Scotland's National Dementia Strategy

June 2010

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SCOTTISH GOVERNMENT

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Foreword from the Minister for Public Health and Sport

Dementia is a national priority

Dementia is a national priority for this administration, and this strategy was devised last year to reflect the importance we all attach to this agenda – and also to build on the significant work which was already underway in Scotland in key areas such as early diagnosis, improving care pathways, and public awareness.

Yet we know that people with dementia and their carers and families are still often left feeling dissatisfied and frustrated by their experience of services, despite the level of resources already in the system, estimated at £1.7 billion each year. Given the challenging times we all face in the next few years in terms of public spending, it is crucial that we tackle this agenda strategically now, if we are to begin to fundamentally reshape the model of dementia care, especially as we expect the number of people with dementia to double over the next 25 years, with all that entails in terms of demand for and pressure on services. Wider work is taking place to look at how we plan and reshape services for our ageing population, and this strategy will also begin to influence that reshaping agenda for dementia services.

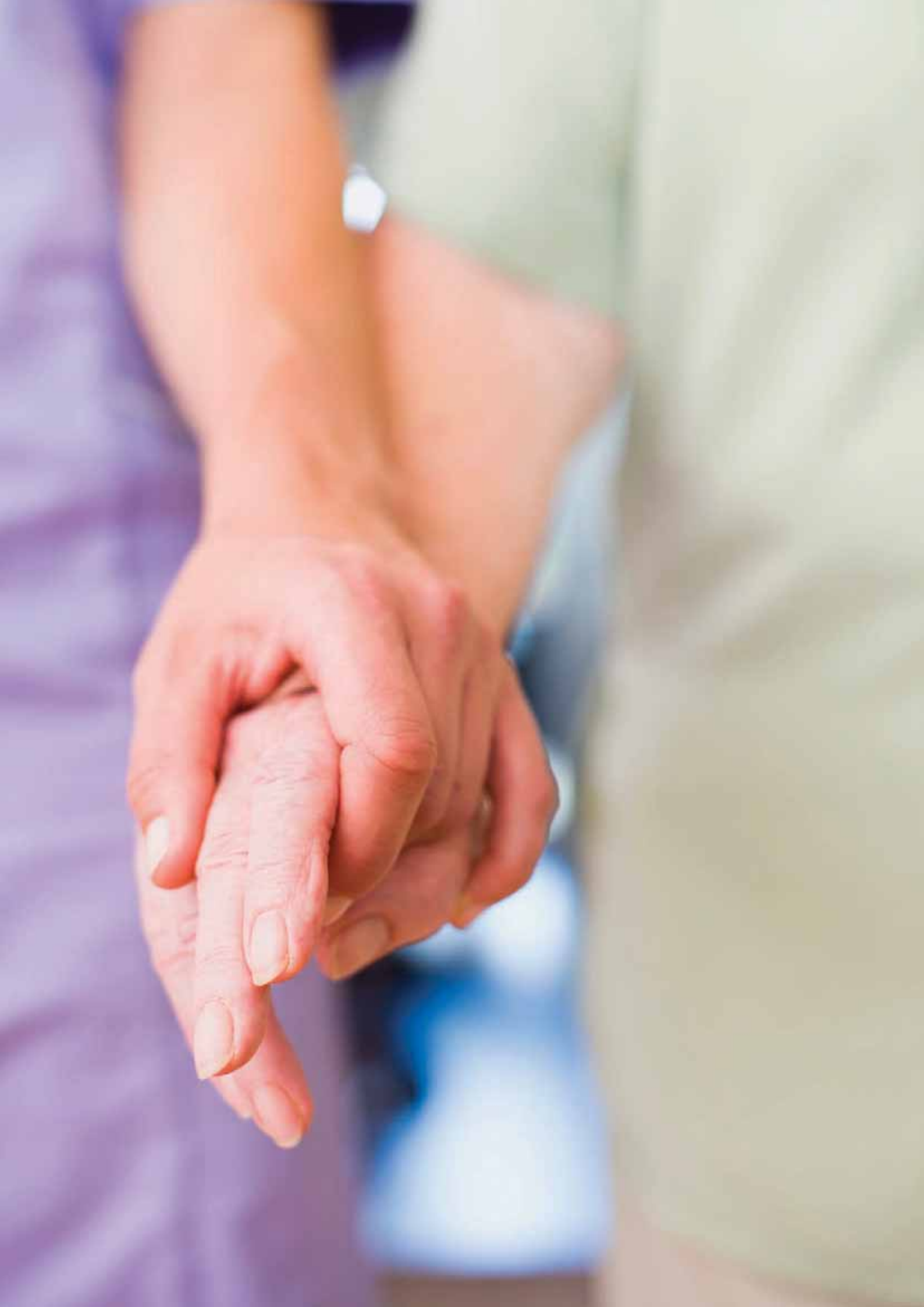
We've worked intensively over the past year with our partners in health and social care, in the statutory, voluntary and private sectors, in order to identify the best levers for changing and improving the entire system of dementia care. At each stage of the journey of someone's dementia there are things we need to do better – for example in providing far more consistency in the quality of post-diagnosis support; improving the experience of those with dementia and their carers in general hospital settings; and at all times ensuring that people are treated with dignity and respect. In that respect, this strategy reflects our endorsement of the Scottish Parliament's Cross-Party Group on Alzheimer's *Charter of Rights for People with Dementia and their Carers in Scotland.*

This strategy will therefore transform dementia services by developing common standards of care for the first time; by producing a framework to ensure that all staff who provide care and support are skilled and knowledgeable about dementia; and by significantly improving care pathways, and strengthening the integration of health and social care services – including in the area information-sharing. We will also continue to improve the level of diagnosis of dementia, and develop work to reduce the use of psychoactive drugs in managing the illness.

This large programme of work over the next 2-3 years will be overseen by a monitoring group, which will be a core part of what needs to be and will be a shared endeavour between the Scottish Government, local government, the NHS, the voluntary and private sectors.

I'm gratified by the amount of time and effort that's been devoted by so many of you to developing this strategy, and I'm convinced that its implementation will drive real changes in dementia services, and so improve the experience of care for those with dementia, their families and carers.

Shona Robison
Minister for Public Health and Sport



Foreword from COSLA

even in these straitened times,we must continue to strive to get the fundamentals of dementia care right

This strategy is about getting dementia care right. It is about advancing a reform agenda rather than rolling out a big programme of investment. The reality is that the strategy will be taken forward amidst the most stringent spending cuts for a generation.

But even in these straitened times, we must continue to strive to get the fundamentals of dementia care right – to see the person, not the condition; to ensure that people's rights are respected and that they are able to live with dignity; to ensure that health and social care professionals work collaboratively in order to improve outcomes; to ensure that people with dementia are offered medication *only* where it benefits the individual; to ensure that if a person with dementia finds themselves in hospital, the quality of care they receive is of the highest order; and to ensure that when people with dementia leave hospital they are given every opportunity to return to their own home rather than move to a care home.

These are some of the elements within the strategy that we need to work hard on over the coming months and years to ensure we improve dementia care for those who need it.

This strategy also sits within a wider context. We will see this strategy launch at around the same time as the carers strategy and our strategy on self-directed support.

Together, these are three pillars of a larger reform agenda that recognises carers as equal partners in care placed at the heart of the health and social care system, and which will see more control given to individuals to choose the care and support that is best for them.

Those three pillars speak to a reform agenda that is nothing less than a fundamental reshaping of our health and social care system. We know that public spending is expected to fall sharply over the next 3 years and yet, as a result of our ageing population, demand for formal health and social care services is set to grow dramatically. The reality is that the health and social care system that we currently have is unsustainable. That is why the Scottish Government, Scottish local government and NHSScotland are driving forward a reform agenda that looks to fundamentally transform the way in which health and social care services are designed and funded.

Within that broader agenda, we will need to get dementia care right; and I firmly believe that this strategy is capable of delivering that change.

Councillor Ronnie McColl
COSLA Spokesperson on Health and Wellbeing

Foreword from Alzheimer Scotland

Alzheimer Scotland welcomes this strategy and believes it is a significant step forward in tackling many of the difficulties experienced by people with dementia and their families. The strategy has been developed in partnership, and we have welcomed the opportunity to ensure that the views of our members and the people and families we represent, as well as our knowledge developed from years of campaigning, have been listened to and are central to the strategy's objectives.

It is unfortunate that it is only now, in such an uncertain economic climate, that dementia is receiving the necessary level of government priority. Whilst we appreciate the pressure the economic climate places on national and local government, we remain convinced that progress towards a world-class dementia service would have been greatly accelerated by new money to help services to make changes. However, we are pleased that BIG has indicated their intention to aid the development of post-diagnostic support and early intervention. We welcome this strategic investment and will do all we can to assist in the effective use of these valuable funds.

We know that the resources already committed to helping people with dementia and their families can be better used and we agree with the proposed change actions and reshaping of resources outlined in the strategy. We also believe that some of the most important issues do not require additional resources: respecting people with dementia and their families as equal citizens, with the dignity they deserve, costs nothing.

a significant step forward in tackling many of the difficulties experienced by people with dementia and their families

The strategy is built on these principles and has at its heart the rights of people with dementia and their families to support that is personalised, timely and consistent.

Dementia is not a normal part of growing old, but dementia is part of normal everyday life for many people in Scotland. We must ensure that health and social care professionals, mainstream local services and communities across Scotland understand dementia and are encouraged to play a part in making a difference in the lives of people with the illness. This strategy is a strong start and we look forward to both supporting its implementation and to developing a further strategy in 2013.

Henry Simmons
Chief Executive Alzheimer Scotland

Foreword from The Scottish Dementia Working Group

The Scottish Dementia Working Group, for those who do not know us, is a campaigning and awareness-raising group, formed in 2002. All our members have a diagnosis of dementia.

We were delighted when the Scottish Government announced in July last year that the first Scottish Dementia Strategy was on its way. It is something our members have wanted for a long time. And we have been very pleased with the way our members have been involved with the development of the Strategy from the start, as representatives on the five workstreams and as a partner in running the consultation events. We are particularly grateful for the time the Minister for Public Health, Shona Robison, gave to meet with us to discuss our priorities.

The Strategy has now been launched, but this document is just the start. Implementation must now be the priority for all of us. And we have some big challenges ahead. We have to break some of the old moulds and look at new ways of providing services. Support, from a well-trained workforce, needs to be centred on the individual and grow with the individual as the condition progresses.

We must ensure that the needs of minority groups, such as BSL users and people from diverse ethnic groups, are not missed. The needs of younger people with dementia have in the past been lost.

We hope the Strategy will mean that no one should find themselves without appropriate support because communication, cultural needs or age restrictions create barriers to support.

As a national group, our members are well aware of significant differences in access to quality support across Scotland. We look forward to the Strategy being truly national and finally putting an end to the postcode lottery.

