One Person
One Team
One System

One Person

supported by people acting as

One Team

from organisations behaving as

One System

Foreword

One Person, One Team, One System

The creation of the NHS is arguably the best gift that the British people have ever given to themselves. For the British public it is our most important institution. Its basic principle of health care, free at the point of delivery, with equal access for all, is part of the soul of the nation. However the loyalty inspired by that principle generates an attachment to a model of health and care that might threaten its very future. The preservation of that basic principle demands change.

In 2014 the NHS is facing a very different disease challenge from the one that existed at its inception in 1948. Broadly, the main challenge in 1948 was infectious disease; now it is people with multiple long term conditions, poor mental health, disabilities and frailty. Over two thirds of the money spent by the NHS and social care is on this group of people, who for the most part (but by no means exclusively) are experiencing the diseases of old age. Most people over 65 have more than one long term condition, over 75 two or more. In short you collect more as you get older. Sometimes people's problems are just a consequence of getting very old. Good care for these citizens requires us to look at them and their health and care needs as a whole. Yet in many ways the health and care system still behaves very similarly to that of 1948; based on hospitals and focused on specialties that look after a person's body parts, not the person as a whole.

To understand the consequences, I encourage readers to think about the case of Mrs P that is set out fully in chapter 1 of this report. To summarise, Mrs P is widowed and lives on her own a few miles away from her daughter. She is 85, has breathing problems, high blood pressure and diabetes.

In a good month (without an emergency visit), she will see ten different professionals from the health and social care world – each of whom has a specific task. Most of her days are spent waiting for someone to come and carry out some care.

The value of each intervention doesn't last much longer than the visit itself, because no one is making these interventions add up to more as a whole. Mrs P is a sick woman, but her life is not only dominated by her ill health – it is also dominated by fragmented health and social care.

Last year Mrs P went to A&E five times, and on two occasions she had to be admitted to hospital for breathing trouble. Both her periods in hospital came about because the various elements of care did not help to identify early deterioration. In total she spent 30 days in hospital in emergency beds. This is what happens to millions of people as a result of our fragmented system of care. It would be better for Mrs P if she saw fewer people who were better coordinated and better informed about her care and health. Many of us can bring to our mind people we know who have similar stories.

What people with multiple conditions and complex needs say is: 'I want you to care for the whole of me, and act as one team'. This is what we require commissioners and providers of health and social care to achieve: **the needs of one person addressed by people acting as one team, from organisations behaving as one system**. This starts with a conversation – listening to what you really want and takes account of your physical health, mental health, functional needs, environment and degree of empowerment. An integrated team from health and social care works with you to achieve the outcomes you wish for, with an overriding aim to help you maximise your independence and improve your overall wellbeing as a human being.

This includes the information and support to co-manage your conditions wherever possible. There are no multiple teams involved; specialist knowledge is pooled to achieve the outcomes that matter to you. There is a single designated person to help coordinate your care and act as your advocate in the system. The home is made a safe care environment. You, your carers, families and communities are seen as partners.

Recent reforms have further fragmented the services for people, taking us in the opposite direction. New competition rules impede necessary changes, for example in cancer provision or primary care, and the loss of knowledge from experienced people leaving the health and care system has created a form of organisational dementia. Front line organisations face a Hydra like array of accountability arrangements, yet with no clear strategic leader. Social care has faced the most devastating cuts, impacting on the independence of people but also the wider system. It also cannot be correct that 'doing the right thing' for people and a local care economy, by reducing hospital admissions and attendances, risks subjecting those hospitals to a failure regime.

We can all celebrate the success of rising life expectation. Yet because most of us are living longer, the next fifty years will see a growth of at least two and a half times as many people suffering from multiple problems. Unless action is taken, by 2020, the maintenance of the current level of service provision could require over £30 billion across health and social care (assuming no alteration to eligibility for free social care). This is as much as we spend each year on defence. Status quo is not an option.

This document is the outcome of 10 months' work by the Independent Commission on Whole Person Care set up by the Shadow Secretary of State, who will receive the report. Members were not chosen for any political allegiance, but their knowledge and expertise. The findings are based on the organisational arrangements in England, but the principles are applicable elsewhere.

The case for fundamental change to reflect the different population in 2014 and the care challenge is detailed in the first part of this report. This case is most strongly voiced by people themselves – for example the narrative describing person-centred, coordinated care developed by National Voices. The Commission believes we can only create a sustainable health and care system if there is a new compact with the citizens of the country for the longer term. However a new radical approach is needed for the next parliament to put the health and care system back on track.

The emphasis of this report is recommendations for an incoming Government in 2015. They are built on three themes: giving meaningful power to people using the health and care system; reorienting the whole system around the true needs of the population in the 21st century; and, addressing the biases in the established system that prevent necessary change happening. For too long health and social care have been considered separately. They are inextricably linked. However we do not believe the answer includes yet another major structural reform at this time. The scale of recent reforms so damaged the NHS and care system that we believe it would not survive intact from a further dose of structural change. We are not saying that the current structures are right, or that they won't need to change in the future – they aren't and they will. We reflect some of that in our recommendations on national organisations. However, relationships and culture trump structures. We should not focus now on what the structures are, but the relationships among them, the people who work in them, and what they do. This is the essence of care and what really matters. These changes may not be as tangible and headline grabbing as scrapping and creating organisations. Arguably they are, taken together, more radical.

Our recommendations tackle deeply ingrained practices and biases within the system. They are issues that have been impervious to the many reforms of the NHS, but have also often meant little change to the day to day experience of people using health and care services despite the large scale of a reform process. At the heart of our report is looking at health and care services holistically, with the person, not the institution at the centre. It recommends a set of policies that will focus on helping people stay well, manage their illnesses and promote their independence; it will suggest how payments to different providers of care can be aligned to encourage them to put the people's interests first; and, it will encourage health and social care to work in partnership for their communities, without proposing expensive and distracting structural reorganisations.

The evidence we outline is clear. Such an approach enables the necessary move to more care at home, including specialised care. People are much less often subjected to the trauma of unscheduled admissions to hospital, and adverse events, such as falls, are less likely to happen. This is better for the individual, but also more efficient for the system as a whole. These are not new ambitions. Many health and social care reforms have had such aims at their heart, and yet their delivery is not realised, largely because they treat health and social care separately and structurally. We believe our recommendations are more comprehensive – whole system change for whole person care. They also recognise flexibility needed for different parts of the country, and include the

dismantling of some of the most protected barriers to change which have hindered previous reforms. We think they are deliverable by 2017, and certainly within the lifetime of the next Parliament.

The longer term response to the scale of the care and financial challenge I outlined at the beginning of this foreword needs an honest dialogue with citizens to reshape the health and care system. We recommend an independently conducted National Conversation backed by all major political parties on the scope, provision and funding of health and social care as a single issue, to be completed within 12 months of the next general election. The conversation will recognise the need for a fundamental holistic agreement with the country on what health and social care should be, how and where it is delivered to maximise the quality of care, and how it should be paid for. We envisage a process not dissimilar to the preparation that went into the NHS plan before its publication in 2000, but with the meaningful involvement of citizens.

Our recommendations need to be viewed themselves as a whole integrated set of proposals to begin recalibrating the health and care system around that whole person view. They are not 'pick and mix'. They are a renewed, determined shift along the journey to a solution to the challenges, and provide hope. They are also not a final word. We have not been able in this report to cover children's care and end of life care, both important areas for whole person care. However I would also like to think that our recommendations help reignite a shared purpose for all people working in the health and care system – care – and that the system operation and incentives we propose will keep people healthier and out of hospital.

We are trying to help millions of people lead better lives. Each of them is an individual and to explain our vision of how a better system would work I return to the case of Mrs P. The report considers how her life would improve if health and social care services adopt the whole person approach.

The key outcome important to Mrs P is for her independence to be maintained. To achieve that outcome, a contract is agreed with her health and social care providers. Let's imagine how it works. Every three months Mrs P and her daughter are asked if they feel that her independence has been better maintained under this contract than before. They are also asked for suggestions for outcome measures important to Mrs P for the next three-month period.

In order to ensure Mrs. P's independence, the accountable lead provider is incentivised to ensure that care is coordinated in such a way that will make her home, herself and her daughter capable of dealing with the high need that she has. This will be achieved by each social and health carer being expected to work with each other to increase the ability of Mrs. P, her daughter and her home to work with that level of high need. Each input is aware of the previous episodes of care and what the next will be; the total inputs are coordinated to achieve the outcomes that matter to Mrs. P. Information is shared and accessible by Mrs. P or her daughter.

Mrs P will still be a woman who is quite ill, but she will now expect that all of the care that she receives will add to her and her daughter's capacity to stay at home. Her care advocate works directly to her GP and ensures that every health and social care professional works to a proactive plan, developed in collaboration with her and her daughter. Her GP liaises regularly with a consultant geriatrician who has the capacity to work with the range of other specialists for her conditions in order to construct an overall continuum of care, where each specialist knows they have to work with another to deliver the best outcomes for her. Every professional who goes into Mrs P's home has a responsibility to provide both specific care, but also to place that care within the broader aim of maintaining the whole person's independence. Mrs. P has not had a hospital admission in the last 12 months.

This is a realistic expectation for the many people in the country like Mrs P. It will be achieved when organisations behave as one system, people within them as one team, all working towards goals set with the individual person.

Acknowledgements

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The case for change

- Our patterns of need have changed much faster than our health and care system has been able to change. Our population is ageing, and many people are now living with long term conditions, disabilities and frailty. The number of people living with multiple long term conditions is set to grow substantially.

- People want coordinated services which work together around them, but are often left frustrated by the fragmentation of health and care services and the problems that this causes for them and their families.

- People are interested in their lives rather than health and care services, and it can be easy for policy and policymakers to miss what matters most to ordinary people. Older people in particular emphasise the importance of their independence.

- Policy tends not to recognise the realities of care. Most care is delivered by people themselves and their families. Most clinical care is delivered in primary care. Hospitals are overflowing with people who don't want to be there and who could be cared for just as well in the community and at home if the services were available. Yet despite decades of notionally 'patient focused' and 'primary care led' policy, acute hospitals are still the magnet towards which people are drawn. This is bad for people, bad for quality of care and ultimately unaffordable.

- Social care services are under more strain than any other part of the system, with many people across the country increasingly (and inconsistently) finding themselves unable to receive support.

- Overall it is clear that our health and care needs as a population are changing, and the increasingly fragmented health and care system needs to change to meet this need. Care needs to be better coordinated around the whole of a person's needs, particularly for older people and those with long term conditions and complex needs.

- Lessons need to be learnt from examples of more coordinated models of care in action. We believe achieving a shift towards coordinated, person-centred care requires a fundamental shift in the way that health and care is delivered, and can't be achieved within the existing fragmented system.

- This policy report looks at health and care services holistically, with the person, not the institution, at the centre. It proposes a set of recommendations that will focus on helping people stay well, manage their conditions and promote their independence; it suggests how incentives can be aligned across health and care organisations to encourage them to put people's interests first; and, it encourages health and social care to work in partnership for their communities, without proposing expensive and distracting structural reorganisations.

The provision of care

- Any government in 2015 must facilitate the growth of new forms of coordinated provision. Providers of health and care need to work together to provide a more coordinated approach to meeting the whole of a person's needs, based around the outcomes that matter to those people using the services.

- A number of different provider models are developing to deliver coordinated care. These models often focus on working together to coordinate care for key segments of the population – or being accountable for the care of whole local populations, such as the Alzira model in Valencia.

- Local flexibility in creating these provider arrangements must be encouraged. What makes sense in inner city Birmingham is not likely to make sense in Cornwall. Health and care regulators must allow locally determined changes to services based on collaboration to happen, placing considerations of care firmly before those of competition. Citizens must have a meaningful say in the design of services in their area.

- Extended primary care services will be a central part of this new form of provision. Primary care systems in England will need to extend the scope and range of their activity to provide more coordinated services for people in the community and at home.

- Whatever its form, this type of provision must recognise the importance of the person and their own home as a central part of that provision, and must support people, their families and carers for the majority of the time that they manage on their own. Access to smart technologies to support people in managing their own care and informing their decisions will be crucial. Technologies like Facebook, Skype and Whatsapp have allowed families to stay connected even when they are far apart. We recommend the development of the role of NHS Choices to create a personalised health hub that will enable families and friends to support each other through ageing and ill health, even when far apart. NHS Choices should be opened up to enable entrepreneurs to leverage its content to create websites and apps that meet people's demands in many different ways. It is time for the NHS and social care to join the 21st century.

- These new models of coordinated care will involve more care provided by services in the community. Yet we must equally recognise that services from local hospitals will be as necessary as ever – but they will also have to be necessarily different.

Getting the right people working in the right way

- Health and social care are people businesses. If the direct experiences of people using health and care services is going to change, then the way that those services are delivered will also have to change. Delivering the type of care which responds to our changing needs will require professionals acting as one team, who work with people to plan and coordinate their care to support them in achieving the outcomes that matter to them.

- People learning to work together doesn't happen by magic. It needs to be designed and planned into practice, research, guidelines, training, education, workforce planning and leadership development. This requires a substantial revision of existing arrangements: Health Education England, Local Education and Training Boards, professional regulators, leadership training, and numbers of generalists trained. We make recommendations in these areas to facilitate multidisciplinary working and joint training, including joint leadership training between health and social care.

- Training and education must also recognise that, for the majority of the time, people and carers manage their conditions on their own. Therefore support to assist people to co-manage their conditions whenever possible must become the default operating model – moving from doing things to people to with them.

- Caring for those people who care is also a vitally important aspect of care provision which often doesn't receive enough attention. It is essential that our health and care system is both one in which you would be happy for your loved ones to receive care, while also being one in which you would be happy for your loved ones to be employed and giving care. This doesn't just mean paid carers; informal carers in particular must get more support locally, some who are regularly providing care for more than 50 hours per week with little or no support, often at great cost to their own health and wellbeing.

Information solutions

- If whole person care is to work, then the ability to share information and data across organisations is crucial. Information governance is important, but it should be the servant of the process, not the master. The meaningful use of information must be embedded as a core part of the way that health and care functions and is commissioned.

- People should own and control access to their own health and care information, which should also be completely accessible by default by their GP. We believe that the development of person-owned electronic health and care records should be driven through national 'meaningful use' requirements – a set of standards governing their development and use.

- We include a proposed strengthening of the duty for providers to share this information across the health and care system. The assumption will be sharing to care, with citizen opt out. Most people receiving care assume this happens now – but it doesn't.

- If people really are to be involved in their care and in shaping their local services in a meaningful way, then the access to quality information is crucial. Access to people friendly information to enable informed treatment and care decisions, and transparency about the performance of local services is equally important. Technology and information is a great leveller of power gradients. Evidence shows that providing people with good quality information and engaging them in their own care can achieve better outcomes and lower costs. It also helps people to take greater control of their own care and their own conditions.

- Commissioners and researchers need access to better information to support integrated decision making. Accessing the right data and information to support commissioning and research can be made much easier and simpler.

- Commissioners must also prioritise the collection and use of information from people to help them commission for person defined outcomes, and these outcomes need to be accurately measured and reported. We believe that the separate national outcomes frameworks for health, social care and public health ought to include standardised generic measures that enable coordinated performance monitoring across health and social care.

Helping people stay as well and independent as they can

- Whole person care should not only include joining up services to respond to the health and care needs of the population, it should also involve a whole systems approach to supporting people to stay healthy in their minds and bodies throughout their lives – from childhood through to old age.

- There is a social gradient in both health and health inequalities. Tackling health inequalities requires action across society, but a particular emphasis must be placed on supporting children to give them the best possible start in life – particularly those from more deprived backgrounds. The range of services available to support children and their families – from health and care support to housing and benefits advice – should be better coordinated locally, particularly in areas with poor primary health care services.

- Older people also benefit greatly from targeted approaches aimed at maintaining their independence and wellbeing. A strong evidence base exists which tells us the kind of approaches which work for helping to keep older people well. These must be implemented in a coordinated way in all local areas to provide holistic care for this group of people.

- In all groups in society, the social and physical environment in which people live has a profound impact on their health, independence and wellbeing. While recognising that action is needed across a range of areas of policy and society, we target two key areas where policy approaches could work better to support people's health and wellbeing: obesity and housing.

- Most adults in England are overweight, and the increased risk of illness due to obesity is well documented. We believe that the current model of industry self-regulation has failed to adequately address the environment which can encourage unhealthy behaviours. A more effective policy approach must be developed aimed at addressing the challenge of obesity.

- There are over 1.3 million people who work in the NHS and a further 1.5 million people working across adult social care. The NHS alone is one of the biggest employers in the world. We recommend the creation of a national campaign to promote the health of the NHS and social care staff, where they are supported and encouraged to look after their own health, and where hospitals, care homes, GP practices and other workplaces become healthier places to work.

- In all groups in society, housing has a large impact on people's health and wellbeing. The current inflexibilities in the housing system need to be addressed so that the home environment can better support people with disabilities, complex problems and their changing needs. This is particularly important for older people, who currently face an almost binary choice between continuing to live in an increasingly unsuitable home, or entering residential care. We lag other countries in such provision. Progressive care housing is one preferred model.

Making the money work

- There will be a substantial funding gap in health and care over the coming years which must be faced by any government in 2015. Simply meeting demand for health and care services will be very difficult. This is the financial context for whole person care which we describe throughout this report.

- This care and financial challenge requires an honest dialogue with the citizens of the country. We therefore recommend the commissioning of an independent National Conversation, backed by all political parties, which would recognise the need for a longer term agreement with the people of the country on what health and social care should be, how and where it is delivered, and how it should be paid for.

- Such challenging times require each local health and care economy to provide collective system leadership to focus on whole person care. We believe revised and developed health and wellbeing boards, or analogous local arrangements, provide a locus for that leadership – which should include leading local providers.

- We believe that budgets need to be treated as a whole across health and social care: the 'locality pound'. This should be agreed by the health and wellbeing board, and form the basis of a jointly agreed commissioning plan for people with multiple problems, disabilities and frailty in that geography. Existing commissioners should have a responsibility to enact that plan.

- Existing payment mechanisms and the way the money flows around the health and care system need to change to reflect the needs of today's population. Commissioners must use new ways of paying for care which recognise all of a person's needs rather than separating them. We believe that episodic payment systems (the payment by results tariff in particular) must be replaced by whole person payment systems (a new capitation tariff) for people with multiple long term conditions, disabilities and frailty. Payments for providers should be linked to outcomes which matter to the people using the services, with incentives aligned across all providers involved in a person's care. Over time, this type of whole person payment system should also be developed for larger segments of the population. The commissioning of primary care should be aligned to these local goals.

- In some places, local relationships may advance to a position where there is a desire for there to be a formal single budget for health and social care, or Joint Ventures. We recommend the development of permissive legislation to allow this to happen where it is wished for locally.

The wider system changes needed

- If this vision for whole person care is to become a reality, there are a number of elements of the broader system which will need to change. In many cases these are unglamorous changes in the background of the health and care system. They are, however, changes which we think are needed to make whole person care the norm across England.

- We believe that the central structures of the health and care system must properly reflect the need for joint working that we describe throughout this report. We therefore make recommendations about the system leadership for whole person care, alongside recommendations for the development of an appropriate regulatory environment to help enable its development. This includes revising NHS England into a wider, more inclusive organisation involving local government – Care England – whose structure and functioning is better aligned to the true population needs.

- We recognise the need to strengthen community health and social care services for the system to be able to provide care focused on keeping people independent in their own homes. Central government needs to align responsibilities to help achieve this. We believe that a bridging fund is likely to be needed over the term of a parliament.

- The focus of the health and care system's research and quality standards must also reflect the strategic needs of the whole system. There is a paucity of research on people with complex needs, the true frontier of healthcare, despite £1 billion of public spend on clinical research. There needs to be a review of the decision making processes and prioritisation for public funded research. We also recommend the establishment of an internationally linked research centre for managing people with multiple problems and complex needs.

What would whole person care mean for you?

I shape my own care around the outcomes that matter to me

I, and my community, have a real say in our local services

I have one person acting for me to make the system work

I understand more about my problems, staying healthy, and what I can do for myself

I own my own health and care information, which is shared with my permission

My experience of a service matters to those who pay for it

I receive more care in my own home and the community

Everyone involved in my care knows my goals and works together as one team

The case for change

A. The nature of the problem

Across the developed world health and care systems face the problem that what they have to offer does not fit with the main needs of the population they serve. We face the same problem, which has arisen because our patterns of need have changed much faster than the systems have been able to change. Need has changed because of the success of health systems and social, environmental, and economic factors.

Changing needs

The driver of increasing need that is usually described first is the ageing of the population; the number of people in Britain aged over 85 increased from 416,000 in 1971 to over 1.1 million in 2009, and is expected to reach 2.6 million in 2032[1]. It is worth noting, however, that increasing life expectancy has been accompanied by increasing healthy life expectancy, although the length of unhealthy life has increased overall[2] – in other words, length of healthy life has not increased as much as total length of life. Analysis of the drivers of cost pressures facing the NHS over the coming years suggests the growth in demand for care because of long term conditions is at least equal to, if not more than, the pressure from a growing and ageing population in and of itself[3]. And on top of this pressure from the growth in demand, there will be funding pressures too from the rising costs of providing healthcare, such as costs of drugs and technology[4].

Older people use health and care services heavily. People over 65 consult general practitioners (GPs) five times more often than the average for the population[5]. They account for 62% of total bed days in hospitals in England, 68% of emergency bed days, and 80% of deaths in hospital[6].

The average age of people in hospital is over 80. More than three quarters of people receiving care in registered residential and nursing accommodation in England funded by councils are aged 65 and over, with 43% aged 85 and over[7]. Four of five people receiving community-based home-care services are aged 65 or over. The number of people aged 65 and over in England with care needs, such as difficulty in washing and dressing, has been projected to grow from 2.5 million in 2010 to 4.1 million in 2030[8].

People who would have died decades ago now remain alive but living with a long term condition. One in three people in England has at least one long term condition, and most people with a long term condition have more than one[9]. The number of people with three or more conditions is expected to increase from 1.9 million in 2008 to 2.9 million in 2018[10]. The prevalence of multiple long term conditions is strongly related to social class. Compared to social class I, people in social class V have 60% higher prevalence of long term conditions and 30% higher severity of conditions[11]. The poorest develop multiple long term conditions some 10 years before the wealthiest[12].

People with long term conditions currently account for half of all appointments with general practitioners, 64% of outpatient appointments, and 70% of all inpatient bed days[13].

About a third of people with long term conditions also have a mental health problem. These problems are interrelated in that people with long term conditions are more likely to develop mental health problems and those with mental health problems are more likely to have long term conditions[14].

It is not sensible to manage these problems separately, yet the present system that separates physical, mental, and social care does just that. Currently health care costs increase by 45% for a person with a long term condition and a mental health problem[15]. Among people over 65 admitted to hospital, 60% will have or will develop a mental disorder during their admission[16].

One of the commonest long term conditions is dementia. Around 800,000 people are living with dementia in the UK today. By 2021 this figure will have risen to over a million and will have grown to 1.7 million by 2050[17]. Four fifths of people in care homes live with dementia or severe memory problems, and one in three people over 65 will die with dementia[18]. The prevalence of dementia increases sharply with age, affecting 6% of those aged 65 to 69 but nearly two thirds of those over 95[19]. Around half a million people in Britain live in residential or nursing homes, with 92% of places provided by the voluntary or private sector[20]. About 43% of people in these homes fund their own care, and when 'top ups' are included around 57% contribute to the cost of their care[21]. In addition, some 185 million hours of home care are provided with 89% provided by the voluntary or private sectors[22]. Data on how many people are having to fund their own care are unreliable, but the best estimate is that some 400,000 people are paying for care[23]. Provision of advice to these people is poor.

The social care system depends on the input of unpaid family carers. 5.8 million people in England and Wales – one in ten – are providing unpaid care to family and loved ones. Of these, 3.7 million people are providing free care for between one and nineteen hours a week, with 1.4 million caring for more than 50 hours[24].

It is projected that by 2030 some 600,000 more older people will have significant care needs, the number of younger adults (aged 18–64) with learning disabilities will have risen by 32% to around 290,000, and the number of younger adults with physical or sensory impairment by 7.5% to 3,100,000[25].

Each year there are about 460,000 deaths in England[26]. We know little about how people die (as opposed to what they die of), but the suspicion is that many die badly. Certainly most people don't die where they choose to die[27]. 'Place of death' is used as a proxy for quality of dying. Almost two thirds of people would prefer to die at home and almost a third in hospices. A tiny proportion would chose to die in hospital but nearly 60% do die there[28].

What do people want?

Person-centred, coordinated care

One of the biggest frustrations experienced by people and their carers is the lack of coordination between the services that are there to help them. People want better coordination of services which work together around them[29,30].

