ENGAGING WITH CARE

A VISION FOR THE HEALTH AND CARE WORKFORCE OF ENGLAND

Sandra Dawson, Zoë Slote Morris, Will Erickson, Graham Lister,
Beth Altringer, Pam Garside, Marian Craig

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FOR RESEARCH AND POLICY
STUDIES IN HEALTH SERVICES

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Acknowledgements

Preface

Identifying future issues relevant to health and wellbeing is vital to understanding policy implications. The Policy *Futures for UK Health* project began in 1998, with the aims of aiding policy development by highlighting predictable and probable trends in health, exploring the unpredictable nature of future policy and health outcomes, and involving stakeholders in discussions on these issues.

This Nuffield Trust report focuses on the third phase of the *Health Policy Futures* series and is based on work by a team led by Professor Dame Sandra Dawson at the Judge Business School at Cambridge University. This third and final phase of work examines the current health and care needs of people in England and the human resources and facilities that will be required to meet these needs in the future. It develops three scenarios for how patients, citizens and carers (both professional and informal) might engage with the health and social care system in 2022 and looks at the implications of each.

With a new prime minister and health ministerial team in place this year, the time is ripe for considering the future shape of England's health and social care system. We hope that this report will stimulate discussion on possible future scenarios of care requirements and relevant policy directions and solutions. Indeed, as the authors state, to ensure that the next generation has a health and care system that meets its needs, it is vital to start planning now.

Kim Beazor
Chief Operating Officer
The Nuffield Trust

EXECUTIVE SUMMARY

Health and care needs in England will change dramatically over the next 15 years, but the people we recruit and train and the facilities we build now will still be part of the landscape in 15 years' time. The decisions we take now will affect health and care in 2022. While it is impossible to forecast with precision, we can imagine possible futures and plan policy directions accordingly.

Several factors point toward a looming crisis in the provision of care, including:
- an ageing population
- increasing chronic disease
- greater expectations for health and wellbeing
- increasing demand for care
- greater strains on public finance
- an anticipated shortfall in informal carers
- a possible decline in community support and 'volunteerism'
- conflicting views and increasing anxiety about emphasising self-care
- problems of recruitment and motivation of formal employed carers.

This Nuffield Trust report, part of the *Health Policy Futures* series, explores the development of three possible scenarios of the English health and care system in 2022. Each scenario is associated with a different type of engagement with health and care and is shaped by different sets of policies.
- *The engaged consumer* in a health system shaped by transactions between paid and unpaid participants.
- *The engaged worker* in a health system shaped by leading engagement with those who provide care, including informal and self-carers, as well as paid employees.
- *The engaged citizen* in a health system which minimises the causes of illness and maximises wellbeing through fully engaging citizens and their communities.

The scenarios are not mutually exclusive. The main issue is not which of these scenarios is most desirable, but how to achieve an appropriate balance between diverse imperatives. The authors report that several common assumptions emerged:

- change in the health and care system must continue, but at a pace that allows workforces to be engaged
- To be effective, system change must be accompanied by cultural change, so the engagement of workforces in the design and implementation of reform is essential
- policy must be refocused on the improvement of health and wellbeing
- special measures will be needed to address disadvantage and social isolation
- the dominant model of health and care should be recognised as long-term care
- leadership will be required at every level in the system and in the community.

The authors highlight conclusions for action for policymakers, health and care leaders, educators, workers and members of the public.
Four key messages are highlighted:

- individuals, families and communities – particularly those who are disadvantaged – need to feel empowered and supported to take control of their health, wellbeing and care
- political central control must be disengaged from local solutions and local governance
- system change must be supported by changes in education and training
- a basic insurance package for the 21st century must be defined.

> *"Individuals, families and communities need to feel empowered and supported to take control of their health, wellbeing and care."*

Delivering these changes, the authors argue, demands that health and social care leaders re-engage with the public and workforce to create services fit for the future. While engaging at all levels may slow reforms, it is the only way to achieve lasting change. This does not mean that reform must move at the pace of the slowest; it requires bold vision and leadership, beyond the time limits or political constraints of governments. Such visionary leadership must provide the motivation for reformulating professional values and stimulating a public re-imagining of health, care and wellbeing in the 21st century. We can hope to replace a health and care system led from the centre with one based around a focus on patients and communities, connections – professional and organisational – rather than boundaries, and an emphasis on local rather than national solutions. In this new world it is the workforce itself, embodying core values and inherently responsive to patient and community need, that will lead much of the way.

1. OVERVIEW

The programme for the reform of health and care services is in danger of stalling. Despite a massive increase in resources during the past five years, public perception of the National Health Service (NHS) has focused on recent local budget adjustments and reaction to consumer choice has been muted. While salaries have increased at an unprecedented rate, health and care workers are weary of reform. The call for greater personal responsibility for health and care has not attracted mass support. What is now needed is not more reform but a re-engagement with consumers, health workers and citizens, in re-imagining and co-creating a shared vision of their future health and care services. The July 2007 changes of government, with the arrival of a new prime minister and ministerial health team, and the reviews being undertaken by opposition parties, make the release of this publication timely for considering the future shape of England's health system.

> *"What is now needed is not more reform but a re-engagement with consumers, health workers and citizens."*

This report focuses on the future of England's health and care workforce, defined to include all who have critical parts to play, whether as paid employees, informal carers or citizens in their roles as self-carers and members of society. The aim is to provide impetus to policymakers, health leaders, educators, practitioners and members of the public who will be creating the future of English health and care over the next 15 years.

An analysis of current trends and key issues lead into a scenario-building exercise with an expert group, then to a consideration of new solutions. We sought to use a method which would avoid viewing a future solely through the lens of contemporary conventional wisdom or in reaction to negative aspects of the present. Ways forward are discussed that are plausible within broadly mainstream but different values sets and administrative and political boundaries.

The report identifies trends and challenges which can help to define the common ground in health and care policy, while allowing for different policy directions at national and local levels. The intention is that those involved in health will be able to understand their roles and contributions and to feel empowered to influence health and care policy.

Several factors point toward a looming crisis in the provision of care, including:

- an ageing population
- increasing chronic disease
- greater expectations for health and wellbeing
- increasing demand for care
- greater strains on public finance
- an anticipated shortfall in informal carers
- a possible decline in volunteerism and community support
- conflicting views and anxieties about an increasing emphasis on self-care
- problems of recruitment and motivation of formal employed carers.

These issues and others reviewed in this document, led to the development of three scenarios portraying the English health and care system in 2022. Each scenario is associated with a different axis of engagement with health and care and is seen as being shaped by different sets of workforce and policy measures (also referred to as policy *levers*) which are designed to achieve them.

- *The engaged consumer* in a health system shaped by transactions between paid and unpaid participants.
- *The engaged worker* in a health system shaped by leading engagement with those who provide care, including informal and self-carers, as well as paid employees.
- *The engaged citizen* in a health system which minimises the causes of illness and maximises wellbeing through full engagement of citizens and their communities.

The scenarios are, of course, caricatures and are neither exhaustive in representing all possible futures nor mutually exclusive. They focus on different approaches to the problems of shifting resources to health promotion and illness prevention, increasing responsible health behaviour, informal and self-care, containing costs, maintaining acceptable services and improving outcomes through different aspects of engagement. The main issue that emerged in our discussions was not which of these scenarios is most desirable, but how to achieve an appropriate balance between vital yet diverse imperatives. Several common assumptions emerged as the scenarios were developed.

- The English health and care system will require continuing development, and therefore change.
- This will require workers to re-examine their working cultures.

- Policy must be refocused on the improvement of health and wellbeing.
- Special measures will be needed to address disadvantage and social isolation.
- The dominant model of health and care should be recognised as long-term care.
- Leadership will be required at every level in the system and in the community.

In reviewing the scenarios and the policy levers which will deliver them, it became clear to members of the expert group that they could discern a unifying vision of the features required to achieve the positive aspects of each form of engagement (consumer, carer and citizen) while avoiding their potential negative impacts. The report concludes with a vision of a fully-engaged society, offered as a basis for discussion about where our health and care policies may take us, particularly in terms of the implications for the workforce who will meet our health and care needs over the next 15 years. This vision is not intended to take any particular political perspective, although clearly many of the policy options are political in nature.

1.1 A unifying vision: the fully-engaged society

By 2022, engaging the public as consumers leads to health and care services that are *more responsive to the needs of the public and patients.* This does not require that everyone has to make active choices, as the engagement of a significant minority is sufficient to create the dynamic for improvement. *Carefully regulated opening of health and care provision to competition from public, social and privately-owned enterprises* facilitates this shift, stimulating innovation and improvement.

One area of continuing political debate is the *definition of health and care services and standards* covered by a national basic health and care social insurance system, funded by taxation and user charges designed to motivate responsible health behaviour. There has been no major withdrawal of services, but the extension of home care, the continual development of new treatments and rising expectations of standards place great strain on health financing. Independent regulators engage in social marketing, which involves the application of marketing techniques to social goals such as improved health and wellbeing, and consult with commissioners, the public and the care workforce to engage them in decisions about health and care standards.

Defining the basic insurance package and its impact on the health and care insurance rate, which is separately identified in national accounts, remains a political issue. Patients may choose higher standards of treatment and care, paid for out of top-up insurance schemes or out-of-pocket expenditure. It is an important point of principle that such additional services are considered unnecessary to basic health and care, although where this point lies can never be a purely technical decision. Equally, while there is broad consensus on the benefits of a mixed economy of health providers, political decisions are made about the extent of support

for private sector care, for example, in the form of tax exemptions for top-up insurance. Governments have distanced themselves from operational health and care management but remain fundamentally responsible for basic policy.

The challenge for the commissioners of health and social care is to respond to articulated consumer preferences while safeguarding the rights of the disengaged consumer by maintaining a focus on basic rights, equity and access for disadvantaged groups. The initial introduction of choice of provider had little impact. It was seen simply as a choice between similar hospitals differing only in waiting times, and available only to those who could choose to travel. Services became truly responsive to the public only when the culture of health and care services evolved to reflect the most important preferences of consumers, expressed through a variety of mechanisms of local representation, voice and choice. Once this occurred, services could be commissioned to meet community and individual preferences. Even more important was the engagement of individual patients in detailed choices during the planning and provision of personal health and care plans, and the 'co-creation' of care programmes and individual care options. This, in turn, depended on the evolution of professional culture and values in health and care.

The *professional values of the health and care workforce of 2022* still place great emphasis on responsibility to patients, but now recognise the need to engage and listen to patients and share responsibility for health and care decisions. Teamwork and organisation in meeting complex needs is now highly valued, with a greater emphasis on the long-term wellbeing of the patient. The self-image of the health professional as someone who intervenes to save the patient in acute care has been replaced largely by an image of a guide for people with long-term chronic care needs. Other values have shifted in response to changing technology. For example, the ability to access and communicate knowledge is now more important than memorising medical facts. These changes have required a substantial re-examination of the training and continuing education of health and care workers.

At first, the *engagement of health and care workers in national reforms* threatened to slow the process of reform. For example, professional organisations naturally represented traditional professional views. Greater impetus was achieved by local engagement within public, social and private provider enterprises. Once health and care workers were engaged at this level, they began to develop a stronger sense of allegiance to the aims and values of local service providers and a greater sense of interdisciplinary teamwork. This helped local teams to rethink the way that they work together to provide health and care services which meet patient expectations at a reasonable cost. In 2022, new team roles which emerge are less likely than before to be seen as a challenge to any given existing professional identity. Instead, these roles are viewed as part of a continuum of the health and care process, supported by a culture of ongoing learning from experience and relationship building between participants.

In 2022, health and care workers will contribute to the *funding of their own professional training* as preparation for a career in which they must continue to learn and develop not only in technical competence, but also as managers and leaders of services for patients. This contrasts with previous generations' expectations of training for a 'job for life'. iChanges to the contractual and pension arrangements of health and care workers are required also to support their new forms of employment. Staff participation in organisational ownership becomes commonplace, with clear roles at the board level and/or in working teams which are recognised and rewarded for the performance that they achieve for the patients they serve.

This does not mean that the independence of spirit or the sense of personal responsibility of health and care workers has been lost. Staff will still help patients and the public to oppose changes that they feel are not in their best interest. This is part of local citizen engagement with commissioners and providers of health and care services.

Local governance arrangements support and represent communities defined in many different ways (e.g. locality, patient, faith, ethnicity) to provide supervision of the executive agencies that commission and provide health and social care, as well as other services such as health promotion and protection, social housing, consumer and environmental protection, education, policing, parks and transport.

A wide range of *community partnerships for health and wellbeing* evolve to include local provider agencies, local businesses and community self-help groups. Local engagement also helps to establish a sense of personal and family responsibility for health and care. This is reinforced by *health and wellbeing assessments* for individuals and communities, and co-payment systems that motivate personal engagement with self-care and positive health and wellbeing programmes. *Community service* is recognised by community service awards and the provision of basic income support as well as training and relief support for family care workers.

These developments, taken together, have resulted in a social movement for health and wellbeing in a fully-engaged society.

1.2   Conclusions for action

Conclusions for action emerge from this analysis for policymakers, health and care leaders, educators, workers and members of the public.

a.   Policymakers

- Policymakers need a forum to develop a shared vision for health and care, which is sufficiently inclusive to encourage broad support, even after the articulation of differences in strategy and opinion.