Despite the many challenges that lie ahead, we remain optimistic that the Strategy will soon begin to make a dramatic difference to the lives of people with dementia and their carers. Time scales have extra importance for those of us that havedementia. Sometimes we invest our effort for those who will follow. But we also want changes to happen in our lifetime.

We all have it within our power to effect the changes needed to ensure the best quality services for people with dementia, their carers and families across Scotland. Together we can make the Strategy work.

Edward McLaughlin
Chair, The Scottish Dementia Working Group

Executive Overview

People who have dementia and those who care for them are entitled to dignity and respect and should be able to access services that provide support, care and treatment in a way that meets their personal needs. The Scottish Government and its partners in local government, and the voluntary and private sectors, are committed to delivering world-class dementia services in Scotland, by:

- developing and implementing standards of care for dementia, drawing on the Charter of Rights produced by the Scottish Parliament's Cross Party Group on Dementia;
- improving staff skills and knowledge in both health and social care settings;
- providing integrated support for local change, including through implementation of the dementia care pathway standards and through better information about the impact of services and the outcomes they achieve;
- continuing to increase the number of people with dementia who have a diagnosis to enable them to have better access to information and support;
- ensuring that people receiving care in all settings get access to treatment and support that is appropriate, with a particular focus on reducing the inappropriate use of psychoactive medication; and
- continuing to support dementia research in Scotland.

In taking this work forward there will be a particular focus on two key change areas:

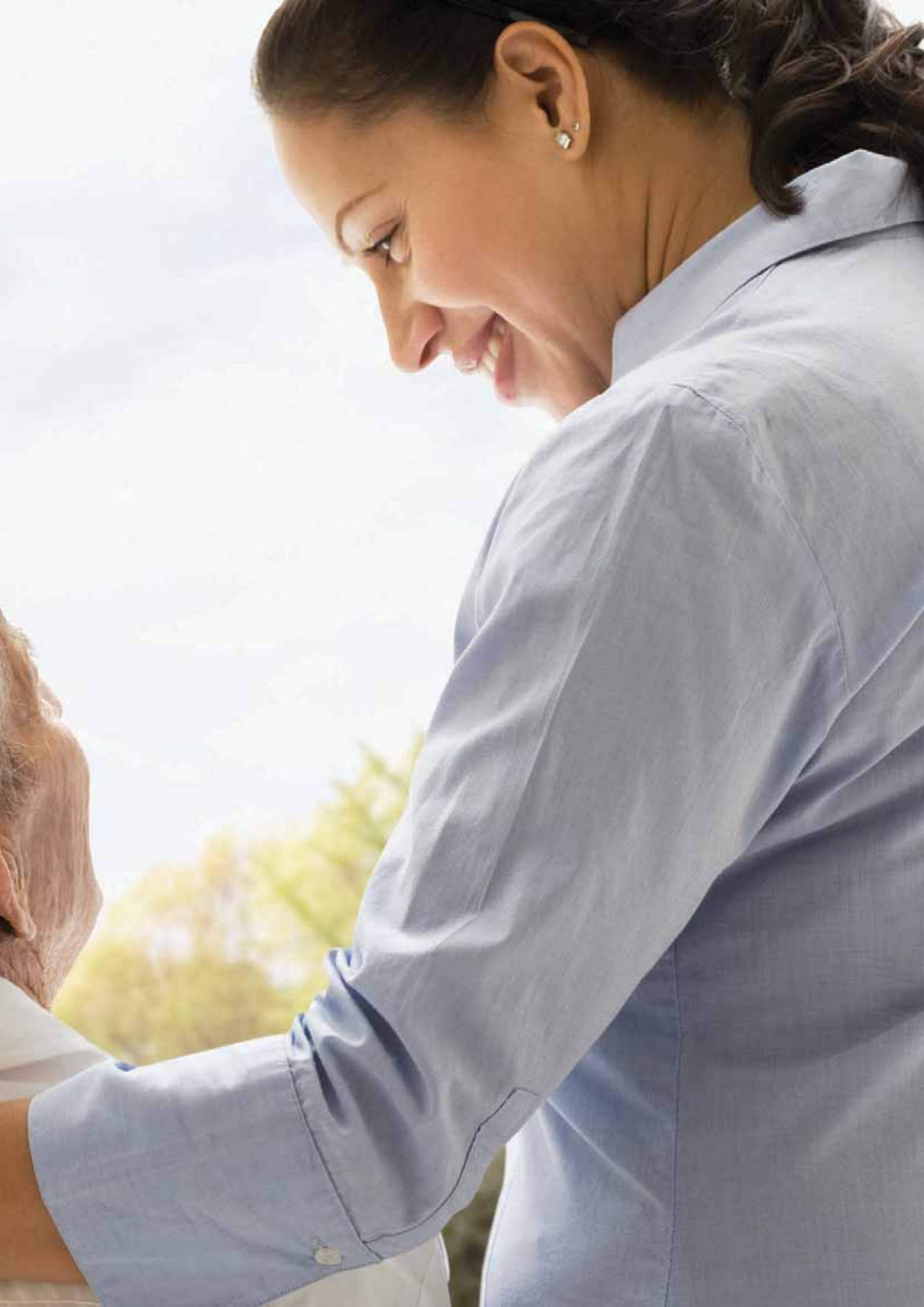
- following diagnosis, by providing excellent support and information to people with dementia and their carers; and
- in general hospital settings, by improving the response to dementia, including through alternatives to admission and better planning for discharge.

Improvements in each of these two areas will bring immediate benefits to people with dementia and their carers, as well as improving efficiency and quality of the care system, releasing resources to improve access to care.

The work to deliver the Strategy will be overseen by a Dementia Strategy Implementation and Monitoring Group involving all the key partners responsible for taking forward the changes, as well as people with dementia and the people who care for them. This Group will publish an Annual Report in June 2011 and June 2012.

This Strategy has long-term objectives, but there is an immediate focus on action over the next 3 years. We will commission a revision of the Dementia Strategy which takes account of progress and learning which will be overseen by Implementation and Monitoring Group and completed by June 2013.

This Strategy has long-term objectives, but there is an immediate focus on action over the next 3 years



Introduction

1 Dementia is a significant issue for people in Scotland. It is a condition which changes the lives of those diagnosed and of those close to them. There is recognition that, despite much good work, there are critical challenges and important gaps which must be addressed if people are to receive the services they need. This is particularly urgent in the context of the increasing numbers of people with dementia due to demographic changes.

2 The aim of this strategy is to deliver world-class dementia care and treatment in Scotland, ensuring that people with dementia and their families are supported in the best way possible to live well with dementia.

3 The strategy identifies five key challenges and addresses these by focusing on two key service delivery areas: improving support after diagnosis and improving hospital care. It also sets out a further eight specific actions which will support improvements in care and treatment.

4 Dementia is an umbrella term used to describe a range of brain diseases characterised by a progressive decline in intellectual and other mental functions. While Alzheimer's disease and vascular disease are the most common causes, there are a number of other less common forms of dementia. Dementia is a terminal condition.

5 Early on in the illness, the symptoms will be mild, often principally affecting memory. As the illness progresses, it will increasingly affect understanding, reasoning, decision-making, communication and every area of everyday activity. Many people also experience psychological symptoms and changes in behaviour.

6 People with dementia and their carers need support early on to come to terms with the illness, to manage its symptoms and to put in place legal, financial and care arrangements for the future. As time goes on, people with dementia need increasing help with everyday activities and personal care and eventually will require constant support and supervision. Much of this care is provided by partners and family members, who themselves need support to enable them to do so.

Dementia directly affects the lives of the partners, family members and friends who provide care and support

7 There are approximately 71,000 people with dementia in Scotland, around 2,300 of whom are under the age of 65. As our population ages, the number of people with dementia will increase and we expect the number to double over the next 25 years. Prevalence of dementia increases with age; around 1.5% of the 65 to 69-year-old population are affected, increasing to about one in three of the 90-plus age groups.

8 The majority, 63.5%, of people with dementia live at home in the community, with an estimated 36.5% of people with dementia living in care homes. Up to 70% of the care home population may have dementia.

9 Dementia directly affects the lives of the partners, family members and friends who provide care and support and experience the emotional, physical, practical and financial impact of caring.

10 Alzheimer Scotland estimate that the costs associated with dementia are £1.7 billion per annum. Of that cost, about £600 or £700 million is the cost of care and treatment services provided by the NHS and local government. The remainder is the contribution made by carers. The cost to the NHS is probably an underestimate given the greater understanding we now have of the cost of dementia in general hospital settings.

11 There is evidence that healthy living behaviours, such as following a good diet, engaging inregular physical activity and maintaining social relations, may reduce the overall risk of a person developing dementia later in life. The Scottish Government will continue to work with partners to promote a healthy lifestyle. However, there is no particular measure which can prevent dementia.

Action Since 2007

12 This strategy is not the first work that the Scottish Government has taken on dementia. Since May 2007 a number of actions have been undertaken by the Scottish Government and its partners in the statutory and voluntary sectors to improve dementia care and services in Scotland and examples of these include:

- Dementia has been established as a national clinical priority by the Scottish Government.

- The Scottish Dementia Forum, chaired by the Minister for Public Health and Sport, which brings together representatives from the statutory and voluntary sectors as well as people with dementia and the people who care for them, has been created and has met regularly.

- A target for NHS Boards to deliver agreed improvements in the early diagnosis and service response to people with dementia by March 2011 is in place and from March 2009 to February 2010 there was a net increase of 3290 in the number of people on the GP register.

- Post-diagnostic support pilots have been launched in three local authority/health board areas in 2007 with £600,000 of Scottish Government support (more information on these pilots is set out below).

- NHS Health Scotland, in partnership with Alzheimer Scotland, have updated and widely distributed a number of publications: *Coping with Dementia – a Handbook for Carers; Worried about your Memory; Facing Dementia – how to live well with your diagnosis; Understanding Dementia – a Handbook for Young Carers*, and a DVD of the handbook for carers has been produced.

- The Scottish Dementia Clinical Research Network was established with over £1 million of Scottish Government support to improve the quality and quantity of dementia research in Scotland and to enable those with dementia and their carers to have greater access to participation in research studies.

- Alzheimer Scotland have put in place a network of 19 Dementia Advisers in 18 local authorities, and now also fund three Dementia Nurse posts in NHS Lothian, NHS Borders and NHS Ayrshire and Arran.

- Local authorities are developing innovative approaches to enable more people to live safely and comfortably in their homes with their families for longer and particular examples of this are included under the heading *Key Service Delivery Area: care in general hospital settings, including alternatives to admission.*

- The national Telecare Development Programme which helps more people in Scotland live at home for longer, with safety and security has been established and is having an impact on the lives of people with dementia (more information on this work is included below).

- *Taking Charge – a short guide to self-directed support for people with dementia and their carers* was published by Alzheimer Scotland, aimed at raising awareness of self-directed support – a way for individuals to work with the social work department, other organisations and paid workers to put together a package of care that suits their needs and the way they want to live their lives.