This is often described as integrated care. Yet it can be confusing when people talk about integration and integrated care, as people don't always mean the same things when they use these words. One review of the literature found 175 definitions of integrated care[31]. In simple terms, integrated care is about coordinating services around the needs of the people who use them, and follows that those who plan and provide care must use the person's perspective as the organising principle of service delivery[32]. It may be better called person-centred, coordinated care[33].

National Voices, a coalition of more than 140 UK-based health and social care charities, have developed a first-person narrative to explain what the gold standard of this type of care looks like[34]. Its key points are as follows:

- I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me

- I am supported to understand my choices and to set and achieve my goals

- I work with my team to agree a care and support plan

- My care plan is clearly entered on my record

- I have regular reviews of my care and treatment, and of my care and support plan

- I have systems in place to get help at an early stage to avoid a crisis

- I always know who is coordinating my care

- I have one first point of contact. They understand both me and my condition(s). I can go to them with questions at any time

- When I use a new service, my care plan is known in advance and respected

- I know in advance where I am going, what I will be provided with, and who will be my main point of professional contact.

Older people's priorities

Older people are increasingly the main 'customers' of health and social care services, and a study of what people entering old age wanted emphasised two key priorities:

- to have services that enabled them to maximise and retain their independence;

- to be valued as individuals and not stereotyped because of their age[35].

Doctors may concentrate on length of life, but old people emphasise independence over length of life.

The conclusions of the study said[36]:

Many participants stressed the value of low-level preventative services, and wanted access to cleaning and maintenance as much as – or more than – they wanted personal care. Some wanted health and social care to be more coordinated, and felt that the division between these services was unhelpful from the point of view of the service user. The highest priorities of many participants were issues that are not conventionally viewed as 'care' services. They saw improved transport for all, and better leisure and educational opportunities, as essential underpinnings of effective care.

Another study of the needs of older people reminds us how easy it is for policymakers with their emphasis on services to miss what matters most to their 'customers'[37]:

Older people talk about their lives, not services. Thus someone may talk about the joys of seeing children and grandchildren, and yet about feeling lonely or not bothering much with meals since the death of a partner. Alongside this, they may have problems with practicalities – the payment of bills, getting the rubbish out in the proper recycling bins or putting drops in their eyes. 'We all want ordinary living', as one person commented in the end-of-project consultation.

Failures of present systems to meet changed patterns of need

Our present health and social care systems are fragmented, divided in broad terms into hospitals, general practice, community services, mental health services, hospices, and social care. Health care continues to be free at the point of delivery while social care is means tested and increasingly funded by those who need care and their families[38]. Most hospice care, while generally high quality, is also not for profit or charitable funded.

Hospitals provide types of care that cannot be provided anywhere else, although technical developments have meant that much care that could be provided only in hospital can now be provided in the community. This trend will continue. Yet about a third of hospital bed days are used for cases where admission might have been avoided by alternative treatment or care management[39]. The National Audit Office estimates that at least one fifth of admissions could be managed effectively in the community[40]. Deprivation is strongly linked to rate of emergency admissions that could be managed in the community and largely explains the considerable geographical variation in the rates of such admissions[41]. In other words, those who are the most deprived are being admitted to hospital because of the inadequacy of community services. Emergency admissions that could be managed in the community are increasing at a more rapid rate than emergency admissions that need hospital care[42].

The recent urgent care review shows that 40% of people attending accident and emergency departments are discharged requiring no treatment[43]. This does not mean that it was wrong for these people to seek care and advice, but it does suggest that in many cases the problem could have been dealt with elsewhere if the right services were available. The review also showed that about and up to half of 999 calls requiring an ambulance to be dispatched could be managed at the scene.

It's also important to remember that hospitals can unwittingly be dangerous places, particularly for older people with cognitive disorders. About one in ten people admitted to hospital experiences an adverse event, and a third of adverse events lead to moderate or greater disability or death[44]. Adverse events are roughly twice as common among those aged 65 are over compared with those aged 16-64[45].

About a third of people receiving care in hospital have dementia, and admission to hospital is disorientating for such people. Older people with dementia have the highest rates of adverse events, and admission to hospital may be a terminal event or make it difficult for the person to return to the community[46]. People with dementia experience prolonged hospital stays, 27% longer than others admitted who do not have dementia, and are more likely to be readmitted and die in hospital[47]. Many people over the age of 65 develop new dependencies in activities of living when admitted to hospital – some studies have suggested between 30% and 60%[48]. People with long term conditions also report worse care experiences in hospital[49].

The picture that emerges is that there are too many instances where people are having to come into hospital for care that could be better provided in the community.

There is also the well described problem of 'supplier-induced demand' with hospital care[50]. Hospitals and intensive care units once provided quickly fill up – like new roads and prisons.

It has been known for a long time that most health problems are managed by people themselves. It's a minority of problems that are presented to the health care system – and isn't necessarily the problems that doctors would regard as the most serious. Many problems presented to GPs are not 'diseases' recognised in medical textbooks but an amalgam of physical, social, personal, and family problems. GPs and their teams are adept at managing these problems, but relatively small changes in the threshold at which people decide to consult GPs or GPs decide to refer people for specialist can result in considerable strain to the system.

General practice has long been regarded as one of the great strengths of the NHS, but it is also characterised by wide variation in quality and performance. The number of GPs per 100,000 varies from 50 to 80[51], and generally the 'inverse care law' applies in that the most deprived areas have the lowest quality general practice. Rates of referral to hospital vary tenfold[52]. There is considerable variation in almost everything in general practice – prescribing, access, clinical care, inclusion of patients in decision making, uptake of technology: everything. The Care Quality Commission has just completed a review of a 1000 practices and found that a third failed one standard and that 'in nine practices there were very serious failings that could potentially affect thousands of people'[53].

Much of general practice is not well equipped to provide a broader range of services, making it harder to shift resources into the community. And the proportion of the NHS budget spent on primary care is currently declining from 10.4% in 2005/6 to 8.04% in 2012/13.

Community services are not directly connected to general practice but provide a wide range of services, including district nursing, health visiting, and allied health professionals. It's difficult to find information on the quality of these services, but there's a widespread impression that their productivity can be low. The Care Quality Commission has recently announced its intention of putting more resources into inspecting these services[54]. Many of these community services have been taken over by hospital trusts. It remains to be seen whether this will lead to improvement of services and greater integration.

Community mental health services are yet another set of services provided in the community, and the Care Quality Commission recently reported a deterioration in their performance – with 14% of those who have complex mental health problems saying that they did not have an NHS care plan. Of those that did have a care plan, only 46% said they definitely understood it[55].

Mental health services are under great strain. A Freedom of Information request by the BBC showed that average bed occupancy levels in 28 acute adult trusts are running at 100%. The Care Minister has said: 'Current levels of access to mental health treatment are unacceptable. There is an institutional bias in the NHS against mental health and I am determined to end this'. The impression of the medical director of the England's leading mental health trust is that demand for care is increasing and that the service is in crisis and unsafe[56].

Social services are under greater strain than any other part of the health and social care system. Demand for care is growing rapidly, but funding in real terms has been reduced by Local Authorities consecutively for the last four years. A reduction of £800 million is planned for 2013/14. People are increasingly (and inconsistently across the country) finding themselves unable to receive support, with 87% of councils setting their eligibility for care for 2013/14 at 'substantial' needs or above. Even where care is provided this is often at inadequate levels, including fifteen minute homecare visits[57]. As the King's Fund said in a recent review: 'More and more people are becoming disengaged from a care system that is increasingly dysfunctional, driven by crisis rather than the promotion of wellbeing and prevention'[58].

The UK spends about £80m on hospice and palliative care services, about a third of which is from the government. A previous chief executive of the NHS has described end of life care as the most important characteristic of a high quality health system.

Conclusion

The health and social care needs of the population have changed rapidly and are continuing to change. The increasingly fragmented health and social care system has not changed at the same pace – and so is increasingly unable to serve the needs of the population. Care needs to be attuned more to the needs of people, particularly older people who are by far the heaviest user of services. Most older people are more interested in independence than length of life, and ironically an admission to hospital that could be managed in the community may be the event that ends their independence. Care needs to be better coordinated around the whole of a person's needs.

Resources will need to be invested in community services, but at the moment it is community services that are the most stretched. The trends are in the wrong direction.

B. Providing better care for people with long term conditions and complex needs in England: key lessons from the evidence so far

Coordinating care for those people whose care is most fragmented will be an essential part of responding to these challenges.

The treatment and management of long term conditions is the greatest challenge facing health systems around the world today. As the first part of this chapter has outlined, the rising prevalence of multi-morbidity compounds the problem. People with multiple long term conditions, disabilities and frailty often need care and support that spans traditional service boundaries, including those between primary and secondary care, health and social care, and other service areas such as employment, social welfare and housing. The failure to coordinate care and support people across these boundaries means people often experience care that is fragmented, overly disease-centered, inefficient and inappropriate for their needs.

The policy response in England, as in many other countries, has been to focus attention on strengthening community services (to allow more care to be provided in the community rather than in hospitals) and to initiate a search for better ways of coordinating or integrating care. These are challenging objectives that have proven very hard to achieve in practice, and which are central to the work of this Commission. Various pilot projects have been launched, some of which have been formally evaluated. What follows is a brief summary of key lessons distilled from reports by people involved in evaluating the major national integrated care projects launched in England in the last few years.

Managing change

- Programmes that involve a fundamental change in the way organisations work need from three to seven years at least to bed in[59,60,61,62,63,64,65,66].

- Leadership is key, and leaders need to develop a persuasive vision and a shared narrative. Effective partnerships require shared governance arrangements and agreed goals[67].

- Understanding the local context and building from the bottom up is essential. Models cannot be successfully transplanted from one place to another without adapting them to the local circumstances. Local leadership and staff ownership is crucial[68,69].

- While effective local leadership is crucial, it is important not to place too much reliance on it. There must also be simultaneous innovation at the organisational and management level to support changes at the clinical or service level[70].

- Projects that are seen as 'add-ons' to existing services may not be sustainable in the long term. Engagement with GPs and hospital specialists is crucial for producing a more integrated delivery system, but this can be difficult[71,72].

- Integrated health and social care commissioning through a single organisation may help to produce more robust, sustainable local initiatives[73].

- Scaling up and mainstreaming small-scale locality-based projects is tricky. A federated or umbrella approach that retains the local focus and allows scope for local creativity may work best[74].

Content of programmes

- Some of the most promising projects have involved people, carers and social care users in design and governance of the programmes[75].

- A holistic focus that supports people and carers to achieve their personal outcome goals is preferable to a purely clinical or disease focus[76,77,78,79].

- Staff need training in personalised care planning and shared decision making, which is fundamentally different from the way most have been trained to date. It is important not to underestimate the scale of the cultural change required[80]. Brief training programmes are insufficient on their own to achieve the necessary changes in practice[81].

- Named care coordinators are essential to support people with multiple health and care problems[82,83].

- Inter-professional collaboration with all professions having equal influence and respect appears to be important. This requires effective communication between multidisciplinary team members[84,85].

- Technological solutions may help but they are not sufficient on their own. They must be accompanied by training and support for staff to promote a more person-centred approach[86,87,88].

- Access to shared records can be important for improving communication and for care coordination, but ambitious plans to develop integrated record systems have been a stumbling block in several projects[89,90,91,92].

- Building awareness of community support among both providers and commissioners, including provision of electronic directories of community and voluntary services, can be a good way to meet people's needs[93,94,95,96,97]. Commissioners should be willing to commission non-statutory, non-traditional services.

Conclusion

These messages highlight the work underway to coordinate care for people who need it in England, but also show the scale of the challenge to make this type of care the norm. It is clear that community services need to be strengthened, allowing more care to be provided in the community instead of in hospitals, including preventative care to reduce the need for hospital admissions, and that people's care needs to be coordinated around the whole of their needs – physical, mental and social. Indeed we believe that achieving this requires a fundamental paradigm shift in the nature of health and care delivery, and can't be achieved within the existing fragmented system.

Building upon lessons from similar approaches in England and abroad, this report outlines the Commission's vision for making this type of coordinated, person-centred care the norm in England: whole person care. This report looks at health and care services holistically, with the person, not the institution, at the centre. It proposes a set of recommendations that will focus on helping people stay well, manage their conditions and promote their independence; it suggests how incentives can be aligned across health and care organisations to encourage them to put people's interests first; and, it encourages health and social care to work in partnership for their communities, without proposing expensive and distracting structural reorganisations.

One Person, One Team, One System

The provision of care

1

For health and social care provision to stop being fragmented and to provide coordinated whole person-centred care, it will be necessary to radically change the way in which these fragmented services are provided. This starts with understanding that the person and the home are the centre of care.

Box 1: What might whole person care look like?

Mrs P is widowed and lives on her own a few miles away from her daughter. She is 85, has breathing problems, high blood pressure and diabetes. She has one carer to help her get out of bed and a different carer to help her with her lunch. Over a month, she is visited by both a nurse from the Diabetes Service and a separate nurse to check her oxygen usage. She also visits her GP practice about once a month to either see her GP, collect her monthly prescriptions, or see her practice nurse. Last year she went to A&E five times, and on two occasions was admitted to hospital for breathing trouble. On the first occasion she was in hospital for 20 days, because the hospital did not know that she had recently been started on diuretics by her practice and her fluid accumulated again which prolonged her stay. This exacerbated her breathing problems, and she was anxious about being discharged home. On the other occasion she was in hospital for ten days. Following both of these hospital visits she had visits twice a week from the district nurse to deal with her longstanding leg ulcers and her social care increased during her recovery.

In an average week, she sees four different social care staff and two different nurses. Over an average month (without an emergency visit), she will see ten different professionals from the health and social care world – each of which has a specific task. This volume increases during and after each exacerbation.

Mrs P and her daughter recognise that each of these interventions are helpful and try and make some coherent sense of them all – but taken as a whole life experience it is bewildering. Most of her days are spent waiting for someone to come and carry out some care. In economic terms, each intervention does in a very specific way add some value to Mrs P's life. But the value that is added doesn't last much longer than the visit itself, because no one is making these interventions add up to more as a whole. Each intervention does not link with the next to add value to each other. The economic problem of fragmented care can be expressed this way; the failure to work collaboratively means that each aspect of value added evaporates over time. Mrs P is a sick woman, but her life is not only dominated by her ill health – it is also dominated by fragmented health and social care.

Another economic way of looking at this fragmentation is to look at it in terms of wasted time and days for the person. This is a very different currency from money, but is one that can be very persuasive for the individual, their families and their carers. For Mrs P, 30 days were spent in hospital in emergency beds. Both spells came about because the various elements of care did not help to identify early deterioration. When she then required high acuity care, her home was not made into a location where her high level of need could be normally dealt with, and this lack of safety led her to go to hospital. One spell of twenty days was longer because in diagnosing her with a breathing problem she was not identified as having fluid overload problems. Both spells were longer because she did not feel her home was a safe place to be with her breathing problem. At most this wastes thirty days of her life over that year, as well as the impact on her family.

She also spends many days waiting for various strangers to come and visit at times that fit in with their own organisations and not with her life.

It would be good if she saw fewer people who were better coordinated and better informed about her care and her health. So, for instance, when she visits the GP surgery for her blood pressure, it would be good if she met a nurse who was aware of all the different inputs of care she was receiving.

An alternative to this could be constructed by a joint commission from the CCG (Clinical Commissioning Group) and the Local Authority for an outcome based, person-centred coordinated care contract for the frail elderly. This includes Mrs P. The contract could be commissioned in three levels of frailty, defined through risk stratification, with a different cost associated with each level. The commission for Mrs P is based on last year's costs for health and social care, and the contract is paid on a mix of inputs and outcomes that are important to Mrs P. The key outcome of maintaining independence is agreed. Every three months Mrs P and her daughter are asked if they feel that her independence has been better maintained under this contract than before. They are also asked for suggestions for outcome measures important to Mrs P for the next three month period.

In order to ensure Mrs P's independence, the accountable lead provider is incentivised to ensure that care is coordinated in such a way that will make her home, herself and her daughter capable of dealing with the high need that she has. This will be achieved by each social and health carer being expected to work with each other to increase the ability of the Mrs P, her daughter and her home to work with that level of need. Each input is aware of the previous episodes of care and what the next will be; the total inputs are coordinated to achieve the outcomes that matter to Mrs P. All organisations involved in Mrs P's care work together to achieve these outcomes at the right cost. Information is shared and accessible by Mrs P or her daughter.

Mrs P will still be a woman who is quite ill, but she will now expect that all of the care that she receives will add to her and her daughter's capacity to stay at home. Her care advocate works directly to her GP and ensures that every health and social care professional works to a proactive plan, developed in collaboration with her and her daughter. Her GP liaises regularly with a consultant geriatrician who has the capacity to work with the range of other specialists for her conditions in order to construct an overall continuum of care, where each specialist knows they have to work with one another to deliver the best outcomes for her.

Every professional who goes into Mrs P's home has a responsibility to provide both specific care, but also to place that care within the broader care of maintaining the whole person's independence.

....

The context for the provision of whole person care

The fragmentation of care

Most people who are sick or in need of social care have a variety of different health and care needs rather than needing a single intervention. The existing health and care system has developed in such a way that each of these different needs are currently being met by different services, often provided by different organisations. At the least this leads to problems of confusion, and at worst the duplication and fragmentation of services that does harm through failing to address the whole of a person's needs – physical, mental and social.

However, this does not mean that we should be expecting everyone in health and social care to do everyone else's work. As in other services and industries, the division of labour is beneficial for people using services. The development of specialisms in medicine and social care has saved lives and relieved distress. Yet in other industries and services, the division of labour and the application of specialist activity is organised into a coherent approach to developing the whole chain of a service. Individual experts recognise that their expertise fits within an overall approach to delivering the totality of that service – in industrial language, they are organised into a supply chain.

In health and social care that is not the case.

This fragmentation has become a bigger problem over the past few years because of the increased number of older people living with several long term conditions – a problem which we know will grow even more sharply over the coming years. Yet the current health and care system has been created to respond to single episodes of care – typically involving treatment in hospitals – rather than collectively treating the needs of the whole person across organisational boundaries. This provides fragmented care which causes

problems for people and their families.
Each individual fragmented service also provides problems for every other fragmented service because the handovers between these services are often poorly carried out. Therefore most providers and many professionals themselves recognise the overall failure of fragmented care.

Yet the organisations that make up the health and care landscape were born and have developed with fragmented missions; over 65 years, these heterogeneous organisations have developed very differently from each other because since their creation they have been organised by Government in very different ways. For example, from 1948, NHS acute hospitals have been developed as large nationalised organisations; GPs on the other hand are small private sector businesses; residential care and domiciliary care are provided by small private organisations. Our point is not simply that these organisations provide very different services, but that they do so with very different organisational forms.

These fragmented organisations have been further fragmented by the development of specialisms within medicine and care. The development of these specialisms takes place within as well as between organisations. Therefore a single hospital today will have a large number of different consultants who will be working with different body parts and different conditions. This means that people experience a large degree of fragmentation not just between organisations, but within them. Yet we know that hospitals work better when their approach is not simply disease specific[98]. We should not underestimate the scale of the shift in culture and practice needed in these existing provider organisations to achieve whole person care.

These specialisms are in themselves good things in that they have saved many lives and relieved much distress; we are not saying that all health and care staff should be expected to do the same thing. What we are saying is that specialist knowledge needs to be pooled to treat the whole of a person's needs.

This fragmentation is further compounded through the current separation of health from mental health. Since Victorian times, mental illness has been considered different from other aspects of health; because it was not understood exactly how it could fit with standard models of disease, mental illness was kept separate from other types of illness. However, now that it is clear that mental health conditions are not different from other types of

ill-health, such a separation is no longer tenable. Indeed, evidence cited in our case for change highlights the interdependence and complex causal relationship between physical health and mental health, and the fact that at least a third of those living with long term conditions have a mental health condition.

Commissioning has not yet succeeded in overcoming this fragmentation. Commissioning in both health and social care has become used to commissioning inputs and not outcomes. In the NHS, this commissioning of inputs has encouraged hospital trusts to expand the amount of activity undertaken, leading to the chronic overuse of (episodic) hospital based treatment; in social care this has created a system that provides spells of domiciliary care lasting 15 minutes, and which is predominately focused on responding to crises. This commissioning of inputs has also created a system where the vast amount of resource is spent on the care that would come towards the end of a pathway of care – emergency care beds in the NHS and residential care in social care. The paradox that this Commission must tackle is that a system that has developed fragmented care has also encouraged the most expensive care that moves people out of the homes they want to stay in.

The recent report by the National Audit Office makes the same point: the fact that there are so many people going into emergency beds in hospitals is partly an outcome of the fragmented health and care that has become the norm[99]. In many cases we must remember that admission to hospital is because of a lack of adequate alternatives locally.

Where care takes place

Most NHS care is organised around the assumption that health care takes place in its buildings, and not in the person's home. In recent years there has been an emphasis on moving some health care out of hospitals and into the community, under the banner 'closer to home'. This may be an improvement on the traditional model, but still suffers from the same misconception; the location where nearly all health care takes place is in fact an individual's own home. While some of this care will be from community services, most of this care is delivered by people themselves, their family, friends and carers. If this did not happen, health care would descend into an immediate crisis.

This is particularly significant for people with long term conditions. Viewed from the perspective of the Department of Health, people with long term conditions are heavy users of health services. Yet the individual with a long term condition spends a very small proportion of their time in direct contact with professionals. This is likely to amount to no more than 0.03% of their time in an average year (3 hours out of a total of 8,760 hours). The rest of the time they and their families manage on their own, so people and their families provide most of the care already.

The same is true for social care: most social care takes place in the person's home, and is carried out by people themselves, their family, friends and carers. Yet unlike NHS care, a greater proportion of 'official' social care recognises the home as the central location of care, and organises domiciliary care within the home. The reality is that it is social care interventions that often keep someone out of hospital. For person-centred coordinated care to be achieved, the system as a whole will have to recognise that, in the future, where appropriate, the home must increasingly become a normal location for higher acuity care to be safely delivered – for example, chemotherapy or blood transfusions. Some of this will depend upon aids and adaptations to the home, some will depend upon the better use of new technology to communicate with official health and social care services, but most of this will need the development of greater capacity amongst people, their family, friends and carers to work safely with people with complex needs in the home. It will also require the development of new forms of provision which allow access to specialist expertise in the community, rather than being largely confined within hospital institutions. This will refocus the goals of that expertise from its current focus on making the person as healthy as possible before returning to their home, into a focus on maintaining independence at home to ensure no admission to hospital is required. The relatively healthy sector of the population must have access to specialist expertise to help early diagnosis and prevention of progression.

The chapter's key themes

For health and social care provision to stop being fragmented and to provide coordinated whole person-centred care, it will be necessary to radically change the way in which these fragmented services are provided. We believe that:

- *Commissioning based on achieving collective outcomes will require providers of care to work together to provide a coordinated approach to meet the whole of a person's needs*

- *There is no ideal model of provision to deliver person-centred, coordinated care; the best organisation of provision to achieve this will depend upon local context*

- *Any new model of provision must recognise the importance of the person and their own home as a central part of that provision – individualised, not institutionalised*

- *An environment must be created where new models of coordinated care, with new organisational forms, are able to develop locally.*

Achieving a shift from fragmented to coordinated provision

We believe that commissioning whole person care based on achieving collective outcomes is one of the drivers that can have sufficient power to change the existing model of fragmented provision. This view is developed in detail in chapter 5. In short, we believe that health and social care budgets need to be used collectively to commission outcomes for the whole person, defined by the person – not inputs from fragmented organisations. Yet existing payment systems in health and social care drive in the opposite direction. This has led to the fragmentation of care rather than coordinated care which meets the whole of a person's needs. We believe that a new model of commissioning must therefore change the way that care is paid for to incentivise the provision of coordinated care which treats people as a whole, and delivers the outcomes that matter to them. The needs of people with complex and multiple long term conditions in particular require a holistic approach to commissioning across the whole care economy. New whole person payment mechanisms must therefore be used to align incentives between providers to encourage the delivery of more coordinated models of care locally.

Yet rather than starting with what this type of commissioning looks like, we begin with what the provision of this type of coordinated care looks like – and we should be clear that this model of commissioning will radically change the nature of provision.

As we can see from the example at the front of this chapter, moving from the current fragmented model of provision to person-centred, coordinated care would change every service interaction in Mrs P's life. Every organisation providing an element of care – whether that be dressing a leg ulcer, cooking a meal or taking blood pressure – would be required not only to excel in delivering that element of care, but would also have to work collectively with all other aspects of Mrs P's care to provide a coordinated approach to keeping Mrs P as independent as possible. Providers within this model would be incentivised to collaborate and innovate to find new ways of providing the whole of Mrs P's care to deliver the outcomes that matter to her. And these outcomes must be delivered at the right cost; that is, care for Mrs P must be driven by value – a goal collectively held by all parties across the care system[100]. What we are describing may be a shift which everyone agrees with, but this shift is one which will involve real change in every service currently operating across the care system.

