems. Alongside formal services, a significant portion of care for people living with Alzheimer's disease and dementia is provided by 'informal' carers who too often pick up the burden of care when their loved ones fall through the cracks in formal systems.

Services are facing unimaginable pressures following COVID-19 and with demographic changes all but guaranteeing demand will further increase over the coming years, investment in the core health and social care services that diagnose, treat and care for people living with Alzheimer's disease and dementia is essential.

Treatment (with medicines) is currently a small part of the conversation for Alzheimer's disease. The available treatments for Alzheimer's disease in the UK only temporarily treat the symptoms, they do not modify the disease by halting or slowing its progression. However, recent scientific advances in the treatment of Alzheimer's disease mean that we can begin to look forward to a time when the disease can be delayed, slowed or prevented. These treatments – disease modifying therapies (DMTs) – are now on the horizon for patients in the UK and Europe, with the first DMT recently approved by the US FDA.[2]

DMTs are most likely to be effective for patients at the earliest stages of the disease pathway before Alzheimer's disease has caused the brain damage associated with symptoms like dementia. However, the current healthcare system in the UK is not designed to find, detect, diagnose or care for these patients with Alzheimer's disease in the very early stages. Patients are currently almost always diagnosed relatively late, once Alzheimer's disease is causing the memory loss and confusion associated with moderate dementia. For DMTs to reach the patients they could benefit we will need to identify and precisely diagnose patients much earlier.

There are therefore two concurrent challenges facing Alzheimer's disease and dementia services: urgently funding and supporting health and care services for patients with moderate and late-stage Alzheimer's disease and dementia; and transforming the way the health service identifies and diagnoses people living with the earliest stages of the disease to ensure the potential of DMTs can be realised.

The first of these challenges is well known in the community and Government – even if Government action is still sorely lacking – but the second is less recognised and poorly understood. To begin to remedy this, Roche convened a workshop with expert clinicians, carers and patient group representatives to discuss the challenges in the current Alzheimer's disease pathway, consider how the introduction of DMTs might create hurdles, and ideate solutions.

This report captures the conclusions from that discussion, both setting out a vision for the future of Alzheimer's disease services and identifying key steps that should be taken as soon as possible. Roche has prepared the report and retains editorial control, all participants have had the opportunity to review in draft form. As co-chairs, we'd like to express our gratitude for everyone who attended and contributed to the roundtable and this report.

There are seismic challenges to overcome, particularly at a time when health and care services are still struggling to recover from COVID-19. We know the ideas and recommendations in this report can only be the start of a conversation that needs to include the whole Alzheimer's disease and dementia community. We hope the report acts as a catalyst in that process and we look forward to engaging with the whole Alzheimer's disease community to move towards a system capable of providing the best possible care, support and treatment for patients, now and in the future.

Professor Ramin Nilforooshan
Consultant Psychiatrist

Saba Zaidi
Roche

Definitions

Alzheimer's disease and dementia

Alzheimer's disease affects the brain through a build-up of abnormal proteins called 'plaques' and 'tangles', which disrupt nerve cell functions and, over time, cause nerve cells to die.[3] The build-up of these proteins begins up to 20 years before symptoms emerge.[4] Alzheimer's disease is the most common cause of dementia.[5] Dementia describes a set of symptoms that impact on function (activities of daily living), and may include memory loss and difficulties with thinking, problem-solving or language. Alzheimer's disease is progressive, which means the symptoms gradually get worse over time, with the clinical presentation and severity varying from person to person.[3]

Early detection of Alzheimer's disease

The early detection of Alzheimer's disease is the identification of the physiological or pathological changes associated with Alzheimer's disease, which do not rely on changes in any clinical measures of cognitive function. The presence of underlying pathological changes is measured by the relevant "biomarkers", a distinctive biological indicator that may indicate the presence of the disease.[6] These biomarkers can be detected using methods such as analysis of cerebrospinal fluid (CSF), positron emission tomography (PET) imaging, and potentially in the future, use of a blood test. The presence of biomarkers alone – without the associated clinical changes to cognitive function – can only detect those potentially at risk of developing Alzheimer's disease, it cannot be used to diagnose the condition.[7]

Diagnosis of Alzheimer's disease

The diagnosis of Alzheimer's disease refers to a clinical diagnosis once cognitive symptoms have appeared.[9] Currently within the UK, this diagnosis is more than often based on a patient's clinical history (functional decline) and a cognitive assessment alone. However, taking an approach which looks at the patient's underlying biology as well will increase the accuracy of this diagnosis of Alzheimer's disease.[8] This diagnosis should be as timely as possible following the appearance of symptoms, to allow the patient and their loved ones to access the treatment and support that they need. In the future, rapid diagnosis will be crucial to accessing DMTs.

Disease modifying therapies

A "disease modifying therapy" or a disease modifying treatment is, in contrast to a symptomatic treatment, a therapy that will modify the expected course of the disease by slowing or halting the progression. A recent FDA approval has meant that a disease modifying therapy for Alzheimer's disease is currently available to patients in the US, but not in the UK or Europe.[2] A great deal of research is underway to make more treatments available. Recent evidence has shown that a treatment would likely deliver more impact in the early stages of Alzheimer's disease and would therefore rely on achieving early detection and then diagnosis.[9]

Contents

Roche is a pioneer in pharmaceuticals and diagnostics, focused on advancing science to improve people's lives. Roche is committed to working to improve the diagnosis, treatment and care for people living with Alzheimer's disease and dementia in the UK and convened the workshop to continue these conversations. Roche funded the workshop and the development of this report.

Roche initiated, developed and funded the workshop that informed this report which has been written by Incisive Health. Participants were selected by Roche with the help of the co-chair and have all had the opportunity to review this report.