13 This is not a comprehensive list of all the action that has been taken, but is illustrative of the commitment in Scotland to tackling the challenge of dementia.

The Rights of People with Dementia and their Carers

14 In 2009, the Scottish Parliament's Cross-Party Group on Alzheimer's published its *Charter of Rights for People with Dementia and their Carers in Scotland.* This was based on the recognition, following the work of Alzheimer Scotland and others over many years, that:

- the nature of the illness means that people with dementia have great difficulty in protecting their own rights;
- there is still much stigma and discrimination against people with the illness;
- people with dementia don't have equal access to high quality dementia care services; and
- support for those who care for people with dementia is often overlooked, so that their health suffers with the stress of caring.

15 This strategy adopts the principles set out in the Charter. In summary, these are that people with dementia and their carers have the right to:

Participation, including rights to accessible information and support to participate in decisions that affect them; to live as independently as possible with access to community facilities; to full participation in planning care; and to be assisted to be involved in policy-making.

Accountability, including rights to enjoy human rights and fundamental freedoms including full respect for their dignity, beliefs, individual circumstances and privacy; and to the accountability of organisations and individuals responsible for care and treatment for the respect, protection and fulfilment of their human rights.

Non-discrimination and equality, including rights to be free from discrimination-based age, disability, gender, race, sexual orientation, religious beliefs, social or other status.

Empowerment, including rights to appropriate levels of care providing protection, rehabilitation and encouragement; to help to maintain maximum independence, physical, mental, social and vocational ability and full inclusion and participation in all aspects of life; to access to social and legal services to enhance their autonomy, protection and care; and to health and social care services provided by people with appropriate training on dementia and human rights.

Legality, including rights to have the full range of human rights respected, protected and fulfilled, regardless of diagnosis; to information, participation in decision making and the appropriate remedies; and where someone lacks capacity to take a specific action or decision, the requirement that anyone acting for them has regard for the principles and provisions of the Adults with Incapacity (Scotland) 2000 Act.

Preparation of this Strategy

That work has been taken forward in collaboration with a wide range of individuals

16 In May 2009 the Scottish Government made a commitment to prepare and publish a Dementia Strategy. That work has been taken forward in collaboration with a wide range of individuals and organisations with a knowledge of dementia and a commitment to improving care and services.

17 The initial work was taken forward through five workstreams, which focused on the following areas:

- Treatment and Improving the Response to Behaviours that Carers and Staff find Challenging
- Assessment, Diagnosis and the Patient Pathway – Improving the Journey of People with Dementia and their Carers
- Improving the General Service Response to Dementia
- Rights, Dignity and Personalisation
- Health Improvement, Public Attitudes and Stigma

18 Each of the workstreams produced a report which included detailed recommendations, all of which have informed the development of the strategy and many of which are incorporated directly in this Strategy. The membership, reports and recommendations are available on the Scottish Government website at: **www.scotland.gov.uk/Topics/Health/health/mental-health/servicespolicy/Dementia**

19 In addition to the activity of the workstream, we undertook two phases of consultation. The first was the Dementia Dialogue which took place during the Autumn of 2009. The second was a series of engagement events from March to May 2010 where we tested the emerging recommendations from the workstreams. A report on the response to the consultations is available at: **http://www.scotland.gov.uk/Topics/Health/health/mental-health/servicespolicy/Dementia**

20 The preparation of this Strategy document was undertaken by the Scottish Government, working with the support and engagement of a Dementia Strategy Management Group drawn from the chairs of the workstreams and other key dementia stakeholders.

21 The importance of promoting inclusion and reflecting the diversity of Scotland's population was highlighted by the workstreams and particular questions were included in the engagement events. In addition, there will be an Equality Impact strand to the implementation of the Strategy.

The Challenge

Significant resources are already being invested to provide support, care and treatment

22 We face a series of key challenges which we must address if we are to deliver world-class dementia care and treatment in Scotland. The challenges extend beyond the organisation and delivery of services to include the knowledge and skills of health and social care staff as well as public attitudes and beliefs in respect of dementia.

23 Significant resources are already being invested to provide support, care and treatment for those with dementia and the people who care for them. However, the vast majority of these costs are focused on high-cost long-term care services such as care homes and inpatient care.

24 There are gaps in provision which mean that many people with dementia are not receiving an appropriate service. There is little in place following diagnosis to support people to come to terms with and manage their condition and to plan ahead. Pressure on social care services means that people may not receive support at home until their needs are deemed critical or substantial. These gaps mean that preventative support which could avoid crises may be unavailable, increasing the potential need for more expensive services later on.

25 Services can sometimes appear uniform and inflexible and though expensive, may not always be what is wanted or needed, particularly, if they do not mesh well with people's existing informal systems of care. What is often needed is better support for a person's existing system of care rather than something that will replace it.

Five Key Challenges

26 There are five key challenges that we must address if we are to make improvements in the outcomes for people with dementia and their carers.

Fear of dementia that means people delay in coming forward for diagnosis

27 People can be reluctant to go to their General Practitioner if they are worried that they may have dementia. Some people wait 2 years or more before seeking help. They are concerned that they will be stigmatised or lose control of their life. They do not think there will be any real benefit from getting a diagnosis. These concerns may also be shared by family members or friends, with the consequence that though they may see that something is wrong, they are reluctant to take any action or to encourage the person they are worried about to seek help. This means in many cases diagnosis is delayed and that treatment or other interventions that can improve quality of life over time are not offered.

28 In some cases, where people do seek help, they may not receive the appropriate response as some General Practitioners may be reluctant to diagnose or to refer for further assessment. However, we are seeing good improvements in this area due to the work that NHS Boards have been doing to increase the number of people with a formal diagnosis of dementia and also as GPs are offered more assistance to provide support and information to those with dementia and their carers.

29 If we can improve people's understanding of the benefits of early diagnosis we can encourage more people to seek help early. That means that they can receive treatment and support when it is likely to have the greatest benefit. In 2008, the Scottish Government undertook a trial project in Dundee and Perth designed to encourage more people to seek information or support if they were concerned about their memory. That work told us that people were more likely to seek help if they thought that support and help would be available if they did have dementia. Improving post-diagnostic information and support is therefore a key first step in tackling the fears that people have about coming forward for diagnosis. Work to tackle that gap is a key component of this strategy. We will build on improvements that we make in that area by further action to raise public awareness of the value of early diagnosis, founded on increased confidence in the quality of treatment and support that will follow.

Information and support after diagnosis for those with dementia and their carers is poor or non-existent

30 When people do receive a diagnosis, they and their family often do not get the information and support that they need to be able to cope with the life change, manage the condition and plan for their future. People with dementia and their carers often feel abandoned and left on their own. This is a very challenging period in someone's life and they and their family need all the support that can be made available to come to terms with the illness and to find ways of living well with it.

31 If we can improve both the quality and availability of post diagnostic support we believe that we can improve people's quality of life as well as prolong the period during which they are able to live independently with the support of their family and friends. More effective post-diagnostic support should include access to information about dementia, therapeutic support to help with emotional adjustment, support to self-manage the symptoms, help with legal, financial and future care planning and access to peer support.

General healthcare services do not always understand how to respond well to people with dementia and their carers, leading to poor outcomes

32 People with dementia who have other health problems are more likely to be inappropriately admitted to hospital, are more likely to stay longer in hospital, to the detriment of their own wellbeing and exacerbating problems the NHS faces from delayed discharges, and are more likely to be discharged directly to a care home.

33 The particular needs of people with dementia are often poorly understood by healthcare staff working in general medical settings such as general hospital wards and Accident and Emergency Units. This means that they do not always receive the most appropriate response. This reflects the knowledge and skills of staff in these areas and the support which is offered to them.

People with dementia and their carers are not always treated with dignity and respect

34 Inappropriate admissions can be addressed by increasing the availability of 'step-up' intermediate care services that offer a temporarily higher level of care for someone living at home to cope with a short-term need, instead of the person going into hospital. Specialist support and improved staff training for care homes can assist them to continue caring for residents who might otherwise go into hospital and help to ensure that any admissions are appropriate.

35 Addressing the knowledge and skills gaps for nondementia-specialist staff in hospitals can improve the quality of care that people with dementia receive while in hospital.

36 On discharge from hospital, where the person was previously living at home, facilitating a return home should be the starting point, as it usually is for other patients. People with dementia in hospital are often further disabled and confused by the hospital environment and by their physical ill health, and so may appear less able to cope at home than is the case. 'Step-down' services, which offer rehabilitation following a hospital stay can increase the number who return to their own homes.

People with dementia and their carers are not always treated with dignity and respect

37 This was a strong message coming out of the consultation and engagement processes and reflects a key theme from the Mental Welfare Commission and Care Commission report, *Remember I'm Still Me*. That report told us that people in care homes often experience impersonal care, with little activity, and that there is overuse of medication to address behaviours that staff and carers find challenging.

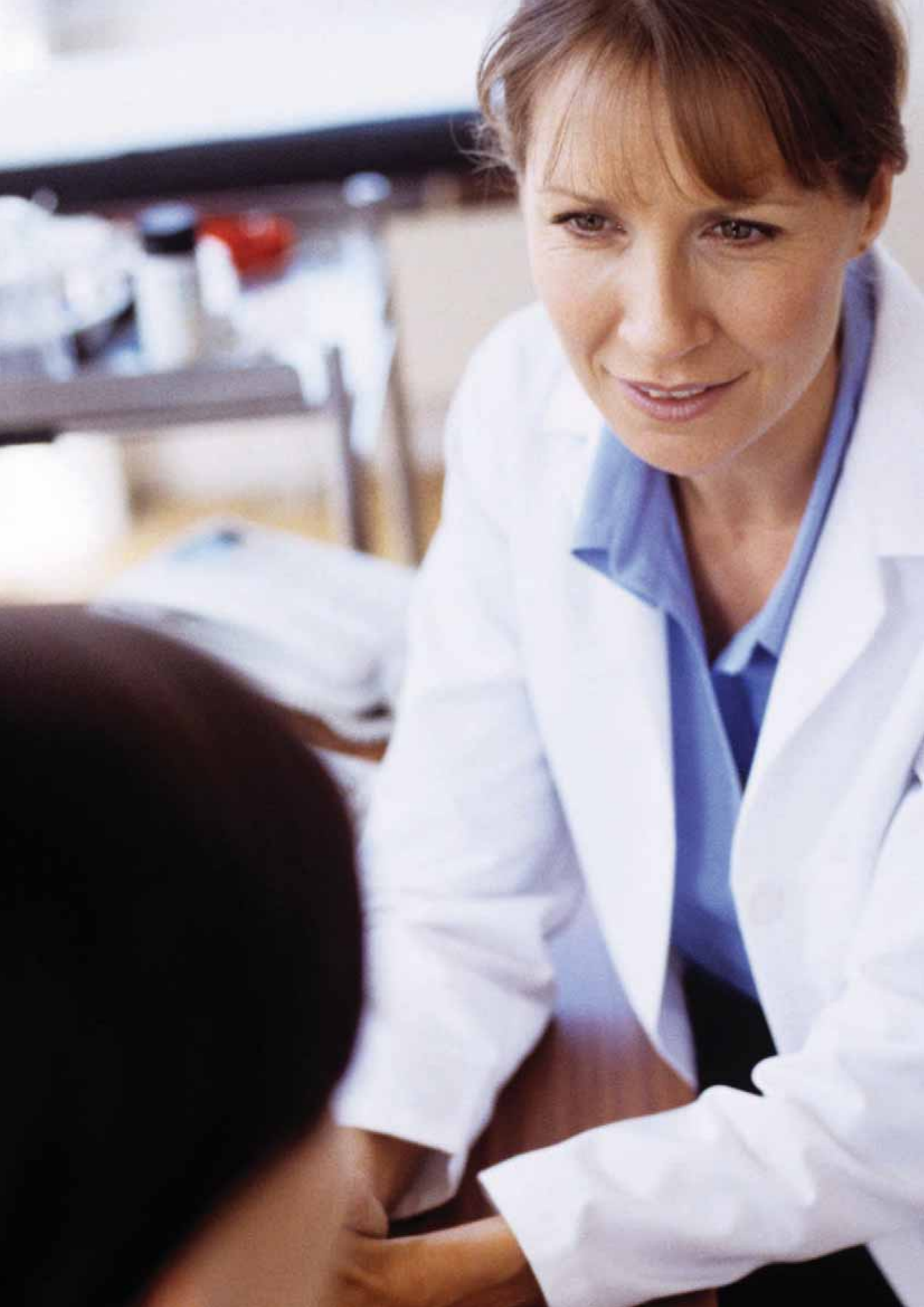
38 Treating people with dementia and carers with dignity and respect in care and health services is part of their basic human rights. It also contributes directly to a person's quality of life and their overall health. Local leadership has a key role in shaping staff behaviours within the health and care systems and can reinforce messages delivered through training and the setting of standards. Inclusion and valuing of people with dementia and their carers is good for us all.