The organisation of coordinated local provision

Outcome based care is something which is receiving growing interest both nationally and internationally; while in their infancy, a number of forms of outcome based contracts have been let or are being developed in a number of places across the country. These contracts require providers of care to collectively achieve outcomes for defined population groups. The challenge is to make this shift towards outcome based care the norm. The effective management and delivery of these contracts will require a different overall organisational and governance structure than is currently seen in care economies across England. This will require a fundamental change in the nature of provision.

Yet it must be recognised that there is no single 'ideal' model of provision to deliver outcome based care; local providers of health and care must be at the heart of developing solutions to achieve this shift, with the means to do so necessarily dependent upon local context. The main organisational forms emerging to support the delivery of outcome based care in England are the accountable lead provider model (Box 3) and the alliance group of providers (Box 2). Despite their different forms, both of these models aim to improve outcomes through aligning organisational incentives across the health and care economy. The successful delivery of both models require local health and care providers to work collectively to deliver services which provide the best outcomes while optimising resources; for example, this will likely mean investment in the social aspects of care, including services carried out by the voluntary sector, to avoid costly acute activity (for example, see Box 4).

Box 2: Alliance contracting

'The first thing we do when there is a problem, and because this is an alliance, is ask "How can we help? You are not performing. What's the problem? Can anyone else in the alliance help?" And we put resources in. Because the idea of an alliance is that nobody fails. We either all fail or all succeed[101].'

The central assumption of alliance contracting is that organisations can achieve better outcomes – particularly in the delivery of complex services – by working collaboratively within a single overarching contract. An alliance contract aligns incentives between these organisations through the construction of a common set of outcomes, encouraging collaboration to enable the delivery of coordinated services while sharing risk and accountability between alliance partners. Organisations within the alliance only gain if the alliance as a whole delivers the commissioned outcomes; they must therefore work collaboratively to deliver services which work with each other to achieve their common aim.

These type of contracts have been most commonly used in the delivery of complex programmes within the construction industry, yet are increasingly being used to aid the integrated delivery of health and care – for example in New Zealand, where a number of macro and meso-level networks have been developed using alliance contracts to enable the coordination of care[102,103]. Studies suggest that this type of approach in New Zealand has driven a shift in resources from acute hospital care towards services provided in the community[104]. Unlike a traditional commissioning model where a commissioner holds a number of different contracts to deliver a chain of services – each with specific performance measures, conditions, and related incentives – alliance contracting involves

collective ownership and accountability through aligning performance measures across all organisations involved in the delivery of these services. Importantly, this type of contract enables collaboration between distinct organisational entities; it is a means to deliver integrated services without the need for the development of integrated organisational forms. Specific pain/gain share mechanisms are pre-agreed by parties within the alliance and defined within the contract itself, yet are necessarily linked to overall contract outcomes; collective success leads to collective gain, and underperformance effects the whole alliance.

Centrally, this approach aligns organisational incentives to deliver common system outcomes. Alliance contracts are therefore a mechanism to enable the coordinated delivery of complex health and care services across multiple providers, which incentivise investment in primary and community services to maintain health and reduce unnecessary acute activity which is bad for people and the system.

Box 3: Accountable lead provider model

The primary goal of the accountable lead provider model is ultimately the same as that of an alliance contract: to overcome system fragmentation by joining up the delivery of complex services to provide better outcomes. Yet the lead provider (or prime contractor) model offers an alternative means to overcome this fragmentation, through the appointment of a single party responsible for the delivery (and coordination) of these services and achieving commissioner defined outcomes: the accountable lead provider.

Within this model, the accountable lead provider is typically allocated a capitated budget to manage all care services for a specific population group – which may be a whole population within a defined geography (for example, the Alzira model in Valencia[105,106,107]), a clearly defined segment of this population (for example, a contract for older people's services – as is being developed in Oxfordshire), or for a group of people with related conditions (such as the MSK prime contractor model in Oldham[108]). This contractual form shifts risk from the commissioner to accountable lead provider, who is responsible for achieving commissioner defined outcomes for the specified population within the allocated budget.

The prime provider is incentivised to coordinate services around the needs of those using them, invest in high value preventative interventions, and ensure collaboration between providers involved in the delivery of the whole service. It is not expected that the accountable lead provider will provide all services which they are accountable for – indeed, in the delivery of complex services this will be rare; the prime provider is incentivised to coordinate the delivery of services between all organisations involved in providing that care around defined outcomes. It may also be the case that a number of organisations are able form an appropriate commercial and governance structure to jointly become the accountable lead provider for a given contract.

One example of this approach in action is the Alzira model in Valencia[109,110,111]. Under this model, a single provider is accountable for all of the health care provided to its regional population. UTE-Ribera receives a fixed capitated budget every year from the regional government to provide universal access to its health services for people living in the region. Since 2003, the contract has included primary care services (with aligned incentives for GPs) – it was initially just a secondary care model – but it doesn't currently cover social care. Evidence suggests that quality and outcomes have been improved, and money has also been saved by the commissioner – the capitated budget is around 75% of the cost per person elsewhere in the region. While there are a number of differences between systems in Spain and the UK, there are also similarities; there are certainly lessons which can be learnt for the development of similar models in England. Extending this model to include social care services would be a clear advance towards whole person care.

The development of Accountable care organisations (ACOs) in the US – established under the Affordable Care Act (2010) as a delivery model intended to improve quality while reducing costs – have also shown early promise as a potential vehicle to help drive this shift in the nature of provision[112]. While specific arrangements vary depending upon local context, the basic ACO model involves a provider-led network collectively accountable for meeting quality standards (agreed locally between the provider group and the payer) for the care relating to a defined population. Providing that they deliver care which meets the required standards, ACOs can share a proportion of any financial savings made; more mature ACOs may also accept a level of downside risk.

Indeed the type of provision that we are describing may be best referred to as a shift towards the delivery of accountable care: 'a system in which a group of providers are held jointly accountable for achieving a set of outcomes for a prospectively defined population over a period of time and for an agreed cost'[113]. Evidence from accountable care systems globally shows the potential benefits that can be achieved through provision focused on collectively delivering outcomes that matter. Evidence from these systems suggests that health outcomes can be improved, alongside improvements in quality and experience of care[114]. These improvements have been particularly strong for people with complex needs. Evidence of cost savings (or containment) within these systems has been more variable; while a number of accountable care systems have delivered impressive savings[115], evidence of financial benefits is stronger in well-established systems and may take time to be realised[116]. They fundamentally seek to improve value.

We envisage the development of accountable, integrated provider networks – involving different providers of care working together – collectively responsible for delivering outcomes for defined population groups. For example, in the case of Mrs P we have suggested that this could be through the development of a single contract for the care of the frail elderly within her local area, with specific outcome measures developed by Mrs P and her carer; a group of providers from across the local health and care economy (including the voluntary sector) would then be collectively responsible for delivering these outcomes that matter to Mrs P, at the right cost. Commissioning based on achieving collective outcomes will help drive this shift towards coordinated delivery – described further in chapter 5. This new model of care for Mrs P will likely mean that she will receive more care in her own home aimed at keeping her independent. This might be from specialist teams previously based in the hospital, or from local services which help her to meet new people in the community, or to help her go shopping. The services would be joined up by Mrs P's care coordinator: her advocate within the system. Whatever its form, this new model of care will mean that all organisations and professionals involved in the delivery of Mrs P's care will have to collaborate to provide coordinated services organised around meeting the whole of her needs, which work around her as their organising principle.

Yet while it is our view that there will be a number of different models for the provision of whole person care, it is equally important to emphasise one type of organisational form that we are not suggesting. One apparently common sense way to think about ensuring genuine joint provision is to place all services that need to work together into a single organisation. This is based upon a traditional assumption that a single management structure can tell all of its component parts at the front line to work together, and through that mechanism jointness is assured. In fact, of course, within health and social care there are many examples where a single organisational structure fails to develop person-centred coordinated care. Hospitals have a unified management structure, but very few of them provide person-centred coordinated care. One of the main complaints made by people using the system is the failure to achieve this within an organisation; specialisms dominate care, rather than are dominated by a whole person approach.

In chapter 5 we make a number of recommendations about how to incentivise the delivery of this type of outcome based care through the commissioning process – specifically through the development of outcome based contracts. By the time of the next election, we might expect a few of these contracts to be tested and new forms of provision emerging. Yet a radical shift is needed to make this type of provision the norm across the country. A new government could expect that over the five years of that government, this form of provision moves from being unusual to usual. Government should outline their expectation of the growth of this form of provision, while ensuring that an environment is created which allows it to happen.

Extended primary care within the community

A central part of this new form of provision is likely to be the role of extended primary care. The existing primary care system is typically based around small, isolated general practice units, who often don't collaborate well enough with each other and with other community-based services to meet the whole of a person's needs optimally. The current model of primary care can be inflexible and inadequately connected to other areas of care (such as specialist teams, community care providers, local pharmacies and social care services) to provide coordinated care for the people it serves – particularly those people with long term conditions and complex needs.

We therefore believe that new models of primary care must be developed which are able to coordinate a range of services for local populations within the community, take on a more proactive rather than reactive role in population health management (while maintaining the local connection that matters to individuals), and which have the right organisational and governance structure to allow these shifts to happen. We support the direction mapped out in the recent King's Fund report on new ways of contracting to help develop these new forms of primary care[117].

The scope and range of primary care services will therefore need to change to be able to provide more coordinated services for people in the community and at home. Work from the Nuffield Trust suggests that for primary care systems to move from a traditional model towards a more coordinated, integrated approach, they generally need to:

- be larger

- increase access to a wider range of services and professionals as part of the primary care team, or working closely with them in a coordinated way

- provide better out of hours services, and

- provide better continuity of care for those people who most need it[118].

Achieving these shifts will require the development of new provider models within primary care and the community, which should be encouraged. There are a number of potential organisational forms which can be used support the development of extended primary care, and evidence suggests that local context must play a vital role determining the right model. For example, primary care networks or federations (e.g. Tower Hamlets), super-partnerships (e.g. Whitstable Medical Practice), regional and national multi-practice organisations (e.g. The Hurley Group) and community health organisations (e.g. Bromley by Bow Centre) have all shown promise in being able to deliver high quality care which meets the challenges facing the existing primary care model in England[119]. Collaboration with community based services and social care will be essential for these new models to provide coordinated care able to meet the whole of a person's needs. A further challenge for primary care will be achieving these required changes alongside the need to maintain the local nature of general practice which people and communities value.

New organisational forms in primary care must be properly aligned with local arrangements across the whole care system to ensure the coordinated delivery of outcome based care.

Recommendations

1.1 A new government in 2015 must outline expectations and milestones for the growth of new forms of coordinated provision. Local flexibility in the development of new provider models must be encouraged by Government so that different integrated models of care can develop according to the needs of local populations – for example, ACOs, where there is local appetite to do so.

1.2 These changes must be enabled by the system. For example, Monitor and the NHS Trust Development Authority must encourage through their performance management the development of new outcome based models of care, rather than performance managing Trusts against their ability to develop positive balance sheets around the existing episodic model of care. Health and care regulators must allow new provider structures to form where this will benefit people using the services. They should place considerations of care firmly before those of competition – including the growth of new (and larger scale) models of primary care.

Where whole person care takes place

Whole person care will only thrive if it recognises that nearly all health and care takes place in the home. A new model of provision must therefore see people's homes as the central location where care takes place, with local services organising around this basic principle.

Alongside this is the recognition that the main providers of care are actually people and their carers – not professionals. As we outline at the front of this chapter, it is likely that the person with a long term condition spends no more than 0.03% of their time in an average year in direct contact with a health professional. The rest of the time they and their families manage on their own. The concept that only professional providers of care will be the future providers of care is flawed. One-size-fits-all care will be replaced by personalised care, and technology – most likely created outside of formal healthcare – accessed directly by citizens will be a driver of innovation. Access to such technology, alongside the provision of information, is a key part of enhancing the power of people needing care. It is also a key part of helping families and friends to support each other in their care. Technologies like Facebook, Skype and Whatsapp have allowed families to stay connected even when they are far apart. We recommend the development of the role of NHS Choices to create a personalised health hub that will enable families and friends to support each other through ageing and ill health, even when far apart. NHS Choices should be opened up to enable entrepreneurs to leverage its content to create websites and apps that meet people's demands in many different ways, and to help families and friends support each other in new ways. It is time for the NHS and social care to join the 21st century.

Formal health and care provision must therefore evolve to recognise the centrality of the home, the individual and their informal support network as part of that provision. While recognising the importance of the home is part of the existing culture in social care, the NHS still believes that most health care takes place in its buildings, and therefore fails to see that 'provision' and 'providers' need to concentrate on improving the efficacy of the home as the location of health and social care provision.

The NHS must also recognise the role of specialist expertise beyond the confines of hospital buildings; there is a need to deinstitutionalise our basic concept of health care delivery for whole person care to be achieved. The report of the Future Hospital Commission begins to recognise this necessity, calling for specialist medical teams to work in partnership with partners in primary, community and social care to support people outside of the hospital[120]. This alignment of specialist knowledge with primary and community care must form a central part of whole person care, allowing for a greater focus of that specialist expertise on keeping the population well in their own homes rather than treating people once they require acute care. As part of achieving this we believe that GPs should view all unscheduled admissions, including readmissions, to be Significant Adverse Events, which need to be reviewed within a framework of continuous quality improvement.

It is not our intention to recommend particular models of care, but to encourage the wider thinking necessary to meet the challenges faced by the system. For example, this approach to delivery could be further extended though the decoupling of clinical expertise from hospital institutions, with the arrangement of specialists into independent organisations based within the community. In effect, a group of specialists could allow for their services to be commissioned independent from hospital institutions, but retain admission rights within a local hospital through an 'In-reach-beds' arrangement. The focus of their care would be centrally determined by the communities they work within – not the needs of the hospital as an institution. This model will be more appropriately suited to some specialties than others – Rheumatology would be one example where the need for inpatient beds has hugely decreased while community need has grown – though should be considered locally as part of a new model of provision. The challenge is to ensure that there are suitable alternative arrangements in place that allows the provision of specialist skills into the wider community while still preserving the important intercommunication that attachment to a physical institution currently facilitates. It is likely that specialist treatment which does require care in hospitals will take place in nationally recognised specialist centres, which work with primary, community and social care services to ensure that their specialist expertise is not confined to the hospital building.

Recommendations

1.3 The person and their home should be at the centre of care – individualised, not institutionalised. We recommend active encouragement of technological innovation to support people and their carers for the 99% of time that they look after themselves, and the increased involvement of specialists in the community setting to begin to deinstitutionalise our basic concept of healthcare delivery.

1.4 We recommend the development of the role of NHS Choices to create a personalised health hub that will enable families and friends to support each other through ageing and ill health, even when far apart.

Box 4: Coordinated person-centred care – a vignette

Bob lived alone and had severe chronic obstructive pulmonary disease (COPD) which precipitated almost six-weekly emergency admissions for severe exacerbations of his disease. Healthcare had invested heavily in the prevention of such unscheduled admissions with Telehealth, Pulmonary Rehabilitation courses and community based COPD service provision, but he still regularly presented in a poor state requiring hospital admission.

An enablement team asked Bob himself what he wanted. He said he wanted to visit his wife who had been in a local care home with dementia for two years, on a regular basis. Transport was arranged for him to visit her regularly twice each week.

Bob did not suffer a further exacerbation requiring admission over the ensuing six months. Analysis of the case suggests that the situation differed only in Bob himself having the motivation to seek early intervention when he himself knew he was beginning an exacerbation so that he did not miss his visits to his wife. The cost of providing this transport was minuscule in comparison with a single emergency admission – but it came from social care funding rather than traditional health funding.

Getting the right people working in the right way

2

Whole person care requires professionals acting as one team, who work with people to plan and coordinate their care to support them in achieving the outcomes that matter to them.

The context for the whole person care workforce

Whole person care requires professionals working as one team, who support and empower people to play an active role in managing their own health and care as far as is possible. It also requires a broader view than just health and care professionals as part of that team providing care and support, and the development of new skills to be able to care for people with complex and multiple conditions in the community.

Yet there is likely to be a shortage of people trained to meet this need over the coming years. The Royal College of Nurses has projected a potential 28% fall in the number of nurses by 2022[121], and the Royal College of GPs forecasts the need for an additional 10,000 GPs to meet the needs of the future[122]. In social care, there could be a shortfall of 1 million workers by 2025[123]. These projections don't include the existing and growing pressures on the informal workforce – the largest group of carers who receive the least support. Yet despite the clear problems in meeting demand for care caused by projected workforce gaps, the complex needs of people with multiple long term conditions cannot be met by simply increasing the number of people working in the existing fragmented model, in the existing fragmented way.

Much healthcare is poorly coordinated, disease-centred and inappropriate for people's needs, especially for people with multiple long term conditions. Its staff are typically focused on the treatment of a single problem. Social care is mainly geared to those deemed eligible for state support, with little effective help for the majority who are not. Across both health and social care the culture tends to be paternalistic and dependency creating. The emphasis is on doing things to people rather than with them, despite the fact that most people look after their own and their families' health most of the time. Yet traditional practice styles too often create dependency, discourage self-care, ignore preferences, undermine confidence, do not encourage healthy behaviours, and do nothing to challenge fragmented care. Professionals are largely ignorant of the potential contribution of the voluntary sector, and do not act as effective sign-posters to voluntary sector support. Commissioners and the voluntary sector itself are largely enthusiastic about expanding the role of the voluntary sector, however stakeholders lack awareness of where the current gaps are in provision and where the voluntary sector could offer its services to help[124].

This fragmentation is compounded by the heterogeneity of the health and social care workforce. In 2012, the NHS staff headcount in England alone was over 1.3 million[125], with further healthcare staff employed by a relatively large (and growing) number of independent healthcare providers. The adult social care workforce in England was approximately 1.5 million in 2012, with an estimated 17,000 organisations involved in providing or organising adult social care at 39,000 establishments[126]. On top of this there are over 5 million informal carers, including family and friends.

Caring for those who provide care is also a vitally important aspect of workforce development which often doesn't receive enough attention; our health and care system must be one in which you would be happy for your loved ones to receive care, while also being one in which you would be happy for your loved ones to be employed and giving care.

Yet the existing system is not always one where those providing care are adequately trained, reimbursed or valued – particularly in social care. More support is also clearly needed for informal carers – some who are regularly providing care for more than 50 hours per week[127].

The House of Care

We want to place people powered care at the heart of health and care system. In developing our recommendations, we have drawn upon the key themes of the House of Care model[128] – a coordinated service delivery model focused on care planning and support for people with long term conditions (**Figure 1**). The house is a metaphor for the supports that need to be put in place to deliver more proactive, personalised and better coordinated care. The model has a particular focus on primary care professionals, but has wider implications for the broader health and care workforce.

Devised to help primary care staff and commissioners reorganise local services, it explicitly places the person at the heart of the delivery system. The house has a foundation, two walls and a roof.

The left wall represents engaged and informed services users; the right wall is health and care professionals committed to partnership working; the roof is the practice infrastructure and organisational systems that must be adapted to support personalised care planning; and the foundation is the responsive local commissioning body and community stakeholders that enable this change to take place. The model acts as a checklist for local providers and commissioners to ensure they have everything in place to deliver care that is both person-centred and well-coordinated, and has significant workforce implications, both short and medium term.

A central aim of this model is individual empowerment. People who have the knowledge, skills and confidence to manage their own health tend to lead healthier lifestyles, make informed and personally relevant decisions about their treatment and care, are more likely to adhere to treatment regimes, experience fewer adverse events and use less costly healthcare[129,130]. Therefore our aim should be to inform, empower and educate all users of health and social care services, including the workforce, to achieve better health outcomes and greater value for money.

Figure 1: The House of Care
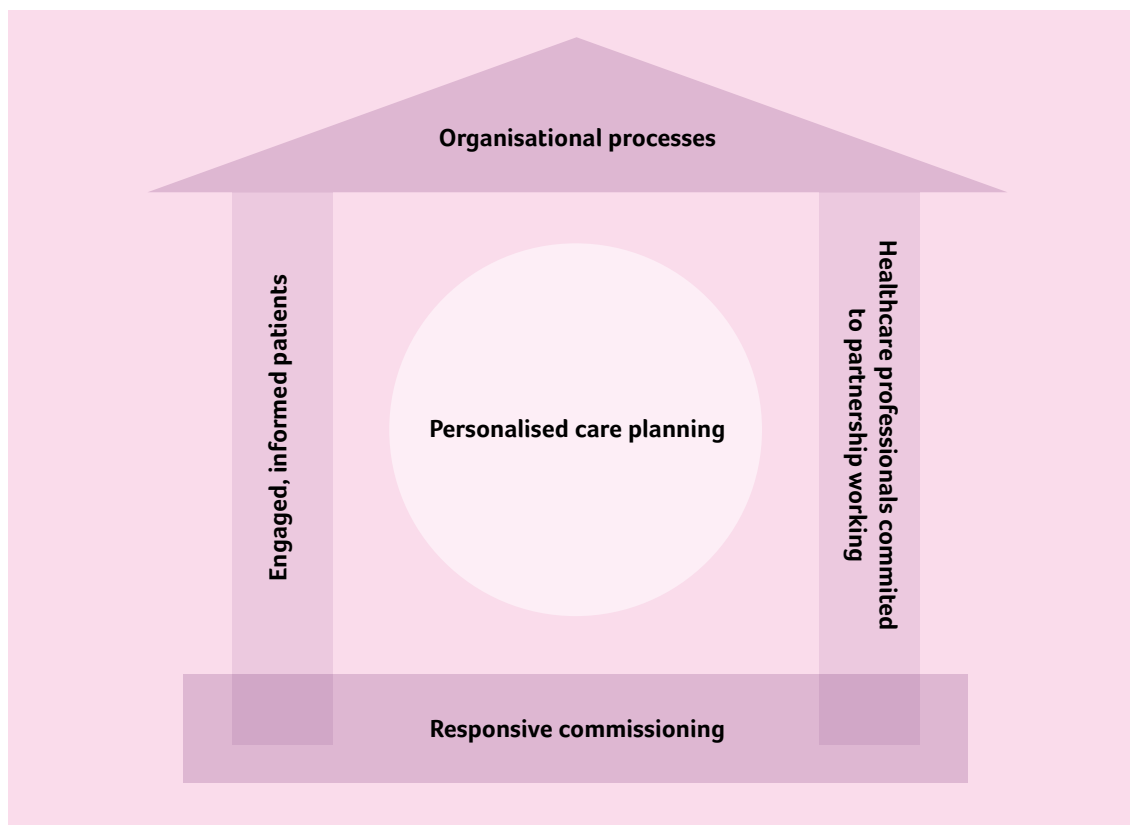
The chapter's key themes

Health and care professionals carry out some of the most valuable work in society. For the organisation of this care to best meet the whole of a person's needs, we believe that:

- *Co-management and shared decision making must be embedded as an essential part of care provision, and the workforce shaped to deliver this by default*

- *Multidisciplinary team working must be the norm for the care of people with multiple conditions and complex needs, with a single point of contact for the person receiving care*

- *Professional training, system leadership and local workforce planning must respond to these needs*

- *Increased support must be given to the largest group of carers: friends, families and volunteers.*

Co-management and shared decision making

We know that people with long term conditions are the largest drivers of cost and activity across the health and care system. Yet despite this, the proportion of time that people with long term conditions spend engaging with professionals is tiny compared with the time that they themselves spend managing their own condition. People with long term conditions have to deal with multiple effects of living with these conditions — they must administer their own treatment, often on a daily basis, monitor their symptoms, and learn how to avoid future exacerbations by adopting healthy lifestyles. They also have to deal with the practical, emotional and social consequences of the condition. And a growing number of people have more than one long term condition. Dealing with multiple and complex conditions can make managing on your own a particularly complex task, especially for people who have mental as well as physical health problems. People with long term conditions in England do not currently receive sufficient support to co-manage effectively[131,132].

In the past, health and social care has been typically dominated by a top-down and paternalistic approach, where staff have a dominant role in deciding what treatment options are in people's best interests.

Co-management is about giving people the tools to better manage their own health, while transforming the relationship between person and professional to become a collaborative partnership[133].

There is good evidence which shows the benefits of supporting people to co-manage their conditions. It can improve people's quality of life, clinical outcomes and (positively) change their patterns of contact with health and care services[134]. Evidence suggests that co-management can reduce unnecessary and costly hospital admissions[135]. Embedding shared decision making and co-management for this group of people is therefore an essential part of providing better, more holistic care, and a more efficient system.

There are a number of interventions which can be supported to promote better co-management; the provision of information (and support) is one of these interventions which we support within this report, as is described within our information solutions chapter. Yet appropriate interventions will be dependent upon individual need. We believe that embedding the House of Care model as the coordinated delivery system for this group of people will enable the delivery of the right care according to individual need. This may be a widely held aspiration, but one which we believe cannot be delivered effectively without the other changes we advocate in this report. At the centre of this delivery system is personalised care planning, where people are encouraged to play an active part in determining their own care and support.