- The central focus of health policy needs to move away from short-term operational management, perhaps through a separation between policy and operations via an independent NHS board.
- Greater political focus is required on the determinants of health, the regulation of health and care standards and the limits of entitlement.
- Local governance and the regulatory framework should provide political space for local engagement to produce integrated local solutions, with sufficient devolution to ensure local ownership.

b. Health and care leaders

- Good leadership, built on trust, management competence and a common vision of the future, is vital during times of change.
- Health and care leaders must develop and share a coherent vision of the future, along with a plan for how aspirations can be achieved, based on national and local consultation, which encourages involvement and buy-in, rather than resistance.
- Managing change requires that leaders listen to people and help them think through the meaning and need for change for each locality, group and individual involved.
- It is essential to build leadership at every level in health and care services and communities. Leaders should develop other leaders to inspire, execute and evaluate as change is created.

> *"Health and care leaders must develop and share a coherent vision of the future that encourages involvement and buy-in."*

c. Educators

- Educators of health and care workers must be closely engaged in the development of a vision of future skill requirements in the health and care fields.
- Skill requirements need to change to create greater flexibility within and between skill groups and careers.
- Skill requirements must include increased emphasis on:
  - *organisational and workplace skills* – to lead and manage change and create networks and alliances
  - *communication skills* – within multicultural, multidisciplinary contexts to enhance listening and learning, advice-giving and social marketing
  - *knowledge management skills* – with a focus on retrieving and using information and communication systems, recording experiences and developing and sharing valuable lessons
  - *skills* in navigating complex systems – whether of a patient's body or social context.

d. Health and care workers

- Health and care workers must be engaged in redesigning services, not only through professional and representative organisations but as members of local public, social and private sector enterprises.

- Professionals should be encouraged to re-examine the values that drive health and care in the context of future demands.

- A range of policies are required to support training, give respite relief, link informal and formal care and provide appropriate recognition and financial relief to informal carers.

e. Citizens

- There is an urgent need to enlist patients, families and the public in thinking through their personal health, care and wellbeing plans.
- The key to engagement with the public on local health, care and wellbeing could lie in linking personal plans to co-design of services.
- Patient empowerment needs to be supported by social marketing, which involves listening to and communicating messages about social goals. This includes the aim of encouraging greater uptake and support mechanisms for those people who are less likely to use these connection channels and more likely to have complex health and care issues.
- Local governance should be reassessed to engage citizens in all services that affect health including:
  - consumer
  - housing
  - transport
  - education
  - environment
  - policing
  - planning, and
  - health and care.

In distilling final thoughts, four key messages are highlighted.

- Individuals, families and communities – particularly those who are disadvantaged – need to feel empowered and supported to take control of their health, wellbeing and care.
- Political central control must be disengaged from local solutions and local governance.
- Key parts of system change must be supported, with changes in education and training.
- A basic insurance package must be defined for the 21st century.

The effective delivery of these changes depends on leadership and vision to re-engage with the public and care workforce in co-creating health and care services for the future. While

engagement at all levels may slow reforms, it is the only way to achieve lasting change. This does not mean that reform must move at the pace of the slowest; it demands bold vision and leadership, beyond the time-limits or political constraints of governments. Such visionary leadership must provide the motivation for the reformulation of professional values and public re-imagining of health, care and wellbeing in the 21st century.

1.3   The report

This report is divided into five main sections. Chapter 2 describes the methodology and the starting point in current policy. Chapters 3 and 4 present key trends and issues and options for action in the supply, demand and organisation of formal, informal and self-care and comments on the personal experience of care. Chapter 5 presents three scenarios for engagement, discusses their implications for health policy futures and identifies policy levers which would position the workforce to bring each scenario to fruition best. Chapter 6 draws together these scenarios to show a vision of a fully-engaged society, capturing the benefits of each and avoiding their disadvantages. The report concludes with recommendations for action by each of the parties involved.

This report deals only with England. Since devolution of health and care policy responsibilities in 2000, the home countries are following somewhat different paths in the development of health and care policies. While the underlying trends and pressures are similar, their policy responses and visions for the future may differ to some extent.

Health and care needs will change dramatically over the next 15 years, but the people we recruit and train and the facilities we build now will still be part of the landscape in 15 years' time. Decisions we take now will affect health and care in 2022. While it is impossible to forecast with precision, we can imagine possible futures and plan policy directions accordingly.

Background review papers which provide fuller discussion of the trends and issues covered in each chapter can be found at www.jbs.cam.ac.uk/research/health/polfutures/restricted

2. APPROACH TO ANALYSIS AND STARTING POINT IN CURRENT POLICY

2.1 Aims

This report develops scenarios for English health and care policy and examines options for change, focusing on the development and organisation of all those who will be involved in providing health and social care, including self-carers and informal carers, as well as those in paid employment. The time horizon is 15 years from now, so each of the scenarios are meant to reflect the position in 2022.

The report has three aims. The first is to analyse current policies and trends in order to identify routes to action based realistically on understanding the tension between policy objectives and barriers to implementing them. The second is to construct scenarios as a basis for considering new solutions and planning for the future. The third is to identify robust recommendations.

2.2 Approach to analysis

While "there are no facts about the future", a range of methods can be used to explore probable, possible and preferable futures[1][2]. The trends in this report are based on an analysis of literature and trend data relevant to the future of care. Engagement with an expert reference group and wider professional networks supplemented the process[3] (the membership of the expert group is shown in the Appendix on page 87).

Ten background papers on key themes were prepared for this study.

1. The Policy Context.
2. The Social Context Relevant to the Demand, Supply and Reconfiguration of Care: Trends and Implications.

3. Economic Appraisal: Organising and Developing the Workforce.

4. Macroeconomic Trends, Uncertainties and Breakpoints.

5. Literature Review of Trends and Issues in the Formal Care Workforce.

6. The Informal Care Workforce: Trends and Policy Implications.

7. Self-care: Trends and Policy Implications.

8. The Lay–Professional Relationship in Health: Trends and Policy Implications.

9. The Changing Workforce from the Patient Perspective.

10. Three Future Scenarios and Associated Policy Levers for Health and Care in England in 2022.

Summaries of key trends were reviewed by the expert group, which was divided into two subgroups. One subgroup considered the trends most relevant to producing a desirable future; the other directed its attention to the trends which would produce an undesirable future. Also, consideration was given to policy levers which would contribute to desirable and undesirable outcomes.

There was considerable overlap between the two groups, both in a slightly jaded sense of the present and their views on those trends which would be most relevant to the future of care. Key trends were identified as follows:

*   increasing rates of chronic illness and disability

*   rising expectations for health, activity and care in old age

*   anticipated technological innovations in diagnosis, treatment and communication, which will further inflate patient demand (and costs) for new technologies (or the political costs of denying them)

*   the continued inability of the health and social care system to meet demand

*   anticipated slowdown of growth in health spending relative to Gross Domestic Product (GDP) and public spending

*   increasing rates of migration, placing greater strain on the health and social care system and bringing mixed implications for workforce management planning

*   generational differences in attitudes toward care provision and the welfare state, with the young appearing willing to take more responsibility for their health and care than previous generations

*   an empty emphasis on empowering patients and a neglect to empower those who are professionally trained

*   fragmentation of work environments in health and care and lack of continuity in teams

*   staff shortages

- staff turnover, particularly of experienced staff skilled in problem-solving

- poor staff morale, and fear that the sense of commitment for service to others will be lost

- increasing emphasis on offering patients a choice of providers.

Both groups demonstrated a strong tendency to envisage a future in terms of reaction to the negative aspects of the present rather than a vision of the future. Within this context, a composite scenario was drafted and circulated to the group for comment, inviting them to consider the points in the argument where there could be divergence. Comments were elicited through email, as well as through six supplementary interviews with members of the expert group who had been unable to attend the meeting. Three scenarios were developed:

Scenario 1.   The *engaged consumer* in a consumer-led health system

Scenario 2.   The *fully-engaged health and care worker*

Scenario 3.   The *engaged citizen* in a system which minimises the causes of illness and maximises wellbeing through fully engaging the community.

These three scenarios, along with the implications of each for the workforce and the policy measures designed to achieve them, were put before the reconvened expert group for their comments. This feedback was used to generate a further composite "vision" of a fully-engaged society to seek, where realistically possible, to embody the positive and address the negative aspects of each form of engagement. It is important to note that the outcome of the group discussions does not imply that all members agreed with the conclusions.

2.3   Current policy directions

It is now common to observe several factors pointing to a looming crisis in the provision of care in this country. Key factors influencing this trend include:

- an ageing population

- the increasing prevalence of chronic disease

- greater expectations for health and wellbeing

- an increased sense of entitlement to care, and

- an anticipated shortfall in informal carers, coupled with problems of recruitment and retention of formal (paid) carers.

Current policy envisages that, in the future, technologically supported environments will enable the public to take greater responsibility for protecting their own health and self-managing disease[4]. Such future aspirations for health and wellbeing were given prominence in the "fully-engaged scenario" set out by Wanless[5]:

> "In the fully-engaged scenario, people live longer and in better health… [There] is a dramatic improvement in public engagement, driven by widespread access to information – for example, through media such as the internet and digital television. Public health improves dramatically with a sharp decline in key risk factors such as smoking and obesity, as people actively take ownership of their own health… These reductions in risk factors are assumed to be largest where they are currently highest, among people in the most deprived areas. This contributes to further reductions in socio-economic inequalities in health… [O]n average, people make one more visit to their GP each year compared to today. The very old rapidly start experiencing higher levels of hospital care than at present, because they demand more and doctors are much more likely to provide them with care based on their clinical need alone, not their age."

Such a scenario is predicated on profound changes in citizens' perceptions and actions. It envisions a changed health system that is responsive to patient demands, offering new services in new ways and providing seamless care across a variety of settings. Greater focus is given to health promotion, disease prevention and higher levels of self-care, all of which are seen to lead to reduced demand for formal care. The fully-engaged scenario has been given policy form in several ways:

- although originally set out in the NHS Plan[6], increased policy emphasis on self-care and greater personal responsibility has been given great emphasis in more recent policy documents[7][8], and by the extension of programmes such as the Expert Patients Programme (EPP)[9][10] and the Working in Partnership Programme[11]

- an increased emphasis on health promotion and disease prevention, most obviously in *Choosing Health*[12], and reiterated in *Our Health, Our Care, Our Say*[13]

- reconfiguring care closer to the patient and focusing on developing primary and community care (and greater integration between health and social care), as set out in *Our Health, Our Care, Our Say*, as well as centralising other functions, such as emergency medicine[14][15][16]

- greater policy emphasis on addressing inequalities in health, by improving the health status of those with the poorest health[17]

- initiatives aimed at 'modernising' the training and accountability of the formal workforce[18][19][20]

- replacing patient and public involvement forums with Local Involvement Networks, to encourage greater engagement on health and social care issues[21]

- proposals for a joint commissioning framework for health, care and wellbeing show the intention both to integrate these services at a local level and to withdraw from over-detailed targets and controls. At the same time, the current Local Government White Paper emphasises the importance of supporting community leadership and involvement in local policy at a community level[22][23].

Underpinning and guiding current and proposed policy are a set of assumptions that services should be more personalised and reflect individuals' needs and preferences, give everyone access to high-quality care, get the best value for taxpayers' money and give staff the opportunity to work flexibly and innovate. Implicit in these policy initiatives is an assumption that providing care differently will help to contain costs.

Although inherently appealing, pursuing the fully-engaged scenario in practice is proving difficult. Policy interventions designed to address recruitment and retention difficulties, and shortages and gluts in the formal workforce, have yielded mixed results[24]. Realising the policy aspiration of seamless, patient-centred experiences for those needing care across disciplines and locations remains a challenge[25], and integrating social and health care has been particularly difficult[26 27]. The available evidence of demand for greater patient participation in self-care is limited or mixed. There is a sense of bewilderment and frustration among professionals and patients as they experience change without obvious perceived benefit.

The production of health is labour-intensive, and formal workforce issues receive considerable attention from policymakers, professional groups, think tanks and academics. Despite the increasing recognition that health is 'co-produced' by laypeople and professionals, most policy attention focuses on training, work process design and management issues of the formal workforce. Less policy attention is given to the *relationships* between those involved in care, particularly at the boundaries: for example, the introduction of private sector providers creates a perception of a barrier to integrated teamwork across organisations, and changes in the registration of patients with a practice, rather than an individual general practitioner (GP), may be seen to undercut a central personal relationship.

A brief overview of policy as it relates to each subset of the broadly-defined health and care workforce is now presented.

a. The NHS workforce

In 2006 the NHS directly employed or contracted through GP practices 1.34 million people; approximately 675,000 of these were professionally qualified clinical staff. Of this number 126,000 are doctors, 398,000 are nurses, and 150,000 have other clinical qualifications.