Family members and people who support and care for people with dementia do not always receive the help they need to protect their own welfare and to enable them to go on caring safely and effectively

39 People who care for people with dementia suffer higher levels of stress and ill health themselves than the general public. While many people take great satisfaction from providing care for a loved one or friend, it can also be a significant personal challenge. If there is a lack of appropriate support and the challenge of offering care becomes too great for a person to sustain, then the consequence may be that a person with dementia may need to be admitted to care.

40 The Nuffield Council on Bioethics propose the principle of autonomy which extends the concept of dignity and includes the idea of supported decision-making promoted in part by encouraging relationships that are important to the person in maintaining their sense of self. Services that are able to address the support needs of family and carers are more likely to be able to ensure that such relationships can be maintained over time and by doing so promote the wellbeing of people with dementia.

41 The Scottish Government will shortly publish its Carer's Strategy which will set out the action that it will take in conjunction with partners in local government and the voluntary sector to better meet the needs of carers to enable them to care effectively as well as to maintain their personal health and wellbeing. That Strategy will complement and reinforce the work under this Strategy which has a particular focus on those who care for people with dementia.



Transformational Change to Deliver World-class Dementia Care and Treatment in Scotland

42 There is no 'quick fix' available to answer all the challenges that we face. Transformational change across the social and health care system is necessary if we are to deliver the improvements that that have been identified over many years and the need for which is reinforced by what people have asked for in our engagement and consultative events.

43 Part of the response to the challenges is about effective partnership working between the NHS, local government and the voluntary and private sectors, respecting the separate contribution and capability of each, but also understanding our collective ability to achieve change through integrated working. The engagement of these partners in the creation of this Strategy gives confidence about a continuing mutual commitment to this agenda.

44 More importantly, it is about working collaboratively with people with dementia and their carers. This collaboration is essential on two levels. At an individual level it is about working with people to ensure that their care and support is fully personalised. At another level it is vital that people with dementia and carers are fully engaged in framing and developing policy. The work that we have undertaken to produce this strategy would have been impossible without the direct contribution of the Scottish Dementia Working Group, whose members all have a diagnosis of dementia, and other individual people with dementia and carers who have been actively involved.

45 We need to recognise that this Strategy is being published during a difficult economic climate with significant pressures on public finances. Scotland's people are living longer and the number of people with dementia is increasing. The challenge we face is how to design services that meet people's needs while recognising that there will be continued pressure on budgets for the foreseeable future. Given the anticipated reduction in public finance, this strategy is not about doing more of what we already do; it is about changing practice and doing things differently.

46 The consultation and engagement events confirmed the views expressed in the workstreams that people are looking for a different kind of service. People want the health and social care systems to work better together, with better co-ordination and information sharing. However, they also want the change to go further than that, with more good quality community support and services for people with dementia and their carers, including both low level preventative initiatives and intensive alternatives to continuing care. They want services which maximise capacity for independence and which connect or reconnect people with dementia with the people and activities important to them.

People want the health and social care systems to work better together

47 There is also a demand for a shift in the way services are arranged for people. A personalised approach means that that people with dementia and their carers can, with support, take control of choosing the services which fit best with their lives and with the natural supports available from friends, family and neighbours, rather than being slotted in to existing services. Agreeing a set of outcomes for the individual and the amount of money available to meet these outcomes allows people and their families to use the resources available creatively. This approach has recently been consulted on by the Scottish Government in the context of its draft Self-directed Support Strategy. People want to see better use being made of natural supports, peer support and wider community resources, to ensure that people with dementia are enabled to live well with dementia and remain part of their communities.

48 While we have presumptions about the economic and cost implications of working differently, at present our knowledge is more limited than we would want. For example, although there is some positive research, we would ideally like more evidence to back up our strong belief that improved post-diagnostic services, as well as being better for those with dementia and their carers, are also a good financial investment. We believe that such services will increase capability, allow for planning and better management of the illness over time and so delay the point at which a person may need access to a care home or other intensive supports.

49 We also believe that we can reduce the number of people with dementia who develop a physical illness and are admitted to hospital unnecessarily by providing a higher standard of care at home, or at times through intensive support. If we can achieve that change across the system we can both reduce the direct cost to the NHS and reduce the costs that fall on local government. This is because the temporary extra support will prevent or delay permanent admission to a care home. We are developing the evidence base for this through many of the new approaches to care which are being piloted throughout Scotland as part of the Reshaping Care agenda.

They want services which maximise capacity for independence and which connect or reconnect people with dementia with the people and activities important to them

50 There is also evidence which shows that it is possible to reduce the number of people with dementia living in care homes who are admitted to hospital, by providing better specialist dementia training and support to care home staff. Similarly, the Telecare initiative, which is sponsored by the Scottish Government, suggests the use of technology can actively promote wellbeing as well as reduce costs. The examples of dementia cases in the *Care Package Cost Modelling Report* by Newhaven Research in March 2010 show that the use of telecare in community-based support packages resulted in overall cost savings.

51 In all of this we have a common interest in changing how services are delivered. People would generally prefer to stay at home and continue to receive care and support from their family. This is usually a less expensive option, and would continue to be so even as we improve the supports that are made available to those with dementia and their carers. Doing the right thing gives a benefit to the individual, their family and to the wider community. This underlying principle of shifting the balance of care is at the heart of the service redesign that we believe is possible within dementia services.

52 At the moment we may be able, in some cases, to demonstrate how working differently could improve the quality of care, fit better with the expectations of people with dementia and carers and be a more cost effective approach. However, we cannot yet quantify the system-wide effects of such changes. In some cases it is likely that improved working in one part of the service, rather than releasing resources elsewhere, will reduce waiting lists for access to those services. This is an improvement, but not one that releases resources. In other cases it may be that a genuine saving can be achieved. Throughout the process of implementing this Strategy it will be important to seek to protect the community resources that are available to provide dementia care even as the nature of the particular services change.

53 This transformational agenda must be closely aligned to the work on Reshaping Care for Older People, being taken forward jointly by the Scottish Government, COSLA and NHSScotland, along with other partners. That work is looking at the overall organisation and redesign required of care, health, housing and wider community supports for older people in Scotland in the context of the demographic and financial challenges. A public engagement phase is currently underway which will continue until September 2010 and we will ensure that we make clear links between the outcomes from the work on Reshaping Care and the recommendations in this Strategy. More information about the Reshaping Care work is available at: **http://www.scotland.gov.uk/Topics/Health/care/reshaping**

Our Model for Change

54 There are clear changes that we can make to contribute to the wider transformational change agenda across the health and social care system. We have identified two key service delivery areas in which immediate change is required – post-diagnostic information and support and care in general hospital settings, including alternatives to admission.

55 In addition, we have identified a further eight change actions to support that focus and to make improvement throughout the care pathway for those with dementia and their carers. All of these actions will be difficult within the current economic context; but we believe that with a strong partnership ethos we can deliver on our ambitions.

56 Unless we are collectively effective across the system and disciplined about pursuing improvements and changes at each stage of the dementia journey, it is unlikely that that we will realise the benefits. For this reason supporting implementation and monitoring change, including in respect of outcomes, will be an essential part of the change process.

Key Service Delivery Area: Improved Post-Diagnostic Information and Support

> We will work to improve the support and information that people with dementia and their carers receive following diagnosis.

57 In setting out the key challenges above we clearly recognised the importance of improving access to and the quality of post-diagnostic support and information. Ideally this should take place following an early diagnosis, but in many cases that will not be possible as diagnosis will only take place after the dementia has made significant progress. That means that those planning and managing services need to take account of the range of needs that different people with dementia and their families and carers may have.

58 During 2008 the Scottish Government funded NHS Health Scotland to make the publication *Facing Dementia – How to Live Well With Your Diagnosis* more widely available through general practice and other routes so that people would have the best written information to hand. But this is only one dimension of the support that people with dementia and their families and carers need and our objective is to ensure that people have access to a range of responses including:

- Information about the illness, including appropriate therapeutic and pharmaceutical treatments;
- Emotional support and where appropriate, counselling, to deal with the impact of the diagnosis;
- Support to put in place legal arrangements to maximise the person's control over future decisions made on their behalf such as powers of attorney and advance statements;
- Advice on welfare benefits and other practical matters;
- Training and support for both the person with dementia and their family member or carer in respect of self-management of the illness and its symptoms;
- Support to plan ahead for the person's future needs, discuss options for future care and set out their wishes;

we clearly recognised the importance of improving access to and the quality of post-diagnostic support and information

- Peer support for people with dementia and their carers;
- Advocacy services;
- Information about Alzheimer Scotland's Dementia Helpline for further information and support.

59 The Scottish Government has supported three post-diagnostic support pilots which use different models to address some or all of these issues and to explore how support can best be offered.