Introduction

Alzheimer's disease and dementia place a terrible burden on the people living with the conditions, their friends, family and carers, as well as NHS, social care services and wider society.

As of winter 2021, there are currently no disease modifying therapies (DMTs) available to patients in the UK that can delay, pause or prevent the onset and progression of Alzheimer's disease – the most common cause of dementia. However, with the recent approval of a DMT in the US, these treatments are now on the horizon for patients in the UK and Europe.

- This report is the result of a workshop with an expert group of Alzheimer's disease stakeholders that was convened by Roche to discuss the challenges in the current Alzheimer's disease pathway, consider how the introduction of DMTs might create issues, and ideate solutions.
- The focus on a future where DMTs are available was deliberate, allowing participants to discuss a possible future scenario where effective treatments that slow disease progression are available to patients who present with cognitive impairment alongside confirmed Alzheimer's disease pathology (via a biomarker test).
- Discussion at the workshop was dynamic and wide ranging, and all participants recognised that the ideas generated in the room can only be the start of a conversation with a wider group of stakeholders. These will need to include epidemiologists, public health experts, data scientists, social care professionals, technology companies and primary care (both GPs and other community health care professionals), as well as the wider community of neurologists, geriatricians, psychiatrists, specialist nurses, pharmacists, carers, patient group representatives and policymakers who were present at the workshop.
- Everyone at the workshop wants to express their gratitude and admiration for the clinical and non-clinical staff across the country, in health and social care, as well as the thousands of unpaid carers, who strive to deliver the best possible care for people with Alzheimer's disease and dementia – even in the face of systems and structures that too often make their roles more difficult.
- We hope the recommendations represent both a realistic appraisal of the work needed to stabilise and improve the current system for diagnosing and caring for patients with dementia, and a vision for the future for how services could change to deliver a DMT.

The dementia clinical pathway

Through this report, we structure our discussion from the perspective of the person and patient as their symptoms develop, from being fully healthy to having severe dementia. Alzheimer's disease will be the pathological driver in around two-thirds of patients who develop dementia symptoms,[10] but it is unclear how many of the people who are pre-symptomatic with biomarkers present, or with mild cognitive impairment, will go on to develop dementia caused by Alzheimer's disease.

This pathway has been simplified, but the basic progressions and steps are:[11,12]

Healthy

People without cognitive impairment and with none of the underlying pathology associated with the development of Alzheimer's disease.

Pre-symptomatic, but with biomarkers present

People without cognitive impairment but with evidence of the underlying pathology that could indicate the likely development of Alzheimer's disease. This group of people will be cognitively unimpaired, with the biomarkers only detectable with a biological test.

Mild cognitive impairment (MCI)

People with detectable cognitive impairment that is greater than that associated with normal ageing, but not as marked as someone with early-stage dementia.[11] Unlike someone with dementia, the cognitive impairment associated with MCI is unlikely to get in the way of the person's everyday life.[13] Not everyone with MCI will go on to develop dementia.[13] If the MCI is linked to the development of Alzheimer's disease, the pathology associated with Alzheimer's disease will also be present.

Early-stage (mild) dementia

People with cognitive impairment associated with dementia to an extent that it is impacting on their daily lives. Dementia can have a number of different causes, but if Alzheimer's disease is causing the dementia, then the underlying presence of the biomarkers associated with Alzheimer's disease will also be able to be detected through testing.

Moderate dementia

The symptoms associated with dementia will worsen and the person will likely need additional support with everyday tasks from a carer or family member. If Alzheimer's disease is causing the dementia, then the underlying presence of the biomarkers associated with Alzheimer's disease will also be able to be detected through testing.

Severe dementia

The symptoms associated with dementia will be markedly affecting the person's daily life and they will eventually need full time intensive care and support. This is most often provided in a care home but can also be delivered at home. If Alzheimer's disease is causing the dementia, then the underlying presence of the biomarkers associated with Alzheimer's disease will also be able to be detected through testing.

Summary of recommendations

The group suggested key recommendations that would improve the current system across the patient pathway, but the greatest focus was paid to the earliest stages of detection, diagnosis and care.

Recommendations have therefore been divided in to:

Changes needed to stabilise and support the current system in the near term

Key recommendations include:

- Developing a national public health strategy for dementia prevention, drawing on the 12 modifiable risk factors identified by the Lancet Commission as accounting for 40% of cases of dementia worldwide[14]
- Improving the population health messaging on brain health, including ensuring that NHS Health Checks are used to inform 40- to 64-year-olds about the roles of smoking cessation, treating high blood pressure, moderating alcohol consumption, social interaction, physical exercise, diet and treating hearing loss in maintaining brain health
- Investing in the diagnostic infrastructure for Alzheimer's disease – particularly in cerebrospinal fluid (CSF) testing capacity
- Ensuring that patients diagnosed with MCI are offered further investigations into the underlying cause, for example CSF testing, if they would like it. This will require significant training for primary care workers to better understand the benefits for patients of diagnosis via CSF testing
- Significantly investing in NHS Continuing Care to ensure that patients with a diagnosis of Alzheimer's disease and/or dementia (who are entitled to it) have access to NHS funded care support
- Making every possible effort to support social care (both domiciliary and care homes) to ensure that people living with Alzheimer's disease and dementia receive the high-quality care they need
- Targeting resources to increase the dementia workforce – including both NHS and social care workers

All of the recommendations are explored in the remainder of this report in greater detail.