Care planning is the means of ensuring that individuals' values and concerns shape the way in which they are supported to live with and self-manage their long term condition(s)[136]. In pre-arranged appointments, they engage in a collaborative care planning process, identifying priorities, discussing care and support options, agreeing goals that the individual can achieve for themselves, and co-producing a care plan with a shared record that is used to review progress on a regular basis. This demands new skills in risk communication, shared decision making and co-management support that are not routinely taught in professional training programmes. And professionals must be willing to listen to people and adapt clinical protocols when necessary.

Care coordination

Implementing personalised care planning requires clarity about who is responsible for ensuring that all actions and follow-up arrangements agreed during the process are implemented. Some of the agreed actions will be for the person with long term conditions to implement themselves, for example lifestyle changes, but in other cases the professional must implement the agreed action, for example a referral to another service or community resource or whatever is deemed appropriate by both parties.

This care coordination role can be carried out by any health and care professional (for example, a social worker or community matron), or someone from the voluntary sector. They act as a person's single point of contact to and advocate in the system, working with the person to identify their needs and preferences and offering support and follow up. The process of providing ongoing support is sometimes termed 'health coaching' – support provided by a trained individual (either in person or remotely – for example by telephone or internet), who uses motivational, non-directive techniques to offer people help with decision-making and overcoming any problems encountered[137].

A review of the literature highlights that the diversity of different interventions associated with care coordination roles makes comparison difficult, but that care coordinators (or 'navigators') may be effective in assisting older people with chronic conditions as they move between care settings[138]. In a recent comparative analysis of five case studies of care coordination programmes for people with long term and complex chronic conditions in the UK, the role of the care coordinator was identified as a crucial enabler for the success of these programmes[139].

Yet coordinating care for people is not an easy task. Several integrated care pilot projects have adopted a variety of techniques to improve care coordination, with mixed results[140,141,142,143,144]. These evaluations illustrate the scale of the challenge. While it is possible to get staff from different professional backgrounds, employed by different organisations, and paid out of different budgets, to work better together, breaking down the cultural barriers and agreeing shared goals in a coordinated manner is difficult and takes time. Frequent structural reorganisations can easily blow the projects off course and demonstrating improved outcomes is hard. A key element for success is strong leadership.

Recommendations

2.1 Supporting co-management and shared decision making should be the default operating model for all professionals and a commissioning requirement. This will require a system wide focus on skills covering the following topics: person-centred care; consumer engagement; self-care; health literacy; health information sources; safety and risk; risk communication; shared decision making; personalised care planning; co-management support; health coaching; motivational interviewing; co-production; and multi-professional team-working.

2.2 Each person with complex needs should have a single identifiable individual who will act as their advocate in coordinating care to the wishes and best interests of that person. That individual advocate may be from statutory or voluntary sector.

2.3 Professional training bodies should be asked to incorporate these skills into their programmes and ensure they are assessed adequately and included in appraisal and revalidation procedures. All professional training courses across health and care should involve the people using those services, their carers and other lay people in teaching and assessment. Training in these competencies must also be required for existing health and care staff. Health Education England (Care Education England – below) should be asked to produce a new workforce strategy that is aligned with the components of the House of Care model and supports personalised care planning.

Working as one team

Alongside the need for shared decision making and personalised care planning, professionals involved in the delivery of care must work as one team to provide coordinated care which meets the whole of a person's needs. Multidisciplinary working is needed for whole person care. Yet while there are some good examples of collaborative working in pockets across the country, the current health and care workforce is typically fragmented, with clear boundaries, distinctions and divisions between (and within) health and social care.

The healthcare workforce in particular is characterised by a high degree of specialism, currently structured to deal predominantly with episodic treatment in hospitals, rather than focused on treating the whole of a person's needs across a continuum of care. While the needs of people are complex and overlapping, the system is one of specialisms that look after body parts, rather than collectively treating the person as a whole. There is therefore a need to join up these specialist elements to better coordinate people's care both within and across organisations providing care. This specialist expertise must also no longer be confined solely to the hospital setting, but should form part of more holistic, community based models of care, as is described in the previous chapter of this report.

Evidence from successfully integrated models of care both nationally and internationally shows the vital importance of multidisciplinary working to achieve coordinated care[145,146]. While there are a number of important factors to getting partnership working right, success critically relies upon team members aligning goals and working together[147]. This is not helped when financial flows incentivise different behaviours. Multidisciplinary working is particularly important for the care of older people with complex and overlapping needs. Comprehensive Geriatric Assessment (CGA), for instance, is an important example of multidisciplinary working which can greatly enhance quality of care for older people which is explored later in this report, and this type of collaborative working must be seen as the norm where it is in the best interests of people needing health and care services.

People often refer to the practical barriers to partnership working. Varied terms and conditions of service for staff within multidisciplinary teams are commonly cited as a cause of tension and dissatisfaction. Yet while there is some evidence to support this, it also suggests that this is a barrier which can be largely overcome[148]. The difference between NHS and local government pension arrangements are also often quoted as a barrier to full integration. These issues must be reviewed, in some cases to align perception with reality.

Box 5: Community resource teams in Pembrokeshire[149]

Community resource teams (CRTs) in Pembrokeshire, Wales, offer an example of an evolving programme of coordinated care which uses multidisciplinary teams and care coordinators to help provide better care for people in the community. The programme aims to improve quality of life and confidence for people with complex health and care needs, while reducing unnecessary admissions to hospital. The CRTs are part of a wider programme to deliver integrated care to people in the community in Pembrokeshire.

The services of the CRTs are available to anyone with multiple health and social care needs deemed to be at risk of hospitalisation. Most people supported by CRTs are older people with multiple long term conditions – in 2012, their average age was 74. In the summer of 2013 (July), there were 120 people being actively case-managed by the CRTs. Since the CRTs were first created in 2011, they have been involved in nearly 1,500 people's care.

The CRTs are multidisciplinary. They are made up of social workers, occupational therapists, physiotherapists, district nurses, specialist nurses and voluntary sector brokers. The team's voluntary sector brokers can arrange for the provision of other services from local third sector organisations to suit people's needs and to help them remain living at home – such as arranging outings, befrienders, day-sitters who offer respite care, dog walking and gardening services. Other health and care services can also be accessed by the team when needed, such as speech and language therapy or dietetics.

Individual packages of care are developed for each person using the service. A care coordinator acts as a person's main point of contact, and they work with the CRT, the person and their carer to tailor personalised packages of care which will help the person remain living in their own home. The care coordinator is part of the multidisciplinary team, who meets weekly to discuss each case.

The CRT also works closely with specialist teams in the hospital to manage the interaction between the acute and community setting for people with complex needs, seeking to prevent avoidable admissions and enable people to return home early if admitted to hospital. These relationships between the CRT and acute teams are still being developed, and the need for clear channels of communication between the community based CRT and the acute teams has been highlighted as a key lesson from the programme.

The programme is still evolving, but the initial results have been positive. The majority of people using the service are satisfied with it – data collected in 2012 shows that 55% of people reported improved or restored confidence – and 38% reported that they feel more independent following the involvement of the CRT. Attributing changes in service use directly to the CRTs is difficult, and trends in the data will be established over time, yet data from 2012/13 is also positive: it shows that there has been a reduction in admissions for people with chronic heart disease (CHD); length of stay for people with diabetes, COPD and CHD is below the mean for the region; and the county also has the lowest number of delayed transfers of care out of the three areas covered by the health board.

Multidisciplinary training

The need for multidisciplinary working must be reflected in the way that health and care staff are trained.

Undergraduate training for health and social care professionals is largely uni-disciplinary, which exacerbates the fragmentation often experienced by people receiving health and care services. Medical training in particular is problematic. The existing model is based on specialisation and sub-specialisation; there are more than 60 medical specialties and over 35 sub-specialties, and this number is growing[150]. Of course, the development of specialisms has saved many lives and will continue to do so, but in a multimorbid world there must be a rebalancing of specialist and generalist knowledge to best meet people's multiple and overlapping needs.

The Shape of Training review[151] provides a good basis for addressing this balance in medical training.

To meet the needs of the population the system serves, we believe that undergraduate training across health and care must have a clearer focus on multidisciplinary working, and involve a greater focus on the alternative (and connected) services which can help address a person's needs – including housing, for example, and other services which support the citizen. People are currently required to navigate a complex system of care across multiple organisations and care settings – a system which itself often fails to have a clear enough understanding of its constituent parts and how they fit together. Health and care professionals who see themselves as part of one team providing a person's care will help to overcome this fragmentation that people face, and we believe that this begins with how they are trained.

Yet a focus on undergraduate training in itself is insufficient. It must also be recognised that the vast majority of the workforce who will be delivering care over the next 10, 20 or more years will be staff who are already working within the system. Despite this, less than 5% of the national training budget within the NHS (£5bn) is allocated to training and development for existing staff[152]. This budget is far smaller for those working in social care, the voluntary, community and faith sectors. A greater emphasis must therefore also be placed on training for existing staff which is oriented towards multidisciplinary working and enabling co-management.

It is also important to recognise the diversity of the health and care workforce – particularly those who are not trained at university. Indeed, social work is one of the few university qualified professions in social care, and the vast majority of social care workers are not registered professionals but will have earned qualifications while in work. In the NHS, healthcare assistants (HCAs) make up around 24% of the nursing care workforce, yet their training is neither compulsory nor consistent[153]. Both social care support workers and HCAs are taking on increasingly challenging tasks – having to care for frail older people with multiple conditions – yet their training is hugely variable[154]. As the Cavendish Review notes, some employers are failing to meet their duty to ensure competency within their staff before they start caring – indeed, some staff training has simply involved a DVD to watch at home. And the fact that these staff work in silos when they aim to meet common needs further fragments this picture.

The Cavendish Review has begun to address some of these issues, recommending the development of a Certificate of Fundamental Care (and Higher Certificate of Fundamental Care) which includes minimum training standards and shared competencies across the health and social care workforce. The recommendation is that the Care Quality Commission (CQC) should require HCAs in health and support workers in social care to have completed the Certificate of Fundamental Care before they can work unsupervised. This is something which the government has supported, and we feel that making it happen must be a priority for the system.

Safety and quality improvement training

Alongside the need for professionals from different organisations to work well together to provide coordinated services, the whole care workforce needs to be driven by an approach to continuous quality improvement which is itself focused on the needs of the people using these services.

World leading service organisations create a culture in their workforce that consistently and continually seeks to analyse and improve what they do – crucially, driven by the views of those whom they serve. This does not happen by accident. High quality organisations and systems across the world all show a similar systematic approach to training their workforce in quality improvement methods. This type of approach empowers teams to improve outcomes and lower costs. This culture starts with system leaders, but is embedded throughout the whole workforce, and can be generated through professional training.

For example, in Sweden, the Jönköping Academy for Improvement of Health and Welfare aims to introduce knowledge about quality improvement and good leadership into practice within the health and social care system. It has developed a multiprofessional Masters programme in Quality Improvement and Leadership in Health and Welfare Services, aimed at health and care leaders but including a diverse range of staff – including employees from Jönköping city council, doctors, nurses, social workers and finance staff[155].

This type of approach to continuous quality improvement is not only essential for the provision of whole person care, but also for a wider system approach to safety and quality – this is also one of the lessons that tends to emerge from inquiries into care failings, such as those at mid-Staffordshire or Winterbourne View.

The care system needs to recalibrate around active system learning, which itself helps to change the culture from one that is professionally driven, to one that is user driven: people powered care.

Recommendations

2.4 Multidisciplinary working must be the norm. Professional training bodies must therefore place a far greater emphasis on multidisciplinary team working. The Royal Colleges, the General Medical Council, the Nursing and Midwifery Council, the Health and Care Professions Council and other standard-setting groups should be asked to ensure that collaborative care planning and effective multidisciplinary team working are key components of training, with quality-assured curricula and appropriate assessments. Training in these competencies must also be required for existing health and care staff.

2.5 The development of generalist training for doctors, nurses and other health professionals should be encouraged, balancing the current trend towards increasing specialisation.

2.6 We recommend a comparative review of the terms and conditions that apply to professionals working in health and social care, in order to identify and clarify any fundamental differences and examine their impact.

2.7 Quality improvement methods and training should be core to curricula for all staff, and over time (within 10 years) all CEOs and Clinical and Operational Directors should be expected to have advanced knowledge of these techniques and a record of implementation.

The environment for workforce development

Whole system leadership

System leadership across health and care must create an enabling environment for these shifts in the care workforce to happen.

If we want professionals to work in partnership to provide people with coordinated, person-centred care, then it's logical that the system leadership responsible for workforce training and development works in partnership too: shared leadership across health and care. We therefore believe that Health Education England must be transformed to become Care Education England, with its responsibilities broadened to include social care training and its membership and governance revised accordingly. Partnership working at the top of the system will help ensure that the shape and skills of the whole workforce reflect the changing needs of today's population.

This joined up approach must also be reflected in the way that leaders are trained across health and care. For team members from different organisations to be able to align goals and work together well, strong leadership is vital. We therefore believe that the NHS Leadership Academy should be revised to drive the skills needed for whole-system leadership, available to staff across the system. Its focus should be developing effective health and care leaders who take a whole system view. The Leadership Academy should become part of Care Education England and have a joint approach to leadership development.

Local workforce planning

Local workforce planning must also help create the enabling environment for the shifts described so far in this chapter to happen. Those responsible for planning and investment locally must recognise that the shape of the workforce will need to change to become one that is able to provide coordinated care for people across organisational boundaries, with the right range of skills to be able to provide more care and support for people with complex conditions in the community and at home.

Newly formed Local Education and Training Boards (LETBs) – part of Health Education England (Care Education England) – will play an important role in creating this environment. LETBs have been given the responsibility for bringing together education, training and development locally to improve outcomes for those using the system, commissioning training and education to match the workforce plans of local providers.

Yet a strong message from our consultation process has been that many LETBs are dominated by medical interests – particularly those of secondary care providers – which restricts their ability to do things differently. While a number of LETBs have successfully achieved representation from a range of perspectives, including leaders from the community, primary care and mental health sectors and carers, their membership and governance typically mitigate against these aspirations. Like Health Education England (Care Education England), LETBs must ensure that their organisation and structure properly represents the interests of the whole health and care economy. We therefore believe that LETBs must be reformed locally to ensure a balance of professionals and commissioners from social care, mental health, primary and community care and public health, as well as secondary care. This will ensure that investment goes into providing the right staff in the right numbers with the right skills in the right place.

Aligning local investment in education and training with the joint outcomes required of the health and care system as a whole will also be essential to ensure that the local workforce is adequately equipped to deliver whole person care. This will require substantive engagement with local commissioners and health and wellbeing boards.

Recommendations

2.8 **Health Education England should be transformed to become Care Education England, with its responsibilities broadened to include social care training. Its membership and governance must be revised accordingly. The Leadership Academy should become part of Care Education England, and its role and governance revised to drive the skills needed for whole-system leadership across health and care.**

2.9 **LETBs must be reformed locally to ensure a balance of professionals from social care, mental health, primary and community care and public health, as well as secondary care. They must also include service users and carers. Investment in education and training by LETBs must be aligned with the joint outcomes required of the health and care system as a whole, which will require engagement with local commissioners and health and wellbeing boards.**

Caring for those who care

Support for carers

While the main focus of this chapter so far has been the professional workforce, there is also a clear need to give greater support to families, friends and volunteers providing care for those who need it. With approximately 3 million volunteers across health and social care[156], and more than 5.5 million informal carers[157], the informal workforce is almost three times the size of the formal workforce.

We believe that carers in particular don't get enough support. The number of people requiring informal care is set to grow over the coming years – from 1.1 million in 2010 to 3 million in 2030[158], but the support that they get is often insufficient or non-existent. A recent YouGov survey of UK cancer carers shows that more than 1 in 5 (22%) – 240,000 of the estimated 1.1 million – cancer carers perform healthcare tasks such changing dressing, and over half of these (53%) are doing so without information, instruction or training. Of those with no training, 1 in 3 feared this might result in the person they care for needing to be admitted to hospital and 1 in 9 say the person was actually admitted to hospital[159]. It is thought that more than half of carers for people with Dementia are not getting enough support for them to carry out their role properly[160].

Caring can have a huge impact on people's health and wellbeing. The majority of older carers have long term health problems or disabilities themselves, and half of older carers reported deterioration in their own health over the past year[161]. The financial impact of caring is also staggering. A 2013 survey showed that, because of their caring role, 60% of carers have seen a reduction in income, 45% have given up work and 42% have reduced their working hours[162].

Well-supported carers provide better care and report better wellbeing outcomes themselves[163]. The system must therefore place a far greater emphasis on offering local support for informal carers within the community. Carers are entitled to an assessment of their needs, yet many carers aren't aware of this entitlement and often don't have an assessment or receive local support to help them in providing the care that's needed. The Dilnot Commission identified the need for improved assessments to support carers and identify appropriate support; this is something which we fully support, and must be properly resourced at a local level. The provision of quality information – as outlined in our information chapter – must be an essential part of this support (see Box 6).

Box 6: Carer information and support programme[164]

In 2010, the Alzheimer's Society began a three-year project to develop an information and support programme for family carers of people with dementia.

The Carer Information and Support Programme (CrISP) aims to improve the knowledge, skills and understanding of those caring for a person with dementia, by providing effective support and up-to-date, relevant and evidence-based information. It also seeks to facilitate peer support within a shared learning experience and a safe accessible environment.

The programme includes:

- clear, practical information about dementia, legal and financial issues, benefits and local services

- practical tips and strategies for coping with the impact of dementia

- guidance about getting help, support, advice and further information

- guidance about support available from the Alzheimer's society.

This information and support is provided through a number of different workshops, split into two parts: understanding dementia after diagnosis, and living well with dementia as it progresses. CrISP has now been delivered over one hundred times, and has benefited more than a thousand family carers. 100% of surveyed carers said they would recommend the programme to other people supporting someone with dementia, and 98% of felt more confident about finding help and support for themselves and communicating with the person they cared for.

An evaluation of the programme by the University of Brighton in 2012 highlighted the positive results of providing carers with information and support. The analysis found that the information provided on the programme supported caring practices, improved people's understanding of dementia and its progression, and helped people to access practical suggestions for support. Carers felt that developing a better understanding of dementia and its likely impacts helped them to develop the skills and confidence in supporting the person that they cared for. The programme also helped carers to become more assertive in seeking the available services and support that they needed for them and the person that they cared for.

Exploitation in care

It is essential that our health and care system is both one in which you would be happy for your loved ones to receive care, while also being one in which you would be happy for your loved ones to be employed and giving care. Yet the existing system is not always one where those providing care are adequately trained, reimbursed or valued. This can have a drastic impact on quality of care, while also fundamentally failing those individuals providing care themselves, negatively impacting upon their own health and wellbeing.

Care workers – typically women – carry out some of the most important work in our society, caring for the sick, elderly and disabled, often at unsociable hours and in a physically and emotionally draining environment. Yet there are a number of long term and systemic problems within the care sector which has led to the work that they do being undervalued. Indeed, there is strong evidence of exploitation in the care sector. For example:

- Between 150,000 and 220,000 care workers are paid less than the National Minimum Wage (NMW), often due to breaches of NMW and Working Time regulations[165]

- It is estimated that around 300,000 care workers are on zero-hour contracts, out of a total formal workforce of around 700,000[166]

- Over 41% of care workers do not receive specialist training to help deal with people's specific medical needs, such as dementia and stroke-related conditions, and nearly a third receive no regular ongoing training[167].

These conditions have created a number of deeper issues in the care sector – for example, a large dependence on migrant workers on low pay, particularly in London. They also have a large impact on the health and care sector as a whole, so require a whole system approach to be adequately overcome.

These issues are fundamental to the success our health and care service, and must be addressed by any incoming government in 2015. Whole person care will not be achieved unless those providing care are valued and adequately equipped to provide the best quality of care for people and their families. Some of these issues – such as those in relation to training – are addressed in part within this paper, but others – particularly in relation to non-payment of the minimum wage and the use of zero-hours contracts – are beyond the scope of our work, but will be reviewed as part the Kingsmill Review reporting in 2014. We support this work and emphasise its importance.

Recommendation

2.10 Improved assessments to identify appropriate support for carers must be a local priority. The provision of information for carers should form part of this support.

Information solutions

3

Joined-up, good quality information is needed to help people better manage their own health and wellbeing, for professionals to provide better care, and for the system to ensure that the care provided meets the whole of a person's needs and delivers the outcomes that matter to them.

Types of information

When we talk of 'information' as an enabler of coordinated, person-centred care, what do we mean? Broadly, we distinguish between four main types of information:

A   **Information *for* people** – which can help the public make better decisions about their own health and wellbeing, and enable people to take more responsibility for managing their own conditions and care. Information for people must be seen as an intrinsic part of the health and care service – as a core part of a person's care. A further distinction could be made between information about a service (for example, opening times) and information about a person's treatment and care options.

B   **Information *about* people** – helping us work in a more integrated way across organisations and care settings, ultimately enabling the system to provide people with better, coordinated care. Detailed information about people must be used by commissioners to drive local commissioning decisions, and shared between providers to coordinate care.

C   **Information *from* people** – in relation to feedback on the care that they receive, and information about their own conditions and preferences. This information can help drive provider improvement, be shared with other people to help them understand and manage their conditions, and can be used by commissioners to better understand population and individual need. Both information about and from people is also necessary for research.

D   **Information *about* the system** – such as operational performance data, which can help drive the spread of best practice across organisations, while highlighting areas where care needs to be improved.

Underneath these types of information sit a number of enabling elements – such having data systems which can talk to each other, an enabling legislative environment, the availability of the right technology, and public and professional appetite (and skills) to use information effectively. Our recommendations focus specifically on the first three types of information outlined here – information about the system, while important, does not form part of our recommendations for whole person care.

The information context for whole person care

Effective use of information across health and care – and more broadly – is a key enabler to the delivery of coordinated, person-centred, whole person care[168,169]. Successful models of integrated care are underpinned by their effective and innovative use of information[170] – without it, whole person care isn't possible. Yet the effective use and provision of information in accessible ways is not sufficiently prioritised within the existing system. Health and care data is often incompatible, and is not always used in a way which supports coordination of care. Much data isn't collected in a way which aids effective use or sharing; much data isn't systematically collected at all.

Yet problems of incompatibility, while significant, should not be overstated – much collected data can be used in a joined-up way, but organisations within the system rarely look at how information can be linked across care settings to map the whole person's care journey. Much routine data is routinely underexploited across the system[171].

While these challenges of access, collection, collation and compatibility exist both within and across health and care, they may be most acute in social care. Data systems in social care have been developed and used predominantly to fulfil a variety of operational needs in managing Local Authority commissioned services; different Local Authorities have different data collection requirements. Around five suppliers account for the majority of systems in use across the country and innovation is limited. Although there are some national information returns, there is little direct comparative analysis – there is no hospital episodes statistics (HES) equivalent for social care – and many systems use free text fields which make modelling difficult[172]. These difficulties are compounded by the diversity of the provider landscape. Many social care users also fund and organise their own care with little involvement from statutory services, making them even more out of the information and data loop than others. Again, however, these challenges are not insurmountable; while there may be difficulties in collation, person-level data can in many cases be mapped across health and social care to provide an accurate picture of a person's care journey and patterns of services[173] – as shown in **Figure 2** below.

The need to ensure personal confidential information is not disclosed inappropriately is crucial, but in a properly designed and implemented system, with appropriate protection of personal identity, there is no reason why it should be a barrier to making progress. Information governance across health and care is complex. In the NHS alone, there are a number of different laws regarding the use of confidential information[174] – yet in themselves, these laws fail to give a full explanation of data legislation and guidance; guidelines from a number of statutory, regulatory and professional bodies must also be taken into account alongside various professional guidelines[175]. Complicating this further is the fact that this picture is in flux, and is subject to competing interpretations. In short, the rules regarding the use of people's data are characterised by complexity and ambiguity.

Indeed recent legislation – or its interpretation – has been seen to make data sharing more difficult; this was a key barrier to whole person care highlighted within our consultation process, alongside overly bureaucratic processes to share information. There is a necessity to strike the right balance between data sharing and confidentiality: the need to share information to benefit the quality and coordination of care that people receive while also maintaining the people's right and ability to restrict what of their data is shared. Our understanding is that there is currently nothing contained within information governance that precludes the transfer of person identifiable data in the interests of direct care.