Our Model for Change
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Lothian Post-Diagnostic Support Pilot

This pilot is being delivered by the Dementia Services Development Centre and focuses on providing information and training for NHS and social care staff, including giving general practitioners good information about local post-diagnostic support services for people with dementia and their carers, providing training to acute general hospital staff, running local information days and visits for staff and offering formal accredited dementia training. The pilot will be formally evaluated, but the key emerging findings are that education is vital and general staff need education even more than specialist staff because most social care and health care staff know little about dementia; carers are crucial and health and social care staff need to learn how to support them; and support is available that is underutilised.

Renfrewshire and East Renfrewshire Post-Diagnostic Support Pilot

This pilot is managed by Alzheimer Scotland, working with East Renfrewshire Community Health and Care Partnership, Renfrewshire Council and Renfrewshire Community Health Partnership. The pilot is intended to model how to support, enable and empower people with early dementia, and their carers, to be able to come to terms with and manage the illness and to take control of the services they need now and in the future. Project staff provide information, advice, signposting, emotional and practical support to people recently diagnosed with dementia, following a referral from the memory clinic. They aim to support people to find ways to maintain the important relationships in their lives and to remain involved in their communities.

Using person-centred planning tools, the project assists people with dementia, at a pace appropriate to the individual, to understand the impact of the illness on their lives, plan ahead for their future needs, discuss options for future care and set out their wishes for the future. The aim is to help people to be in a position, when they begin to need services, to use self-directed support to take control of the support they require and to make best use of their natural supports including support from family, friends and community.

The project will be formally evaluated but some of the emerging findings are that these planning techniques can help people with dementia plan for their future support; that although diagnosis tends to be late when natural support networks are often already lost, people can be reconnected into mainstream community activities; and that it takes some time for a person receiving a diagnosis to come to terms with the diagnosis and get to the point where they are able to plan for their future.

Shetland Post-Diagnostic Support Pilot
This pilot is run jointly by the Dementia Services Development Centre and Alzheimer Scotland and Includes the provision of information and training for health and social care staff and awareness events to connect the community to available support, and has similar emerging findings.

60 In addition to the work already under way, on 5 March 2010, BIG in Scotland (BIG is the Big Lottery Fund and is responsible for distributing National Lottery good cause funding) announced its intention to create a new fund of £50 million to produce a fundamental improvement in outcomes for young people leaving care and for older people with dementia and their carers. The focus of the funding will be to improve individual lives.

61 BIG is currently developing this fund, but it is likely to focus on the support which is available immediately following a diagnosis. BIG considers that investing the money in this way will have an immediate impact on the quality of life for many people, and create capability that will enable people to live independently and on their own terms for longer. We will work together with BIG and other partners to develop these new approaches and services to ensure that they work effectively as part of the overall care and support system.

62 The Mental Health Collaborative (the Mental Health Collaborative supports NHS Boards to make the improvements needed to deliver against key national targets set out by the Scottish Government) has begun to work with NHS Boards to establish local indicators to track the work that they are doing to improve their local post-diagnostic services. This work will feed directly into the work to establish data points within the local Integrated Care Pathways for Dementia and will enable us to track progress in making improvements in this key service delivery area.

Key Service Delivery Area: care in general hospital settings, including alternatives to admission

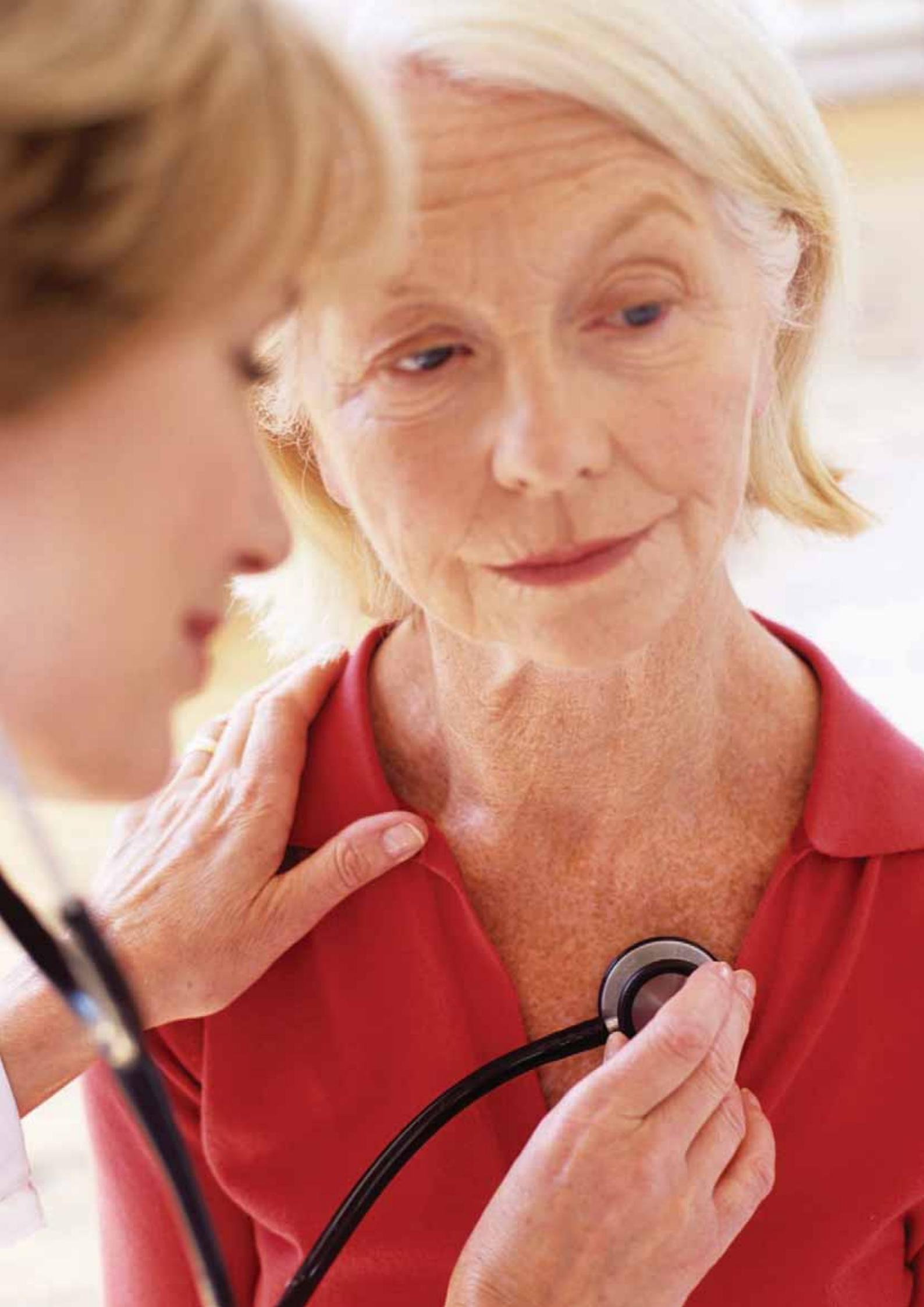
We will work to improve the response to dementia in general hospital settings, including through alternatives to admission and better planning for discharge.

63 Currently, all too often, an emergency admission of a frail person with dementia into a busy general hospital can be disabling. Admission to a general hospital can have a significant impact on a person with dementia. For some it might be the first opportunity for their dementia to be recognised. For others, how staff in hospitals plan for and provide care and treatment that takes account of the person's dementia will affect the quality of the outcome of the treatment and the chance of the person requiring higher levels of care once they are discharged.

64 A person with dementia should only be admitted to hospital when the necessary treatment cannot be provided where they live. A person's health and social care needs should, where possible, be met by health and local authority services in the community, so that the person with dementia is not subjected to unfamiliar surroundings and people. Being in hospital can cause stress and anxiety for anyone; for a person with dementia whose ability to reason and remember is impaired it is particularly difficult and can significantly impact on their ability to function.

The Enhanced Assessment and Support Team in North East Fife is a jointly-funded health and social work team which provides community assessment and short-term care to older people with dementia and mental health difficulties as an alternative to hospital admission. The team provides rapid, co-ordinated comprehensive assessment and care management services and is a viable alternative to hospital-based psychogeriatric assessment and treatment for many people. The team operates a 7-day assessment and out-of-hours service and is based in a local health centre with excellent links to primary care and community staff. An initial evaluation of the service demonstrated improved outcomes for people and their carers, a reduction in inpatient beds, length of stay and day hospital attendances and a reduction in admissions to care homes.

North Lanarkshire Council and NHS Lanarkshire have developed an integrated day service model which provides assessment, treatment and support to older people with dementia and complex care needs. The service helps support appropriate discharge planning and prevents avoidable re-admissions. The service has the capacity to operate over 7 days and at evenings according to need. A positive evaluation was undertaken in 2008 and the model has been extended across North Lanarkshire.



65 When admission to hospital does happen, whether planned or on an emergency basis, the hospital environment and the care and treatment the person experiences need to meet the standard expected for any patient and to be appropriate for somebody with dementia. This includes making the physical environment of the hospital more dementia-friendly, minimising the number of times a person has to move beds, and importantly ensuring staff knowledge about how to meet the needs of people with dementia.

66 Hospital staff need to know who has dementia or a cognitive impairment, in order to provide the best care and treatment. There are two elements to this. We need to improve assessment of people admitted to hospital who might have dementia or a cognitive impairment. This is particularly so where somebody is admitted in an emergency, for example through A&E.
We also need to ensure that where someone with a diagnosis of dementia is admitted to a general hospital, information about the person's diagnosis and needs is communicated to staff and built into the care planning process.

67 Where somebody is admitted to hospital who does not have a diagnosis of dementia, or where the information is not available, for example, in an emergency, and staff suspect that the person could have a cognitive impairment, an assessment should take place once the person has received emergency treatment for their medical condition and is stable. It may be that information may be available from the person's carer.

68 Planning a person's care, whether they have an existing diagnosis of dementia or whether dementia is suspected when they arrive at hospital, is essential to getting the best possible outcomes. This includes multi-agency planning before somebody is admitted to hospital so hospital staff have the right information about the person's needs and preferences to ensure that they get the right care while they are in hospital, through to planning the support that is required to support the person and their carers when they are discharged from hospital.

Hospital staff need to know who has dementia or a cognitive impairment, in order to provide the best care and treatment

69 It is currently common for people with dementia to be discharged from acute hospital care directly to a care home. The likelihood of their then being able to return to their own home or a more independent home setting is vastly reduced. When someone with dementia who was living at home is discharged from hospital, facilitating a return home should be the starting point. Planning for discharge needs to be designed so that decisions about a longer-term approach to care are not taken immediately. There should be an opportunity for the person to recover from their hospital stay and regain abilities before any decision is taken about long-term care. There should also be an assessment of the needs of their carer. Intermediate care provides models of how services can be designed to help people make the transition from hospital to return home.

In Edinburgh some home care services have already been redesigned to focus on 'reablement' which aims to assist people, including people with dementia, to regain life skills and independence following illness, admission to hospital or a deterioration in the person's condition.