System wide changes needed to prepare for disease modifying therapies (DMTs) in the future

Key recommendations include:

- Digital tools that that have greater sensitivity and specificity than currently available cognitive screening instruments and eliminate inter-observer variation might have a role in facilitating earlier diagnosis including by monitoring changes in cognition over time
- People presenting to primary care with cognitive impairment should be fully assessed to rule out non-dementia causes of cognitive impairment. Cognitive impairment should not be ruled in or out on the basis of simple cognitive tests with arbitrary cut-offs
- If these causes are ruled out, they should then be referred to a specialist clinic (a Cognitive Service) to understand the pathology causing their cognitive impairment
- These Cognitive Services should have access to advice from a Cognitive multi-disciplinary team (MDT) of clinicians, including a neurologist, geriatrician, psychiatrist, psychologist and specialist nurse as well as other relevant professionals. If diagnosed with Alzheimer's disease, the MDT would ultimately make the decision on whether prescribing a potential future DMT was appropriate and ensure the system for monitoring and management of the patient was in place
- Dedicated counselling support should be available for patients and carers who, for whatever reason, are not eligible for any potential future DMTs
- Social care and welfare support should be integrated into patient and carer communications following diagnosis to ensure that there is one point of contact for patients to advise them on relevant services
- People presenting to primary care with symptoms of moderate or severe dementia should not be excluded from referral to the Cognitive Service for the underlying pathology of their dementia to be investigated where appropriate, and to ensure that necessary support is in place

Background to Alzheimer's disease and dementia in the UK

Alzheimer's disease and dementia are the leading cause of death in the UK.[15] In 2019, there were over 850,000 people living with dementia and Alzheimer's disease in the UK. This represents 1 in every 14 of the population aged 65 years and over.[16]

Dementia can also affect younger people. There are more than 42,000 people in the UK under 65 years old with dementia.[17]

As the population ages in the coming decades, the number of people living with dementia will continue to increase. At the current rate of prevalence, by 2040, there will be over 1.5 million people with dementia in the UK.[16]

More than half of the UK public (52%) know someone who has been diagnosed with a form of dementia. Typically, this is a family member such as a grandparent or parent (26%),[18] with their relations then becoming unpaid carers for their loved ones.

Diagnosis

- During COVID-19, the diagnosis rate for dementia in those aged over 65 has dropped from 67.6% in February 2020[19] to 61.9% in May 2021.[20] From this, we can estimate that nearly 270,000 people living with dementia over the age of 65 do not have a diagnosis[20]
- Confirming that someone with clinical symptoms of Alzheimer's disease has the pathological features of the disease in their brain requires specialist testing – whether through a PET scan or spinal fluid – to identify the presence of the abnormal proteins associated with the disease[7]
- In the UK, these specialist tests are only recommended by NICE for some patients in limited circumstances[21] and, before the pandemic, only 2% of patients who attended a memory assessment service were referred for one of these specialist investigations.[22] This means that the majority of patients with Alzheimer's disease are diagnosed on clinical grounds without biomarker confirmation of the underlying cause of their cognitive impairment.

Care

- Formal Alzheimer's disease and dementia services have faced funding and capacity challenges long before COVID-19, but these have only worsened during the pandemic. Across the NHS and social care, the workforce crisis has intensified during the pandemic and there are serious concerns going into the winter of 2021 that already overstretched services will struggle to cope[23]
- There are estimated to be over 670,000 people in the UK acting as primary, unpaid carers for people living with dementia. Without this unpaid care, it is estimated that the Government would need to spend an additional £11 billion on dementia care[24]
- Caregivers can feel a sense of relief once their loved one has been given a diagnosis by a memory service but will be faced with long-lasting challenges as the person continues to deteriorate.