Figure 2: Theogram mapping an individual's interactions with the health and care system as part of Nuffield Trust analysis.
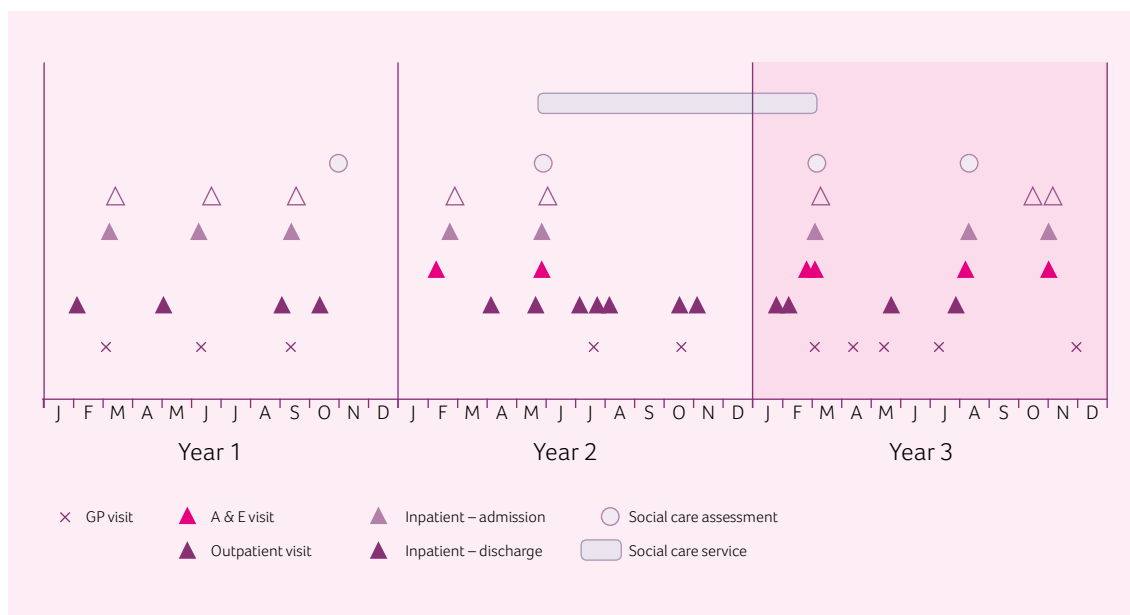
However, the definition of direct care is not always understood, and sharing information across different providers of care – organisations who employ doctors, nurses, social care staff – should be made much easier and simpler. The existing ambiguity leads to risk averse practice by front line professionals: the recent information governance review[176] – Caldicott2 – found great confusion among staff on what data could be shared about individuals, with a fear of Data Protection and the Information Commissioner dominating practice. Caldicott2 recommended an 'if you care: share' approach, but a broader commitment to data sharing by independent and not-for-profit organisations would be welcomed. As a result of Caldicott2, there is also work on-going to review the feasibility of having more unified information governance toolkits for all health and social care staff. The public assume that data is shared widely across the system, but the reality is very different.

We also believe that the availability of pseudonymised information for commissioners and researchers – that is, information about a person's care which doesn't identify them individually – is essential for whole person care. The current lack of access hinders good commissioning, and ultimately impacts upon quality.

People themselves are also often faced by a confusing array of information and advice sources and services. Accreditation of information is not sufficiently widespread or understood. Information and advice services are frequently disease specific and do not best serve the person with multiple problems.

Within this environment of complexity and ambiguity, the key purpose of information must not get lost: to help provide the best possible outcomes for the people served. That the system currently doesn't consistently use information to drive better outcomes for people and their families is a failure of health and care. This is not only a clinical failure but a moral failure – a failure which severely impacts upon the health and care system's ability to deliver high quality care every day across the country.

The chapter's key themes

Centrally, we believe that the ability to exchange data between systems (interoperability) of data and its meaningful use as information are vital components of the provision of whole person care. These elements frame our following recommendations, which fit within four broad areas. For whole person care to become the norm, we believe that:

- *Information must be seen as a core service in its own right, enabling people to better manage and control their own care*

- *Person-owned information should be shared across the care system, with a presumption of sharing between providers of care unless the person decides to restrict*

- *Systems themselves must be sufficiently compatible to allow information to be shared*

- *Commissioners must have access to better information to support integrated decision making.*

The provision of information

For whole person care to become a reality, information must be seen as a core part of the health and care service – as a necessary component of a person's care.

There is a body of evidence which shows the benefits of providing people with quality health information; it has a positive effect on people's experience of care, health behaviours, status and outcomes, alongside benefits in terms of service costs and utilisation[177,178]. It also helps create user engagement and empowerment, which is not only an essential element of whole person care, but can also have financial benefits for the health and care system[179]. Individuals using services have many decisions to make, including decisions about who to consult and where, decisions about which advice to follow, and decisions about which treatment, support service or course of action would be best for them. They require reliable information and decision support when these decisions are complex. One study in the US found health costs to be 8-21% higher for those people who were least active in decisions and the management of their own care compared with the study's most active participants[180].

Using good quality information to foster effective and share decision making therefore has both financial and clinical drivers – alongside the clear moral and ethical imperatives of information provision.

Enabled through the availability of high quality information, people who are engaged with their care can play a number of roles as active co-producers of care, through:

- understanding the causes of disease and the factors that influence health

- self-diagnosing and treating minor conditions

- knowing when to seek advice and professional help

- choosing appropriate healthcare providers

- selecting appropriate tests and treatments

- monitoring symptoms and treatment effects

- being aware of safety issues and preventing errors

- coping with the effects of chronic illness and self-managing their care

- adopting healthy behaviours to prevent occurrence or recurrence of disease[181].

This type of information – information *for* people – includes a range of different elements, such as decision-aids, information about local services and treatments, and active sign-posting and navigation. The range of potential information initiatives available to the system may be best described as a continuum of interventions – from passive elements of information provision to more active support to drive behaviour change or help decision making[182]. Using information to help encourage co-management and co-production will likely have the biggest impact for people living with long term conditions who account for 70% of health and care spend[183], and is a central component of the House of Care model[184] supported by this Commission.

Yet information in itself is not a panacea; it is important to recognise that high quality information must be combined with active educational, professional and informal support to provide better outcomes for patients and service users[185,186]. Issues of (in)equity in relation to information provision require careful thought – particularly in terms of health literacy and the (varying) ability of individuals to access and use information effectively. Information without sufficient support for those who need it could act to widen existing health inequalities[187].

Levels of functional health literacy were assessed among a UK population health sample in 2007[188]. This found that 11% of people struggled with basic tasks such as reading instructions for taking medicines. Those with low health literacy were more likely to be older, male, poorer, and in worse health. Even people with good basic literacy and numeracy skills may struggle to understand and interpret health information in a way that prompts them to act appropriately to protect or enhance their health. Tackling inaccessibility of information requires carefully developed approaches targeted at those who might otherwise be excluded through their individual level of literacy and numeracy or because they are members of a less well heard or marginalised community. It is also important to

address the health information needs of the whole population. Various strategies for improving health literacy have been evaluated. There is evidence that patient information materials (printed and electronic) can have a beneficial effect on people's knowledge and understanding of their condition, their ability to make appropriate health decisions, and their sense of empowerment[189,190,191]. Specially targeted interventions can help to increase knowledge and understanding in people with low health literacy if they are well designed[192].

Therefore the role of care professionals in recognising the importance of both information and support, and tailoring information services to suit individual need, is essential. Information prescriptions have been used effectively in some areas of the NHS. They should be extended to become the norm for all people to receive at all consultations. They are an important way of increasing people's understanding and through that understanding to influence their care.

For information provision to be established as a service in itself, the system must ensure that information made available for the public is quality information. While we recognise that it is impossible to regulate all health and care information advice services – particularly considering the amount of information generated and available online – we see the importance of building on the Information Standard with an 'information quality mark' that can be awarded to those meeting a standard in health and social care information and advice.

Box 7: The value of information provision – a vignette

A man caring for his wife who had dementia at home was not made aware that pressure sores were a potential risk, or of how to reduce that risk or spot the early signs.

His wife went on to develop a pressure sore which took intensive support from district nurses to treat. This caused a great deal of pain and distress. It also required costly support from the district nurses.

This might have been avoided if the man and his wife had been given information on pressure sores and how to avoid them. Information could have helped them maintain their independence, enabled his wife stay healthier and suffer less pain, and saved time and money for the system itself.

Figure 3: The patient information forum's simplified model of the case for information

'Infomediaries'
Health information specialists and health care staff – providing information, signposting and navigation services

Quality consumer health information
Available in a variety of formats, throughout the health and wellbeing journey

Support resources
Decision aids; community-based self-management education; health coaching; telephone counselling etc

Good communication and support
To help people understand and make efficient use of relevant health information; and to help inform choices

Increased satisfaction and reduced anxiety and stress

Education and support
To increase people's ability, confidence and motivation to change their behaviour, and to help inform choices

Greater patient engagement

More self-care of minor ailments

More shared decision-making

More self management of long term conditions

Better quality care

Greater clinical effectiveness

Enhanced patient experience

Improved patient survey

Low costs

Reduced demand for GP services and unplanned care

More appropriate use of services, including screening rates

Fewer hospital admissions and less time in hospital

Less major surgery

Reduced variation in procedures

Safer, more efficient use of medicines

Greater productivity, lower staff turnover, less absenteeism

Reduced litigation and claims for compensation

Better outcomes

Treatment in line with patient professionals

Better adherence to treatment

Safer, more effective use of medicines

Healthier behaviours

Improved health, quality of life and psychological wellbeing

Increased self monitoring

Greater health literacy

Reduced health inequalities

Fewer complaints and medical errors

Recommendations

3.1 Information provision must be treated as a core health and care service. This must include active support for those who need it, including targeted interventions to help increase the knowledge and understanding of people with low health and care literacy. The effective provision of information must be reinforced through quality regulation for all health and care providers. Skills for information provision and support must for part of health and care staff's mandatory (and on-going) training, and information prescriptions should become the norm.

3.2 We recommend the application of an Information Quality Mark to accredited providers of health and social care information and advice.

Information sharing between providers of care

Alongside its provision, information must be shared across the health and care system if person-centred, coordinated care is to happen quickly[193]. Yet while almost everyone agrees that information needs to be shared to provide coordinated care, information currently isn't being shared consistently across different health and care providers; while there are some examples of good practice, the national picture is one of fragmentation, where information remains in siloes rather than following people and their care. This is something which needs to change.

There are a number of barriers to widespread information sharing across health and care. Some of these barriers are technical. Data itself needs to be compatible to be able to be shared: interoperability – the ability for various data sets to be able to 'talk to each other' – enables the flow of information between different areas of the system without requiring a single, monolithic IT function. Yet the issue of compatibility should equally not be overstated; much data can be used in a joined-up way across the system, but organisations rarely look at how information can be effectively linked across care settings to map the whole person's care journey. The absence of an appropriate means to share information between organisations, professionals and the public – such as electronic

health records (often called personal health records when people are given access or control of their own health information) – is also a clear barrier to both the sharing and personal ownership of information. These issues are explored below and appropriate recommendations made.

Alongside the technical barriers to information sharing, there are further barriers relating to issues of information ownership and governance.

Our understanding is that there is currently nothing contained within information governance that precludes the transfer of person identifiable information in the interests of direct care. Caldicott2 and the Government's response confirm this position. However, we believe that the rules need to make it easier for different providers of care to share information about people and their conditions. The duty to share should be enhanced to help ensure that people's care is properly coordinated as they move between different care settings. As Caldicott2 rightly highlights, the public assume a greater level of information sharing than currently happens today[194].

We outline a concept of implied consent for person-owned health and care information to be automatically shared across all providers of care for direct care, unless the person opts to restrict. Legislation, whether national or European, should be reviewed to ensure that it does not present an impediment to the provision of whole person care.

Related to the ability to share information is who owns it: who does medical and care information belong to, and who has the right to determine what is shared? At the moment, medical records are technically owned by the Secretary of State for Health – not the people who the information relates to. We believe that this needs to change.

Person owned information

At the centre of the Commission's vision for giving meaningful power to the users of health and care is the rapid development and use of integrated, person-owned electronic health and care records.

The terms used to describe electronic records which people themselves can access vary considerably, along with the exact definitions of what people mean when they use them[195]. People often differentiate between Personal Health Records (PHRs), as those which are available for people themselves to access, and Electronic Health Records (EHRs), as those which contain information

about people which can be shared between providers of care. Yet we envisage the availability of a record across health and care which combines both of these elements. Therefore in this paper, when we talk of person-owned electronic health and care records we mean records which are available electronically to both people and health and care providers, but which are owned and controlled by the person that the records relate to. The absence of electronic records available to all people involved in providing care – particularly when caring for people with complex needs – is a significant barrier to coordinated care[196]. And it is the view of the Commission that this information must be owned by the person.

We believe that the development of person-owned electronic health and care records should be driven through the development of national 'meaningful use' requirements – a term borrowed from the US – rather than an(other) attempt to develop a national IT system. Meaningful use requirements would help to ensure that the potential benefits of electronic records are realised through establishing a set of standards governing their development and use, and allowing health and care providers to earn incentive payments for meeting these requirements.

At their core, meaningful use requirements should outline the central recording and where different mapped reporting standards for care data (explored below under the heading 'compatibility of systems and information'), requirements for the use of electronic records, and clear milestones and timelines for their development. We do not believe that these requirements should mandate a particular technical solution to deliver these requirements, though may outline examples of good practice which can be adopted locally. Encouragement should also be given to the development and availability of innovative assistive technology that can enable all people to access their data and information to support their care.

Within this context it would be people themselves who own and control their own care information – not the Secretary of State. Individuals would be able to access their electronic health and care record online at any point, ask for incorrect information to be corrected, and understand and control who saw their health and care information. They would not be able to remove information from their record, or change the status of clinical results. GPs should have complete access to the records of people on their registered list.

We believe that there should be an assumption of implied consent to the automatic sharing of this information across providers of health and social care for direct care, unless the person opts to restrict. This model of person-ownership has the ability to cut through the complexity of information governance, with people themselves able to control the flow of their personal information. An assumption of automatic sharing will make it much easier for health and care professionals to access information to benefit the quality and coordination of care that people receive. We are not proposing a binary in/out – share or don't share – model. What we are proposing is that the default assumption would be that people's information is automatically shared between providers of care, for professionals across health and social care to access as required for people's care; people should be able to 'opt out' of this automatic sharing of their information if they wished, based on a model of person-ownership, with their information flowing based on their consent when needed.

Box 8: Lessons from the US

There are lessons which can be learnt from the adoption and success of personal health records in high performing systems across the US. The two short examples outlined below describe systems where information about people and their care has been shared across care providers, while also being shared with the users of the system.

Veteran's Health Administration

The Veteran's Health Administration (VA) is a large integrated healthcare provider network which provides fully integrated services for military veterans across the US – most of which are elderly and typically suffer from complex needs. More than 44% of the VA's patients are aged over 65[197].

The VA has used innovations in technology to improve quality of services for a number of years, including the development of a comprehensive, integrated electronic health record available across VA providers. This system is also linked to a personal health record system – 'My HealtheVet', introduced in 2003 – where people can securely access their own health information held within their electronic record, while also accessing a variety of other sources of information to support co-management and informed decision making. People are also able to upload a variety of their own health information, record and track personal health measurements, and set personal health goals on the same online system.

As of 2011, there were over 1.3 million registered users of My HealtheVet, with a median age of 61. The system has had high levels of user satisfaction, with an overwhelming majority of those using the system happy to recommend it to other veterans[198].

Kaiser Permanente

Similar to the VA, Kaiser Permanente also uses a comprehensive electronic record system available across providers, linked to an electronic record available to its members: 'My Health Manager'.

Kaiser Permanente is the largest non-profit health maintenance organisation in the US, serving 1.8 million people across eight regions. Kaiser Permanente is an oft-cited example of a highly successful virtually integrated care system, and is recognised as one of the highest performing systems in the US. It receives high levels of member satisfaction, excellent ratings for clinical quality alongside lower delivery costs when compared with other providers in most regions in which it operates[199]. My Health Manager was introduced in 2007, allowing members to:

- View past visit information, latest test results, immunisations, allergies and healthcare reminders

- Exchange secure e-mail with their doctor's office

- Schedule appointments and manage prescriptions (such as ordering repeat prescriptions)

- Learn about specific medications in KP's health encyclopaedia

- View health information and use features on behalf of a family member

- View follow-up instructions for past visits

- Take or review a health assessment[200].

Between 2007 and 2010, members' visits to doctors' surgeries reduced from 72% to 58% of contacts, and secure messaging rose from 12% to 28% of contacts between members and their doctor's office[201].

Compatibility of systems and information

Data from different systems needs to be compatible to be able to be shared. Interoperability enables the flow of information between different areas of the system.

A lack of interoperability is often identified as a key impediment to whole person care – it was an important theme highlighted within our consultation process – and is something which is recognised nationally as a central priority for the health and care system. It is also something which is essential for the development of integrated health and care records available across multiple care providers. Interoperability standards have been developed centrally for a number of years, but we believe that the adoption of standards which apply across health and care must be a legislative requirement of software developers and health and care providers.

Work to develop comprehensive information standards across health and care is ongoing. The Professional Records Standards Body is working to provide common standards for records across health and care. NHS England also plans to instruct the Health and Social Care Information Centre (HSCIC) to collect far more complete data sets from hospitals from 2014, while also outlining (with the HSCIC) plans for the development of a fuller health and care data system through the 'care.data' programme, which will see the development of a Care Episode Service. This Care Episode Service will include a greatly enriched hospital dataset, mental health data, GP data, community health services data, social care data, clinical audit data, and disease registry data[202]. This emphasis is something which we support, and both of these elements – information standards across health and care, alongside a comprehensive care data service – must be supported and rapidly advanced by an incoming government in 2015. At the same time, it is essential that this is done in a way that commands public confidence and supports people's ability to opt out if they wish. The inclusion of national reporting standards within meaningful use requirements must be used to help drive this shift towards interoperability. Common use of the NHS number across health and social care will also be an essential part of this shift, and is something which is already happening in many areas across the country.

Data has been successfully integrated across health and care (and beyond) in some parts of the country to benefit those the system serves. This has often involved the use of 'middleware' technology able to link heterogeneous data sets without the construction of a central IT system. Therefore while

recording and reporting standards must be nationally defined, solutions to meet these requirements should be necessarily locally driven. Where care data still isn't properly collected – for example, in community services – ensuring that programmes are in place with timelines to do so must be a priority for providers. In practice, this will mean complying with all newly developed recording and reporting standards and including data reporting and management standards in contracts. Where possible, data collection should include self-funders as well as Local Authority funded residents.

Recommendations

3.3 **People must be given ownership of their own health and care records. The development and use of electronic health and care records should be governed by the creation of nationally defined standards: 'meaningful use' requirements. These should include a single set of national recording and where different mapped reporting standards for health and care data, and the adoption of these standards must be required by law for both software developers and health and care providers, reinforced through provider contracts.**

3.4 **The default assumption should be of implied consent for people's information to be shared across health and care providers for their direct care. People should be able to 'opt out' of the automatic sharing of their information.**

3.5 **As part of this drive towards national interoperability, it must be a requirement for all organisations providing (health and social) care to use the NHS number.**

Information for commissioners and researchers to support decision making

While information needs to be shared between providers across the system, it also needs to be available in a pseudonymised format to commissioners to support good decision making and good commissioning. Health and care commissioners currently have insufficient information about their populations from which to make effective commissioning decisions; coordinated, joined-up care can't be achieved without access to coordinated, joined-up data[203]. The broader the access that commissioners have to a range of relevant data, the more effectively they will be able to commission. Indeed, health and social care data may not be the only data that will benefit health and care commissioners – data in relation to housing, for example, viewed alongside typical health and care data, will give commissioners a broader picture of a whole person's needs. This information must also come from people; commissioners need to develop comprehensive approaches to collecting and using information from their populations to help support them in commissioning for outcomes.

It should firstly be recognised that data which already exists could be used much better to support commissioning decisions locally. Existing data relating to different aspects of care – if joined up – can be used for predictive modelling, evaluating health and care interventions, informing service (re)design, whole system value for money studies, and developing methods to pool financial risk across populations. Yet routine data is currently underexploited by commissioners across the system[204].

The 'Routes from Diagnosis' approach developed by Macmillan demonstrates the potential benefits of linking and analysing routinely collected pseudonymised data. Data is used to map people's cancer journeys from diagnosis through to death, enabling an understanding of what happens to people with cancer throughout their cycle of care – clinical outcomes, interactions with health services and associated costs. This knowledge can then be used at a local and national level to inform commissioning and the redesign of cancer services where this will improve value. Programmes have focused on acute data because of the difficulty in accessing other sources of data, but Macmillan are keen to incorporate primary and community health care data as well as data from palliative care and social care. This is still perceived to be a significant challenge, but one for which a duty exists to overcome due to the benefits to care.

A number of other organisations such as Localis have also emphasised the importance of drawing on a range of data sources from a variety of local partners in order to develop the quality of joint strategic needs assessments (JSNAs) necessary for better commissioning. However, they have found that local government officials are uncertain about the rules of data sharing in the absence of individual consent or statutory requirements. This again has led to an overcautious response which hampers effective

commissioning. Health commissioners have also faced uncertainties due to (varying) interpretations of information governance – including uncertainties over validating invoices from providers from outside their area, and tracking frequent (and high cost) service users. A number of areas have halted the development of risk stratification and early identification schemes using information across health and care as a response to these concerns[205].

We believe that the availability of quality pseudonymised data which links information from a variety of sources and care settings is essential for commissioners (and researchers) to map care journeys, identify opportunities for interventions and service redesign, and to stratify populations in relation to risk. These are all essential elements for the development of whole person care. Pseudonymised data is also vital for the evaluation of interventions and service redesign[206] – which must be actively encouraged – and the availability of data for researchers and evaluators to carry out this analysis should be promoted by any incoming government. This pseudonymised information should only be made available in strongly controlled, safe environments. We believe that the simplification of the process to achieve Accredited Safe Haven Status (the necessary controlled environment) would be a clear step towards achieving this, and would allow for radically improved access to information; this must also include organisations who seek to use pseudonymised information as a means to provide better outcomes for people using health and care services through their analysis (including third sector organisations) – not just commissioners and commissioning support units (CSUs).

We also believe that collecting and using information from people must be embedded as a central component of the health and care commissioning process. Whole person care centres upon the delivery of outcomes that matter to the people who use the care system; community commissioning can only be achieved if commissioners have sufficient information on the preferences, needs and desired outcomes of the population that they serve, alongside information on the outcomes achieved by local services. Health and care commissioners must therefore engage with the public in a variety of different ways to obtain this information, which must be seen as an essential element of commissioning and delivering care for the public.

The use of appropriate metrics to monitor progress will be essential for person-centred outcome based commissioning. The separate national outcomes frameworks for health, social care and public health

ought to include standardised generic measures that enable coordinated performance monitoring across health and social care. Since a fundamental goal of whole person care is to ensure that people are given personalised support to develop the knowledge, skills and confidence they need to effectively manage their health, it will be important to obtain their reports on their experience of care and its outcomes. Numerous survey instruments have been developed for gathering data on people's experience (PREMs) and their reported outcomes (PROMs), but there is currently no consensus on which should be used to monitor care for people with long term conditions. A coordinated approach to measuring outcomes across health and care will be needed for whole person care.

Recommendations

3.6 There must be greater access to and promotion of the use of de-identified (weakly pseudonymised) data within a strongly controlled environment for health and care commissioning, audit, planning, case management, purchasing care pathways, individual budgets and invoice validation.

3.7 There must be greater access to and promotion of the use of end user irreversible psuedonymised data. This should not simply be restricted to the HSCIC and commissioners, but should include organisations who are using information as a means to provide better outcomes for people using health and care services. We recommend the simplification of the process to achieve the necessary controlled environment, which should ideally be controlled through regulation and a contract with liabilities and penalties.

3.8 Person-defined outcomes must be accurately measured and reported as part of the collection and use of information from people. The separate national outcomes frameworks for health, social care and public health ought to include standardised generic measures that enable coordinated performance monitoring across health and social care of function and morbidity and not simply mortality.

Helping people stay as well and independent as they can

4

Whole person care should not only include joining up services to respond to the health and care needs of the population, it should also encompass a whole systems approach to supporting people to stay healthy in their minds and bodies throughout their lives – from childhood through to old age.

30 wasted years? A whole systems approach to improve health and wellbeing

Advances in social policy and public health in the 20th century have laid the foundations for a 21st century world where a child born today could expect to live for 30 years of active meaningful life beyond the age of 60[207]. However, current failures in social policy and public health result in many children of today leading an unhealthy life with little prospect or expectation of enjoying extra meaningful years after 60. Many people currently living into old age also suffer avoidable loss of independence and poor health.