Staff numbers have grown by 27% since 1996, with a small reduction in numbers in 2006[28]. While this review is not directed primarily at current workforce policy in the NHS, it is important to acknowledge the unprecedented rise in staff numbers achieved during the past five years. In the prevailing labour market this has demanded exceptional pay increases and international recruitment. A longer term strategy might have allowed time to train and develop UK staff, but political and public demand for improved services and the opportunity presented by increased funding dictated this rush for growth. Plans for staff engagement were

Figure 1: Boundaries and relationships between carers and locations of care
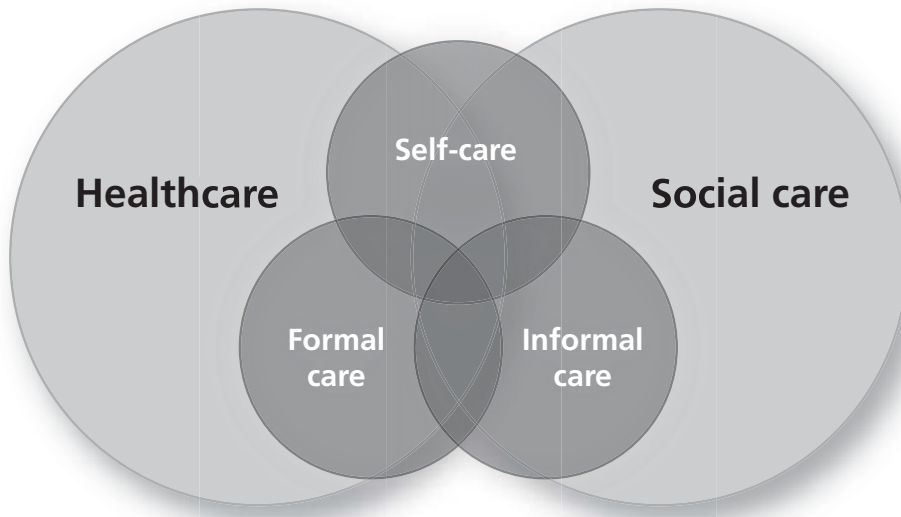
The figure shows the complexity of relationships in the health and care workforce. It illustrates the difficulties in strictly defining health and care roles (for example, a nurse, who is a formal care worker, may engage also in informal care for a relative, or self-care). It also shows the relative importance of self-care and informal care in the system.

an early element of the reform programme and met with some success. Until recently, staff satisfaction and turnover rates were improving. A survey in 2003 of 200,000 staff undertaken by the Commission for Health Improvement showed that 73% of staff were happy in their jobs (compared to 68% in manufacturing), and that 71% were happy with their leaders[29]. However, the demand for immediate resolution of the deficits revealed in 2004/05 by new NHS accounts was equally a political imperative, and this affected training and development budgets and undermined public and staff confidence.

In 2007, the House of Commons Health Committee on Workforce Planning[30] outlined the challenges faced by the NHS since 2000 and the problems which have been addressed, including:

• an increase in staff numbers in response to the Wanless Review[5]

- the impact of the European Working Time Directive (passed by the European Union (EU) in 1993 and the UK in 1998), extended to doctors in 2004
- the need to manage the migration of staff from many different countries.

It also described the sudden reduction in recruitment and training budgets brought about by the revelation of NHS deficits in 2004/05. While coping with these issues, a number of policy measures were introduced, including:

- the response to the previous House of Commons Health Committee report published in 2000, *A Health Service of All the Talents*[31]
- the NHS Plan[32] and subsequent scheme for *Improving Working Lives* published later in 2000[33]
- a plan and toolkit for staff involvement, *Working Together*, launched in 2002[34]; a linked initiative, *Shifting the Balance of Power*, required every Trust to appoint a local involvement leader to champion staff involvement in the Trust[35]
- changes to contractual arrangements for medical staff and the creation of NHS employers so that staff are now employed locally[32 36]
- the introduction of the *Modernising Medical Careers* programme in 2005[37]
- promotion of new work organisation in terms of local community enterprises as third-sector providers of health and care alongside private and public services, as outlined in *Social Enterprise in Primary and Community Care* by the former Secretary of State for Health, Patricia Hewitt, in 2006[38]. A mixed economy of providers is accepted.

Continuing efforts were made to improve the efficiency of NHS staff by modernising healthcare practice and encouraging more flexible teamwork. These efforts, supported by the Modernisation Agency, and its successor, the NHS Institute for Innovation and Improvement, had some impact. However, it is difficult to tell if overall productivity rose or fell during this period. Some argue that increasing resources diminished the pressure for productivity improvement. Office for National Statistics studies show that, if measured by activity or output per staff member, productivity fell by 1.3% a year, but if output is weighted for quality, the studies show rises of up to 1.6%[39].

At the same time there was a discernable undertow of resentment. For example, while changes to GP contracts brought improved pay for the achievement of the *Quality and Outcomes Framework*[40] targets for health improvement, there were complaints that this reduced GPs' flexibility to respond to other patient needs. Equally, targets set for Trusts, particularly those concerned with meeting waiting time limits, were seen as limiting other service improvements and reducing local autonomy. These issues are acknowledged in the current consultation on local accountability for commissioning health and social care, which focuses on the need for a broader accountability framework with greater autonomy at the local level[41].

While resources were generally increasing, these problems were less evident. However, when deficits were found in NHS accounts for 2004/05 amounting to 0.4% of the total[42], and a political decision was taken to resolve them within a year, cuts were made in some training budgets. Further, it seems that many service adjustments which involved, for example, transferring services from hospitals to primary care, were seen as part of a "crisis" in NHS funding. At the same time, a problem emerged with the system for allocating training places for newly-qualified doctors[43], which appeared to disregard their personal record or needs. This had a dispiriting effect on staff and public confidence[44][45].

b. Social care workforce

Policy measures to modernise the social care workforce were set out in the White Paper *Modernising Social Services*[46]. There are around 1.2 million social care workers across the UK, representing around 5% of the UK workforce[47]. The number rises to 1.8 million if early years and childcare providers, foster carers and education assistants are included. Of the 1.2 million, some 600,000 are employed in the voluntary sector, which includes many thousands of charities, 250,000 work in the NHS and some 300,000 work in local authorities. Local authority social care workers include 76,300 qualified social workers and 20,400 occupational therapists. Independent sector care homes and home care services employ some 540,000 staff. There is wide consensus that demand for formal health and social care from a professionally-qualified workforce will continue to increase.

Social care workers are most likely to be older women with little training, often working less than full time. The sector is expanding rapidly to meet growing demand for care of the elderly. The policy agenda for modernising social care includes:

- the creation of a National Care Standards Authority to regulate all care homes, and recognised social and healthcare services, ensuring that they meet minimum standards
- the introduction of the General Social Care Council to raise professional and training standards, including the introduction of new qualifications. Basic registration of all social care workers and a structured training scheme were introduced in 2005[48]. As of 2007, there are 90,000 registered social care workers
- a Social Care Institute for Excellence to promote best practice in social care, including the development of initiatives to integrate social care with other aspects of health and care, drawing on mental health services, family support and early years services, health and social care centres, and creative housing partnerships
- the Dignity in Care initiative, designed to champion the rights of older people with respect to care.

c.   Informal care and self-care

The Department of Health defines informal carers, also known simply as carers, as those "looking after, or providing some regular service for, a sick, disabled or elderly person"[49]. Carers provide unpaid care for family members, friends, neighbours or others who are sick, disabled or elderly, whether within their own household or other households. Their list of activities is broad and includes shopping, cleaning and supervision, as well as personal care and sometimes medical tasks, including giving injections and monitoring for the potential side-effects of medication. Care provided to someone in an institution or with a temporary illness both fall outside this definition, as does care provided for pay or care provided through a voluntary organisation[49]. Normal parental care for healthy children is not considered care work, although care for children with chronic conditions is defined in this way.

The 2000 General Household Survey (GHS) estimated there to be 6.8 million carers in Great Britain alone[49] and 5.9 million[50] were recorded in the April 2001 UK census[a]. The number would be greater if the definition were widened to include those who provide important emotional care to those living in care homes. The majority of carers are female (3.4 million females, 2.5 million males), and a surprisingly large number (114,000) are children aged under 15, or elderly (360,000 aged over 75). Two-thirds of carers were caring for fewer than 20 hours a week, and one-fifth were caring for 50 hours or more. Women were slightly more likely than men to be caring for 50 hours or more, while men were slightly more likely than women to be caring for less than 20 hours.

Support for informal carers features as part of many recent and current policies:

- the cross-departmental strategy *Caring about Carers*, launched in 1999 by the prime minister, was designed to provide support and respite for carers, and in particular, to identify and support children who are carers[51]

- the White Paper *Our Health, Our Care, Our Say*, published in 2006, which picked up issues of support for carers and self-care as a high priority[52]

- local strategies for enabling informal and self-care were called for in the paper *Supporting People with Long-term Conditions to Self Care*, published in 2006. This called for cross-sector action at a local level and individual support to help patients and carers to personalise their package of care[53]. Also, measures such as the Expert Carers Programme[54] and local information services were supported

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a. Some discrepancy appears in the numbers quoted in the literature related to the self-reported nature of the data. Wanless (2006) favours the larger 2000 GHS figure, while the advocacy and support group Carers UK uses the smaller figure (Wanless D. *Securing Good Care for Older People*. London: King's Fund, 2006; Maher J, Green H. *Carers 2000*. London: Office for National Statistics, 2002).

- The New Deal for Carers consultation website was launched in 2007 to review and supplement the original strategy[55]. Actions under consideration include:
  - wide consultation with carers, voluntary organisations, local authorities and others to develop a new national strategy
  - a help and advice call centre for carers
  - new arrangements for emergency respite care
  - the Expert Carers Programme to train and empower carers.

d. Self-care

The Department of Health defines self-care as "care taken by individuals towards their own health and well being, and includes care extended to their children, family, friends and others in neighbourhoods and local communities"[7]. Dean[56] suggests that while there are numerous definitions of self-care, it is essentially about patient autonomy and influence. Wanless defines self-care as that "administered by the individual suffering disease, such as self-medication or self-checks"[57], and this is the understanding most commonly used.

The NHS Plan of 2000 recognised self-care for the first time as one of the key service elements alongside primary, intermediary, secondary and tertiary care. The preceding discussion of informal care indicates that informal care and self-care are often classed together in policy terms, as was the case with the *Our Health, Our Care, Our Say*[46] White Paper and a further paper from the Department of Health, *Supporting People with Long-term Conditions to Self Care*[43]. The policy aim of self-care is supported by a range of other policy initiatives such as National Service Frameworks, the new contract for GPs and public health policy[12], and forms an integral part of the new care arrangements emphasising care that is closer to patients[13]. The EPP has been the largest formal self-care intervention in England so far. Other initiatives defined as promoting self-care include NHS Direct, NHS Choices, HealthSpace[107] and NHS walk-in centres. Alongside new provision of self-care services runs the deregulation of pharmacies, allowing patients greater access to over-the-counter medicines and health advice[58].

3. TRENDS AND ISSUES: GENERAL CONTEXT

The general context framing this report includes the social, economic and technological trends and issues that are expected to influence supply and demand for future care. Summary highlights are presented here with more comprehensive discussion in the background papers.

3.1 The social context

a. Disease and disability

There are continuing differences in levels of self-reported health: for example, people from northern England are more likely to report longstanding illness, as are the unemployed and those of lower socioeconomic status[59]. In 2004, 35% of the population reported having a longstanding illness, compared with 21% in 1972[59]. In Britain, 11 million people live with a disability, an increase of 22% since 1975[60]. An increasing proportion of diseases in the future will be of a chronic nature, requiring health and social care over long periods of time. The Office for National Statistics reports that one in six British adults suffers from a neurotic disorder (most commonly anxiety, depression or both). Although this number remained stable between 1993 and 2000[61], the number receiving treatment doubled during this period. Nevertheless, only one in four of this group presently receives any kind of treatment for their condition[62], and we can anticipate large increases in need and demand. In addition, neurodegenerative disorders are increasing. The number of people with Parkinson's disease, for example, is expected to double to 200,000 by 2030[63].

> *"In 2004, 35% of the population reported having a longstanding illness, compared with 21% in 1972."*

In 2000, 19% of boys and 17% of girls under 20 reported a mild or severe disability[64]. This reflects a 62% increase in the number of young people reporting disability since 1972. The increase is explained by better diagnosis, increased reporting and an increase in the number of children with complex problems surviving longer[60]. The most common forms of disability are asthma, mental disability, autistic spectrum disorder and behavioural problems.

b. Lifestyle

In the last decade, levels of physical activity have declined. While gym membership has increased since 2000 and some 14% of the population visit a gym in the UK[65], half of the population does no exercise. Trends in daily activity show that trips by foot are down 16%, trips by bike are down 18% and private car ownership shows a steady increase[66].

Smoking is declining, from 45% of the adult population in Great Britain in 1971 to 24% in 2005. Of these, 68% have reported a desire to quit[67]. Overall, alcohol consumption has risen alarmingly since the 1970s[68], as has the number of people in the UK who drink heavily[69]. These lifestyle changes – reductions in smoking and increases in drinking – are reflected in mortality rates[67][70].

c. Social inequality

Overall, education and affluence levels are increasing in society[71]. However, relative inequalities persist and are unlikely to decrease, not least because of the impact of globalisation.

Current policy efforts have been more redistributive than in the recent past. For example, efforts to address child poverty may go some way towards limiting the effects of poverty on some families and communities in the longer term, but the impact of inequality on early lives still will be felt in the future[72].

d. Social support

The number of single-person households has risen by 31% during the last three decades[73], and by 2011 it is expected to represent 32.7% of households[74].

Trends in social capital are mixed. Perceived levels of social support are reasonably high, but there is a significant minority of people who do not have friends and family available for support[75]. More people report satisfactory friendships than satisfactory family relationships[75].

Younger and single people are less likely to report trust in their neighbours than older people[75]. If this is not a life-cycle effect, further decline in social capital can be expected. One explanation for this difference is that older people have lived in their neighbourhood for longer.

Declining social capital will impact on care indirectly by reducing health outcomes which, for example, are negatively associated with feelings of discrimination[76], and directly by reducing the pool of informal carers available.

e. Demographic change

The population is ageing[77]. The use of health and care services increases with age[78], and so demand for care will increase at the same time as supply may be shrinking. Furthermore, older people with chronic conditions tend to need a complex mix of health and social care matched to their individual circumstances and resources.

Immigration continues to create greater diversity in society[79]. Meeting the health needs of immigrants will be important not only for social justice and social cohesion, but also for the containment of some communicable disease[80]. Currently, most minority ethnic populations are younger than the majority of society, but their needs will increase in future as the population ages and familial care becomes less prevalent[81].

Trends in internal migration show that people and their care needs cluster in particular places, and movement from one GP to another[82] negatively impacts continuity of care.