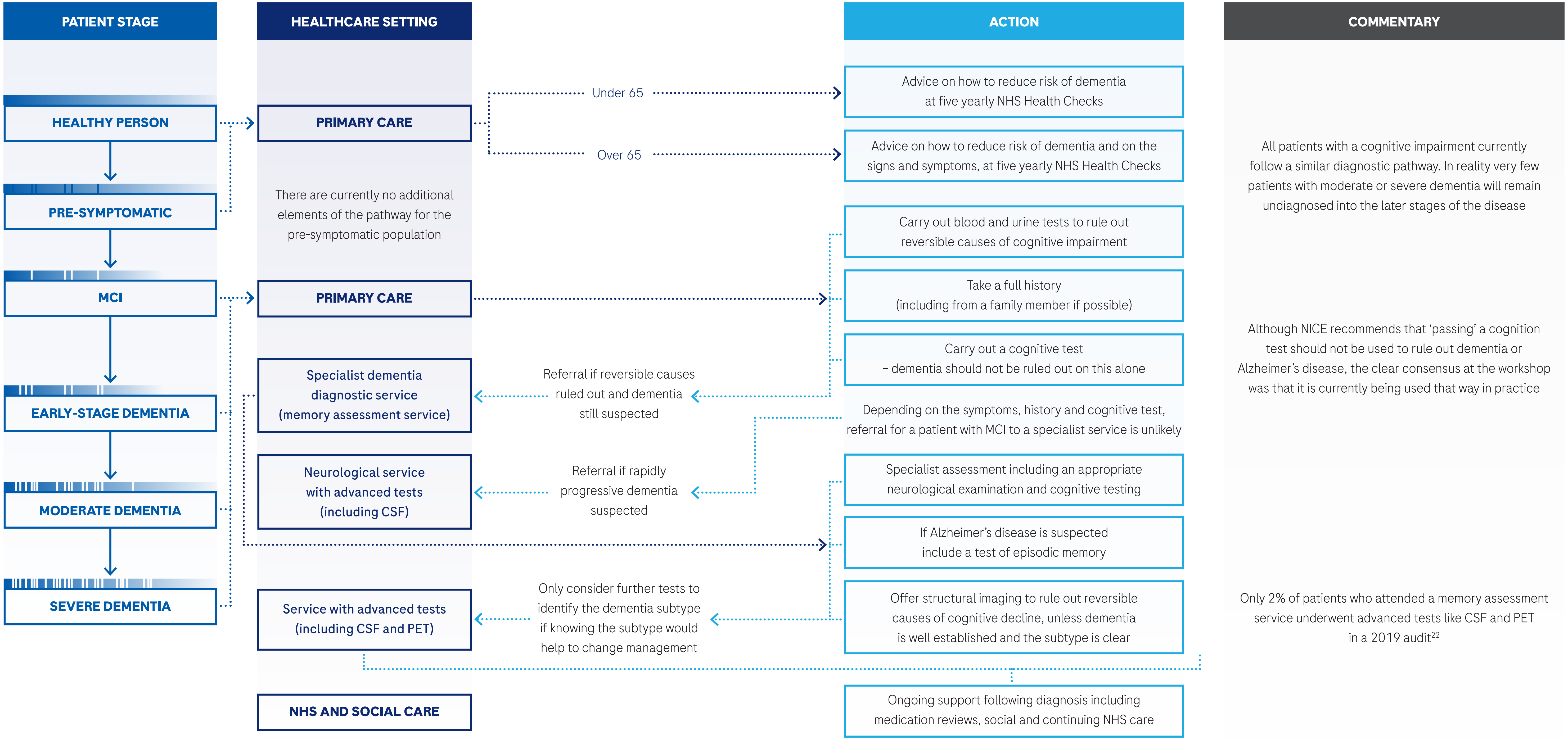
Financial burden

- Alzheimer's disease and dementia cost over £34 billion per annum across the UK. 45% of these costs are accounted for by social care, 40% by informal care, and the remaining 14% from health care[25]
- The cost of Alzheimer's disease will grow significantly in the coming decades as the population ages.[26] By 2040 the costs could rise to over £80 billion.[25]

The current pathway for dementia

The current pathway for patients with dementia is complex and varies across the country depending on the approach of local services.

The current diagnostic pathway, from the patient perspective, is set out below. The pathway incorporates guidance set out in relevant NICE guidelines and quality standards as well as the lived experience reported at the workshop.[21] NICE do not have published guidelines for MCI.



PATIENT STAGE

HEALTHY PERSON

PRE-SYMPTOMATIC

MCI

EARLY-STAGE DEMENTIA

MODERATE DEMENTIA

SEVERE DEMENTIA

HEALTHCARE SETTING

PRIMARY CARE

There are currently no additional elements of the pathway for the pre-symptomatic population

PRIMARY CARE

Specialist dementia diagnostic service (memory assessment service)

Neurological service with advanced tests (including CSF)

Service with advanced tests (including CSF and PET)

NHS AND SOCIAL CARE

Under 65

Over 65

Referral if reversible causes ruled out and dementia still suspected

Referral if rapidly progressive dementia suspected

Only consider further tests to identify the dementia subtype if knowing the subtype would help to change management

ACTION

Advice on how to reduce risk of dementia at five yearly NHS Health Checks

Advice on how to reduce risk of dementia and on the signs and symptoms, at five yearly NHS Health Checks

Carry out blood and urine tests to rule out reversible causes of cognitive impairment

Take a full history (including from a family member if possible)

Carry out a cognitive test – dementia should not be ruled out on this alone

Depending on the symptoms, history and cognitive test, referral for a patient with MCI to a specialist service is unlikely

Specialist assessment including an appropriate neurological examination and cognitive testing

If Alzheimer's disease is suspected include a test of episodic memory

Offer structural imaging to rule out reversible causes of cognitive decline, unless dementia is well established and the subtype is clear

Ongoing support following diagnosis including medication reviews, social and continuing NHS care

COMMENTARY

All patients with a cognitive impairment currently follow a similar diagnostic pathway. In reality very few patients with moderate or severe dementia will remain undiagnosed into the later stages of the disease

Although NICE recommends that 'passing' a cognition test should not be used to rule out dementia or Alzheimer's disease, the clear consensus at the workshop was that it is currently being used that way in practice

Only 2% of patients who attended a memory assessment service underwent advanced tests like CSF and PET in a 2019 audit[22]

The challenges in the current system

Using the same clinical pathway, we have highlighted the current challenges throughout the system. Challenges are presented from the perspective of the patient, but commentary on wider issues impacting services and society has also been included.

The challenges across the pathway are severe and will only worsen with demographic changes. This is before we consider the additional capacity implications for some elements of the pathway from the introduction of a DMT.