Whole person care should not only include joining up services to respond to the health and care needs of the population, it should also encompass a whole systems approach to enable people to make healthy lifestyle choices and support them to achieve the highest possible levels of health and wellbeing throughout their lives. The preventative aspects of whole person care must therefore include a wide range of potential interventions across the lifecourse. In this sense, a single chapter within this report could not (and does not) claim to be comprehensive. Instead, we have identified a small number of targeted interventions in two groups of society who particularly require coordinated support – children and older people – while highlighting further areas where policy must adapt to support people of all ages to stay healthy.

These recommendations should be placed within the broader whole person care approach running throughout this paper, focused on creating a shift within the health and care system from reactive repair to proactive care and prevention. This includes the substantive recommendations focused on empowering people to take more control of their own care and wellbeing where appropriate.

There is a social gradient in health and health inequalities. The social determinants of health – the conditions in which we are born, grow, live, work and age – shape these unequal health outcomes. Inequities in power, money and resources limit people's capability to live a full and healthy life. Evidence shows that health inequalities exist within and between countries across the world. For example, there is a difference of 17 years in male life expectancy between countries in Europe[208]. Young men living in the poorest 10% of postcodes in England are almost five times more likely to attend A&E as those in the richest 10%[209]. Tackling these differences in health outcomes requires action across many areas of policy and society, but particular focus must be placed on supporting children – particularly those who are socioeconomically deprived. Key adverse health outcomes could be reduced by up to 59% if all children were as healthy as the most socially advantaged[210]. We therefore make recommendations for targeted approaches aimed at providing the right support to give children the best start in life.

Targeted approaches are also needed to support our ageing population to achieve higher levels of health, independence and wellbeing in old age. We have made the point throughout this report that the existing health and care system too often fails to provide coordinated, person-centred care for people and their families – particularly for older people with multiple and complex long term conditions.

The existing fragmentation of care fails to meet the whole of an older person's needs, and often results in missed opportunities to avoid admissions to hospital. Yet a strong evidence base now exists to target key risks to health independence and wellbeing in old age. We believe that a targeted preventative approach for older people should include a focus on falls, the early identification of threats to older people's health and wellbeing, and comprehensive geriatric assessment for fair older people.

In all groups in society, the social and physical environment in which people live has a profound impact on their health, independence and wellbeing. Preventive aspects of whole person care must therefore pay attention to environmental factors. Two of the major drivers of poor health and wellbeing in all age groups are eating too much high fat and high sugar foods, and sedentary lifestyles with reduced physical activity. This has led to the crisis of obesity. The increased risk of illness and death due to obesity is well known, yet most adults in England are either overweight or obese[211]. We believe that the existing model of industry-self regulation should be replaced with a more effective policy approach to tackling obesity across society. We also recognise the large impact the home environment has on people's health and wellbeing. Existing inflexibilities within the housing system – particularly in terms of housing options for older people – must be addressed for the provision of whole person care. Currently many older people are faced with a binary choice of remaining in their own existing home, even if unsatisfactory, or institutionalised care often after a crisis. This is not good for them or the system.

The chapter's key themes

Whole person care must focus on creating an environment where people are supported to stay healthy in their minds and their bodies throughout their lives. There are many aspects to prevention beyond the scope of this report, so we have focused on a small number of key areas consistent with the thrust of this document. As part of a broader approach to prevention, we believe that:

- *A stronger emphasis must be placed on providing the right support to give children the best start in life, with better integration of services targeted at children and their parents*

- *Targeted preventative interventions for older people should include a focus on falls, the early identification of threats to older people's health and wellbeing, and comprehensive geriatric assessment for fair older people*

- *A more effective policy approach should be developed for tackling obesity in the general population, rather than the current model of industry self-regulation*

- *The housing market must become more flexible to better suit people's changing needs, particularly in terms of the housing options for older people.*

Targeted approaches in children and their parents

As we outline at the front of this chapter, health outcomes are not equally distributed. In England, people living in poorer areas of the country will typically die 7 years sooner than those living in the richest areas, and spend more of their (shorter) lives living with a disability (the average difference in disability-free life expectancy between these groups is 17 years)[212]. The social determinants of health shape these unequal outcomes, and inequities in power, money and resources limit our capability to live a full and healthy life.

In order to tackle these inequitable and avoidable differences in health outcomes, action is needed in many spheres of health and society. In particular, we believe that a strong emphasis must be placed on supporting children and their parents to give children the best start in life. This goal is the highest priority objective in the Marmot Review: *Fair Society, Healthy Lives*[213]. This seminal report recognises the importance of early years on future health and wellbeing, and the positive impact that a good start in life can have on reducing health inequalities. In order to deliver the aim of giving every child the best start in life, it is important to recognise that it is not simply a case of providing more services for children. It is about doing things differently within existing budgetary constraints and making better use of the whole system, with a focus on the wider determinants that can contribute to future ill-health. Yet as the Marmot Review highlights, children's services are underfunded, so a redistribution of the prevention budget may be justified. Stopping unhealthy habits from starting is generally more cost-effective than changing established habits.

We know that future health and wellbeing of children is correlated with socioeconomic status, so a key focus must be on targeted interventions to support the socioeconomically deprived. Above all, preventative interventions aimed at children should locate children within the broader context of the family, recognising the huge impact families and

parenting has on child health, wellbeing and a raft of other life outcomes. It is particularly important to support children and their parents in communities which are affected by high levels of socioeconomic deprivation, where there is also often poor development of traditional primary health care services. We therefore believe that local permission should be given where there is agreement between Local Authorities and health care leaders to build on the concept of the Sure Start Children's Centre as a focal point for the delivery of whole person preventive care for children and their parents.

There are a vast array of services offered to children and their families. In areas with poor quality primary health care, Sure Start Children's Centres could bring these together under one roof (real or virtual). Sure Start Children's Centres could be the place where every parent knows that they can get advice on and access to child-centred services, regardless of where that service is delivered or who it is commissioned by. We do not propose this as a universal model, as we believe that there should be local determination of the right approach to coordinating children's services, but we believe that this model could be an attractive means of delivering whole person preventive care to children and their parents in areas of high socioeconomic deprivation.

To illustrate the type of benefits that this approach can bring, the following case studies highlight people's experience of the integration of maternity services within a Sure Start Children's Centre.

Box 9: Integration of maternity services within two Sure Start Children's Centres

Ann's story

Ann became pregnant. She had been pregnant many times, and had had three live births. Ann was a single parent and had exposed to domestic abuse. Two of her children had been removed from her care by social care, and her eldest lived independently. As a previous drug user, Ann was under the care of a drug rehabilitation unit. She had also been a heavy drinker prior to becoming pregnant, and was a heavy smoker.

The facilities and groups at the Children's Centre helped this vulnerable woman to turn her life around, and demonstrate to social services that she could keep and care for her baby.

Ann's midwife initially ensured that she was registered with the Centre, and people at the Centre soon became familiar faces; the receptionist, for example, would welcome her each time she came and ask her how she was. She became a recognised member of the Children's Centre, which became a place where she felt comfortable and her surroundings were safe and familiar. She gained confidence, and with the support of a Family Prevention Worker at the Centre was able to access key groups including those for breastfeeding and stopping smoking. Being in a place where she felt respected and included, she successfully quit her long term addiction to nicotine. She had regular contact with a benefits and housing advisor based at Centre.

When her baby was born, she was able to attend sessions at the Centre that focused on bonding with the baby, which was deemed an important requirement of keeping her baby out of social care. These included the postnatal baby massage and baby yoga groups. She went on to attend the postnatal drop-in sessions for baby weighing with the health visitor, and then the 'Stay and Play' for under 1s to meet other new Mums. The receptionist again was important for Ann, as she would provide on-going continuity: 'looking forward to seeing you next time'.

Having a safe place to return to and get out of the house was a valuable part of her integration into the local community. She managed to stay off drugs and alcohol, and one year on was still accessing the facilities provided at the Children's Centre. She has also met and befriended other women in the local area, creating an informal yet powerful peer support network.

Grace's story

After suffering a miscarriage earlier in the year, Grace, aged 17, wanted to become pregnant again. Her parents were unhappy about this and relationships became increasingly difficult between Grace's parents and her boyfriend.

This hostility meant that neither family knew of the second pregnancy. After an initial appointment at the GP's surgery, Grace's midwife arranged to meet them at a local Children's Centre in order to complete a Common Assessment Framework (CAF) for much needed support. The midwife was able to meet Grace and her partner at a choice of Children's Centres – Grace and her partner both lived with their respective parents in different areas – and they chose to meet her at the Children's Centre nearest to Grace's parent's house, which is on her bus route. The assessment

was completed, a worker was allocated and a joint visit was arranged, again at the Children's Centre, as the families were still unaware of the pregnancy.

The worker then met with the couple fortnightly at either of their two local Children's Centres, and assisted the couple with their housing application and benefit support. The couple managed to secure a tenancy, along with furniture and white goods for their new house. The families were eventually told of the pregnancy and the couple now have a daughter. The couple are extremely grateful for the support they received and the ability to meet with professionals at the Children's Centre.

Recommendation

4.1 Provide an option for Sure Start Children's Centres to be the hub for all children's health and wellbeing services locally, with better integration of associated services. Consideration should be given for the transfer of funding and commissioning responsibility and accountability for Sure Start Children's Centres from the global Local Authority financial allocation to the Public Health budget.

Targeted approaches for older people

Older people are the 'core business' of the health and care system, and will be to an even greater extent in future since their numbers are projected to increase rapidly over the next twenty years.

This report has made the point that the existing system fails to provide coordinated, person-centred care, particularly for older people with multiple and complex conditions. It is not only our hospitals that are currently ill-equipped to meet the needs of older people; the same is true to varying degrees of primary care, mental health and indeed right across the health and care system. All relevant organisations and professionals are struggling to overcome structural and cultural barriers to provide older people with joined up care, yet this is undoubtedly what they need. We have argued that this is because most older people have a number of different needs, but our health and care system typically responds to each of these needs separately. Indeed, our social care system isn't really a

'system' at all: the social care available falls far short of the demand and its quality is often barely adequate, if that.

70% of people over 75 live with a major long term condition and a quarter live with two or more[214]. We have noted throughout this report that for many older people, the impact on their health and wellbeing is less the severity of a single condition, more how well they are able to manage living with several of them all at once. So rather than care being planned in a way that accounts – say – for an older person's heart disease and osteoarthritis together with their social care and housing needs, what is offered is usually piecemeal and fragmented, as well as often entirely inadequate in terms of social care and housing. This substantially increases health risks and frequently results in missed opportunities to avoid admissions to hospital.

People need care that responds to them as a whole person and treats them with dignity and respect. We therefore have to direct our efforts and resources at enabling services to work together around an older person, including housing and social care, as well as all kinds of medical care. To do this, we have argued that the system needs to align incentives and measure performance in ways that reward early intervention and prevention and the long term, sustained wellbeing of older people. This is particularly emphasised in the following chapter which addresses financial flows and incentives across health and care.

More fundamentally, we need to move from a culture of welfare and passive care to one of capability and empowerment. Achieving this requires change across the lifecourse, but within old age a strong evidence base now exists to target key risks to health independence and wellbeing:

- In the general population of older people, falls and their consequences have a profound impact on people's lives, with the first fall often signaling to an older person that they have become frail. In order to reduce the risk of falls, it is clear that it is best to raise levels of exercise and physical activity in the whole population of older people, alongside schemes to ensure that hazards in the home are identified and addressed

- A broad range of other risks to health independence and wellbeing in old age typically emerge in the seventh decade, and a systematic approach in this group to identifying and responding to these risks based on the priorities of the older person should be a key part of holistic preventive care for older people, alongside schemes to ensure that hazards in the home are identified and addressed

- In a small group of older people, extreme levels of frailty are experienced and associated with heavy use of acute hospital and long term care services. For this group, it is cost-effective to undertake comprehensive multi-disciplinary assessment and care by old age specialist teams.

Whole system falls Prevention as part of a broader preventive approach

We know that falls are a very big issue for older people:

- Falls and fractures in people aged 65 and over account for over 4 million hospital bed days each year in England alone[215]

- Around 1 in 3 people over 65 who live at home will have at least one fall a year, and about half will have more frequent falls[216]

- The healthcare cost associated with fragility fractures is around £2 billion a year[217]

- Injurious falls, including 70,000 hip fractures annually, are the leading cause of accident-related mortality in older people[218]

- After a fall, an older person has a 50% probability of having their mobility seriously impaired and a 10% probability of dying within a year[219]

- Falls destroy confidence, increase isolation and reduce independence, with around 1 in 10 older people who fall becoming afraid to leave their homes in case they fall again[220].

A strategic approach to preventing falls therefore makes a lot of sense. Yet although awareness of the importance of falls prevention has increased in recent years, efforts are often patchy within and between care settings and geographical areas.

We know 'what works' in preventing falls: home aids and adaptations, schemes that help to ensure that hazards in the home are identified and rectified before an older person falls and evidence based exercise programmes all have a part to play[221]. One randomised controlled trial showed that a tailored group exercise programme delivered over a nine month period can reduce the risk of falling by as much as 54% – another, based in New Zealand and using home based exercise over a year, showed a reduction of 35 per cent[222].

In addition, broader approaches aimed at improving the health and wellbeing of older people and at avoiding crises can and should have falls prevention as a key feature (for example, see Box 10).

Yet these types of approaches are not widely implemented, or are often not implemented in the best way. Home aids and adaptations that can reduce the risk of falling are often only considered by Adult Services after an older person has fallen and injured themselves, and local government cuts have reduced their availability. Despite the clear potential of evidence based exercise programmes for helping to drive improvements in quality of life and deliver cost savings, older people continue to have only limited access to them. Where such programmes are available, most are altered or scaled down to an average duration of 12 weeks or less, yet we know that a 'dose' of at least 50 hours is necessary to reduce falls[223].

Within the model of whole person care that we have described throughout this paper, the early identification of older people at risk of harm or illness – such as falling – and the development of the right interventions to reduce this risk must be the norm to help older people maintain their independence and avoid unnecessary admissions to hospital. This will be achieved through aligning incentives within a locality around the achievement of a common set of outcomes, and all organisations involved in the delivery of a person's care working together to achieve these at the right cost.

Box 10: Age UK's integrated care pathway

Age UK is currently trialling an Integrated Care Pathway in partnership with CCGs and the Local Authority in Cornwall, and one of the key components is falls prevention. Older people at risk of unplanned admission to hospital are identified through risk stratification with GP surgeries, and they are then offered a 'guided conversation' with an Age UK worker. This worker is part of a local multidisciplinary team led by GPs that brings together health and care staff as well as Age UK paid staff and volunteers, with the clinicians retaining clear clinical accountability.

The aim of the guided conversation is to enable the older person to identify what would improve their quality of life and their wellbeing. A single care plan is then developed and different kinds of help and support are brokered in from a wide range of providers. Falls prevention usually forms part of the services provided.

This way of working fully integrates voluntary organisations and health and care services to provide a combination of medical and non-medical support as part of the care pathway for older people living with multiple long term conditions. Its proactive and preventative approach provides a comprehensive range of services as part of a single care plan with individually specified goals to secure the older person's health and wellbeing outcomes. This includes anticipatory interventions to:

• Meet personal health and wellbeing goals

• Meet physical and mental health needs

• Meet social care needs

• Meet practical support needs

• Maximise income (benefits check)

• Improve social engagement.

The programme is still in its infancy, and only 100 older people have so far been helped, but the results are promising: older people's quality of life, confidence and wellbeing is up by 24%; there is a £4.40 return for each £1 invested; and there has been a 30% reduction in emergency hospital admissions. The next phase is to scale up the Pathway to 1000 people in Cornwall and expand it to additional (contrasting) localities elsewhere, with areas in the North East and London most likely to come on stream soon.

As part of this work, Age UK is modelling a new approach to evidence cashable savings that could be used to secure a Social Impact Bond (SIB). The aim is that the SIB will act like an 'invest to save' programme through utilising external funding streams, which can be adopted with confidence by commissioners to reshape their health and care systems. To do this, Age UK will be testing out different contractual and performance management systems linked to financial modelling. The outcomes that Age UK aim to achieve are:

• Improved self-reported health and wellbeing

• Improved experience of care and support for those on the programme

• Reduction in avoidable emergency admissions of older people

• System wide operational and economic efficiencies/ more cost effective services.

As part of this initiative, Age UK has developed and tested an outcomes framework that can be adapted by local commissioners to reflect local performance and commissioning arrangements. It sets out clear outputs and KPIs such as wellbeing scores and reduced GP attendances and hospital admissions. The framework is reported against on a monthly and quarterly basis, enabling service improvements and achievements to be identified and managed.

Within the first 4 weeks of an individual being identified, a multidisciplinary team review is held and a care management plan is developed with the older person and a volunteer. The older person and the volunteer then work together over the next 3-6 months to enable the older person to achieve their goals. The aim is to 'discharge' the older person within this period having achieved their goals and with a greater sense of control and independence.

Age UK's Integrated Care Pathway is attracting national attention from policymakers who see it as new and exciting, but at its heart is an approach to prevention that is well known but often poorly executed.

....

Early identification and response to threats to older people's health, independence and wellbeing

Recent studies in the Netherlands have shown the potential for high impact on health outcomes and reducing costs of care through a targeted approach in at-risk populations and with a service response based on the older person's priorities[224,225,226,227,228]. This approach to the early identification and response to threats to older people's health, independence and wellbeing has been found to be valid and reliable in different countries and cultures including those with poor, middle income and rich populations, Judeo-Christian, Islamic and Eastern cultures, with a diverse range of systems of funding and delivery of care[229,230].

In England, a national demonstration project has defined a model for identifying at-risk older people, assessing their needs, mobilising a response based on the priorities of the older person and sharing and storing summary information about the needs and priorities of those assessed for supporting person-centred care and assessing population needs. We believe that this approach should be more widely adopted in England as a foundation for personalised preventive care for older people (see Box 11).

Box 11: Warwickshire Shared Assessment System (SAS)

The Shared Assessment System (SAS) in Warwickshire is a collaborative project involving stakeholders across health, council and voluntary sectors. Phase one developed a digitised version of EASYCare for use as a self-assessment for the health and care needs of older people, and linked to a variety of resources through an online database. Access was trialled in a variety of settings (GP receptions, library, lunch clubs and pharmacy) predominantly using iPad technology. Results during this phase showed high levels of acceptability for both users and stakeholders; users found the assessment easy to complete and the information given very useful, stakeholders valued the information collected as record of the older person's needs which complements assessments undertaken in a formal setting.

Two key findings in phase one led to a shift in the approach of the SAS project. Although older people were able to easily self-complete the assessment, most preferred the opportunity for assistance as they greatly valued the time to talk to someone about their concerns. Stakeholders also recognised the opportunity for using population data analysis to target resources and develop services by integrating the information obtained with health records. As a result, phase two focused on a more formalised, targeted approach, from the general population to those considered to be at-risk, and further IT developments were undertaken to ensure information sharing with those subsequently involved in the older person's care.

The model now recommended and being replicated elsewhere is for GPs to write to patients 75+ and invite them to have an EASYCare assessment with assistance from trained Age UK coordinators over the telephone or face to face. The results are used to mobilise information, advice and support based on the priorities of the older person, which is the key to producing a personal and efficient service response. A pdf summary of information is automatically sent to the GP who adds this information to the older person's record, to be referred to during their next appointment.

A response rate of over 50% has been achieved with the majority of users remaining highly satisfied with the approach. One user commented:

> *I am so pleased that I completed the consent form... I was unaware that there are so many different services available to support people like me who feel lonely and isolated. I cannot believe I now have all this support resulting from a tick in a box. Aged 82 my life has changed; I used to dread getting up in the morning as I had nothing to look forward to, now I am so busy!*

The SAS project provides an extremely rich data source which demonstrates the variety of needs and concerns amongst older people in Warwickshire. The top three priorities identified are severe bodily pain, trouble sleeping and loneliness, with the latter leading to an increased uptake for the Age UK Befriending service. Other concerns commonly identified include: hearing, finances, bereavement, falls, and memory loss. Arthritis and heart disease are the most frequently recorded medical conditions with over half of respondents reporting two or more conditions. The demographic information obtained not only helps to provide analysis at a local level but also contributes to cross-cultural comparisons using the EASYCare International data set, which includes over 40 countries world-wide.

With increasing pressure on budgets and demand for statutory services, the Shared Assessment System offers a unique approach through developing formal partnerships with the voluntary sector and makes an important contribution to the quality and sustainability of health and social care systems. The assessment empowers older people who have a choice in the delivery of their care and stakeholders are better placed to target their resources and develop services accordingly.

Quality registries can also be used to evaluate and improve the preventative care process in older people. In Sweden, for example, a national quality registry (Senior Alert) has been developed for evaluating preventive care for older people in the areas of malnutrition, falls, pressure ulcers and oral health. This registry allows an assessment to be made of the care planning process and interventions for older people at risk, and helps professionals to improve services for those people. Data from the registry for the period 2010-2013 showed that 59% of older people were at risk for malnutrition, 56% were at risk of falling and 19% were at risk of developing pressure ulcers. In 2010, 61% of persons at risk in any of the identified areas had a preventive care plan, which increased to 70% by 2012.

Comprehensive Geriatric Assessment in frail older people

Although the term 'frailty' has been in general use for many years, recently there has been much interest in the topic of frailty amongst researchers into the care of older people. In clinical terms it has long been used to indicate concern about an older person's vulnerability.

Falls and delirium are amongst the most common reasons for older people to be admitted to hospital[231,232]. Although much focus of preventive work has been on the management of long term conditions, not all older people who are admitted are living with multiple long term conditions[233]. This has led to further investigation into the factors which determine frailty. The characteristic features are of reduced muscle strength, impaired immunity and impairments of the endocrine system. These impairments result in a reduced capacity to deal with infections or other challenges (such as new drug treatments), and the lack of homeostatic reserve leads to impaired balance and mobility leading to poor mobility and falls. The impact on the brain is such that delirium is common. There is evidence that frail older people are at greater risk of cognitive impairments and dementia than non-frail populations[234].

There is an overlap between people who have multiple long term conditions and those who are frail, with some older people being both frail and suffering multi-morbidity, some non-frail and multi-morbid, and some frail alone[235]. We therefore recommend that systems are developed to recognise frailty based on based on the following definition:

Frailty is a propensity to rapid loss of physical, mental and or social functioning resulting from age related patho-physiological decline.

Frailty is common. Estimates suggest 25-50% of people over 85 are frail[236]. Its consequences are potentially catastrophic for the individual and expensive for the health and social care system[237,238]. Yet there are effective interventions which mitigate its effect based on a comprehensive approach to assessing and responding to the needs of a frail older person by multi-disciplinary old age specialist teams[239,240,241]. This type of approach is often referred to as Comprehensive Geriatric Assessment (CGA).

The core team typically comprises physiotherapy (e.g. for assessment and treatment of gait and balance disorders), occupational therapy (e.g. for assessment and treatment of difficulties in the activities of everyday living such as washing, dressing, going to the toilet), specialist nursing staff who offer a holistic nursing assessment, and a geriatrician who provides a diagnosis and treatment plan for medical issues. In some cases, other professionals may be relevant – such as speech and language therapists if there are swallowing concerns, dieticians where nutrition is a key factor, or mental health staff where there are specialist mental health issues. The team need to work together and form a care plan documenting the relevant actions; they must also have the ability to ensure its recommendations are adhered to, and must be able to review the older person to assess progress and modify the plan in the light of evolving needs[242].

The evidence base is most strong regarding the use CGA in hospital settings (where the medical assessment is usually offered by a geriatrician) but there is also evidence of effectiveness of CGA in the community when the medical component may be offered either by a geriatrician or by a primary care doctor with specialist training and skills in the care of older people[243,244]. There is good evidence that CGA reduced the risk to the older person of hospital admission (or readmission when the assessment is carried out in a hospital setting), of remaining in their own home (rather than in a care home) and of reduced risk of death[245,246].

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Recommendations

4.2 Preventative approaches aimed at improving older people's health and wellbeing should be comprehensive across health and social care. All localities should offer older people preventative checks to identify risks to health, independence and wellbeing and mobilise a response based on the priorities of the older person and their families. For example, a falls prevention strategy as part of a broader approach to improving older people's health and wellbeing. Frailty should be actively sought by health and social care professionals.

4.3 Comprehensive Geriatric Assessment (CGA) must be used in the community, hospitals and care home settings.

4.4 Localities should create a multi-agency quality register (and plan) similar to the Swedish model, based on the needs and priorities of older people, identified through preventative health checks and the outcomes of comprehensive assessments.

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Tackling Obesity

The majority of adults in England are overweight. In 2011, 65% of men and 58% of women were overweight or obese – an increase from 58% and 49% in 1993. Over this same period, the proportion of adults that were classified as obese grew from 13% to 24% of men, and 16% to 26% of women in England[247]. Around 30% of children aged 2-15 were classified as overweight or obese in 2011[248].