In addition, increasing maternal age will have consequences. The direct costs of late childbearing include: demand for funded fertility services; the additional costs of managing riskier pregnancies; and providing a greater number of caesareans[83][84]. The indirect costs include meeting needs for low birth weight and premature babies, and associated morbidities[85].

f. Social attitudes

The expectation of staying active and feeling good into old age is likely to drive demand for health services[86].

Besides widespread belief that the state has a responsibility to provide care to older people, a number of contradictions are apparent:

- people want increasing independence, supported by the state
- they want universal provision and benefits focused on those in most financial need
- they want more care and higher pensions, but they do not want increases in taxation
- they think that levels of inequality are too high, but do not see a role for government to reduce them[87].

"The expectation of staying active and feeling good into old age is likely to drive demand for health services."

The public has a sense of who 'deserves' state-funded support, which is partly dependent upon 'paying in'[87]. However, improvements to healthcare have not satisfied demand[88], while improvements to pensions have gone largely unnoticed by the public[89].

Marked difference in attitudes to care and state support are found between generations. Young people appear less willing to provide care to others, as well as less willing to pay for other people to provide care for others[90]. Whether this is simply a product of their age, or represents a persistent change in attitudes, is important to the future of care.

Public, often prejudicial, attitudes to mental health pose particular challenges for policy in an area where increased need and demand is almost certain. Public education to change social attitudes, as for example in the Scottish "See Me" campaign[91], may be a focus for future development.

3.2   The economic context

a.   National growth and expenditure projections

There has been a steady growth of GDP in the last decade and public spending has increased broadly in line with this, but in recent years the NHS has been allocated an increasing proportion of GDP compared with, for example, education.

The UK is expected to show gradual economic retrenchment in growth rates as the government tries to reduce government borrowing after a series of over-optimistic fiscal forecasts[92]. In current Treasury projections, overall public spending is assumed to rise by only 1.9% a year on average in real terms in the three years from 2008/09 to 2010/11[92].

b.   Employment

In comparison with other countries and other decades, the UK is enjoying a period of relatively low unemployment. UK unemployment figures have declined slightly since reaching a six-year high in November 2006, but employment rates have continued to decline[93].

The enlargement of the EU in 2004 has increased the number of migrant workers in the labour market. Most are young (aged between 18 and 34 years), have fewer dependants who require public services, and receive comparatively low wages relative to their education and skill levels[94].

Higher rates of young people will be economically inactive in future as the economy and labour markets change[95]. In contrast, the proportion of older people in the labour force is expected to increase. Recent years have seen a significant increase in the employment rate of 50 to 69-year-olds (from 48.7% in 1997 to 54.8% in 2005). By 2020, the old-age dependency

ratio will be almost 30% (the ratio of the working age population to persons aged 65 years or older), meaning that fewer members of the workforce will be supporting the needs of a higher proportion of non-working people[96].

c. Trends in the health and social care economy

Real health expenditure has been growing at a rate of 7.4% a year since 2002, but is forecast to slow to 3–4% for the next comprehensive spending review period (2008/09 to 2010/11). In 2006/07 health spend was 8.9% of GDP, compared with 6.7% in 1998/99[97]. There is a recent trend toward greater expenditure on primary care relative to secondary care[98].

Anticipated long-term care expenditure would need to increase from 1.4% of GDP in 2002 to 2.6% of GDP in 2041 to meet demographic pressures, assuming annual increases in GDP in line with Treasury assumptions[99]. This reflects an anticipated increase in demand for formal home care of approximately 60% by 2040[100], and would require an increased tax contribution rate from 1% of wages today to 1.3% in 2050[100]. However, future long-term care expenditure is highly sensitive to assumed rises in the unit costs of care, and could range from 2.2% of GDP to 3.2% of GDP in 2041[99].

Across the whole economy, productivity measured as the value of output per worker has increased at about 2% a year in recent decades. However, much of this improvement has occurred as a result of shifts towards higher value-added activity. While Wanless[5] suggests that the NHS has matched this level of increase in productivity, this is contested by many who claim that the NHS has not achieved significant productivity improvements in recent years[101]. Conventional measures of activity (such as finished consultant episodes) have not kept pace with the increase in whole-time equivalent staff numbers[102], and there is much controversy over how much productivity has increased as a result of recent investment in the NHS. Some argue that less activity per unit of cost (the current trend) can be indicative of higher levels of health care intervention averted[103]. A key to improved productivity is not only to modernise and redesign working practices, including incorporating effective use of new technologies, but also to shift investment to higher value-added activities such as health promotion.

In the decade to 2002 there was little change in the proportion of private spending on healthcare. In 1992 16% of total health expenditure was private, whereas in 2002 this proportion amounted to 17%[97]. Pharmaceutical expenditure has risen by between 7 and 9% a year in recent years[104].

3.3   The technological context

Developments in information and communications technology (ICT) continue. New treatment interventions, point-of-person systems which record and process individual treatment and care plans, and assistive technologies which support care for people with disabilities, can support self-care and independent living for longer[105 106]. The use of NHS Direct and NHS Choices can help people to access knowledge in order to manage their health options, and HealthSpace could be used to enable people to develop personal health and wellbeing improvement plans. In addition, ICT can provide better tools for performance management and increase the capacity to develop complicated social mapping to help target support and health improvement strategies[108]. Further, it can provide better access to employment and training opportunities in the NHS.

However, trends in ICT show a degree of patchiness in take-up and impact. In 2005, 15% of households with incomes in the lowest 20% had access to the Internet, compared with 87% access among households with the highest 20% of incomes[109 110]. NHS Direct, which uses far more accessible phone technology, has been used less by patients of lower socioeconomic status[111], and there is not yet clear evidence of carers making consistent use of on-line support[112]. A more active approach towards diffusion to potential users, including self-carers and the public, may repay small investment.

Genetics and pharmacogenetics could lead to less demand for health and social care services, as treatments become more targeted and efficient and involve fewer side-effects, but also could lead to greater demand for treatment as previously undiagnosed health needs are exposed[113]. Some observers anticipate financial savings as a result of advancements in genetics[114 115], while others do not[116].

4. TRENDS AND ISSUES: THE WORKFORCE OF FORMAL, INFORMAL AND SELF-CARERS

4.1 The formal care workforce

Current policy with regard to the formal workforce was summarised in chapter 2. This section deals with trends and issues for the future.

a. Supply

Supply is out-of-step with current and predicted demand. Too many medical students are choosing specialties over general practice[117], and too many of the remaining health professionals are choosing the allied health professions over nursing[24] to meet anticipated future demand. Moreover, the increasing number of women in the medical workforce is expected to contribute to future shortages[118], as many more women than men work part-time and take career breaks. Of doctors and dentists, 62% are male overall, but doctors and dentists under 30 years of age are split equally between the genders[119]. The same issue is relevant to pharmacy, where 60% of students are women and more likely to work part-time[118].

In order to meet the workforce needs of Wanless's 'solid progress' scenario, by 2020 the healthcare system would require an additional 62,000 doctors, 108,000 nurses and 74,000 healthcare assistants[57], with job growth fastest among doctors and healthcare assistants[120]. An estimated 10,000 new therapists and psychologists would be required to meet the growing demand for mental healthcare[62]. Social care workers are in particularly short supply, as the profession continues to suffer from being poorly perceived both inside and outside the workforce[121]. Half of social care workers work part-time[121]. Retention is also an issue: 15 to 20% of British-trained doctors leave the NHS within just a few years of qualifying, although

the number that leave medicine altogether remains quite small[122]. Psychiatrists are particularly prone to career changes[123].

The formal care workforce is characterised by increasing diversity, not least because England relies to a high degree on health professionals from the developing world, particularly for those jobs with higher qualifications. For example, in London, one in four doctors was born in Asia or Africa, as were one in six dentists, nurses and midwives[119]. A *Code of Practice for the International Recruitment of Healthcare Professionals*[124] was introduced to limit direct recruitment from resource-poor countries, but this did not stop the indirect recruitment and immigration of health professionals. Furthermore, in recent years there has been a rapid increase in the number of social care assistants from new EU Member States[125].

Notwithstanding need, the system today has trained more doctors, nurses and midwives than can be employed in the present financial climate, and risks losing expensively-trained professionals both to the international labour market and to occupations outside health[126].

b. Role substitution, innovation and skill mix

There has been much discussion and experimentation with skill mix, which relates to the balance between the levels of training of untrained, qualified and unqualified staff as well as between staff groups. Those who advocate skill mix changes argue that "workforce size and mix are historical and irrational at best'"[127] often reflecting "silo" focus on individual care roles rather than teams[128 129]. Rather than designing roles and processes around the professions, they advocate that integrated, multi-skilled care should be designed around the patient. Extending such thinking to community-based chronic care suggests the inclusion of patients and informal carers in the redesign[127].

Developments in general practice and nursing illustrate this approach. The introduction of GPs with special interest roles involves the GP taking on tasks which before were solely in the domain of specialists. This trend is welcomed by many, but anxieties have been raised about the adequacy of training, the overall decrease in accessibility to GPs, and increasing demand for more convenient and accessible specialist services, eroding cost savings[130]. Whatever their formal relationships, increasingly close working between GPs and specialists to share knowledge, coordinate better the care of individual patients, and share a wider vision of their role in improving health, is advocated frequently[131].

Increasingly, nurses are performing tasks formerly within the scope of doctors[132 133]. Given the increase in the number of patients presenting minor ailments to doctors, some expect that this trend will continue[134]. However the spread of advanced nursing practice has been

slower and more varied than most predicted. While the evidence on clinical outcomes for nurses is similar to that of doctors, patient satisfaction is often higher for those seen by nurses, possibly reflecting the longer consultation time and the more complete satisfaction of formerly unmet need[135]. However, the evidence for cost savings from substituting nurses for doctors is not overwhelming[135][136]. Although nurses take less time to train, they are more likely to work part-time and take career breaks, and therefore may be less productive for the system during the course of their work lives[137]. Further, it is not clear that adding nurses or nurse practitioners to a practice actually decreases GPs' workloads, allowing them to turn their attention to the most serious or complex cases, although longer-term studies should be done before conclusions are drawn[135]. In a Dutch randomised control trial, doctor workloads actually registered a short-term increase with the deployment of nurse practitioners, possibly because the nurse practitioners uncovered previously untreated conditions, which they then referred back to the GPs, satisfying previously unmet demand[138].

While studies have affirmed the correlation between care quality and higher numbers of nurses[139], a lack of consensus remains around what an ideal, economically justifiable nurse-to-patient ratio might be in which sites of care, and where the point of diminishing returns lies[140]. Also, anxieties have been raised – albeit in a rather stereotypical way – about the balance between emotional support and analytical rigour brought by changes in the boundaries between doctors and nurses, with doctors losing the emotional, caring aspects of their work from which many derive value[118], and nurses losing the qualities that patients especially value[141]. Similar concerns are raised for the loss of the nurse's valuable coordinator role, precisely at the moment when we are becoming more concerned with the provision of seamless care[142]. A broader version of these anxieties is that the strategy of breaking down care into a list of tasks may undervalue the analytic, critical thinking role of all trained health professionals[143][144], and at the same time undervalue 'invisible', difficult-to-measure work[145].

In addition, the roles of healthcare assistants and clerical workers have been re-examined[146], with proposals that healthcare assistants take on nursing tasks and that nurses assume tasks previously performed only by doctors[147]. This is likely to be the case particularly in aspects of caring for the most dependent patients[148]. Use of healthcare assistants is associated with better efficiency and higher patient satisfaction, as they extend the number of tasks that a workgroup can perform for patients in a given amount of time, and with finite resources[149][150][151]. Skills and experience can vary dramatically between healthcare assistants, and so particular note needs to be taken of the need to measure more than educational attainment when considering skill mix developments here[128][145].

Furthermore, new roles are being developed, including:
* community matron
* medical care practitioner
* self-care trainer
* case manager or coordinator, and
* health support worker.

Preliminary evidence on the impact of community matrons has met with mixed results, with some studies reporting a decrease in hospital readmission, improved continuity of care and better adherence as a result of assigning high-risk patients to matrons[152], and others showing little health benefit[153][154]. The medical care practitioner (based on the physician assistant role in the USA), provides a similar role, but as yet it remains unclear what kinds of outcomes or cost savings this role might offer to policymakers in future[155]. Case managers are trained to advise patients and their families on a wide range of practical issues and coordinate care across social and health care. This function has existed for a long while under a variety of titles and with different degrees of training, but its standardisation and expanded deployment holds the promise of more seamless service among various agencies, and may delay or prevent institutionalisation[156][157]. Also, self-care trainers may become an important part of the future workforce[158]. Health support workers have been shown to be highly effective when partnered with health visitors, bringing insight into the local community from which they are recruited[159].

c. Workforce planning and training

While local innovations respond to demand, central mechanisms for planning and training have difficulty catching up[160][161]. Beyond the many uncertainties that the future will bring, both in technological and human service innovation, there is a central dilemma around determining how far professional groups should have control over entry into their profession, the definition of their respective roles, and the distance between the role that a practitioner was trained to do and that which in fact they are doing[162].

> *"Health professionals are still educated for last century's battle against acute illness rather than this century's expansion of chronic conditions."*

Health professionals, particularly the most highly trained, are still educated for last century's battle against acute illness rather than this century's expansion of chronic conditions. All health workers need new skills to handle the challenge of chronic disease management[163], which implies many changes to their professional practice.

There is policy interest in two separable, yet related, lines of development. One is in expanding practitioners' public health role and skills, with an awareness of their role in relation to the

social context of disease and care and a concern for the health and wellbeing of patients in a broader sense, including being competent to deal with the rapid expansion of health knowledge and to share it with their patients. The other is increased attention to working across traditional boundaries. This relates to inter-professional working, as well as working between organisations and agencies. Both these developments imply a shift from a narrow professional focus to one of integrating care and working in teams. These shifts in focus are unwelcome to some practitioners and, while they are important policy goals, they are yet to have a major impact on practice[164][165][166].