PATIENT STAGE	HEALTHCARE SETTING	KEY CHALLENGES	COMMENTARY
HEALTHY PERSON	PUBLIC HEALTH	The national public health system has competing priorities post-COVID-19 and is undergoing a major restructure. Communicating public health messaging on cancer has been prioritised, new capacity will be needed for dementia specific messaging with the scale and reach to meaningful change public behaviour	
PRE-SYMPTOMATIC	PRIMARY CARE	Capacity challenges in primary care makes protecting time for Health Check conversations, particularly on lower priority issues such as dementia difficult The current system is not designed to screen for or detect patients before they develop symptoms. Overcoming capacity challenges, particularly in primary care, will be key to doing so in the future	The UK National Screening Committee does not currently recommend population screening for dementia.[27] In addition to the practical and capacity challenges, there would currently be ethical concerns with diagnosing pre- symptomatic people with Alzheimer's disease. Many of these will be answered once a DMT is available
MCI	PRIMARY CARE	MCI is a poorly defined term and different memory services define and diagnose it in different ways	Changing the diagnostic pathway to achieve a more consistent approach to MCI diagnosis will require significant additional capacity because more advanced testing will require additional resources to the cognitive screening tests currently used in practice
EARLY-STAGE DEMENTIA	Specialist dementia diagnostic service (memory assessment service)	Some cases of MCI might not be diagnosed because the cognitive screening instruments used both in primary care and in memory assessment services are relatively insensitive, particularly in people with high pre-morbid cognitive function	
MODERATE DEMENTIA	PRIMARY CARE	There is a lack of structured information on wider implications of a diagnosis of MCI or early-stage dementia available from one point of contact for driving, housing and welfare, as well as on care needs	
SEVERE DEMENTIA	NHS AND SOCIAL CARE	NHS and social care services for people with dementia and Alzheimer's disease consistently struggle to provide high quality care, due to a lack of resources	Whilst this report focuses on the earlier stages of the pathway, we recognise that improving the care available to people with moderate and severe dementia is the biggest change now that could improve the lives of the most people with dementia

Short term changes to improve the current system

Short term changes are desperately needed to stabilise the current system of diagnosis and care for people living with Alzheimer's disease and dementia.

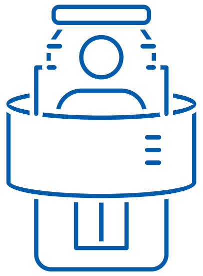
Whilst we are working towards an ideal system that could support the availability of a DMT, there are steps that can be taken in the short term to improve the system both before and after dementia diagnosis.

Healthy and pre-symptomatic but with biomarkers present

- The 2020 Lancet Commission identified 12 modifiable risk factors which account for 40% of dementia worldwide. These are less education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, low social contact, excessive alcohol consumption, traumatic brain injury and air pollution. The UK government and devolved administrations should produce a comprehensive public health strategy to prevent dementia based on these findings
- Brain health prevention messaging should be targeted at the general population to improve awareness of the risk factors of developing Alzheimer's disease and dementia, and the fact that lifestyle changes that can help reduce a person's risk. This campaign can learn from the *"what's good for your heart is good for you head"* Alzheimer's Research UK campaigns, as well as Public Health England campaigns on cancer and dementia
- During the NHS Health Check, GPs should inform 40- to 64-year-olds about the roles of smoking cessation, treating high blood pressure, moderating alcohol consumption, social interaction, physical exercise, and diet in maintaining brain health. They should advise people to look out for the early signs of hearing loss and provide information on how to access audiology services
- NICE should consider producing a clinical guideline for MCI so that a consistent approach to diagnosis, intervention and follow-up can be achieved across the NHS

Mild cognitive impairment (MCI)

- The UK should invest in increasing capacity for, and clinical understanding of, cerebrospinal fluid (CSF) testing to ensure that patients in all parts of the country are able to access biomarker testing when referred by a specialist
- The Government, NHS and Alzheimer's disease community should continue supporting research to establish the evidence base for digital biomarkers – e.g., apps and wearables – for detecting early signs of cognitive change
- A patient diagnosed with MCI should be given information and counselling on the likelihood of them developing Alzheimer's disease or another dementia-causing disease. They should also be offered further investigations into the underlying cause, for example CSF testing, if clinically appropriate. Other information should include the role of optimising mental health (such as treating co-morbid depression or anxiety), vascular risk factor management, treating hearing loss, moderating alcohol consumption, maintaining social networks and use of memory aids in mitigating the impact of MCI whatever the underlying cause
- NICE should consider producing a clinical guideline for MCI so that a consistent approach to diagnosis, intervention and follow-up can be achieved across the NHS