70 There is significant scope for improvement in this area. In particular, the work on change set out below will focus on:

- Improving the assessment of people who might have dementia who are admitted to hospital including through A&E;
- Improving patient information systems so that staff have good quality information about a person's diagnosis of dementia which can be used to plan the person's care;
- Ensuring staff have better information about the person, including their likes and dislikes and routines; this should be provided to the hospital when a person with dementia is referred so that hospital staff will be able to work with the person, not just the diagnosis;
- Reducing unnecessary admissions of people with dementia (but being careful not to discriminate against people with dementia who would benefit from admission) and facilitating timely discharge;
- Better forward care planning with and for people with dementia during admission;
- Better assessment, treatment and management in hospital of frail people, who may have multiple health problems, who have suspected dementia; and
- Improving access to telecare, intermediate care services and reablement.

71 A number of the supporting change actions are directly related to this area of activity, and progress in making improvement will be picked up directly in the implementation and monitoring arrangements.

Actions to Support the Change Programme

I. Common Standards of Care for Dementia

We will develop and implement standards of care for dementia, drawing on the Charter of Rights produced by the Scottish Parliament's Cross Party Group on Dementia.

72 Many of the recommendations produced by the work streams focused on the quality of care and the experience of care. Often expressed in the language of rights, there was a demand for a greater common understanding of what comprises good quality care. Recommendations covered all locations and stages of the dementia journey. While some recommendations were generic, such as the focus on personalisation, others related to a particular point on the journey or setting; for example, the proposal that psychoactive medication should be a last resort and not the first approach to challenging behaviour.

73 We propose to develop standards for quality of care to cover all stages of the dementia journey and all care settings. These standards will be used both as a focus for improvement activity and as the basis for scrutiny by the new health and social care scrutiny bodies and the Mental Welfare Commission for Scotland. They will be publicised widely and form the baseline for quality care.

74 The standards will build on and embed the Charter of Rights of People with Dementia developed by the Cross-Party Group on Dementia and build upon the existing legal rights and protections, including the Millan Principles, which form part of the Mental Health (Care and Treatment) (Scotland) Act 2003.

75 People with dementia and their carers will be directly involved in the development of the standards. This work will be externally commissioned shortly and completed to a timetable to be agreed, but with a completion date in 2011.

II. A Skills and Knowledge Framework for Dementia

We will improve staff skills and knowledge in both health and social care settings.

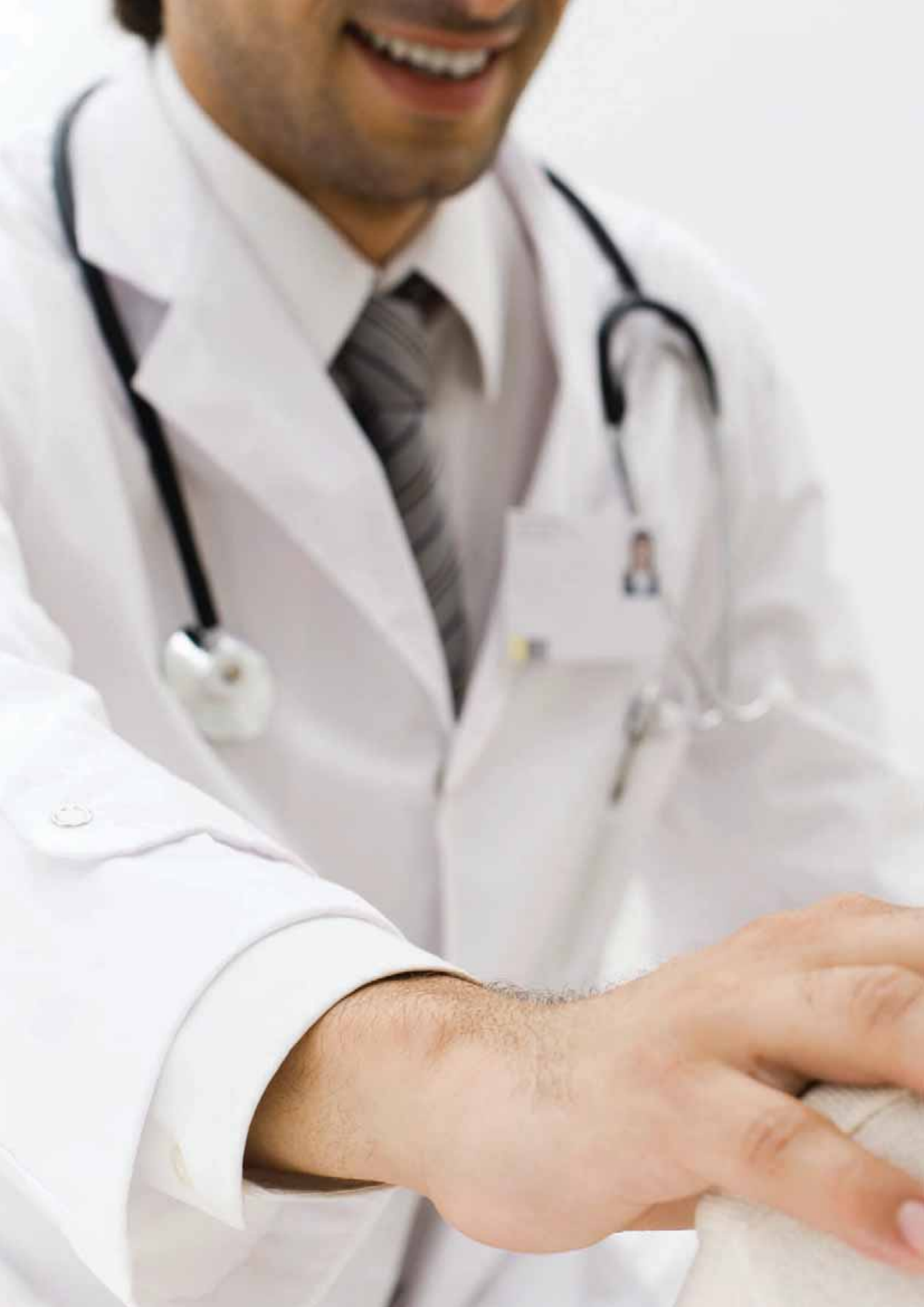
76 Staff working with people with dementia need to have the right set of skills and knowledge in order to deliver services in a way which treats people with respect and dignity and which improves their quality of life and wellbeing. Each of the Dementia Strategy Workstreams identified training as a significant issue. Again, as with quality, there was a range of recommendations that related to this issue which covered many aspects of service and many parts of the workforce. In addition, the engagement and consultation events flagged up problems associated with poor knowledge or skills which meant that staff in different settings did not always provide services that take into account the individual needs of people with dementia. This was not a criticism of staff and staff themselves were often clear in their views that additional training and skills would enable them to better fulfil their role effectively and to the standard that they wanted to achieve.

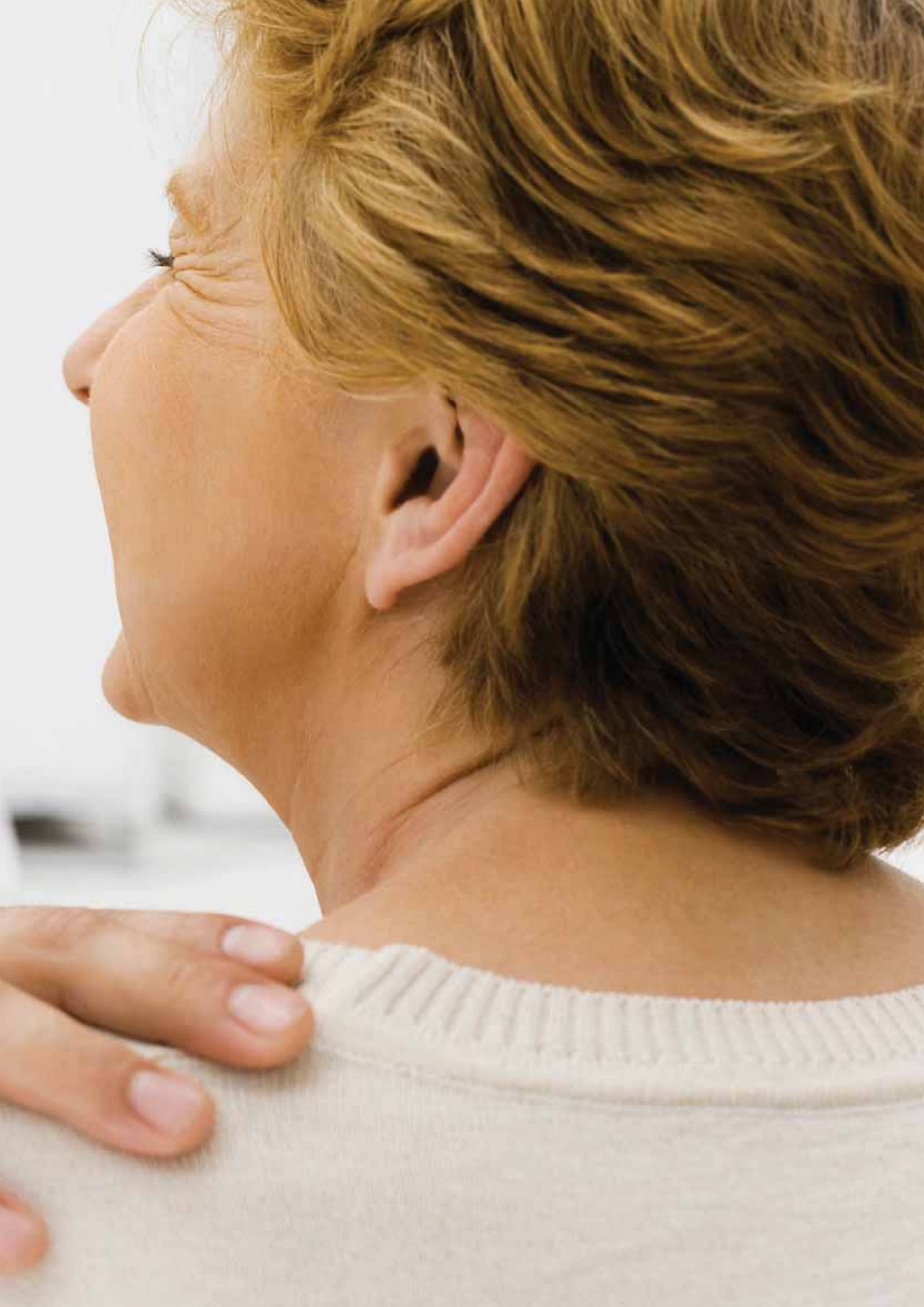
77 We will develop a framework which sets out expectations of the knowledge and skills expected of workers in different settings, not just those who provide specialist dementia services. This will provide the basis for revising qualifications and developing specific training to fill gaps and to inform leadership development. Developing such a framework is a necessary first step to enable us collectively to decide how to make the improvements to the skills and knowledge of staff that are required. It will also allow us to identify the areas which will have the greatest immediate impact so that they can be prioritised.