Increasing emphasis on patient-centred care involves significant mental and cultural paradigm shifts. Trends and issues around the patient are covered in this chapter.

d. Options for action

Improved retention must be a major policy goal. Approaches could include:

• greater opportunities to gain experience prior to commitment to specific career avenues: for example, enabling prospective psychiatrists to experience the psychiatric environment earlier in their training[123]

• greater opportunities for nurses to access continuing education to help them adapt to the pace of medical change, as well as more opportunities for flexible work arrangements and better guidelines as to their precise role[167][168]

• enabling home care workers to experience better management and opportunities for mentoring[46]

• improving healthcare assistants' access to training, increased role definition and opportunities for career progression, including to registered nurse training[169][170][171][172][173][174]. Rather than spending resources advertising nursing careers to the public at large, more could be invested in forging more flexible and accessible pathways between support worker jobs and nursing degrees

• designing care systems which allow professional carers to spend more time with patients and clients. Home care workers derive satisfaction from feeling that they do meaningful work[175]; some nurses feel that less time spent with patients may have a negative effect on their job satisfaction[176]; and healthcare assistants – who often spend the most time with hospital patients – are offered little involvement in the planning or information sharing around patients[177], and would benefit from greater involvement in the care team (as would their patients).

Changing professional values and goals in step with any policy changes in the system must be a fundamental goal for developing the health system of the future. This will be developed only through dialogue between trusted parties in forums with a focus above narrow professional or

short-term political interests, in which all parties feel that their views are valued[178]. Beyond involvement in designing, creating and sustaining change once in post, careful attention needs to be paid to education and training. For example, curriculum reform is needed to enable more effective interprofessional and inter-agency working and patient-involved care. Work is ongoing in training and education[179 180]. In addition, there is evidence from two studies that help may come from a previously unexploited source, in that service users themselves may be a valuable resource as educators as they provide a unique perspective in helping to promote patient-centred medicine: one programme for practitioners taught the importance of interprofessional working and the resulting coherence, continuity and seamlessness of care from the patient's perspective by having classes taught partially by service users[181], while another featured successful self-carers helping others to learn the skills necessary to manage chronic illness[182].

4.2   The informal care workforce

Current policy with regard to the informal workforce was summarised in chapter 2. This section deals with trends and issues for the future.

a.   Who provides care to whom?

Currently, some 70% of all care in the UK is provided by informal carers[183], and nearly everyone can expect to be a carer at some point in their lives[184]. One in 20 people in the UK presently provide more than 20 hours of care a week[49]. Informal carers are difficult to count, and the amount of care they provide is difficult to measure, which can have significant implications on our ability to predict future supply[185]. Policies to encourage people to work longer risk reducing the pool of informal care[186].

> *"Currently, some 70% of all care in the UK is provided by informal carers, and nearly everyone can expect to be a carer at some point in their lives."*

Carers are disproportionately female, older, less healthy, less educated, less likely to be employed and probably less economically advantaged than the general population[49 187 188]. The supply of informal carers has risen very slightly, and men perform more care now than in the past[49]. If supply is to meet demand in the coming decades, the rates of male caring will have to trend upward to meet females' present rates, rather than female rates dropping to male rates[100]. While more than half of carers in 2000 looked after a parent[49], care for spouses will become increasingly significant in future[189]. In the future, carers will be older, frailer and are likely to be required to deliver more complex care[190].

It is important to note that, even when it is motivated by duty or love, the care one receives for free is not always better than that which is paid for, and the potential for poor quality, neglect and abuse exists in this unregulated sphere[191 192].

It is estimated that demand for informal care will begin to take off 10 years from now, peaking around 2040 at 30–50% above current levels[100]. However, unexpected trends may emerge. For example, some individuals may prefer simply to pay for their care[193]. Recent data suggest that while today's elderly show a strong preference to receive informal care, younger groups may prefer to receive formal care in the future[194]. It is unclear, though, whether formal care can be an effective substitute for informal care, and vice versa. So it is by no means clear that the future informal care workforce will increase to meet demand[195], or even that it will increase at all, given the social and demographic factors described in chapter 3.

> *"It is estimated that demand for informal care will peak around 2040 at 30 to 50% above current levels."*

b. The costs of informal care

Those who provide higher hours of care are at greater risk of receiving harm to their health and quality of life, as are female, spousal and cohabiting carers[49 188 190 196], even long after they have concluded their care role[197]. Indeed, for those with heavy care workloads the strain of caring appears to be strongest at the beginning of the care role and at its conclusion[197]. While nearly all agree on the possible negative outcomes of being a carer, emphasis varies between different negative aspects, such as a lack of social support[198], long hours of care[197 199 200], and the erratic or distressing behaviour of the patient[201 202 203 204]. The experience of placing someone in a care home can be damaging for carers, leaving the carer feeling guilt, loss and a lack of control[205 206 207 208].

Determining the costs of unpaid care to society and the economy is difficult and approached in different ways[121]. The costs appear large, particularly if they include:

*   lost productivity in the paid labour market
*   interruptions to carers' education or career advancement
*   the declining health of carers
*   the cost of direct carer support services, such as respite and counselling, and
*   the cost of the work done by carers, if at least some of it were performed by professional staff.

Many carers juggle paid employment and care work simultaneously, and seem to derive some benefit or insulation from carer strain from their paid employment[209 210]. Half of those carers in paid employment change their labour market participation, most commonly by leaving their job altogether. This is particularly true of routine and semi-routine manual workers[211].

While the experience of caring appears largely similar between white and minority ethnic

carers[212], the availability of resources[213] and coping mechanisms[214] may be different in ways that should be studied further to identify how best to target support.

c. The experience of being a carer

Many carers do not view themselves as carers at all, but rather as performing a constituent part of their role of spouse, parent or child[215 216 217]. Some actively choose to become someone's carer, yet most 'drift' into the role, with its accompanying health consequences. One hypothesis of women's increased vulnerability to the harmful effects of caring is that they have less choice than their male counterparts in the decision to become carers[218], and may feel less control and more resentment.

However, many carers derive emotional benefits from caring, even as they simultaneously sacrifice time and health[219]. Many would not choose to give it up, even if substitute care could be provided[220]. The most important benefit revolves around the satisfaction of seeing the person receiving care as safe, comfortable and well looked after[221]. In addition, studies from other countries have identified "enhancement of self"[222] – a closer relationship with the person to whom they provide care, feeling needed and the ability to express one's love through care work – as a significant benefit[223]. These rewards are difficult to define and quantify, but provide an important basis for thinking about motivating and rewarding the informal care workforce.

d. Options for action

Appropriate support for carers must be a major priority because of the health impact on a large part of the population who provides this care and the interaction of informal care provision with demand for formal care. For example, a better-prepared, higher-skilled and more emotionally-supported carer can delay admission to a care home. Reallocating resources towards carer support can be safely viewed as an investment in the capacity of the care system. However, the question remains about how best to deliver that support; a topic on which there is no consensus[203 224]. Many interventions have been attempted which variously target carers, those for whom they care and the professionals who may support them. Evidence suggests that carers particularly value:

- respite services[225]
- family counselling aimed at increasing the social resources of the primary carer[203], giving the carer practical skills and knowledge that can help to improve their perceived ability and competence[203]
- peer support groups[226]
- granting the carer greater control over the care receiver's care plan[227], and
- professional validation and reassurance[228].

Others suggest that compensating carers for their work would help to decrease their burden and increase the incentive to care[121]. Educating professionals to view carers as co-clients, whose needs need to be considered alongside those to whom they are both providing care, would lift a powerful brake on carers' ability and wellbeing[229].

One acute early need which often goes unfilled is that of reassuring carers of their competence and abilities[230][231]. Professionals should be sensitive to carers' lack of active choice to care, so that they may maximise their potentially damaged sense of control as well as validate their own needs[231]. Meanwhile, more support is needed at the conclusion of a carer's 'tour of duty', either in the form of bereavement support[232][233], or better support in terms of validation, information and counselling before, during and after the process of placing the cared-for person in a care home[234][235].

Even when support mechanisms are in place, the question of their accessibility remains. For example, while some carers are able to access information and support through the Internet, older carers, those of lower socioeconomic status and those who care intensively are less likely to use the Internet for lack of training, equipment or time[236]. While women provide more care and tend to be more negatively affected by the care work that they give, it has been suggested that male carers may be less able to recognise and voice their own care needs[237] to seek and receive support.

In addition, particular needs for carers from minority ethnic groups have been identified. They are disproportionately in the group of carers who do not enjoy strong familial social support, live in relatively disadvantaged circumstances[238][239] and do not access existing sources of support because they are unaware that they exist, do not know how to access them, or do not think that they will meet their needs[233][240][241][242].

Options for action must pay regard also to the education, training and management of the professional care workforce. Health professionals speak of caring for carers largely in a reactive capacity, reporting that they do not have the time and resources to be more proactive. They comment on their own lack of training to identify and treat particularly at-risk carers, who are likely to put the needs of the person they care for ahead of their own[243]. Some suggest that, rather than training professionals to care for carers, professionals should be trained instead to understand the resources and support which might benefit the carer best and how to refer them to these, as well as how to convince carers to take advantage of them[242]. Public health values and methods and increased recognition of psychosocial health problems, which are slowly gaining traction in the professional education of doctors and nurses, may bring better recognition and treatment of carer strain.

Workplace flexibility and organisational cultures have a part to play in optimising the number of carers who are able to continue working. Besides severely limiting their financial resources, withdrawal from the labour market can increase social isolation, further destabilise carers'

self-identities, and lead to depression and other health problems associated with carer strain. An inability to balance care and work may lead individuals with alternatives to the opposite conclusion: that is, to withdraw partially or completely from their care work, particularly if others besides themselves are dependent on their income.

A final option for action would focus not on the ways to decrease carer strain, increase carer health status and role longevity, but on ways to engage more informal carers from the outset. There is evidence indicating that offsetting the financial cost of caring may encourage more people to provide care[244], but other options also could be investigated.

4.3 Self-care

Current policy with regard to self-care was summarised in chapter 2. This section deals with trends and issues for the future.

a. Need for clear data to support policy expectations

Self-care is a central plank of present and future English health policy[7 8 11 245], but at the moment it appears more popular with policymakers than patients and the public at large. The Department of Health expects that patient engagement in self-care will improve health outcomes, increase patient satisfaction, empower patients and help to utilise the resources inherent in patients[246], but so far there is no clear data that self-care activities improve outcomes, reduce demand for formal services or save money.

b. Self-care and empowering patients

A growing body of evidence suggests that self-care interventions can improve people's sense of self-efficacy[247]. However, many argue that due to systems constraints and professional attitudes and practices, patients are not enabled to take control[248 249]. Furthermore, some argue that the self-care policy is not to empower, but to shift blame and responsibility onto the individual[250 251]. Self-care is described as allowing professionals to pass responsibility for getting well to the patient[252 253 254] and to "blame" the patient for ill-health[255]. This does not give patients autonomy, but adds the weight of responsibility for getting well to their concerns[251]. The term 'co-creation' is used to describe the mental and cultural paradigm shift we need to achieve if patients really are to partner with professionals and health services to co-create their own health[256].

> *"Co-creation is the mental and cultural paradigm shift we need to achieve if patients really are to partner with professionals and health services to co-create their own health."*

c.   Managing demand through self-care

The Department of Health estimates that 15% of Accident & Emergency (A&E) attendances and 40% of GP time could be avoided, not least because more than two-thirds of GP visits result in prescribing drugs that are available over the counter[257]. Further, there is some evidence that the public performs more self-care than in the past, as sales of over-the-counter drugs[258] and the use of alternative therapies have grown[259], as has use of the Internet for health information and support[109]. While cost-containment is presented as an added bonus rather than as a driving force behind policy, it is a recurring, well-formed argument[7 13]. The Wanless review[5] estimated that for every £100 spent helping patients to care for themselves, £150 could be saved by the reduction of GP and outpatient visits.

The impact of self-care on demand for formal care services is unproven, but with some evidence in support[260 261 262 263]. Another interpretation is that it will simply change demand. For example, although NHS Direct is intended to provide advice, reducing demand for face-to-face contact with GPs, there is some indication that it has not lessened demand for primary and emergency services as much as had been hoped[264]. The expectation that higher levels of self-care will reduce demand for formal care is contested[265], and some anticipate increased demands on professionals' time[266 267], as patients require deeper explanations, more instruction and further negotiation[247]. Primary Care Trusts fear, at least in the short term, that the implementation of self-care support will lead to "increased demand for resources"[246]. Others argue that managing demand could reduce access to care and result in poorer outcomes[268 269].

d.   Improving outcomes through self-care

The evidence of the impact of self-care on improvement of disease outcomes is inconclusive[270], but there are examples of positive interventions[271 272 273]. In one such study[274], 140 men in London were split into two groups: one received standard care for uncomplicated urinary tract symptoms; the other took part in three sessions including lifestyle advice, education about their condition and goal setting. Three months later, 42% of the group receiving standard medical help experienced treatment failure, in that their symptoms increased or they needed drugs or surgery. This was true of only 10% of the self-managing group. The differences between the groups increased through the year-long study.

e.   Demographics of self-care

Being younger[247 266 275], white[276 277], more educated[247 266], of higher economic status[278 279], employed[277] and more affluent[271 276 280] predict higher levels of self-care, as do negative attitudes to healthcare providers[281] and treatments[247 282]. However, illness and the reaction to illness are also important predictors of self-care. Significant variables include:

- the stage of illness[247]
- the severity of condition[247 279]
- the kind of illness[266]
- any co-morbidity[283], and
- adverse effects of medications[283].