Early-stage, moderate and severe dementia

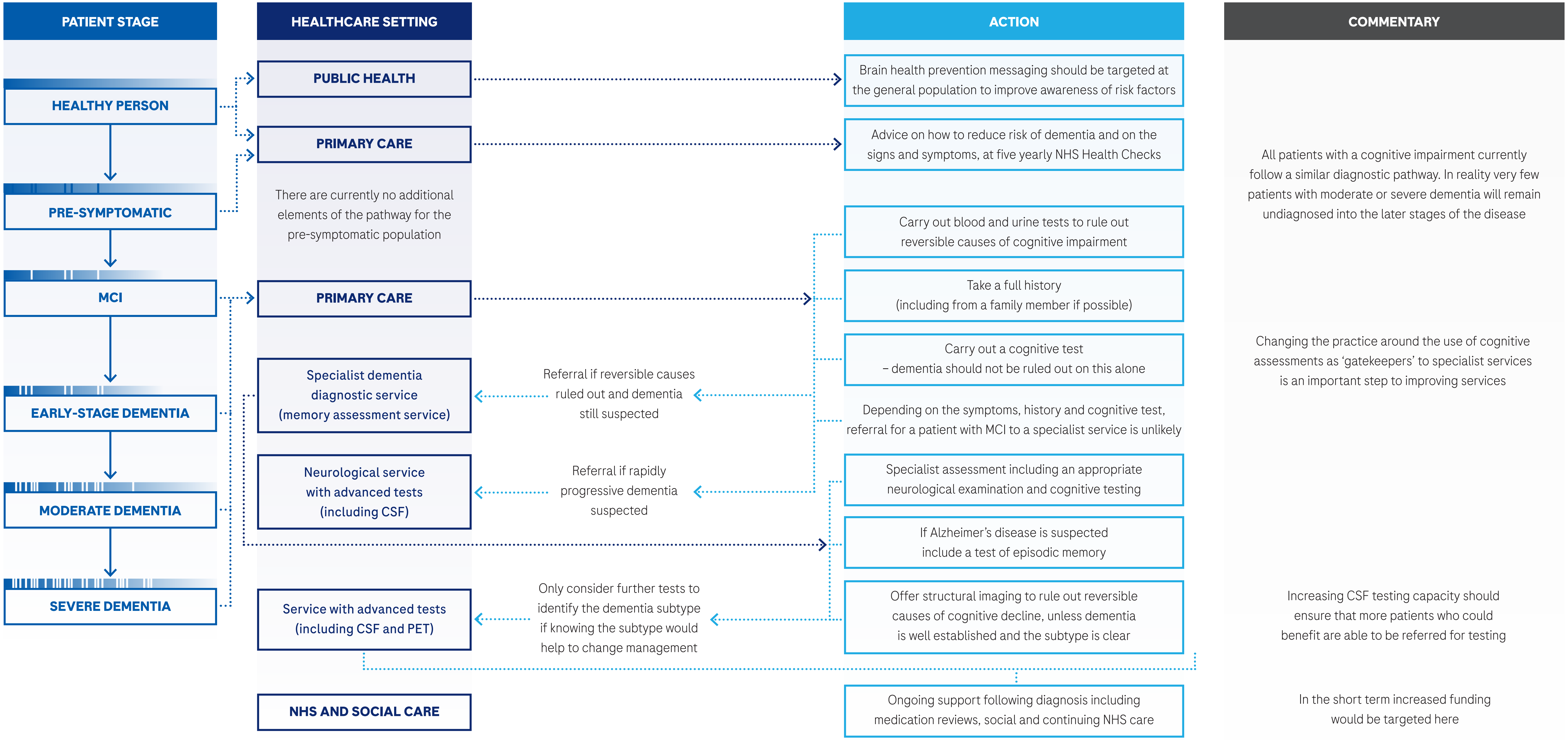
- The UK should invest in NHS Continuing Care to ensure that patients with a diagnosis of Alzheimer's disease and/or dementia (who are entitled to it) have access to NHS funded care support
- Every possible effort should be made to support social care (both domiciliary and care homes) to ensure that people living with Alzheimer's disease and dementia are able to receive care
- The UK should target resources to increase the dementia workforce – including both NHS and social care workers

An illustration of how this pathway would differ from the current situation is set out overleaf.

Short term changes
to improve the current system

The illustration below shows how the the current pathway would differ with the short term changes applied.

The key changes focus on the very beginning and end of the pathway, with the aim of increasing available capacity rather than adding new burdens.



PATIENT STAGE

HEALTHY PERSON

PRE-SYMPTOMATIC

MCI

EARLY-STAGE DEMENTIA

MODERATE DEMENTIA

SEVERE DEMENTIA

HEALTHCARE SETTING

PUBLIC HEALTH

PRIMARY CARE

There are currently no additional elements of the pathway for the pre-symptomatic population

PRIMARY CARE

Specialist dementia diagnostic service (memory assessment service)

Neurological service with advanced tests (including CSF)

Service with advanced tests (including CSF and PET)

NHS AND SOCIAL CARE

Referral if reversible causes ruled out and dementia still suspected

Referral if rapidly progressive dementia suspected

Only consider further tests to identify the dementia subtype if knowing the subtype would help to change management

ACTION

Brain health prevention messaging should be targeted at the general population to improve awareness of risk factors

Advice on how to reduce risk of dementia and on the signs and symptoms, at five yearly NHS Health Checks

Carry out blood and urine tests to rule out reversible causes of cognitive impairment

Take a full history (including from a family member if possible)

Carry out a cognitive test – dementia should not be ruled out on this alone

Depending on the symptoms, history and cognitive test, referral for a patient with MCI to a specialist service is unlikely

Specialist assessment including an appropriate neurological examination and cognitive testing

If Alzheimer's disease is suspected include a test of episodic memory

Offer structural imaging to rule out reversible causes of cognitive decline, unless dementia is well established and the subtype is clear

Ongoing support following diagnosis including medication reviews, social and continuing NHS care

COMMENTARY

All patients with a cognitive impairment currently follow a similar diagnostic pathway. In reality very few patients with moderate or severe dementia will remain undiagnosed into the later stages of the disease

Changing the practice around the use of cognitive assessments as 'gatekeepers' to specialist services is an important step to improving services

Increasing CSF testing capacity should ensure that more patients who could benefit are able to be referred for testing

In the short term increased funding would be targeted here

The ideal future

Should DMTs become available in the future, an ideal pathway can build on the short-term changes suggested above to deliver world leading diagnosis, treatment and care for people living with Alzheimer's disease and dementia.

There may be scope for adopting parts of this pathway in the absence of DMTs, to ensure that people with MCI who do not show memory related symptoms have access to specialist care.

Any service should be underpinned by key principles for the people using them:

Seamless

So patients and their carers aren't obligated to navigate systems for themselves (the fact that multiple charities run trainings for carers and patients on how to navigate the system now demonstrates the challenge).

Patient and carer centric

Putting their needs at the heart of the system, rather than imposing on them.

Co-ordinated

Ensuring that there is one point of contact who can clearly communicate all the information they need from different sources across health, social care and welfare.

The pathway below is based on these principles and the wider discussion at the workshop. We recognise that this pathway is only a 'starter for ten' and we welcome feedback from the wider community on the approach suggested. Given that the key changes for DMTs are concentrated on the MCI and early-stage dementia points of the pathway, the diagram focuses there.