The increased risk of illness and death due to obesity is well documented; obesity is associated with a number of chronic diseases like type 2 diabetes, hypertension (high blood pressure) and hyperlipidaemia (high levels of fat in people's blood, which can lead to the narrowing and blocking of blood vessels), and also with cancer, disability, reduced quality of life and premature death[249]. The prevalence of obesity itself is also associated with socioeconomic position: in more deprived groups of society there are higher levels of obesity[250].

This obesity epidemic is driven by powerful environmental and biological pressures, with multiple factors acting together in a complex set of relationships: in this sense, obesity is a 'normal response to an abnormal environment'[251]. Effective approaches to tackling obesity need to address this 'obesogenic environment' that leads many people to consume more energy than they expend. Although individual actions are an important part of the response, the main focus needs to be applied to the environment in which people make decisions about their diet and physical activity, with a shift in the range of options to make it easier for people to make healthy choices. The interventions to affect this environment will need to be multiple:

> It has been multiple small changes in society which have contributed to the changing population weights. ...we are going to have to intervene in multiple ways to push it back down again, there is not one simple answer[252].

If we are to successfully reverse the obesity epidemic, we will need greatly to extend the range and intensity of our activity. Merely getting better at what we already do is not enough; instead we need to change the way we think about the problem, and generate the political and societal will required to reverse the epidemic.

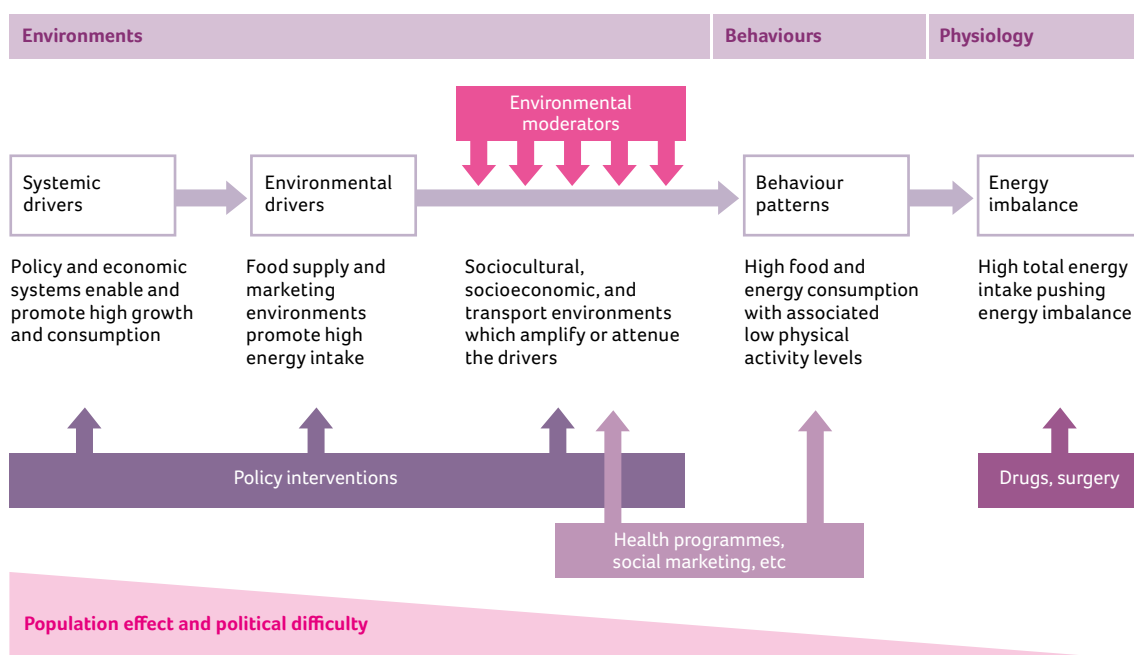Figure 4: A framework to categorise obesity determinants and solutions[253]

Figure 4, above, demonstrates the range of types of approaches that are required to reverse the obesity epidemic, from upstream policy actions that affect the drivers of the obesity system, to individual level interventions such as bariatric surgery. The empirical evidence base is skewed towards the approaches found on the right hand side of the diagram, but there is strong theoretical evidence for the greatest population level impacts arising from the approaches found on the left hand side. It is important to act across all levels, even where there is a paucity of robust evidence; but where this is the case it is even more important than usual to foster an environment in which evaluation and research are the norm.

The decisions made by individuals are shaped by the environments in which they live[254,255]. Over recent decades, obesity has been driven by major changes in both the food supply and physical activity environment, as a result of which it is increasingly easy to over-consume and increasingly difficult to expend energy.

Effective action to tackle obesity needs to move away from light-touch exhortations designed to encourage people to change their behaviour, to active support to help them make healthier choices and live healthier lives. This approach has limited effectiveness, and any impact that it does have tends to be socially patterned in a way that widens inequalities.

It is our view that voluntary approaches with industry to achieve substantive positive change have failed. A structured policy approach is needed to tackle an environment that encourages high energy intake and a sedentary lifestyle[256,257]. We should therefore move beyond the current model of industry self-regulation (the 'Responsibility Deal'). It has failed to achieve its original aims, which can be better realised using effective policy measures. At the same time, the health care system has failed adequately to rise to the challenge of obesity, as demonstrated by recent reports from the Academy of Medical Royal Colleges[258] and the Royal College of Physicians (RCP)[259].

We suggest two approaches at this juncture. Firstly, there is compelling evidence that the workplace is an important venue to promote a healthier lifestyle[260]. This reduces sickness absence and has been shown to increase productivity. With over 1.3 million people who work in the NHS[261], and a further 1.5 million people working in adult social care (employed by a diverse range of providers)[262], the potential benefits of better workforce health are considerable. One theme that emerged in our consultation was that the NHS and other health and care employers can and should do much more to support the health of their own employees. There was widespread support for the idea of a national campaign to promote the health of NHS and social care staff, where they are supported and encouraged to look after their own health, and where hospitals, care homes, GP practices and other workplaces become healthier places to work. And beyond the health benefits to staff, this could have a number of wider benefits too, such as demonstrating to other public sector employers the benefits of a healthier workforce, and enabling health and care staff to become role models for healthier living more generally.

Secondly, we believe that Public Health England – in collaboration with NICE and other relevant stakeholders – should be asked to develop a number of policies for central and local government to begin to create an effective policy environment aimed at addressing the challenge of obesity: Action on Obesity. This should replace the current model of industry self-regulation. We suggest two initial areas for policy consideration.

Recommendations

4.5   We recommend that Public Health England be requested to create a number of practical Action on Obesity policies for central and local government, in collaboration with NICE and other stakeholders. We suggest two initial areas for consideration: (a) advertising and marketing of unhealthy food to all groups in society and (b) opportunities for acting on raw materials which are bad for health – e.g. trans-fats.

4.6   We recommend the creation of a national campaign to support the health of NHS and social care staff – supported by central and local government.

Housing and health

Housing has a large impact on people's health and wellbeing, and the home environment can be a contributing factor to a range of preventable diseases and injuries[263]. This is partly because people spend a lot of time in their homes – particularly vulnerable groups like children and older people, who will likely spend the majority of their time in the home[264,265]. It is also clear that socioeconomically deprived groups are more affected by inadequate housing conditions than the more advantaged[266,267]. As we argued at the beginning of this report, the suitability of someone's housing is a key reason for that person being able to be looked after at home.

The housing system as a whole needs to change in a number of ways to better support people's health and wellbeing. For example, the current system has rigidities in tenure and choice, and an imbalance between the supply of owner occupied and rented properties. We believe that we should strive to create more equality of supply between rented and owned property, and an option for people to move tenure without moving home. The market needs to become flexible with a wider range of mixed tenure options. Design standards for social and private housing should also include the flexibility of buildings to adapt to changing personal needs – for example, adaptability for ageing and disability – and incorporate intelligent control systems such as those that minimise energy wastage and maintain basic levels of warmth in homes responsive to weather conditions.

Whole person care is as much about creating safe care environments at home so that care can be escalated safely in your own home as anything else.

Progressive care accommodation

For older people in particular, the home environment can often be the determining factor that leads to admission to hospital, or not. For example, we have noted that identifying and rectifying risks in older people's homes can help decrease the risk of falls; so too can aids and adaptations in the home[268]. With a few exceptions, there is currently an almost binary choice for older people of increasing care in their existing home that, despite adaptation, may increasingly become unsuitable, or entering residential care. Admission to hospital hastens movement to residential care because people's functional ability gets reduced as an inpatient[269].

The exceptions are when someone resides in progressive care accommodation (see Box 12). This is where people live in their own flat, often entering into the arrangement when they are relatively well rather than after a crisis. On site are communal facilities and a care team. As the care needs of an individual change over time, the care is inputted from this team in conjunction with local social care services. People do not need to move to get the care that they need – it comes to them in house – and the financing arrangements are exactly the same as if the care was provided elsewhere. There are a number of such facilities in the country, largely through Housing Associations. Many people rent their flats, but some purchase a leasehold along with their care.

Box 12: Swadlincote community centre

Swadlincote community centre is an example of what we would call progressive care accommodation.

Initiated by Derbyshire County Council, in partnership with Trident Housing and South Dales District Council, Swadlincote community centre combines flexible housing options and support for older people with facilities which can be used by the whole community. At its heart the complex has a hub with a variety of communal facilities – including a bistro, hairdressers, a 'village hall', internet cafe and an exhibition space. These can be used by residents and the wider community.

The wings of the building contain owner occupied and rented apartments. The apartments are designed to be dementia and disabled friendly. The goal is to maximise independence in a safe, aesthetically pleasing environment. A team of carers is available 24/7 to provide whatever support is needed for residents. The alternative for many would have been a 7 metre square room in a care home. Here care is in your own home, when it's needed. In addition there is a dedicated area for short stay and long stay registered residential care accommodation which includes health, physiotherapy and reablement facilities, and a specialist team for people with dementia.

It is our view that there are significant numbers of people living in owner occupied houses which will become more and more unsuitable for their needs as they get older. Unless people choose to the option of residential care, the existing market is very limited. If the market was able to provide progressive care accommodation that was an attractive, aesthetically pleasing alternative to these options, we believe that significant numbers would choose this kind of accommodation for future living. We expect that this would also bring number of wider benefits. For example, in selling their existing property to move to more suitable accommodation, people would be releasing potential family housing onto the market. They may also be able to use some of their equity from the sale of their property to fund their care needs as they arise. We recommend a stimulus or tax relief be introduced for new build progressive care facilities, to incentivise the development of this type of housing for older people. We also recommend that Local Authorities, through the mechanism of planning permission, receive an allocation of apartments within progressive care facilities for nomination rights for rental for its population.

Recommendations

4.7 **Planning and building regulations need to adapt to changing personal needs – for example, adaptability for ageing and disability – and address existing inflexibilities within the system.**

4.8 **Incentives should be created to encourage the development of progressive care facilities for older people. We recommend that Local Authorities receive an allocation of apartments within progressive care facilities for nomination rights.**

Making the money work

5

Whole person care requires budgets to be treated as a whole across health and care, the alignment of incentives across organisations, and financial flows that move away from episodic to holistic care.

The financial context for whole person care

The financial challenge

The scale of the financial challenge facing the health and care service over the coming years is well documented. This is the context for the development of whole person care that we describe throughout this report.

Since its creation in 1948, NHS expenditure has grown dramatically – at approximately 4% every year in real terms[270]. As a share of national income, NHS spend has more than doubled throughout this period, growing rapidly faster than the economy and total public expenditure[271]. Between the mid-1990s and 2009/10, NHS expenditure grew even faster – at an average of 6.4% a year in real terms[272]. This rapid growth in spending on health care is not unique to the UK – it has occurred across Europe and the OECD. By 2011, spending on health care (public and private) in the UK accounted for 9.4% of GDP compared to the OECD average of 9.3% and 9.9% across the EU. This persistent growth in spending, however, has come to an end; the NHS currently faces a near real terms freeze in spending while it is expected to find QIPP (Quality, Innovation, Productivity and Prevention) savings of £20 billion (from 2010/11) by 2015, aimed at making the service run more efficiently, and this figure is growing. Further similar savings beyond this period are expected to be required, but will be far harder to achieve without transformational change.

As demand for services continues to rise, it is likely that there will be a (large) gap between funding and demand over the next decade unless action is taken. The Nuffield Trust has estimated that the NHS in England could experience a funding shortfall of up to £54 billion by 2021/22 (£44-£54bn)[273] – that is, if the current real-terms funding freeze continues, no substantial productivity gains are made, and the cost of providing healthcare continues to rise. This gap could be reduced if the system can deliver savings targeted through QIPP. If by 2014/15 the equivalent of year-on-year productivity gains of 4% have been made (since 2010/11), this funding gap could be reduced to around £30 billion (£28-£34bn). To close this deficit, NHS expenditure would have needed to return to around its historical average.

The NHS is now halfway through its QIPP plan. Since 2010/11, the NHS has met the headline financial targets. The government's public service pay policy and reductions to management and administrative costs have been the key contributors to savings so far[274]. These central initiatives are not sustainable in the long term, particularly when average earnings across the economy start to increase. The best estimates of NHS productivity suggest that between 2006 and 2010 across the service, productivity increased by 0.9% a year[275]. This is below the Office of Budget Responsibility (OBR) expectations for the trend rate of productivity growth across the whole economy, but reflects that challenges of sustaining high levels of productivity growth in service sectors. 4% per annum productivity growth in the NHS for a decade would be very substantially above past experience in the NHS, other countries' performance and the level of growth expected for the economy as a whole.

It is worth recognising that in the current fiscal context even sustaining a near flat level of NHS expenditure (in real terms) will be challenging[276]. This should also be seen in the context of a relative increase in health expenditure when viewed as a proportion of total departmental expenditure – projected to rise to over a third in 2015-16[277].

Alongside this, there already exists a funding crisis in social care[278]. Demand for care is growing, but adult social care budgets have been reduced by Local Authorities consecutively for the last four years, and a reduction of £800 million is planned for 2013/14[279]. These are dramatic reductions. People are increasingly (and inconsistently across the country) finding themselves unable to receive support, and within this context it is important to recognise the substitution effect which can be seen between health and social care[280]. It is likely that achieving a sustainable health and care service will require further investment in social care and community services to reduce costly emergency admissions within the acute sector – particularly in relation to older people (where 68% of all acute emergency bed days are accounted for by people over 65[281]).

Analysis from the Personal Social Services Research Unit (PSSRU) estimated public expenditure on social care for older people (aged 65+) in England to be just over £12 billion in 2010[282,283]. Under the current funding system, this expenditure is projected to rise to over £16 billion in 2020, and over £25 billion in 2030 (in constant 2010 prices). Total expenditure on care services was estimated to be around £20 billion in 2010, projected to rise to £28 billion in 2020 – with private spend accounting for nearly £7 billion (in 2010) and around £10 billion (in 2020)[284]. The government has considered Dilnot's recommendations and outlined a proposed approach to care and support funding[285]. It is estimated that the government's plans would create an additional £1.3 billion of public expenditure in 2020 – £2 billion by 2030. This additional expenditure is in contrast to the estimated (greater) impacts of the central recommendation of the Dilnot commission – which would cost an extra £2.1 billion in 2020, and £3.3 billion by 2030.

These estimates rely on existing analysis, so don't take into account any more recent funding developments. It is estimated that Local Government as a whole faces a potential funding gap of around £14.4 billion by 2020[286].

Based on these estimates, on current trends and assuming near flat real terms expenditure, the total funding gap facing health and social care could be over £30 billion – as much as we spend each year on defence – and has to be faced by any government. These figures assume the continuation of means tested social care – if this was not the case, the gap would be even larger. It is also difficult to know how much informal care takes place which would be handed over to statutory services if social care were to be provided on the same basis as health care – except that it is substantial.

Across health and care as a whole, simply meeting service demand over the next decade will be extremely challenging. Closing the potential funding gap in NHS expenditure alone represents a major policy and service challenge; alongside the existing crisis in social care funding and projected increases in expenditure required, the challenge facing the health and care system is even greater. Whole person care may contribute towards closing the funding gap (and increase value), but it will certainly not fill it. The annual productivity gains required look too large for the NHS to be able to meet them, based on past performance, evidence from other countries and indeed the performance over economy as a whole.

The future funding and delivery of health and care

The closer integration of services described in this report will help address the funding gap that the NHS and social care faces, and other efficiency measures will help to make a contribution, but it will not solve it. The scale of the task is such that honesty is needed with the public from all political parties about these financial and care challenges and the options available to deal with them.

In our view, a new compact needs to be agreed with the citizens of the country. We argue that the vehicle to achieve this is an independent National Conversation looking at health and social care together, to be completed within 12 months of the next general election and with legislation enacted thereafter to enable implementation from 2020 onwards.

This Independent National Conversation should look at two key areas.

1 **The future funding of health and social care collectively.**
   The tension between what is available in means tested social care and what constitutes free at the point of use healthcare lies at the heart of this question. Councils are prohibited from providing healthcare; this is restated in the Care Bill, retaining the distinctions drawn in the 1948 Act.

Although this is an important step in protecting the principle of a national health service that is free at the point of use, it retains the element of surprise for many that dementia is not seen as a health issue. Recent debate also highlights the inconsistent application of Continuing Healthcare, where care is designated an NHS responsibility. And all this must be seen in the context that we demonstrate in this report of how crucial social care is to the ability to maintain independence and reduce hospital admissions. This partly explains the power of calls for free intermediate care and free end-of-life social care, which can avoid the costs of supporting someone in an expensive hospital bed, especially if they would prefer to be at home in the first place.

Yet the financial context that we have outlined so far in this chapter highlights the enormous difficulty of providing social care free. We need a definition of the NHS and social care offer that works for the 21st century. Undoubtedly there will be no political appetite to reset what is in the NHS free offer. In the context of the integration of health and care services, there is a need for a new compact on the scope of free or subsidised social care and how any extension of the current offer should be paid for. For ourselves, if we could start again with a blank sheet of paper, a single budget for health and social care to treat people's needs would make sense, and should be a longer-term goal.

2 **How and where care should be carried out.**
This National Conversation should also look at the complex issue of the best way of providing care. Integrating health and care services will enable more care to be provided in the home and reduce the need for unnecessary hospital visits. This requires primary care, community services, mental health services, and social care to be strengthened. Local hospitals will be overwhelmed unless we change how they operate. There is strong evidence that focussing some specialisms in centres of high expertise has huge benefits for citizens in terms of the outcome of their care. None of these issues are easy, but the evidence surrounding them is well known to, and debated by, professionals in health and social care. It needs to be debated openly with the people around the country in a neutral, independent way. The public are unlikely to support change unless they have a genuine voice in the process.

The existing payment system is broken

Alongside the big challenges to the system posed by the projected funding gap, we also believe that the current payment mechanisms across health and care require fundamental change to meet the needs of the population of today. Whole person care requires commissioning mechanisms which have a holistic, population view, but the current financial flows and incentives within the system drive in the opposite direction.

Existing payment systems within the NHS are predominantly based upon rewarding episodic treatment in an acute setting. The Payment by Results (PbR) tariff in particular, while successful in reducing long waiting times for planned operations (one of its key initial aims), has incentivised increased hospital activity, while acting as a barrier to collaborative approaches to care delivery across organisational boundaries. Overall, the existing payment system in the NHS has led to the chronic overuse of episodic hospital based treatment, the reward of activity rather than outcomes, and ultimately system fragmentation – all of which act as barriers to coordinated, person-centred, whole person care.

Financial arrangements in the adult social care system are equally fragmented, with complex and overlapping funding and provision arrangements between private and public funding sources, and private and public providers of care. The multitude of private care providers adds to this complexity. Public funding has increasingly focused on those with greatest needs – particularly as rationing of care has become more severe – driven by a reactive, crises oriented approach rather than a focus on early intervention and wellbeing[287].

Despite notable exceptions across the country, a lack of coordination between health and care commissioning often increases this fragmentation. The needs of people with complex needs require a holistic, collective approach to commissioning across the whole care economy. For this group in particular, commissioning needs to be aligned to meet the needs of the whole person – physical, mental and social. Health and wellbeing boards have been created with the aim of bringing together local partners to provide a more integrated view across the whole system, and the Better Care Fund – £3.8bn – while not 'new' money, offers an opportunity to develop new approaches to joining up services locally.

We believe that the financial flows of the health and care system need to change radically to enable the delivery of outcomes that matter to people using the system, and to provide coordinated care that meets the whole of a person's needs.

The chapter's key themes

Within this context, our view is that:

- *budgets need to be treated as a whole across health and social care*

- *currencies must be developed that reflect the needs of people rather than those of organisations*

- *incentives for all health and care providers must be aligned around joint population group outcomes*

- *commissioning must reflect this holistic necessity. We refer to this as community commissioning.*

This will require an approach where effectively managing resources to deliver coordinated, person-centred care is the objective rather than revenue chasing by individual elements of the system. What must be achieved is a system-wide shift from activity to value based care[288] – where the whole system holds the common objective of achieving the best outcomes for the people it serves, at the right cost.

We believe that this type of commissioning based on outcomes is one of the main drivers that has the power to drive the shift from fragmented to coordinated provision described at the beginning of this report. This chapter therefore focusses getting the necessary financial and commissioning arrangements operating at a local level to deliver whole person care. These recommendations need to be seen in conjunction with the further changes at a national level set out in the next chapter of this

report on the wider system changes we also think are needed to support whole person care. In particular, the recommendations calling for the revision of NHS England into Care England, and the identification of single development monies for community health and social care.

Community commissioning

Our vision of community commissioning starts from the perspective of the person, and asks how the care system can collectively respond to meet their needs, defined by them, and delivered as outcomes that matter to them. Personalised care planning is a key component of this – identifying individuals' personal goals and support needs and aggregating these to produce a commissioning plan for the community[289].

This means that budgets need to be treated as a whole across health and social care. Yet it is the view of this Commission that – at this current time – the merging of organisations to achieve this would be inadvisable, expensive, and would delay the benefits achievable through a more collective commissioning approach. It is also worth noting that the Commission's Terms of Reference state no further structural change; therefore any recommendations that we make in relation to the structures of the system need to build upon the current arrangements – which themselves are in their infancy and a period of evolution. Instead, we believe that a model of community commissioning can achieve whole person care through building upon existing commissioning arrangements: collective commissioning between existing organisations across the system, underpinned by a legal obligation to adhere to a jointly agreed collective commissioning plan.

At a high level, our proposals for community commissioning would mean that:

- Revised health and wellbeing boards (or analogous local arrangements) become collective system leaders for integrated care, responsible for developing a collective commissioning plan for their local population with long term conditions, disabilities and frailty

- The collective commissioning plan is based absolutely on the expressed need and desired outcomes of the users of the services, in terms meaningful to them

- The collective commissioning plan is enacted by CCGs and Local Authority commissioners, with common outcomes tracked

- Primary care commissioning is aligned with local system objectives through the development of joint arrangements between local commissioners and NHS England (Care England).

Local system leadership for whole person care

We view health and wellbeing boards as a vehicle for collective system leadership for whole person care, involving the leaders of existing organisations working together to coordinate care and align incentives across their geography. We would place the health and wellbeing board (or analogous local arrangements*) at the centre of the commissioning process for people with long term conditions, disability and frailty (including mental health) – people whose care is often most fragmented and who are heavy users of health and care services. The health and wellbeing board would be responsible for creating a local collective commissioning plan for this group of people – within a nationally defined outcome framework for the development of whole person care. Meaningful public involvement, not simply 'consultation', must be introduced as a necessary step in the development of the plan, which must be based on the expressed needs and desired outcomes of the users of the services. Healthwatch should play a leading role in this locally.

Within this model, we recommend that local health and care commissioners are given a statutory duty to enact the health and wellbeing board's collective commissioning plan for people with long term conditions, disabilities and frailty. The separate health and care budgets would be viewed as a whole: the 'locality pound', encompassing the totality of local resources available for this cohort of the population. Commissioning within this model would follow the principles of outcome based community commissioning – described below ('commissioning for outcomes').

Readiness for community commissioning

We recognise that health and wellbeing boards will need support and development to become the collective vehicle for community commissioning outlined here. While some boards across the country are operating well in a new environment, the experience so far suggests that most boards, by and large, would not yet be ready to take on the

role described above. We therefore recommend that boards undergo a development programme (throughout 2015/16) to ensure readiness for their role within the community commissioning process, including support from the LGA and NHS England (Care England) and local commissioners. It would be expected that all health and wellbeing boards would assume the role outlined above in full from 2017.

As part of this development process, health and wellbeing boards must make sure that the way they operate supports their role as system leaders for health and care. A key part of this will be ensuring whole system representation.