A Californian study found joint pain, immobility, fatigue and depression to constrain people's ability to self-care[271]. Those who suffer disproportionately more ill-health[147 284] are also those who are difficult to engage in self-care initiatives[246 285]: the elderly, the economically deprived and people from minority ethnic communities.

> *"Being younger, white, more educated, employed and more affluent predict higher levels of self-care."*

f. Barriers to self-care from patients, professionals and the system

The current literature does not support the assumption that patients seek to be empowered and to self-care. Patients do not necessarily seek control[251 280 286], and being ill reduces its importance[287]. "Being cared for" may be more valued at times than being empowered[276 287]. Further, some patients may feel empowered by choosing to engage in unhealthy behaviours: for example, not eating healthily[288] or not complying with a care plan[289 290]. Indeed, the idea of several conflicting goals is often used to explain why some patients face difficulties in self-caring, given their social context[263 276]. If self-caring behaviour requires an individual to change their social networks or adopt social practices which reduce their perceived quality of life, it can seem deeply unappealing[291], if not impossible to achieve[276 271].

Professionals' attitudes to patients who self-care are often ambivalent[292]. Thorne et al.[248] suggest that professionals doubt patients' ability to make decisions for themselves and use "blocking tactics"[293], castigation, anger and superior technical knowledge to bamboozle patients[249]. Professionals who do see patients as "partners" tend to view patient participation as gaining active agreement to comply with treatment regimes[294]. Further, some clinicians are reluctant to refer patients to self-management programmes because of the lack of data of what is appropriate for whom[295], and the relative lack of accessible information about these programmes.

Patients who self-care are still required to fit in with "institutional constraints", including "time schedules" and "dwindling resources"[280]. Many institutional barriers to self-care are associated with service provision (for example, being rushed by a doctor's timetable yet having to wait for test results and referrals)[271]. Paterson[294] suggests that if patients are rushed to make a decision, they are likely to allow the professional to make it for them; and Coulter suggests that if practitioners are hurried, they will default to prescribing[247]. Because self-care relies on individuals accessing and using information from health professionals and other sources, some

patients may be favoured over others[296]. Younger, more educated and more middle-class patients seek more information from doctors[158 297 298] and doctors tailor their information provision to the perceived needs of patients[299]. This can result in a "double jeopardy" of passive patients receiving less information because professionals perceive them to be indifferent or incapable. Patients also need to be able to read[278] and to understand and speak the language of dialogue[278], and the information given to them needs to be appropriate[278 300]. Finally, there are physical barriers to self-care including lack of awareness, immobility, transport problems and cost, and occasionally access to supplementary informal care[271].

g. Options for action

Enabling individuals and families to make healthy choices about their lifestyle – diet, activity, sexual relationships, stress, smoking, alcohol and other unhealthy substances – is the starting point for public health[13]. It is now possible to predict, within a very close range, the likelihood of individual and community physical and mental health outcomes on the basis of using a limited number of simple tests and questionnaires which measure health risk or wellbeing. However, simply providing information on individual health risks and strategies for health improvement is not enough by itself. Given the broad range of activities, supported or otherwise, that are considered to be 'self-care', drawing together lessons for future success relies on taking clues from diverse sources and making provision for a range of available and affordable resources, including social marketing (the application of marketing techniques to social goals such as improved health and wellbeing), guidance on steps to take healthy options, counselling support and advice.

> *"Enabling individuals and families to make healthy choices about their lifestyle is the starting point for public health."*

It is important to distinguish between patient empowerment and demand management objectives, for while patient empowerment may lead to reduced demand, patients will only choose to take control if they see it to be in their own interest. It should not be assumed that giving patients the 'right' to self-care will develop their desire to treat themselves.

Self-efficacy, or the "confidence in one's power to perform required behaviour and influence the progression of the disease"[301], is associated with greater self-care tendencies[271 279 302], but this may be because it leads to self-care rather than results from self-care. The stronger a patient's self-efficacy beliefs, the more control they feel that they have over their condition and their ability to prevent complications by improving self-management behaviours[279]. It is argued that future self-care services should aim to develop and enable self-efficacy[271], for example, through developing a patient's problem-solving, goal-setting, coping and action-planning skills[279 303]. For example, one intervention[263] targeting older people discharged

from hospital with a chronic medical condition, yielded patients who enjoyed a higher quality of life, expressed greater ability to manage their own health, had lower information needs and sustained a more positive attitude towards life. The intervention began with a "reflective dialog" about how life would (and needed to) be different in future, and was followed by 12 to 16 home visits. The EPP has been popular also with some participants because it focuses on skills in setting goals which are self-generated, positively formulated and achievable[304].

Interventions which focus on patients appear to be more successful than provider-focused interventions (e.g. automated telephone management programmes and patient empowerment and education programmes[301 305 306 307]). However, practitioner behaviour is clearly relevant in providing support for patients to self-care. One reason offered for the disappointing results associated with provider-focused interventions is that providers wrongly equate giving patients more opportunity to participate in consultations with patient empowerment[301].

The presence of a sufficient number of empathetic, knowledgeable, appropriately trained and approachable staff to support self-care is critical[308]. For example, in a successful intervention targeted at increasing levels of physical exercise in deprived communities in Hull[308], client satisfaction depended on patients having a lot of contact with professionals over extended periods of time. Similarly, participants in a behaviour modification programme in the USA relied on staff to encourage them, track them across institutions, and provide other support services such as arranging transport[309]. People respond differently to interventions[279], and providing different services to different people appears to increase success[310].

> *"It should not be assumed that giving patients the 'right' to self-care will develop their desire to treat themselves."*

Many programmes, including the EPP[285], encounter recruitment problems. Networks are important for recruitment and retention. GPs in particular, but also other workers, can be a conduit to self-care programmes. There is considerable evidence to suggest that the extent and timing of payments influence access to formal care[309], which needs to be taken into account when designing accessible and equitable services.

Access, in terms of physical design and geographical proximity, is also important to the success of some self-care interventions[308 311]. Transport and impaired mobility can be material barriers to self-care[312], which of course cannot be overcome through psychological interventions[271]. More provision of home-based services would address many of the access problems by reducing the cost to individuals who are ill. Engaging 'hard to reach' groups is likely to require focused and decentralised provision.

Supporting self-care depends on developing appropriate technologies and support processes. For example, while an intervention was successful in improving self-monitoring of anticoagulation therapy and patient independence, the test strips crucial to the intervention were expensive[313]. Other technologies include the availability of appropriate alternative sources of advice and support[314]. In addition, the Internet represents a powerful means of emotional and social support[315 316], albeit for those with the time, skill and equipment to access it. NHS Direct, which deploys an old technology in a new way, represents perhaps the most explicit attempt by policymakers to place health professionals in a supportive rather than directive role. However, so far, hopes that minorities, the poor and others with less ready access to information and the Internet would rely on the relatively low-tech service, have not been met[111].

Guideline development is likely to be an important feature of future policy, but as yet, lack of coherent data and comparable evidence prevents GPs and commissioners from knowing how and why to expect patients to self-manage.

4.4 Patients' experiences of care

This section deals with the fourth group of people who play a critical part in interacting with (and some would argue, forming part of) the care workforce: the patients. It reviews issues and trends in the way that patients experience care, their relationships with health professionals and how these relationships are viewed by both patients and professionals. The preceding discussion of self-care should be taken as part of this context.

a. Patient-centred care

Care which can be described as 'patient-centred' is designed to elicit more participation from the patient, is individualised to the particular needs and preferences of the patient, and employs open rather than closed questions and strong listening skills[317]. The importance of patient-centred, individualised care to patients and within health and social care continues to grow, and at least some patients still prefer it to an emphasis on access[318].

Relationships between health professionals and their patients may benefit from seeking a better understanding of the role that health professionals play in patients' larger experiences of living with, and managing, illness[319]. Nurse practitioners appear better able to meet patients' expectations of a warm, empathetic medical encounter, both because of their professional culture and training and their longer consultation times, which allow for more listening, discussion and informal interaction[320 321].

However, there is an argument that in focusing too much on maintaining good patient relations, professionals may become reluctant to challenge patients' strategies for managing their health and illnesses[322 323].

b.   Continuity of care

Interpersonal continuity of care, which involves an ongoing patient–practitioner relationship, is highly valued by patients, particularly by those with life-threatening, chronic and mental illnesses[324] [325] and by health professionals[326] [327]. It is associated with many positive health outcomes, including: increased patient satisfaction, better prevention, more adherence and fewer hospitalisations and A&E visits[328] [329] [330]. It may also be cheaper[331]. However there is a trend away from it[332]. Although young people appear not to mind this much, valuing continuity less than ease of access, we cannot be sure whether this simply reflects their age or represents a long-term change in attitudes[324].

It is not entirely clear whether larger general practices and the policy of assigning patients to practices rather than to GPs necessarily causes less interpersonal continuity[324]. Evidence appears to suggest that some interpersonal continuity is better than none, and that team continuity and information continuity can yield positive benefits as well[333]. However, team and information continuity each have their own organisational challenges, and it is not clear that they are effective substitutes[327].

c.   Patient participation in care

Far more patients desire greater involvement in their care decisions than experience it, and those who would prefer the health professional to make a decision for them nevertheless often desire more information about their care than they receive[334] [335] [336] [337]. Efforts to implement shared decision-making in practice have had very limited success[338].

> *"Far more patients desire greater involvement in their care decisions than experience it."*

Health professionals could be more attentive to their patients' preferences for decisional control, even during the course of a single illness or consultation[335] [336]. Patients who assist in choosing their treatment are more likely to follow it through than those who reluctantly follow their doctor's advice[339]. While tools such as decision aids may help to convey information to the patient more quickly and completely[340], a significant transformation in the way that health professionals conduct consultations may be required to satisfy patient demand for increased participation, as grafting shared decision-making practices onto the existing consultation model seems not to work well, and the ingrained habits of both patients and professionals are difficult to change[341].

d.   Evidence-based medicine

Evidence-based medicine (EBM) is a movement with significant potential to improve health outcomes, as it seeks to apply the best scientifically-derived evidence to patient care. At the

same time, personalisation of healthcare leads to a need to interpret EBM guidelines for and with the patient. "Evidence-based patient choice"[342] and the "informed patient"[343] represent potentially useful models which seek to capture the best aspects of both trends. It must remain open to doctors and patients to agree that the patient's health might respond better to a treatment that differs from that appropriate to the general population[344 345]. However, such developments may require longer consultations with patients.

e. Choice and equity

Currently, the NHS is characterised by an inequitable distribution of care, both in terms of geography[346] and demography[347 348]. While the affluent can opt out of what they consider to be inadequate public services, it remains questionable whether the introduction of patient choice to the NHS will exacerbate or improve entrenched inequalities. So far, most commentators have suggested that greater choice yields deeper inequality[349 350 351]. Consistently superior access among advantaged populations to pertinent healthcare information, and their exploitation of that information to inform their choice, may explain partially the negative relationship between choice and equity. This is in contrast to references in the literature detailing the hurdles faced by disadvantaged groups in attempting to exercise choice. This suggests that choice must be accompanied by special measures to engage disadvantaged groups[352].

f.   Integration of health and social care

Barriers between social and health care continue to confuse patients as well as staff[353]. A particular challenge to uniting health and social care is ensuring that the workforce is competent in interprofessional contexts and adaptive to ongoing change. The care services currently provided to patients involve little, if any, patient input – partly due to the limited services available, and partly because the patient's perspective goes unsolicited. Overall, this marks

> *"Barriers between social and health care continue to confuse patients as well as staff."*

the difference between a service driven by supply and a service driven by demand. Barriers to integration in provision, training and regulation which are embedded in professional, financial and administrative systems should be challenged, with the onus placed on answering why they should be kept, rather than why they should be changed.

g. Public participation

On the one hand, although public engagement and involvement in health and social care system decisions is a priority for the government, only slowly is it affecting structural and systemic change[354 355 356], being described by some commentators as limited and ineffectual, failing to extend beyond defined and delimited political objectives[357]. On the other hand, the

emergence of patient and staff representative boards for NHS Foundation Trusts is progressing[358]. This requires time to mature and wider understanding of the nature and governance needs of such social enterprises.

The need to involve the public and patients is felt by many European health systems, yet it seems that there are no clear examples of success in this field. In England, the structure of local public and patient forums, supported by a central Commission for Public and Patient Involvement in Health, was abolished three years after it was introduced in 2004. These were replaced by Local Involvement Networks with more representative democracy, in the form of public and patient representatives on NHS bodies, as well as Local Authority Overview and Scrutiny committees. NHS policies for involvement have focused on giving 'choice' and 'voice' to public and patient representatives.

h. Options for action

Encounters with health professionals remain at the heart of the public's perception of what constitutes illness prevention and treatment. Tools and technologies for diagnosis, advice and information for both patients and practitioners will continue to increase over the next generation, and inevitably this will change the nature of the patient–professional interaction. While the formal training that professionals receive teaches them to evaluate evidence and solve difficult problems, it teaches them less about how to access or present that information. Information-sharing is a skill which can be taught and form a criteria for recruitment, as can emotional care and sensitivity to a patient's preference for information and decisional control.

Continuity is in the eyes of the patient[359], and efforts should continue toward creating the experience of a seamless care service. This is associated with numerous desirable outcomes, and is particularly valued by the chronically, mentally and seriously ill, all of whom are expected to represent a significant portion of healthcare patients in the future[59][61]. It does not seem impossible that the chronically ill, whose regular consultations may be scheduled in advance, should experience any less of this type of continuity. Team continuity is a lesser replacement for interpersonal continuity, but may also complement it, as may informational continuity.