Key points of the ideal pathway include:

Healthy and pre-symptomatic but with biomarkers present

- Digital tools that that have greater sensitivity and specificity than currently available cognitive screening instruments might have a role in facilitating earlier diagnosis
- People working in primary care should be given the tools and training to interpret and advise patients on the data produced by these digital tools once they are approved

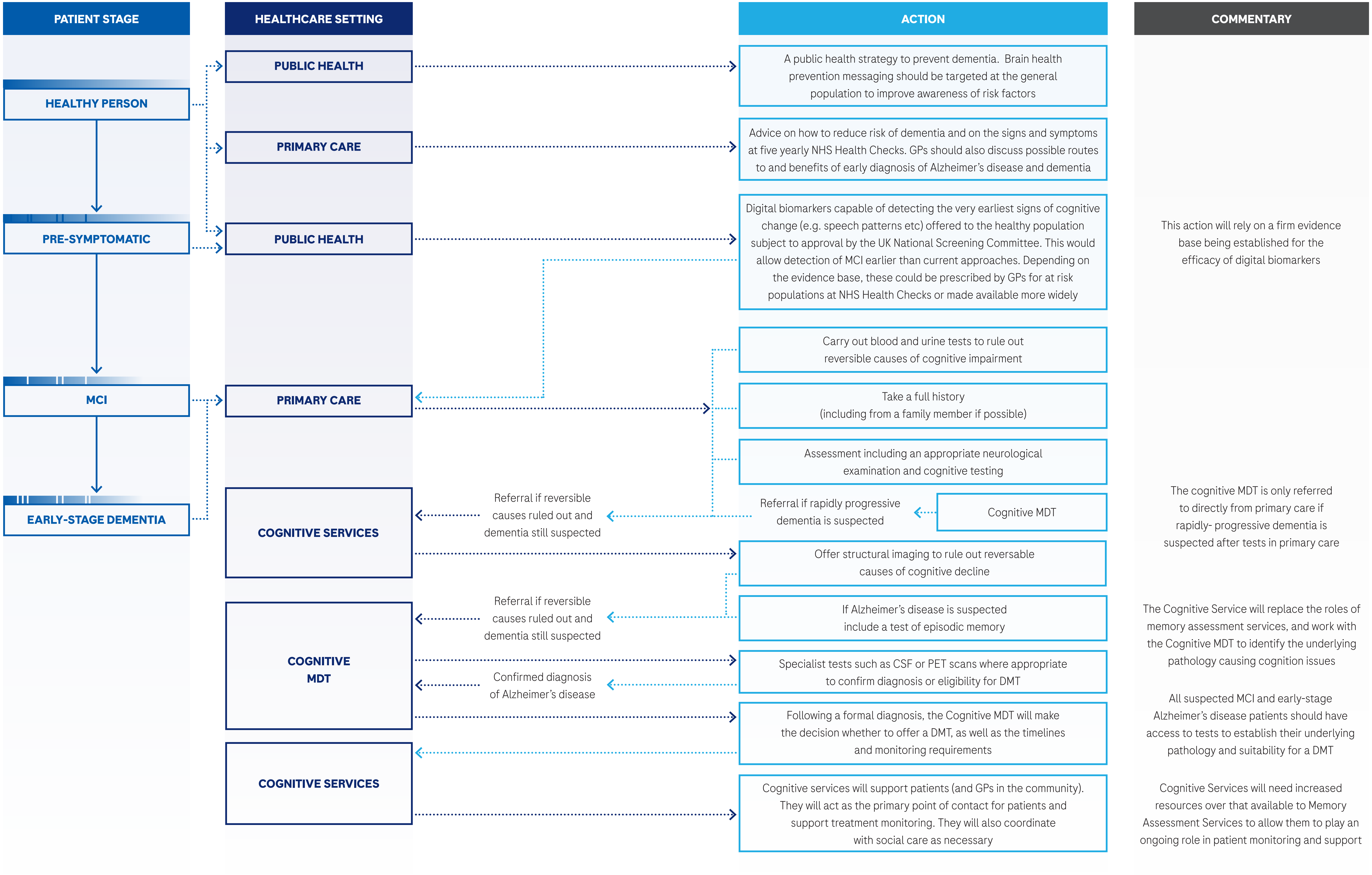
Mild cognitive impairment and early-stage (mild) dementia

- People presenting to primary care with cognitive impairment should be fully assessed to rule out non-dementia causes. Where appropriate, this assessment should include relevant cognitive tests. Assessments should be carried out by the appropriate clinicians, including specially trained nurses and other primary care staff
- GP education on dementia should include information on the diagnostic pathway including history taking, cognitive assessment and investigations such as imaging and biomarker tests to ensure GPs are able to have informed conversations with their patients prior to referral
- They should then be referred to a specialist clinic (a Cognitive Service) to understand the pathology causing their cognitive impairment. Digital tools and blood-based biomarkers are likely to support this referral pathway in the future
- Cognitive impairment should not be ruled in or out on the basis of simple cognitive tests with arbitrary cut offs
- These Cognitive Services should have access to advice from the Cognitive MDT. If diagnosed with Alzheimer's disease, the MDT would ultimately make the decision on whether prescribing a DMT was appropriate and ensure the system for monitoring and management of the patient was in place
- Monitoring and management of patients should be coordinated by Cognitive Services, with integrated support provided by primary care and specialist nurses
- Dedicated counselling support should be available for patients and carers who, for whatever reason, are not eligible for the DMT. This is likely to include all patients with non-Alzheimer's disease dementia (e.g. Vascular Dementia, Dementia with Lewy Bodies, Frontotemporal Dementia, etc) as well as patients not diagnosed until the later stages, which are likely to fall outside of the potential prescribing label for these DMTs
- Social care and welfare support should be integrated into patient and carer communications following diagnosis to ensure that there is one point of contact for patients to advise them on relevant services. This role could be played by a non-clinical "dementia pathway coordinator"

Moderate and severe dementia

- People presenting to primary care with the symptoms of moderate or severe dementia should be referred to the Cognitive Service and have the underlying pathology of their dementia investigated where appropriate
- Following consideration by the Cognitive MDT, if they are unable to access a DMT, other treatment options as well as counselling and welfare support should be started

An illustration of the recommendations for the ideal future pathway is set out overleaf.