While we recognise that the work of the health and wellbeing board must extend far beyond the boardroom, we believe that having the right people around the table at the health and wellbeing board is vital to ensure the whole system perspective necessary for whole person care. One key group which is often excluded from the health and wellbeing board is providers. To be effective in driving whole-system transformation centred upon the delivery of community outcomes, we believe that provider representation must be a necessary part of the formal structure of health and wellbeing boards. King's Fund analysis from 2012 highlighted concern that health and wellbeing boards were failing to engage substantively with providers, with only a quarter of shadow boards incorporating acute provider representation as part of their structure[290]. Updated analysis from last year's survey shows that health and wellbeing boards have increased this engagement, and are connecting with providers in a number of ways beyond the health and wellbeing board and its formal membership (such as provider forums and strategic reference groups)[291]. Yet while this is a positive development, we believe that the vital role of providers in driving transformation locally must be properly recognised; without providers, system change isn't possible.

We also see the role of housing as necessary for the success of the boards. Only 31% of existing boards include a housing lead, yet given the evidence on the (large) impact of housing on individual health and wellbeing[292], it is our view that a Local Authority housing representative should be included on health and wellbeing boards.

* In County councils, the architecture of CCGs and district authorities are more complex. It may well be that analogous arrangements in those areas are more appropriate and better determined locally. The same caveats on readiness outlined in the following part of this chapter would apply.

It is also the case that in some places, particularly metropolitan areas, health and wellbeing boards are demonstrating greater capability and ambition – an ambition shared by the partners making up the board. We think it is right that where there is local desire and agreement to formally create a single commissioning budget for health and social care, legislation should permit that to happen.

Primary care commissioning

Aligning primary care commissioning within the community commissioning process will be vital for the success of whole person care. This requires alignment between health and wellbeing being boards and NHS England in the development of the local collective commissioning plan outlined above. The outcomes defined within the collective commissioning plan must equally be reflected through the commissioning of primary care. Yet health and wellbeing boards across the country are currently concerned about their (lack of) ability to influence NHS England's commissioning decisions[293], which significantly restricts their ability to drive integration locally.

While we believe that primary care should remain formally commissioned by NHS England (and the revised Care England), local arrangements should be developed to ensure the required alignment in the commissioning of care. The nature of these arrangements are best determined locally, but may involve the development of joint committees between NHS England Local Area Teams, CCGs, Local Authority commissioners and health and wellbeing boards to provide local scrutiny and oversight. Fundamentally, the commissioning of primary care needs to be aligned with local population needs in a commissioning system where health and social care are aligned and where 'sense of place' determines the commissioning of services[294]. We believe that these arrangements should be shaped in full to carry out this role from 2017. We also believe that financial incentives for GPs must be aligned with the outcomes required within the health and wellbeing board's local collective commissioning plan – outlined further in the following section of this chapter.

Recommendations

5.2 **Health and wellbeing boards, or analogous local arrangements, should comprise the collective system leadership for services for people with multiple long term conditions, disability and frailty. They would be responsible for a collective commissioning plan informed by the whole budget (locality pound) for this cohort of the population. They will require development and have to demonstrate readiness to do this. As part of this development programme it will be necessary that health and wellbeing boards ensure representation from across the health and care economy – including providers and housing representatives. We recommend a statutory duty placed on commissioners (Local Authority and CCGs) to enact the collective commissioning plan.**

5.3 **We recommend the development of joint arrangements between NHS England (Care England), CCGs and health and wellbeing boards (around the geography of health and wellbeing boards) with the requirement of aligning primary care commissioning to local objectives.**

5.4 **There should be permissive legislation to enable health and care economies who wish to formalise a single budget, with amended accountability arrangements to match, to do so. We see NHS England (Care England) as the approval authority for such arrangements.**

Commissioning for outcomes

The key message from our consultation exercise was the need to align incentives across the whole care system to enable the delivery of coordinated care which matters to people and their families. Community commissioning must therefore alter radically the way in which payment systems currently work across the health and care system: commissioners must drive a shift from fragmented to coordinated provision.

As outlined at the front of this chapter, we believe that the current payment system is broken – particularly for people with disabilities, multiple conditions, frailty and complex needs. Existing payment systems within the NHS are predominantly based upon rewarding episodic treatment, typically in hospitals, rather than rewarding the outcomes that matter to people using the system. This has led to system fragmentation rather than coordination of care which treats the whole of a person's needs. Payment systems in adult social care are equally characterised by fragmentation, driven by a reactive, crises oriented approach rather than a focus on early intervention and wellbeing. We believe that the care system as a whole needs to reward the achievement of outcomes that matter to people using services, while aligning incentives across the health and care system to enable the delivery of those outcomes in a coordinated way.

Alternative payment and incentive structures should be used to drive this shift towards outcome based community commissioning. We believe that the most appropriate payment mechanism to drive this shift is a capitated model of contracting, which recognises all of a person's care needs rather than separating them. Through allocating a capitated payment for the whole of a person's care (full capitation) for a defined time period – typically an annual payment within a longer term contract – providers are incentivised to coordinate a person's care and make sure that this care is delivered in the most appropriate setting, while focussing on prevention and community based services to reduce costly hospital admissions.

Payments within this model should also be linked to the delivery of specific outcomes defined by the commissioner, developed in collaboration with users of the service. Using an appropriate contracting vehicle (explored in chapter 1), all providers involved in the delivery of a person's care share the responsibility for the delivery of the defined outcomes, and are incentivised to treat people as a whole across every part of their care. We believe that this type of payment system which addresses people's needs together – and which encourages providers of care to treat these needs together – is necessary for whole person care. We envisage quality premiums and penalties linked to the outcomes defined within this capitated payment model; no individual organisation should benefit unless all achieve the outcomes that matter to the people they serve.

We therefore recommend that an annual capitation tariff – with different pricing levels for different risk groups – is initially introduced for people with multiple long term conditions and complex needs. The tariff should be stratified for groups of people according to their risk category. This annualised tariff would cover all of the care needs for a person within this group of the population across secondary care, mental health, community services, primary care and social care. This capitated tariff would replace PbR for the population described, segmented by risk not specific disease (or age). Alliance contracting or accountable lead provider models will be the preferred vehicles to deliver contracts of this nature, as we believe that these approaches are most effective in aligning incentives and sharing risk between commissioner and provider(s).

The scope of this capitation tariff should be extended over time. Broader population based capitated payment mechanisms covering larger groups of people should be developed and used by commissioners – for example, capitated payments for all of an older person's care needs, or a capitated payment for a whole local population's care (similar to the Alzira model in Valencia). Similar models used elsewhere – for example, in Spain and the US – have helped to deliver system transformation and improved outcomes for people, while in some cases reducing service expenditure[295].

What this means in simple terms is that we incentivise longitudinal care and cooperative behaviours amongst providers, and disincentivise episodic, fragmented care.

As part of this outcomes focused payment model, incentives for GPs must also be refashioned to reflect local population health outcomes. We recommend that incentives for local primary care be explicitly linked to the outcomes required under collective commissioning plan. This would ensure that local incentives are aligned with primary care commissioning. Similarly, clinical excellence awards for consultants should be determined by performance towards the same locally determined objectives and criteria.

We strongly advise against the use of disease specific or 'pathway' based contracts of this nature, even if 'integrated' with social care and community services. This type of contract persists the silo mentality of existing fragmented provision, and only caters for a minority of people without considering the totality of their needs. Only 14%

of diabetics have just diabetes; only 19% of people with COPD have just COPD. You can't treat a whole person by only treating body parts. Within a model of community commissioning, these disease based contracts would be replaced by capitated (Year of Care) tariffs which take into account the whole of a person's needs.

We envisage that this change in financial flows and commissioning will stimulate different provider models that reflect local needs and plans. These may include models of provision where consultants are no longer tied to hospital institutions, or the development of ACOs to enable the delivery of outcome based care where this is local appetite to do so.

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Recommendations

5.5 We recommend that an annualised capitation tariff be introduced for all of the care needs of people with long term conditions and complex needs. Over time, we recommend the development of broader population based capitated payment mechanisms covering larger groups of people – for example, capitated payments for all of an older person's care needs in a particular geography. Payments must be linked to the outcomes that matter to those people using the services.

5.6 We recommend aligning GP incentives and Clinical excellence awards with locally agreed system objectives.

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What outcomes?

At the heart of this contracting approach must be the influence of those using the system. Individually defined outcomes must be placed at the centre of commissioning, and substantive consultation with the public to define desired service outcomes must be the first step of the commissioning process. Community commissioning must start from the user's perspective, with the system judged (and paid) in relation to how well these outcomes are met.

We recommend that the central outcomes defined within this process are person-defined, developed by and for service user – not the system. For example, a key outcome for older people may be

the goal of maintaining independence in their own home, or for someone else going shopping. Achieving this person defined outcome will require coordination and the achievement of a number of related clinical and system process measures – for example, better control of heart failure or optimisation of polypharmacy, or a reduction in unscheduled admissions may lead to greater independence for the individual. Importantly, the achievement of these person-defined outcomes must be organisation neutral, with all providers (collectively) held to account for their delivery. People are interested in the care that they receive – where it comes from is secondary[296] – and the commissioning process must reflect this fact. This principle lies at the heart of our vision for community commissioning. Outcome measures should be developed and defined in an outcomes hierarchy, or tiers, reflecting different outcomes important to people in relation to different dimensions of health.

The use of appropriate metrics to monitor progress towards outcomes will therefore be essential for person-defined outcome based commissioning. We believe that person-reported outcome measures (PROMS) and person experience measures must be seen as of equivalent importance to clinical and system measures when monitoring people's interactions with health and care services. In chapter 3 of this report, we made recommendations for a coordinated approach to measuring outcomes across health and care. Ultimately, we believe that the care system must move towards a state where the outcome of interactions with health and social care should primarily be to maximise user independence, and provider performance measured against this goal. In the words of one of our clinical members: unscheduled admissions should be regarded as a failure of the system. All provider and system scores in relation to these outcome measures must be visible to the public.

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Recommendation

5.7 We recommend that the central outcomes defined within this process are person-defined, developed by and for service user – not the system. In seeking to measure person-defined outcomes, we believe that person reported outcome measures must be viewed on the same level as clinical and system measures.

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The wider changes needed

6

If one person, one team, one system is to become a reality, then various elements of the broader establishment of the health and care system will need to change – the tendency otherwise will be to revert to business as usual.

We recognise that these are unglamorous changes. They are, however, elements of the system's hard wiring that the Commission believes are essential to achieve the type of whole person care described in this report. Most of us do not know what makes an iPad work; we just know it works. Similarly there are things in the background of the health and care system which must be achieved for whole person care to become the norm. The following recommendations therefore follow from the vision of whole person care and the arguments made in the previous chapters of this report.

Interdepartmental responsibilities

Mimicking the system fragmentation experienced at a local level is the current interdepartmental fragmentation of policy responsibilities. Whole person care needs whole person government. It is imperative that if there is to be joint working at the front line, the high level outcomes required and tracked for both the health and social care budget are the same. The challenge facing us is such that we cannot allow the continuation of central government silos working against the interests of the individual citizen. If we are to see a move to more independence and care at home, then we need to support community health and social care services in particular. We are sure any change will create vigorous opposition, but hope for a mature debate.

Recommendations

6.1 Over the lifetime of the parliament from 2015, £10billion should be identified from within allocated resources to strengthen community health and social care services. This should be routed through Care England, as part of the mandate, and made available to commissioners through the health and wellbeing board's collective commissioning plan.

6.2 In the medium term, there should be a single central government department responsible for health and social care policy with devolved local responsibility for implementation.

Care England

In the same way that whole person care needs whole person government, whole person care also requires whole system leadership. The central structures of the health and care system must truly reflect the need for joint working and multidisciplinary policy-making central to whole person care. We must also end the multi-faceted accountability in the NHS brought about by the recent reforms, with, paradoxically, no clear strategic leadership.

Regulation

Throughout this report we have outlined the impediments to whole person care created by the current fragmentation of the health and care system. More than that, the current separation of responsibilities pulls organisations and policy in different directions. We therefore need to ensure that the regulatory environment is appropriate to facilitate the delivery of whole person care. This requires some specific changes.

Recommendations

6.3 **We recommend that NHS England be revised to become Care England. Care England would need to demonstrate that its structure and functioning reflected the needs of the majority of people using the health and care system. We believe that this would require a substantial rebalancing of professional input to increase that of primary care, mental health, social care, community care and allied professionals, alongside the creation of whole system strategic plans geared towards people with multiple conditions. Care England's mandate should include the requirement to demonstrate fitness for purpose for the delivery of whole person care. This would include the introduction of Non-Executive Board members from local government. Care England would formally be the strategic lead behind which Monitor, the NHS Trust Development Authority and other statutory bodies should align.**

6.4 **Disease specific clinical networks should be reviewed to ensure alignment with the principles of whole person care. The continuation of clinical senates is of questionable value for whole person care and should be abolished.**

Recommendations

6.5 **Responsibilities for national tariff creation and pricing for the NHS should reside in the same organisation.**

6.6 **We recommend that the benefits are considered of a single regulator covering issues of both care and economics, whilst recognising that is not feasible at present. We believe that the Office for Fair Trading's role in reviewing competition decisions should be removed.**

6.7 **We recommend that section 75 regulations be abolished, and replaced with new regulations which support the development of whole person care.**

Research and quality

The government spends more than £1billion per year on medical and health services research. The Cooksey review (2006) pointed to many strengths in the UK's research base, including a long tradition of excellent basic science, but it also identified several cultural, institutional and financial barriers to translating research into practice.

Since then there have been several attempts to close the translation gap by encouraging academic institutions and NHS organisations to work more closely together. Various initiatives have been launched, including Academic Health Science Centres (AHSCs), Academic Health Science Networks (AHSNs) and Collaborations for Leadership in Applied Health Research and Care (CLAHRCs). Evaluation of the CLAHRCs is currently under way, but the general view is that their performance has been patchy. It is difficult to see how such a fragmented approach with secondary care bias could assist implementation.

The Commission believes that government funds for research, and monies provided by the NHS, should be rigorously prioritised to the strategic needs of the health and care system.

Most quality standards are derived from an evidential base that is disease specific; indeed, much of this evidence base often goes to considerable lengths to exclude people with comorbidity. This doesn't fit with the requirements of today's health and care system, and it could be argued that many of the current quality standards are inappropriate. The production of large numbers of quality standards is taken as a sign of safety and quality virility. In reality they are a harbinger of quality impotence in a world of multi-morbidity and complex needs. This is the same in many other countries. Yet good commissioning and good practice requires good data and evidence, which is notable by its absence for multi-morbidity – we are shocked that so little of the £1billion of publically funded clinical research is devoted to the main issue facing the health and care system.

Recommendation

6.9 We recommend the establishment of a complex care research centre out of existing resources, and to seek to do so as part of a multinational effort with others who are also in pursuit of the same objective (such as Ontario and Scotland).

Recommendation

6.8 We recommend ensuring that a greater proportion of R&D funding focuses on whole person care, implementation of existing research and reducing variations in clinical and safety performance. As part of a refocus of publicly funded research to implementation, we also recommend a redesign of Academic Science networks to be multidisciplinary bodies, run as true balanced partnerships between NHS, social care and academic bodies but independently managed.

Full list of recommendations

The provision of care

1.1 A new government in 2015 must outline expectations and milestones for the growth of new forms of coordinated provision. Local flexibility in the development of new provider models must be encouraged by Government so that different integrated models of care can develop according to the needs of local populations – for example, ACOs, where there is local appetite to do so.

1.2 These changes must be enabled by the system. For example, Monitor and the NHS Trust Development Authority must encourage through their performance management the development of new outcome based models of care, rather than performance managing Trusts against their ability to develop positive balance sheets around the existing episodic model of care. Health and care regulators must allow new provider structures to form where this will benefit people using the services. They should place considerations of care firmly before those of competition – including the growth of new (and larger scale) models of primary care.

1.3 The person and their home should be at the centre of care – individualised, not institutionalised. We recommend active encouragement of technological innovation to support people and their carers for the 99% of time that they look after themselves, and the increased involvement of specialists in the community setting to begin to deinstitutionalise our basic concept of healthcare delivery.

1.4 We recommend the development of the role of NHS Choices to create a personalised health hub that will enable families and friends to support each other through ageing and ill health, even when far apart.

Getting the right people working in the right way

2.1 Supporting co-management and shared decision making should be the default operating model for all professionals and a commissioning requirement. This will require a system wide focus on skills covering the following topics: person-centred care; consumer engagement; self-care; health literacy; health information sources; safety and risk; risk communication; shared decision making; personalised care planning; co-management support; health coaching; motivational interviewing; co-production; and multi-professional team-working.

2.2 Each person with complex needs should have a single identifiable individual who will act as their advocate in coordinating care to the wishes and best interests of that person. That individual advocate may be from statutory or voluntary sector.

2.3 Professional training bodies should be asked to incorporate these skills into their programmes and ensure they are assessed adequately and included in appraisal and revalidation procedures. All professional training courses across health and care should involve the people using those services, their carers and other lay people in teaching and assessment. Training in these competencies must also be required for existing health and care staff. Health Education England (Care Education England – below) should be asked to produce a new workforce strategy that is aligned with the components of the House of Care model and supports personalised care planning.

2.4 Multidisciplinary working must be the norm. Professional training bodies must therefore place a far greater emphasis on multidisciplinary team working. The Royal Colleges, the General Medical Council, the Nursing and Midwifery Council, the Health and Care Professions Council and other standard-setting groups should be asked to ensure that collaborative care planning and effective multidisciplinary team working are key components of training, with quality-assured curricula and appropriate assessments. Training in these competencies must also be required for existing health and care staff.

2.5 The development of generalist training for doctors, nurses and other health professionals should be encouraged, balancing the current trend towards increasing specialisation.

2.6 We recommend a comparative review of the terms and conditions that apply to professionals working in health and social care, in order to identify and clarify any fundamental differences and examine their impact.

2.7 Quality improvement methods and training should be core to curricula for all staff, and over time (within 10 years) all CEOs and Clinical and Operational Directors should be expected to have advanced knowledge of these techniques and a record of implementation.

2.8 Health Education England should be transformed to become Care Education England, with its responsibilities broadened to include social care training. Its membership and governance must be revised accordingly. The Leadership Academy should become part of Care Education England, and its role and governance revised to drive the skills needed for whole-system leadership across health and care.

2.9 LETBs must be reformed locally to ensure a balance of professionals from social care, mental health, primary and community care and public health, as well as secondary care. They must also include service users and carers. Investment in education and training by LETBs must be aligned with the joint outcomes required of the health and care system as a whole, which will require engagement with local commissioners and health and wellbeing boards.

2.10 Improved assessments to identify appropriate support for carers must be a local priority. The provision of information for carers should form part of this support.

Information solutions

3.1 Information provision must be treated as a core health and care service. This must include active support for those who need it, including targeted interventions to help increase the knowledge and understanding of people with low health and care literacy. The effective provision of information must be reinforced through quality regulation for all health and care providers. Skills for information provision and support must for part of health and care staff's mandatory (and on-going) training, and information prescriptions should become the norm.

3.2 We recommend the application of an Information Quality Mark to accredited providers of health and social care information and advice.

3.3 People must be given ownership of their own health and care records. The development and use of electronic health and care records should be governed by the creation of nationally defined standards: 'meaningful use' requirements. These should include a single set of national recording and where different mapped reporting standards for health and care data, and the adoption of these standards must be required by law for both software developers and health and care providers, reinforced through provider contracts.

3.4 The default assumption should be of implied consent for people's information to be shared across health and care providers for their direct care. People should be able to 'opt out' of the automatic sharing of their information.

3.5 As part of this drive towards national interoperability, it must be a requirement for all organisations providing (health and social) care to use the NHS number.

3.6 There must be greater access to and promotion of the use of de-identified (weakly pseudonymised) data within a strongly controlled environment for health and care commissioning, audit, planning, case management, purchasing care pathways, individual budgets and invoice validation.

3.7 There must be greater access to and promotion of the use of end user irreversible psuedonymised data. This should not simply be restricted to the HSCIC and commissioners, but should include organisations who are using information as a means to provide better outcomes for people using health and care services. We recommend the simplification of the process to achieve the necessary controlled environment, which should ideally be controlled through regulation and a contract with liabilities and penalties.

3.8 Person-defined outcomes must be accurately measured and reported as part of the collection and use of information from people. The separate national outcomes frameworks for health, social care and public health ought to include standardised generic measures that enable coordinated performance monitoring across health and social care of function and morbidity and not simply mortality.

Helping people stay as well and independent as they can

4.1 Provide an option for Sure Start Children's Centres to be the hub for all children's health and wellbeing services locally, with better integration of associated services. Consideration should be given for the transfer of funding and commissioning responsibility and accountability for Sure Start Children's Centres from the global Local Authority financial allocation to the Public Health budget.

4.2 Preventative approaches aimed at improving older people's health and wellbeing should be comprehensive across health and social care. All localities should offer older people preventative checks to identify risks to health, independence and wellbeing and mobilize a response based on the priorities of the older person and their families. For example, a falls prevention strategy as part of a broader approach to improving older people's health and wellbeing. Frailty should be actively sought by health and social care professionals.

4.3 Comprehensive Geriatric Assessment (CGA) must be used in the community, hospitals and care home settings.

4.4 Localities should create a multi-agency quality register (and plan) similar to the Swedish model, based on the needs and priorities of older people, identified through preventative health checks and the outcomes of comprehensive assessments.

4.5 We recommend that Public Health England be requested to create a number of practical Action on Obesity policies for central and local government, in collaboration with NICE and other stakeholders. We suggest two initial areas for consideration: (a) advertising and marketing of unhealthy food to all groups in society and (b) opportunities for acting on raw materials which are bad for health – e.g. trans-fats.

4.6 We recommend the creation of a national campaign to support the health of NHS and social care staff – supported by central and local government.

4.7 Planning and building regulations need to adapt to changing personal needs – for example, adaptability for ageing and disability – and address existing inflexibilities within the system.

4.8 Incentives should be created to encourage the development of progressive care facilities for older people. We recommend that Local Authorities receive an allocation of apartments within progressive care facilities for nomination rights.

Making the money work

5.1 We recommend the commissioning of an Independent National Conversation backed by all major political parties to define a consensus on the scope of services provided by, and the future funding of, health and social care as a single issue. This should report within 12 months of a new government being formed, to enable its agreed proposals to be enacted from 2020 onwards.

5.2 Health and wellbeing boards, or analogous local arrangements, should comprise the collective system leadership for services for people with multiple long term conditions, disability and frailty. They would be responsible for a collective commissioning plan informed by the whole budget (locality pound) for this cohort of the population. They will require development and have to demonstrate readiness to do this. As part of this development programme it will be necessary that health and wellbeing boards ensure representation from across the health and care economy – including providers and housing representatives. We recommend a statutory duty placed on commissioners (Local Authority and CCGs) to enact the collective commissioning plan.

5.3 We recommend the development of joint arrangements between NHS England (Care England), CCGs and health and wellbeing boards (around the geography of health and wellbeing boards) with the requirement of aligning primary care commissioning to local objectives.

5.4 There should be permissive legislation to enable health and care economies who wish to formalise a single budget, with amended accountability arrangements to match, to do so. We see Care England as the approval authority for such arrangements.

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5.6 We recommend aligning GP incentives and Clinical excellence awards with locally agreed system objectives.

5.7 We recommend that the central outcomes defined within this process are person-defined, developed by and for service user – not the system. In seeking to measure person-defined outcomes, we believe that person reported outcome measures must be viewed on the same level as clinical and system measures.

Wider system changes needed

6.1 Over the lifetime of the parliament from 2015, £10billion should be identified from within allocated resources to strengthen community health and social care services. This should be routed through Care England, as part of the mandate, and made available to health and wellbeing boards.

6.2 In the medium term, there should be a single central government department responsible for health and social care policy with devolved local responsibility for implementation.

6.3 We recommend that NHS England be revised to become Care England. Care England would need to demonstrate that its structure and functioning reflected the needs of the majority of people using the health and care system. We believe that this would require a substantial rebalancing of professional input to increase that of primary care, mental health, social care, community care and allied professionals, alongside the creation of whole system strategic plans geared towards people with multiple conditions. Care England's mandate should include the requirement to demonstrate fitness for purpose for the delivery of whole person care. This would include the introduction of Non-Executive Board members from local government. Care England would formally be the strategic lead behind which Monitor, the NHS Trust Development Authority and other statutory bodies should align.

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6.9 We recommend the establishment of a complex care research centre from within existing resources, and to seek to do so as part of a multinational effort with others who are also in pursuit of the same objective (such as Ontario and Scotland).

Terms of reference

1. Detail the major challenges for health and social care that necessitate whole-person, integrated care

2. Provide examples (UK and international) on how best to integrate physical and mental health and social care

3. Address how to ensure responsive, accountable services that empower users, their families and local communities, including as co-producers of their own health and care

4. Outline the development needs of the workforce and service providers necessary to achieve integrated care

5. Identify the steps for moving from the current system to one where coordinated and fully integrated care is the norm without major structural change and within existing resources

6. We are particularly keen that the Commission tests any recommendations with patients, users and practitioners working in the NHS and social care to ensure they are workable and effective.

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