Proponents of a market approach to healthcare present the possibility of consumer choice in hospitals, physicians and services. Supporters of choice argue that the current situation allows only the advantaged the opportunity to make choices about provision, and that choice will improve quality for all system users. Another possible strength favouring choice is that it may lure the advantaged back to the NHS, provided that choice is used for the purpose of improved service quality[360]. In turn, greater choice may cultivate broader public support for the NHS, thereby averting a scenario where the NHS becomes a safety net for

the poor, provided that an increased emphasis on patient choice does not exacerbate existing inequalities within the public health system.

Safeguarding access within a choice agenda will require special provisions designed, for example, to increase health literacy and self-efficacy among disadvantaged groups. A complementary area of policy emphasis could be public service provision, which would narrow social inequalities through improved education, housing conditions and preventive health services. Others suggest that inequities could be diminished and outcomes improved more by focusing attention on expanding the patient's voice at the individual consultation level[361].

Patients' desire for involvement in their care can change even within the period of the consultation, and health professionals must learn to solicit and be sensitive to changing preferences if patient participation is to gain traction at the consultation level. The test of how much policymakers value patient participation (which is linked to higher satisfaction, adherence and self-efficacy) may be in how willing they are to fund it. While at first the critical question appears to be 'Who makes the decision about treatment?', evidence shows that patients seem to value the process more than they care about whether the decision was truly their own[338], and consultations could be redesigned to reflect this. Reviewing audio transcripts of their own consultations appears to be effective in changing physician behaviour[341].

In order to maximise our use of both EBM and patient involvement in decision-making, relevant evidence-based information needs to be put in the hands of the patient, so that they may consider it alongside their knowledge of themselves and their preferences. This is a difficult task to complete within a 10-minute consultation[362]. Sharing information and reaching consensus takes time, and may demand longer consultations. A series of short consultations may prove even more effective, allowing consultation with family members and other information sources such as decision aids[340] as well as time for questions or concerns to develop. Where shared decision-making has been tacked on to the existing consultation model it has largely failed[341], as the purpose of the original consultation was to transmit information from patient to doctor, not the other way around, as the new model would be designed to do. The relatively new field of conversation analysis may enable a focus on startling differences in outcomes such as patient feelings of efficacy and participation by merely substituting a few words or sentences[363].

Bureaucratic hurdles and conflicting goals continue to stunt efforts to make seamless the care provided between health and social care systems. While some interventions in interdisciplinary teamwork and education have yielded positive results[364], these lessons have had difficulty becoming more mainstream[164]. One particularly promising intervention

brought service users into classrooms to help teach students in the medical, social work, nursing, occupational and physical therapy fields what their teamwork would mean from the perspective of a patient[181].

Public engagement with issues of health policy has proven even more difficult to achieve than patient engagement on the consultation level, and it appears that policymakers may need to clarify the purpose of public engagement, and seek to understand ways to motivate the public to become more involved.

5. SCENARIOS FOR THE FUTURE

Three scenarios for the future of English health and care were generated from the previous analysis of trends and issues. The first scenario, the *engaged consumer*, refers to a health system that is shaped by, and responsive to, the needs of consumers. The second, *the engaged workforce*, describes a system that fully engages the workforce, including informal and self-carers. The third scenario, *the engaged citizen*, involves a system that minimises the causes of illness and maximises wellbeing through fully engaging citizens and communities. The scenarios are described in detail in the on-line background papers[d]. This section describes the levers for change (as they relate to policy, service providers, service users and education and training) which would be required to realise each scenario.

5.1 Scenario 1: The engaged consumer

a. Policy

- Health and care markets are opened to full competition.
- Poorly performing services and whole hospitals may be sold to private companies.
- NHS Foundation Trusts become independent, private not-for-profit organisations.
- A clearly defined and regularly reviewed package of services and standards delimits the scope of the market.
- Pension reform for health service employees facilitates entrepreneurial behaviour.
- Public health funding is ring-fenced.
- Formal carers are organised into social enterprises and networks in response to market demand for more integrated care.
- Informal carers and self-carers join interest groups who advocate on their behalf on issues such as compensation for their work.
- Patients act largely as individual consumers. A minority engage in representative groups.

- Sophisticated use of co-payments incentivises appropriate use of services, and assists those who cannot afford co-payments.
- Supplementary insurance to top up the public insurance package is tax-free.
- Good information is available on risk-rating of premiums and how to use this information.

b.   Service providers

- Formal carers are led by the market.
- Informal carers and patients are led by consumer information. Performance data is publicly available and easily accessible. Those who gather and package this information and rank care providers are very powerful.
- Both voluntary organisations and commercial providers offer financially sustainable care, self-care training and monitoring.
- Formal carers accept, and learn from, greater scrutiny from the public via regulators and others, who organise and package performance data for consumers.
- Informal carers gain visibility through being eligible for payment via individual commissioning of social care.

c.   Service users

- Patients influence the care market through their consumer choices.
- Voucher systems mean that patients either pay the difference to receive more extensive care, or pay higher insurance premiums for more complete coverage. In addition, vouchers can be used to pay informal carers.
- Patients are rewarded for healthy lifestyles and are penalised for unhealthy behaviour, as insurance premiums take account of these.
- Patients achieve better value care through their efforts to understand the options available to them on the market. They rely on consumer information to direct their choices, and can hire care advocates to help them customise their care.

d.   Education and training

- Professionals pay for their own training, while bursaries are available for those with limited means; the bursary to be repaid with specified post-training service.
- New roles which enable more efficient provision of care demand new approaches to training.

- Formal carers receive rewards for innovation and entrepreneurialism and are penalised for not adapting to changing preferences of the market. To succeed, they need to provide information about their services, continue learning and improve their innovative capacity.

- Informal carers are paid for their care work and training through a voucher system.

- Informal carers and self-carers receive training through such tools as the Internet and a market for training and support, with personal guidance for those who find accessing such channels a challenge.

5.2 Scenario 2: The fully-engaged health and care worker

a. Policy

- While public funds remain nationally redistributive, most policy and strategy is devolved to the local level.

- Publicly-available and regularly-updated information is available on levels of health and social care expenditure and its distribution among different sectors of care.

- More workplace flexibility is legislated for informal carers.

- Consultation on cost-effectiveness and clinical effectiveness criteria encourages public debate about what is wanted from the care system, and drives methodological improvements in these evaluation techniques.

- Ambitious partnerships with major stakeholder organisations are forged.

- Formal carers are members of smaller organisations and teams that are largely public sector-funded at the local authority level.

- Professional associations, trade unions and other representative bodies play a leading role in consultation.

- Local and national voluntary organisations provide leadership, representation and a platform for engagement for carers and self-carers.

b. Service providers

- Patients are assigned to an individual lead care coordinator (GPs as well as other members of the primary care team), who is the person charged with supervising patients' passage through health and social care.

- Performance-related pay for formal carers rewards teamwork, communication and shared decision-making.

- Formal carers participate with informal carers and volunteer patients in teams with a remit to service and care.

- Informal carers engage with formal carers through sustained team relationships.
- The development and expansion of formal care is facilitated through the introduction of the role of care 'navigators' and others.
- Formal carers are rewarded by meaningful work and support for innovations in work organisation and interventions directed to improving outcomes.
- Above-inflation pay awards are made where performance meets or exceeds targets.
- Informal carers experience the more intrinsic emotional rewards of their work, which is no longer obscured by the administrative hassle, and sense of isolation and powerlessness, associated with their role in the previous system. Their care role is explicitly recognised in interdisciplinary teams.
- Informal and self-carers are assigned to individual health professionals, not practices.

c.   Education

- Professional education is redesigned to enhance teamwork and communication skills within and between professionals and non-professionals, to foster empathy, leadership, improvement processes, evaluation and learning and to engage across teams and with those under their care.
- Workforce planning (recruitment, training and development) is subject to consultation with representatives of all stakeholders.
- Formal carers engage with one another as a result of their training, as well as more integrated, locally-managed systems.
- Informal and self-carers are trained by their health professionals, attend health classes and participate in distance learning.

5.3   Scenario 3: The engaged citizen

a. Policy

- Health strategy devolves, with health and social care outcome targets set locally.
- The state redirects health and social spending toward underlying factors that determine health and wellbeing.
- Resource allocation systems are redesigned to distribute a proportion of current health resources to other sectors.
- Joined-up policy formulation and planning between health, education, employment and environment agencies is facilitated by a progressive taxation system, including local income tax, which funds long-term care.
- Transparent clinical and cost-effectiveness criteria define core services.

- Good information on outcomes, including indicators of social cost-effectiveness and the effects of investment in preventive health, is widely available. Also, information can be used to track changes in health and wellbeing.
- Formal carers are members of smaller, largely public, organisations at the local authority level.
- Informal carers, self-carers and citizens are engaged in decision-making and mutual support through local participative democracy, voluntary organisations and support groups.
- The school curriculum is redesigned to: maximise employability and self-efficacy; teach health and nutrition, childcare and care of the elderly; and encourage exercise.

b. Service providers

- More integrated, locally-governed systems, as well as better training, helps formal carers to engage with one another and those under their care.
- Formal carers are motivated by the intrinsic emotional rewards of working between different sectors, and with patients who exhibit a high degree of self-efficacy and the ability to change behaviours affecting health.
- Performance-related pay is awarded at the team level, and is based partly on trends in health outcomes.
- Carers buy into locally-set targets.
- Informal carers engage in emotionally rewarding work, which is no longer obscured by administrative hassle and a sense of isolation and powerlessness.
- Informal and self-carers participate in annual wellbeing reviews with formal carers, improving self-efficacy and health literacy.
- Informal carers learn how to care for children and the elderly in primary education and through specific training.
- Community workers, who do not fit traditional models of health or social care workers, help individuals to address lifestyle factors in their lives which are related to health outcomes, such as joblessness and poor housing.

c. Service users

- Free provision of healthcare is limited to a package of services, with means and needs-tested supplementary insurance.
- Self-carers are rewarded for their efforts by better health outcomes.
- Patients receive health, nutrition and exercise training in school.
- Public education is provided in health, wellbeing and social responsibility.

d. Education

- Health professional training is redesigned as solution-based, to build leadership skills which support behaviour change and promote work within and across teams.

- Health and social care professionals are familiarised with the processes of community development.

- Formal carers are trained to engage well across teams and with those in their care.

- Work programmes in the community are designed to develop caring and governance skills, particularly in disadvantaged areas.

6. CONCLUSIONS: FUTURE VISION AND CHALLENGES

Each of the scenarios provides a different lens to view the challenge of seeking engagement from key players in the system: formally-trained employed carers, informal carers and citizens. In reviewing the scenarios and the policy directions from which they could grow, it became clear that a unifying vision could be constituted of the features required to achieve the positive aspects of each dimension of engagement, while avoiding their potential negative impacts. We created one such vision as an interpretation of a fully-engaged society. It is offered as a starting point for discussion about where health and care policies may lead, and their implications for the workforce, as we focus on how to meet our health and care needs over the next 15 years and beyond. This vision is not intended to take any particular political perspective, although clearly many of the policy options are political in nature.

6.1   A unifying vision: the fully-engaged society

By 2022, engaging the public as consumers leads to health and care services that are *more responsive to the needs of the public and patients.* This does not require that everyone has to make active choices, as the engagement of a significant minority is sufficient to create the dynamic for improvement. *Carefully regulated opening of health and care provision to competition from public, social and privately-owned enterprises* facilitates this shift and stimulates innovation and improvement.

One area of continuing political debate is the *definition of the health and care services and standards* covered by what is seen as a national basic health and care social insurance system, funded by taxation and user charges designed to motivate responsible health behaviour. There has been no major withdrawal of services, but the extension of home care, the continual development of new treatments and rising expectations of standards place great strain on health financing. Independent regulators engage in marketing for social goals and consult with

commissioners, the public and the care workforce to engage them in decisions about health and care standards.

Defining the basic insurance package and its impact on the health and care insurance rate, which is separately identified in national accounts, is still seen as a political issue. Patients may choose higher standards of treatment and care, paid for out of top-up insurance schemes or out-of-pocket expenditure. It is an important point of principle that such additional services are considered unnecessary to basic health and care; however, where this point lies can never be a purely technical decision. Equally, while there is broad consensus on the benefits of a mixed economy of health providers, political decisions must be made regarding the extent of support for private sector care: for example, in the form of tax exemptions for top-up insurance. Governments have distanced themselves from operational health and care management but remain fundamentally responsible for basic policy.

The *challenge for the commissioners* of health and social care is to respond to articulated consumer preferences while safeguarding the rights of the disengaged consumer by maintaining a focus on basic rights, equity and access for disadvantaged groups. The initial introduction of choice of provider had little impact. It was seen simply as a choice between similar hospitals differing only in waiting times, and available only to those who could choose to travel. Services became truly responsive to the public only when the culture of health and care services evolved to reflect the most important preferences of consumers, expressed through a variety of mechanisms of local representation, voice and choice. Once this occurred, services could be commissioned to meet community and individual preferences. Even more important was engaging individual patients in detailed choices during the planning and provision of personal health and care plans and the 'co-creation' of care programmes and individual care options. This, in turn, depended on the evolution of professional culture and values in health and care.

The *professional values of the health and care workforce of 2022* still place great emphasis on responsibility to patients, but now recognise the need to engage and listen to patients and share responsibility for health and care decisions. Teamwork and organisation in meeting complex needs is now highly valued, with a greater emphasis on the long-term wellbeing of the patient. The self-image of the health professional as someone who intervenes to save the patient in acute care has been replaced largely by an image of a guide for people with long-term chronic care needs. Other values have shifted in response to changing technology. For example, the ability to access and communicate knowledge is now more important than memorising medical facts. These changes have required a substantial re-examination of the training and continuing education of health and care workers.