78 This work will be taken forward in two stages.

First, we will establish a common understanding of what the baseline knowledge and skills in respect of dementia should be for each particular role (for example A&E nurse or generic social care worker). The description of the required knowledge and behaviours would be relatively short for each role, but should make the links to the impact on how services are delivered. This work will be taken forward by NHS National Education Scotland and the Scottish Social Services Council working together under the guidance of a project board chaired by the Chief Executive of Alzheimer Scotland and completed to a timetable to be agreed, but with a completion date in 2011.

Secondly, we will develop a plan to ensure that people have the appropriate knowledge and skills. This is likely to include embedding new competences into existing frameworks and continuous professional development structures, as well as developing new training opportunities and requirements.





We will also want to measure the impact that investing in staff development has on the quality of outcomes for people with dementia

79 We will also want to measure the impact that investing in staff development has on the quality of outcomes for people with dementia.

III. Integrated Support for Change

> We will provide support for local service change and pilot an integrated change programme in one area of Scotland.

80 Our objective is to produce transformational change across the health and care system that goes beyond changes to elements or parts of the system. We have existing support programmes in place that work with health and social care providers, but we want to develop an approach which enables us to provide change support in an integrated way across all sectors and services and to track the quality and economic impacts of change.

81 We intend to take forward a project focused on a particular geographical area and involving an NHS Board anda local authority to explore the impact of a whole system redesign project looking at the dementia pathway. The pilot will:

- Use a 'strategic lean' approach (lean is an improvement methodology to reduce waste and duplication, improve patient flow and reliability of clinical processes) to map and analyse the entire dementia pathway to identify priorities for improvement action across key partners;
- Use both incremental approaches to change as promoted by collaboratives (these are relatively small changes which build improvements into existing systems and which can often be implemented quickly) **and** step-change (bigger changes, which will be needed to release some of the resources from one part of system to another); initiatives and resources;
- Demonstrate in practice how the different national initiatives can link together at a local level to support improvement;
- Consider the streamlining of current national initiatives and resources;
- Develop practical ways to support partnership capacity to make effective use of resources and deliver service improvements;
- Produce an economic analysis of the impact of changes to assess the degree to which resources can be released to improve care and support in other parts of the dementia care system, taking account of the work already underway on the Integrated Resource Framework; and
- Aim to disseminate learning rapidly across the system–recognising that in most areas NHS Boards and local authorities are not coterminous.

82 We will invite interest from NHS Boards and local authorities with the objective of quickly identifying the pilot site. Once the site is identified, the pilot will begin immediately, with direct support from the Mental Health Collaborative and the Joint Improvement Team. Strategic decisions about rolling out the approach will be taken in due course.

IV. Improved Management and Outcome Information

We will improve the information systems that are in place so that people managing, delivering and scrutinising services have better information about service delivery and outcomes.

83 At the moment the information that we have to monitor, plan and develop dementia services is often poor. We have seen good improvement in local information sources and the use of information in connection with the current NHS dementia target. However, a constant theme throughout the development of the Dementia Strategy has been the need for better information on what is and isn't working. This has to include data on care outcomes, the experience of using services and the efficiency of service provision. Central to delivering this are:

- Information systems fit for purpose that enable collection and reporting on data across the whole system;
- At a national level, a system for producing relevant comparative information;
- Developing the skills of front line staff to use data in their day-to-day work to drive improvement;
- Developing the skills of analysts and managers to ensure effective reporting and interpretation of data; and
- Supporting outcomes-focused assessment, care planning and review such as Talking Points.

84 Some of this work will be taken forward through the development work on integrated care pathways, but unless we are able to address the many information gaps, monitoring the implementation of the strategy will not be possible.

85 The challenge here is similar to that in other mental health services and we have responded to that challenge through the development of the Mental Health Benchmarking Project. That work will be extended to include domains which are particularto dementia to enable the development of a dementia 'balanced scorecard' that takes account of both health and social care settings. The scorecard will address the five key challenges posed within the Strategy and reflect in its indicators the aspirations described in the Strategy. The scorecard will offer both national data and local data and will be a key data source for the Dementia Strategy Implementation and Monitoring Group.

86 This work will be completed by May 2011 and the scorecard will be operational by July 2011 (though some domains will be available earlier). The toolkit produced will be used by services to support the improvement agenda around dementia.

V. Continued work on Diagnosis

We will continue the work to increase the number of people with dementia who have a diagnosis as this improves access to services and support for people with dementia and their carers.

87 Since 2007 the NHS in Scotland has worked to increase identification of the number of people who have a diagnosis of dementia. Our estimate was that fewer than 50% of people with dementia were recorded as having a formal diagnosis. The number of people registered by their GP as having dementia increased from 29,761 in 2006/07 to 31,407 in 2008/09, an increase of 5.5%. From March 2009 to February 2010 there was a further net increase of 3290 in the number of people on the GP register. NHS Boards have local delivery plans in place to significantly increase performance to increase the number of people with a diagnosis of a dementia to 40,265 by March 2011.

88 Diagnosis is important as it is the gateway to effective care and support. Under the GP contract people with a diagnosis of dementia should get annual health checks and their carer should get an assessment of their needs. In many cases diagnosis also allows for drug treatment with cognitive enhancers which are reported by manyto offer a benefit.

89 There is a number of challenges in trying to increase the level of diagnosis of dementia and in meeting the HEAT target. NHS Boards, local authorities and others are having to tackle a range of problems, including the reluctance of people to come forward, because of fear or lack of knowledge, the reluctance of some general practitioners to diagnose people and the efficiency and availability of local diagnostic systems, such as access to memory clinics or secondary specialist services.

90 The current target is due for delivery by March 2011 and we are confident that the national Scotland target will be achieved. However, continuing work on diagnosis is required and we will build that into the monitoring arrangements for the Strategy.

VI. Better response to behaviours that staff and carers find challenging

91 Many of the criticisms of services that were in *Remember I'm Still Me* focused on the poor response in residential care settings to behaviours that staff and carers find challenging, in particular the inappropriate use of medication. The problems identified are not limited to care homes. What is clear is that we must find better ways of working with these issues, that both equip staff with better skills and knowledge of how to work differently and consider how systems and services are structured.

We will ensure that people receiving care in all settings get access to treatment and support that is appropriate, with a particular focus on reducing the inappropriate use of psychoactive medication.

92 First, we must promote positive care to prevent behavioural issues from arising or reaching a crisis point in the first place. This includes ensuring that both family carers and staff understand how best to support people with dementia and the reasons which may underlie particular ways of behaving. There are many factors which can influence the behaviour of someone with dementia, including the behaviour and understanding of other people, the environment, physical discomfort or pain, boredom, frustration and misperceptions. Good communication skills and appropriate support in a good environment can help, as can ensuring that the person with dementia is able to enjoy purposeful and rewarding activities and the opportunity to be physically active. It is important to support carers both through training and information and with respite to give them time away from active caring responsibilities.

93 Secondly, where is it not possible to prevent a behavioural issue from arising, therapeutic approaches should be explored as the first line of intervention rather than drug treatment, with the emphasis being as much as possible on maintaining daily living. This requires both a change of mindset and in many cases new skills focused on direct work with people with dementia and carers. This means that locally there needs to be an awareness of available support resources and how they can be accessed.

94 This is a key focus area for standards (as mentioned above) and perhaps also for further guidance building on SIGN guidance. It also links into the data collected for Integrated Care Pathways, as considered below. We recognise the scale of the challenge in moving from a system that routinely uses psychoactive medication to address behavioural symptoms to a system which prioritises therapeutic care.

95 Thirdly, psychoactive medication should only be prescribed as a last resort after a comprehensive assessment and consideration having been given to the range of care approaches. When it is prescribed, its use should be reviewed frequently. Appropriate pharmaceutical care and safe medicines management systems need to be available to all settings. There is likely to be a link with the work on standards, with the proposal that there should be national standards on safe prescribing, monitoring and administration of medicines to those in care homes and receiving care at home.

96 Work is also required to improve compliance with the legal framework, in particular Part V of the Adults with Incapacity Act, to ensure that where a person with dementia is given medical treatment his or her capacity to consent is properly assessed. Where people do not have capacity to consent the appropriate consideration must be given, including consultation with carers, and the documentation completed.

97 To drive forward this work to improve the response to behaviour that people find challenging we intend to conduct a baseline assessment of the use of psychoactive medication for those with a diagnosis of dementia. This strategy is making a commitment to a reduction in the level of prescription during 2011 and a further reduction for future years. Progress will be monitored by the Dementia Strategy Implementation and Monitoring Group.

VII. Accelerated Implementation of the Dementia Integrated Care Pathway

We will improve the management of care for people with dementia through faster implementation of the dementia care pathway, with a particular focus on diagnosis and responding to behaviour that people find challenging.

98 In 2005 the Scottish Government made a commitment to introduce standards for integrated care pathways (ICPs) for five of the main mental health diagnoses, including dementia. The ICPs for mental health standards have four main elements:

- Process standards: describe the key tasks which affect how well ICPs are developed in a local area;
- Generic care standards: describe the interactions and interventions that must be offered to all people who access mental health services;
- Condition-specific care standards: build on the generic care standards and describe the interactions and interventions that must be offered by mental health services to people with a specific condition;
- Service improvement standards: measure how ICPs are implemented and how variations from planned care are recorded and acted on.

99 Those standards were published in December 2007 and NHS Boards have been working to implement them since then, with first stage accreditation being achieved by all NHS Boards in 2009.

100 The dementia ICP standards focus on key elements of the dementia journey: post-diagnostic support, assessment for therapies and other treatments and managing challenging behaviour. To accelerate implementation of dementia ICPs during 2010/11 NHS Boards will begin to collect data in relation to particular components of their local care pathways, including:

- Data in relation to Standard 14 – that the diagnosis has been explained to the service user and informal carer and that information has been provided;
- Data in relation to Standard 15 – that the suitability of the person for a psychological or psychosocial intervention has been assessed (with further data on service provision to enable us to know how long people have to wait);
- Data in relation to Standard 28 – that a structured and systematic response has been provided where there are behavioural or psychological dementia symptoms (commonly known as challenging behaviour).

101 The data needed for Standard 14 also relates to the provision of post-diagnostic support, which goes beyond the provision of information. As the work on post-diagnostic support develops we will embed this within data collection systems.

VIII. Continued action to support dementia research

We will continue to support world-class research into both medical treatments for dementia and the delivery of care for people with dementia.

102 The Scottish Government recognises that people with dementia and their carers have a major role to play in bringing about change in dementia prevention, treatment and care by becoming partners in research. People with dementia and their carers can:

- bring their expert knowledge of how they experience the condition to the partnership with professional researchers;
- give voice to what they see as the priorities for dementia research; and
- become directly involved by participating in research.