PATIENT STAGE

HEALTHY PERSON

PRE-SYMPTOMATIC

MCI

EARLY-STAGE DEMENTIA

HEALTHCARE SETTING

PUBLIC HEALTH

PRIMARY CARE

PUBLIC HEALTH

PRIMARY CARE

COGNITIVE SERVICES

COGNITIVE MDT

COGNITIVE SERVICES

ACTION

A public health strategy to prevent dementia. Brain health prevention messaging should be targeted at the general population to improve awareness of risk factors

Advice on how to reduce risk of dementia and on the signs and symptoms at five yearly NHS Health Checks. GPs should also discuss possible routes to and benefits of early diagnosis of Alzheimer's disease and dementia

Digital biomarkers capable of detecting the very earliest signs of cognitive change (e.g. speech patterns etc) offered to the healthy population subject to approval by the UK National Screening Committee. This would allow detection of MCI earlier than current approaches. Depending on the evidence base, these could be prescribed by GPs for at risk populations at NHS Health Checks or made available more widely

Carry out blood and urine tests to rule out reversible causes of cognitive impairment

Take a full history (including from a family member if possible)

Assessment including an appropriate neurological examination and cognitive testing

Referral if rapidly progressive dementia is suspected

Cognitive MDT

Referral if reversible causes ruled out and dementia still suspected

Offer structural imaging to rule out reversable causes of cognitive decline

Referral if reversible causes ruled out and dementia still suspected

If Alzheimer's disease is suspected include a test of episodic memory

Specialist tests such as CSF or PET scans where appropriate to confirm diagnosis or eligibility for DMT

Confirmed diagnosis of Alzheimer's disease

Following a formal diagnosis, the Cognitive MDT will make the decision whether to offer a DMT, as well as the timelines and monitoring requirements

Cognitive services will support patients (and GPs in the community). They will act as the primary point of contact for patients and support treatment monitoring. They will also coordinate with social care as necessary

COMMENTARY

This action will rely on a firm evidence base being established for the efficacy of digital biomarkers

The cognitive MDT is only referred to directly from primary care if rapidly- progressive dementia is suspected after tests in primary care

The Cognitive Service will replace the roles of memory assessment services, and work with the Cognitive MDT to identify the underlying pathology causing cognition issues

All suspected MCI and early-stage Alzheimer's disease patients should have access to tests to establish their underlying pathology and suitability for a DMT

Cognitive Services will need increased resources over that available to Memory Assessment Services to allow them to play an ongoing role in patient monitoring and support

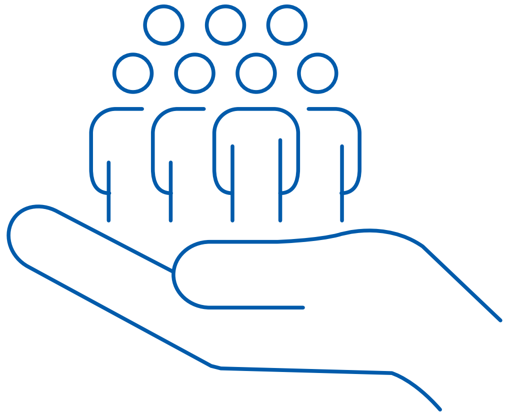
Conclusion

The challenges facing Alzheimer's disease and dementia services are only set to grow in the years ahead. The amount of clinical research in this area presents both hope for patients and their families, and an opportunity to reimagine how we structure the services that care for people with Alzheimer's disease and dementia in the UK.

This report has set out key recommendations both to support services in the here and now and to prepare for the future of DMTs.

Roche is absolutely determined to support the Alzheimer's disease and dementia community to drive the necessary changes to both improve the current system and ready it for delivering DMTs to patients.

We stand ready and willing to work with and support all partners who share our goals



Attendees

- **Janis Cottee:** former family carer and member of tide (together in dementia everyday)
- **Prof Clive Ballard:** Professor of Age Related diseases, University of Exeter
- **Dr Jeremy Isaacs:** Consultant Neurologist, St George's University Hospitals NHS Foundation Trust
- **Professor Roy W Jones:** Director, RICE (The Research Institute for the Care of Older People), Royal United Hospitals, Bath and Honorary Professor, University of Bristol
- **Helen Rice:** Familial Alzheimer's disease nurse, UCL Dementia Research Centre
- **David Thomas:** Head of Policy (Access and Innovation), Alzheimer's Research UK
- **Dr Dennis Chan:** Principal Research Fellow, Institute of Cognitive Neuroscience, University College London
- **Rachel Dorsey-Campbell:** Senior Lead Neurosciences Pharmacist at Imperial College Healthcare NHS Trust
- **Professor Martin Knapp:** Professor of Health and Social Care Policy, Care Policy and Evaluation Centre, London School of Economics and Political Science
- **Professor Ramin Nilforooshan:** Consultant Psychiatrist, Professor at University of Surrey, Co-Chair
- **Saba Zaidi:** Roche, Co-Chair
- **Catherine Davis:** Roche
- **Emma Dodd:** Roche

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together in dementia everyday

Roche and tide are working together to create a fairer future for people living with Alzheimer's disease and other forms of dementia.

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