At first, *engaging health and care workers in national reforms* threatened to slow the process of reform. For example, professional organisations naturally represented traditional professional

views. Greater impetus was achieved by local engagement within public, social and private provider enterprises. Once health and care workers were engaged at this level, they began to develop a stronger sense of allegiance to the aims and values of local service providers and a greater sense of interdisciplinary teamwork. This helped local teams to rethink the way that they work together to provide health and care services which meet patient expectations at a reasonable cost. New team roles which emerge in 2022 are less likely than before to be seen as a challenge to any given existing professional identity. Instead, these roles are viewed as part of a continuum of the health and care process, supported by a culture of ongoing learning from experience and relationship-building between participants.

Health and care workers in 2022 will contribute to the *funding of their own professional training* as preparation for a career in which they must continue to learn and develop not only in technical competence, but also as managers and leaders of services for patients. This contrasts with previous generations' expectations of training for a 'job for life'. Also, changes to the contractual and pension arrangements of health and care workers are required to support their new forms of employment. Staff participation in organisational ownership becomes commonplace, with clear roles at the board level and/or in working teams that are recognised and rewarded for the performance they achieve for the patients they serve.

This does not mean that the independence of spirit or the sense of personal responsibility of health and care workers has been lost. They will still help patients and the public to oppose changes that they feel are not in their best interest. This is part of local citizen engagement with commissioners and providers of health and care services.

Local governance arrangements support and represent communities defined in many different ways (e.g. locality, patient, faith, ethnicity) to provide supervision of the executive agencies that commission and provide health and social care, as well as other services such as health promotion and protection, social housing, consumer and environmental protection, education, policing, parks and transport.

A wide range of *community partnerships for health and wellbeing* evolve to include local provider agencies, local businesses and community self-help groups. Local engagement also helps to establish a sense of personal and family responsibility for health and care. This is reinforced by *health and wellbeing assessments* for individuals and communities, as well as co-payment systems that motivate personal engagement with self-care and positive health and wellbeing programmes. *Community service* is recognised by community service awards and the provision of basic income support as well as training and relief support for family care workers.

These developments, taken together, have resulted in a social movement for health and wellbeing in a fully-engaged society.

6.2   Challenges and conclusions for action

The unifying vision above shows one possible way to address the issues raised as we built scenarios for the future. It would require changes to people and systems, and demand explicit and coherent purpose effectively to guide policy choices. Specifically, these will require action on the part of all key players: policymakers, health and care leaders, educators, health and care workers and the public. The conclusions for action for each group are presented below.

a.   Policymakers

It would be naive to suggest that health and social care policy should not be the subject of political debate. However, the major political parties and other policy bodies can agree to a great extent on the challenges facing health and care in England. It would be helpful to those who will spend their working lives in this field for political parties explicitly to agree on this common ground. Beyond this, where there are differences in their basic vision for health and care, these should be clearly articulated.

- *Policymakers need a forum to develop a shared vision for health and care, which is sufficiently inclusive to encourage broad support, even after the articulation of differences in strategy and opinion.*

It is not helpful for short-term operational management of the NHS to be the central focus of health policy, for "the sound of a bedpan dropped in Tredegar Hospital to reverberate around Westminster", as Aneurin Bevan once boasted.

- *The central focus of health policy needs to move away from short-term operational management, perhaps through a separation between policy and operations via an independent NHS board.*

Political focus on the structure and management of the NHS diverts attention from those areas where political leadership could contribute most in addressing the determinants of health and wellbeing. The rising threats of obesity, alcoholism and mental illness, increasing inequity and the decline in social capital, all demand political action and have been addressed too little and too late by all parties.

- *Greater political focus is required on the determinants of health, the regulation of health and care standards and the limits of entitlement.*

> *"Greater political focus is required on the determinants of health, the regulation of health and care standards and the limits of entitlement."*

At the same time, it is important to allow political space in which local debate on health, care and wellbeing strategy can take place without becoming a challenge to national policy. Local governance for health and wellbeing should

encourage and support local engagement and debate to produce integrated local solutions for health and care.

- *Local governance and the regulatory framework should provide political space for local engagement to produce integrated local solutions, with sufficient devolution to ensure local ownership.*

b. Health and care leaders

The importance of leadership for the NHS during times of great change cannot be over-emphasised. The NHS Institute for Innovation and Improvement is properly charged to develop leadership as sets of skills and qualities, but leadership is also founded in the experience of relationships built on trust, management competence and a common vision of the future. Trust takes time to develop, and in the early stages it can be undermined easily by management failures. Reacting responsibly to failures of financial control or training schemes is crucial, as is learning how to apologise when necessary and taking steps to improve the situation.

- *Good leadership, built on trust, management competence and a common vision of the future, is vital during times of change.*

Any process for leading change requires listening to people and engaging them in a vision of what change will mean for each locality, group and individual involved. Such a vision may be seen as an expression of common values and aspirations, and how these can be achieved. Health and care leaders must develop a coherent vision of the future based on national and local consultation, which encourages involvement and buy-in rather than resistance. In addition, it would be helpful for all leaders in the system to hone their skills in managing change.

- *Health and care leaders must develop and share a coherent vision of the future, along with a plan for how aspirations can be achieved, based on national and local consultation, which encourages involvement and buy-in, rather than resistance.*
- *Managing change requires that leaders listen to people and help them think through the meaning and need for change for each locality, group and individual involved.*
- *It essential to build leadership at every level in health and care services and in the communities. Leaders should develop other leaders to inspire, execute and evaluate as change is created.*

c. Educators

Educators of health and care workers have a strong interest in the future of the workforce, since the people they are training now may be working in health and care during the next 40 years.

- *Educators of health and care workers must be closely engaged in the development of a vision of future skill requirements in the health and care fields.*

- *Skill requirements need to change to create greater flexibility within and between skill groups and careers.*

Changing the skill requirements identified in the course of this review for all health workers stressed the need for a greater emphasis on:

- *Organisational and workplace skills*, including:
    - better understanding of change management
    - effectiveness in multidisciplinary and multi-sectoral teams, and
    - the development of different forms of organisation, including forms that partner with social enterprise and private sectors.

- *Communication skills*, including:
    - listening
    - learning and training
    - giving advice
    - social marketing (listening to and communicating messages about social goals)
    - cross-culture work, and
    - customer services.

- *Knowledge management skills*, including:
    - retrieving and using information and communication systems
    - developing and sharing lessons from experience, and
    - recording observations and experience.

- *Skills* in navigating complex systems: whether of a patient's body or social context, including understanding family and community structures and cultural diversity.

These skills need to be developed within mainstream education and training structures, recognising that there are many different levels and contexts. The aim will not be to develop generic health and care workers, but to create greater flexibility within and between skill groups and careers.

d. Health and care workers

Professional and other organisations representing health and care workers should be encouraged to re-examine the values that drive health and care in the context of future demands. It is important to stress that such re-examination of values does not imply a rejection of past values, but reframing them to match the emerging challenges of the future, doing so in meaningful local contexts as well as at the national level.

- *Health and care workers must be engaged in redesigning services, not only through professional and representative organisations, but as members of local public, social and private sector enterprises.*

- *Professionals should be encouraged to re-examine the values that drive health and care in the context of future demands.*

It is increasingly important to promote self-care and informal carers as an essential part of the future workforce.

- *A range of policies are required to support training, give respite relief, link informal and formal care and provide appropriate recognition and financial relief to informal carers.*

e. The citizen

General public perceptions of health and care services are slow to change. People are not much impressed by reform promises or particular issues about the ownership or methods of managing services; they simply want good-quality local services to meet their needs. While only a small minority become involved in local health and care service issues, a great many people find themselves acting as carers and, of course, virtually everyone is a patient at some stage.

- *There is an urgent need to enlist patients, families and the public in thinking through their personal health, care and wellbeing plans.*

- *A key to engagement with the public on local health, care and wellbeing could lie in linking personal plans to co-design of services.*

While there are information and communication mechanisms that can help with this, such as HealthSpace and NHS Choices, this needs to be supported by communications and marketing (social marketing) aimed at encouraging greater uptake and support mechanisms for those people who are less likely to become engaged and at the same time, because of their social context, more likely to have complex health and care issues.

- *Patient empowerment needs to be supported by social marketing aimed at encouraging greater uptake and support mechanisms for those people who are less likely to use these connection channels, and more likely to have complex health and care issues.*

Patients and the public must be engaged in health, care and wellbeing policy and delivery through active community support programmes. The scenario exercise suggested that this is likely to be the most difficult yet potentially most rewarding area of future policy. It requires reassessment of local governance to engage citizens in all services which affect health including: commerce, housing, transport, education, environment, policing, planning and health and care.

- *Local governance should be reassessed to engage citizens in all services that affect health, including:*
  - *consumer*
  - *housing*
  - *transport*
  - *education*
  - *environment*
  - *policing*
  - *planning*
  - *health and care.*

6.3   Final thoughts

This report has deliberately ranged over a wide canvas, as befits the complex nature of the subject of engaging with care and creating a vision for the health and care workforce of England. Our penultimate word is to highlight just four messages which we see as vital to creating the future.

- *Individuals, families and communities – particularly those who are disadvantaged – need to feel empowered and supported to take control of their health, wellbeing and care.*

- *Political central control must be disengaged from local solutions and local governance.*

- *Key parts of system change must be supported, with the involvement of the workforce and changes in education and training.*

- *A basic insurance package must be defined for the 21st century.*

> *"Leadership is required to re-engage with the public, care workforce and citizens in co-creating health and care services for the future."*

But what, then, is the final word? It is to return to the need for leadership and vision. Whatever the chosen approach to managing change, it is vital to engage those affected in understanding the need for change and where it will lead. Leadership is required to re-engage with the public, care workforce and citizens in co-creating health and care services for the future. While engagement at all levels may slow reforms, it is the only way to achieve lasting change. This does not mean that reform must move at the pace of the slowest; it demands bold vision and leadership, beyond the time-limits or political constraints of governments. Such visionary leadership must provide the motivation for the reformulation of professional values and public re-imagining of health, care and wellbeing in the 21st century.

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GLOSSARY

Term	Definition	Source
Assistive technologies	Technologies that are used to assist people with disabilities, impairments or additional support needs to maximise their independence and potential.	http://www.slads.freeuk.com/slads/Technology/Assistiv.html
Care	Attentive treatment: the provision of whatever is needed for the wellbeing of somebody who is dependent, or physically or mentally challenged. The provision of what is necessary for the welfare and protection of someone or something.	http://www.askoxford.com/concise_oed/care?view=uk
Care home	Residential home providing 24-hour general care but with no registration to provide nursing care.	http://www.nursing-home-directory.co.uk/glossary.htm
Community care	A network of services provided by the NHS, Social Services and volunteers designed to keep people independent, and to support elderly people or people with mental health problems or learning disabilities who might previously have been in hospital.	http://www.cambsmh.nhs.uk/default.asp?id=430
Co-morbidity	The simultaneous presence of two or more disorders.	http://www.cambsmh.nhs.uk/default.asp?id=430
Evidence-based medicine (EBM)	The integration of best research evidence with clinical expertise and patient values.	http://www.openclinical.org/ebm.html
Formal care	Health or social care provided by medical, nursing, allied health professions and social care workers who are paid and professionally trained to accredited standards.	

Term	Definition	Source
Healthcare	The prevention, treatment and management of illness and the preservation of mental and physical wellbeing through the services offered by the medical, nursing and allied health professions.	http://en.wikipedia.org/wiki/Healthcare
Informal care	Care provided to someone in their own home and which is not paid for. Informal carers are also called carers or family carers.	http://www.norfolkcarers.org.uk/glossary/glossaryc.htm
Long-term care	A variety of services which help to meet both the medical and non-medical needs of people with a chronic illness or disability who cannot care for themselves for long periods of time. Can be social or health care, provided at home, community-setting or hospital. Mostly provided to senior citizens. Chronic care is long-term care.	http://www.cpa.org.uk/sap/glossary/glossary.html#L
Residential care	Care for older people in an institutional setting, that is, either in a residential or a nursing home.	http://www.archive.official-documents.co.uk/document/cm41/4192/4192-gls.htm
Respite care	Respite care is temporary relief. It can be provided for an older person or for an older person's carer.	http://www.nursing-home-directory.co.uk/glossary.htm
Self-care	Personal choice in decisions about health; any activity undertaken with the intention of improving health, preventing disease, managing conditions, and restoring health. Often used to refer to self-management of disease.	
Social care	Care received at home, day centres or in residential and nursing homes provided by employees of Social Services and other non-health agencies. It also includes services such as Meals on Wheels, home help for people with disabilities, and children's services such as fostering.	http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/SocialCare/AboutSocialCare/fs/ http://www.openclinical.org/ebm.html en
Workforce	Formal (paid) health and social care workforce, informal carers, self-carers.	

APPENDIX

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ENGAGING WITH CARE

A VISION FOR THE HEALTH AND CARE WORKFORCE OF ENGLAND

Health and care needs in England will change dramatically over the next 15 years, but the people we recruit and train and the facilities we build now will still be part of the landscape in 2022. This report, part of the Nuffield Trust's *Health Policy Futures* series, explores the development of three possible scenarios of the English health and care system in 2022. Each scenario is associated with a different type of engagement with health and care and is shaped by different sets of policies. The authors highlight conclusions for action for policymakers, health and care leaders, educators, workers and members of the public. Delivering these changes, the authors argue, demands that health and social care leaders re-engage with the public and workforce to 'co-create' health and care services fit for the future.

Written by expert health policy analysts from the Judge Business School at Cambridge University, *Engaging With Care* is an important contribution to the debate about how best to model future services. Although the research focuses on England, the report is likely to have wider relevance. It will be of interest to policymakers, health and care leaders, and all those involved in health and care policy study and research.

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