103 The Scottish Government established the Dementia Clinical Research Network for Scotland from August 2008, with over £1 million of funding. The Scottish Dementia Clinical Research Network, together with Alzheimer Scotland, seek to enable people with dementia and their carers to become partners in research, including the opportunity to participate in early studies of potential treatments.[1]

[1] People in Scotland interested in participating in research on dementia can leave their contact details with Professor John Starr, Director of the Scottish Dementia Clinical Research Network, Royal Victoria Hospital, Edinburgh, 0131-537 5023.

Monitoring Implementation of the Strategy

We will put in place robust arrangements to ensure delivery of our agreed commitments and to enable us to track and monitor improvement in outcomes over time through the establishment of a Dementia Strategy Implementation and Monitoring Group which will report annually on progress and review the Strategy by June 2013.

104 We have made a clear commitment to action in respect of dementia and have identified key changes, some of which are already under way and others which will begin as a consequence of this Strategy.

105 While there is a shared commitment to take forward transformational change, the actions and objectives that will deliver that change cross a range of service areas and organisations with different governance and accountability arrangements. Few key changes or improvements are the responsibility of a single organisation.

106 We will put in place robust arrangements to ensure delivery of our agreed commitments and to enable us to track and monitor improvement in outcomes over time. To do that we will convene a Dementia Strategy Implementation and Monitoring Group. The Implementation and Monitoring Group will be chaired by the Scottish Government and include representatives of key stakeholders, including those from the statutory, voluntary and private sectors, the new scrutiny bodies, as well as people who have dementia and their carers.

107 The Group's key tasks will be to:

- Ensure delivery of the eight Actions to support the change programme, including being responsible for considering next steps in relation to particular actions, such as the work on knowledge and skills.

- Monitor the impact of public sector funding pressures on the capacity of partners to deliver on those commitments within the dementia strategy that have a potential resource implication.

- Establish a monitoring framework which is valid both nationally and locally to track change and improvement over time in respect of dementia services. The framework will build on the benchmarking work set out above and where possible will be based on existing data sources or data which is provided through the benchmarking work. It will take account of items such as:
  - The number of people with a diagnosis;
  - The number of people receiving post-diagnostic information and support;
  - Reductions in unnecessary admissions to general hospitals and reduced period of admission for those for whom it is appropriate;
  - Reductions in the use of psychoactive medication;
  - Compliance with Part V of the Adults with Incapacity Act;
  - Increases in social and community activities, including physical activity; and
  - Improvements in the experience of people with dementia and their carers.

- Prepare an Annual Report on progress to be published in June 2011 and June 2012.

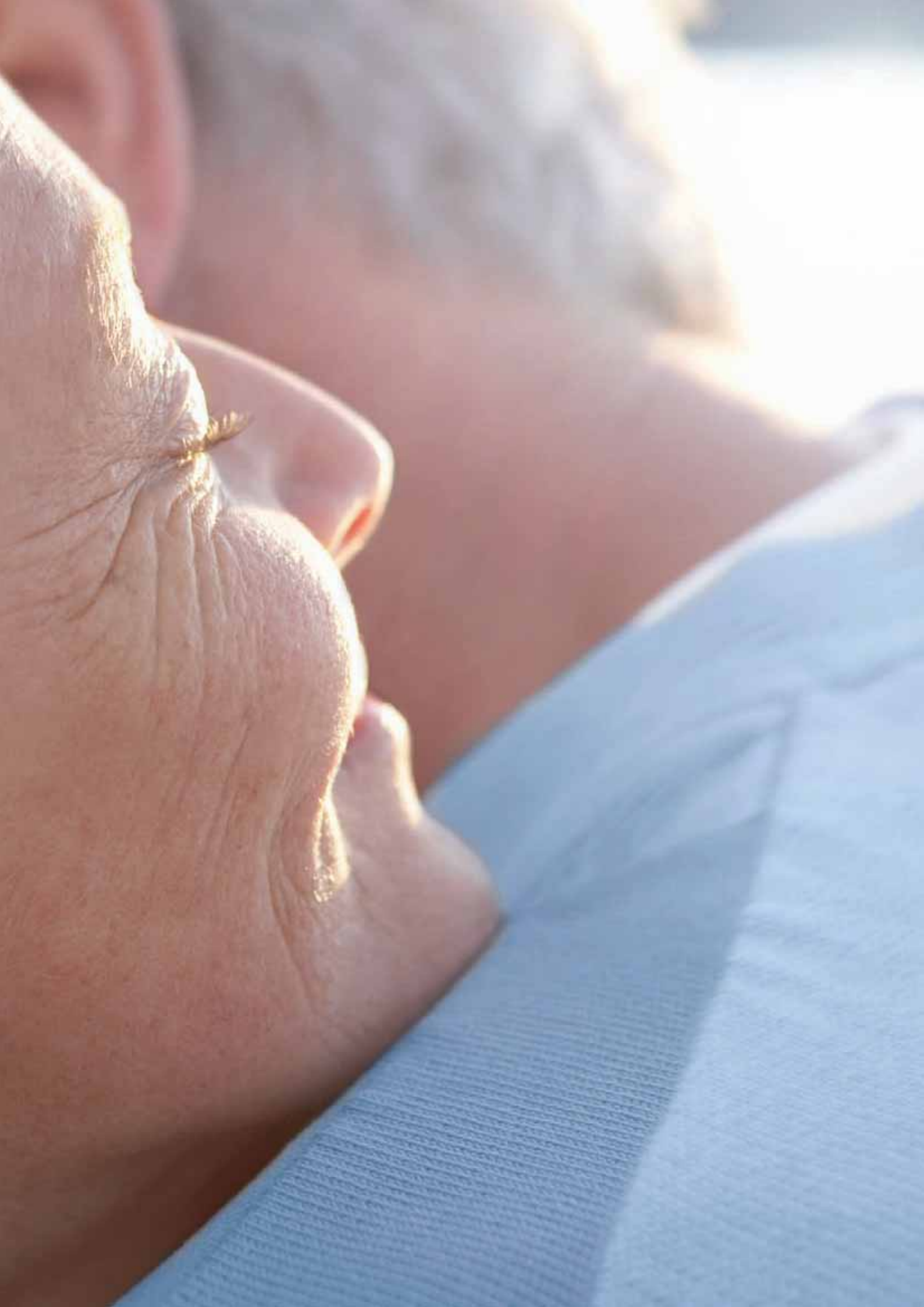
- Commission a revision of the Dementia Strategy, which takes account of progress and learning, to be in place from June 2013.

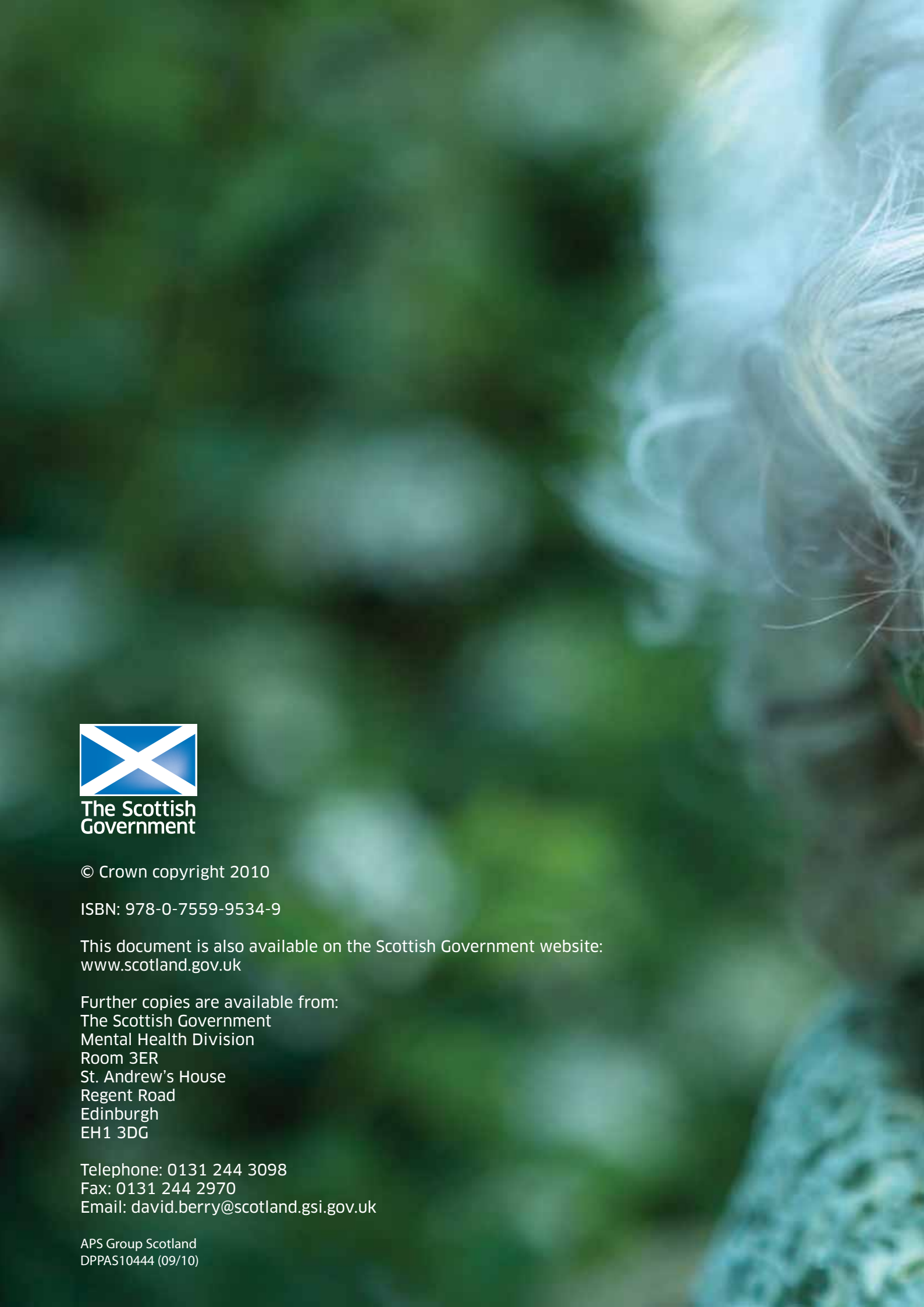
108 The Group will set a timetable for its work, but is likely to meet 3-4 times a year. It will publish progress minutes, papers and reports on the Scottish Government website.

109 The Implementation Monitoring Group is an additional national structure to look at overall implementation. It does not remove the requirement for there to be local progress monitoring and performance management and it does not change the existing accountabilities of statutory organisations. Its establishment is a recognition of the shared commitment to change and the fact that transformational change will only be possible as a collaborative process.

110 The Implementation Monitoring Group will provide reports on progress and issues to the Ministerial Strategic Group for Health and Social Care which is chaired by the Minister for Public Health and Sport.

111 The Dementia Forum, which includes representatives of a wide range of partners, will continue to meet as a broad-based stakeholder group on a regular basis and receive reports on implementation of the Strategy.





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