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Delivering better services for people with long-term conditions

Building the house of care



Key messages

- The management of care for people with long-term conditions should be proactive, holistic, preventive and patient-centred. This report describes a co-ordinated service delivery model – the ‘house of care’ – that incorporates learning from a number of sites in England that have been working to achieve these goals.
- The house of care model differs from others in two important ways: it encompasses all people with long-term conditions, not just those with a single disease or in high-risk groups; and it assumes an active role for patients, with collaborative personalised care planning at its heart. Implementing the model requires health care professionals to abandon traditional ways of thinking and behaving, where they see themselves as the primary decision-makers, and instead shifting to a partnership model in which patients play an active part in determining their own care and support needs.
- In personalised care planning, clinicians and patients work together using a collaborative process of shared decision-making to agree goals, identify support needs, develop and implement action plans, and monitor progress. This is a continuous process, not a one-off event.
- An important feature of the approach is the link between care planning for individuals and commissioning for local populations; it aims to make best use of local authority services (including social care and public health) and community resources, alongside more traditional health services.
- The house of care metaphor is used to illustrate the whole-system approach, emphasising the interdependency of each part and the various components that need to be in place to hold it together. Care planning is at the centre of the house; the left wall represents the engaged and informed patient, the right wall represents the health care professional committed to partnership working, the roof represents organisational systems and processes, and the base represents the local commissioning plan.

- Each of these components has been introduced in one or more primary care sites around England. While few sites have yet succeeded in putting all the components together in one place, all agree on the need to do so to ensure a well-functioning, sustainable system.
- Building the house involves a wide variety of organisations, professional groups and individuals working together in a co-ordinated manner, pooling budgets, sharing data and learning how to get better at delivering holistic, co-ordinated, person-centred care. The report makes a number of **recommendations** on how NHS England, clinical commissioning groups (CCGs), Health Education England, the Department of Health and provider groups can work together to support the transformational change that is needed to improve care for people with long-term conditions.

Background

The need to improve the treatment and management of long-term conditions is the most important challenge facing the NHS. Improving care for people with long-term conditions must involve a shift away from a reactive, disease-focused, fragmented model of care towards one that is more proactive, holistic and preventive, in which people with long-term conditions are encouraged to play a central role in managing their own care.

It is now widely recognised that the care and support needed to live with a long-term condition requires a radical re-design of services, allowing patients to drive the care planning process. Yet despite extensive lobbying from patient groups and numerous policy documents calling for such change, progress on the ground has been slow, with little improvement over the past 10 years. Many of the elements needed to support change have been developed, drawing on international best practice, but they remain isolated and fragmented. Top-down exhortation and targets have failed to influence change and clinical behaviour at the grassroots.

The missing component – a practical, robust, reproducible and transferable delivery system developed by practitioners and service users in England – is now available. Based on the house of care developed and tested by the Year of Care programme (Diabetes UK *et al* 2011), this model differs from other approaches in that it takes, as its starting point, the active involvement of patients in developing their own care plans through a shared decision-making process with clinicians. It is rooted in primary care but addresses the whole system of care, including community resources. It also provides commissioning groups with a roadmap for developing a responsive, whole-person delivery system.

More than 3,000 practitioners and 60 trainers working in 26 communities around England are now involved in **the house of care**. Meanwhile, other programmes such as **QIPP Right Care**, **Co-creating Health**, **MAGIC** (Making Good Decisions in Collaboration), **Personal Health Budgets** and **People Powered Health** have developed complementary strategies designed to ensure that every person with a long-term condition has an opportunity to participate in a collaborative care planning process with effective self-management support.

Earlier in 2013, representatives of these groups and others came together at a workshop organised by The King's Fund to discuss their experiences, share learning and identify ways in which this practical knowledge could be applied across the country (*see Appendix*). In preparation for the workshop, we interviewed several participants to gain a deeper understanding of how they were tackling the shift to a more collaborative model.

This report outlines the key points of their collective learning. We describe the building blocks that make up the house of care and the strategies developed by local teams to

ensure that each of the components is feasible in English primary care settings. We also outline some of the difficulties that must be overcome to produce a fully working model. The house of care has now been adopted as a central metaphor in NHS England's plans for improving care for people with long-term conditions (McShane and Mitchell 2013). It is therefore crucial that commissioners and providers understand the implications of this whole-system change and are clear about what needs to be in place to ensure the successful implementation of the house of care model.

We hope this report will provide a good starting point for CCGs and others wanting to promote more productive partnerships between patients and clinicians. We believe this approach can deliver more effective self-management, better co-ordinated care and improved health outcomes for people living with long-term conditions.

Policy context

Chronic diseases are now the most common cause of death and disability in England. More than 15 million people have a long-term condition such as hypertension, depression, asthma, diabetes, coronary heart disease, chronic kidney disease, or other health problem or disability for which there is no cure. These people tend to be heavy users of health care resources, accounting for at least 50 per cent of all general practitioner (GP) appointments, 64 per cent of outpatient appointments and 70 per cent of all inpatient bed days (Department of Health 2012a). Special analysis of 'Social Care at the End of Life' project data indicates that an estimated 18 per cent of people with long-term conditions are in receipt of state-funded social care (T Georghiou, personal communication 2013), and a small proportion of those with the most disabling or complex conditions (less than 1 per cent of the total) receive NHS Continuing Care support and are currently eligible for personal health budgets (Department of Health 2013).

The prevalence of long-term conditions rises with age, affecting about 50 per cent of people aged 50, and 80 per cent of those aged 65. Many older people have more than one chronic condition, but in absolute terms there are more people with long-term conditions under the age of 65 than in older age groups.

Recent analysis of patient data from Scotland found that 42 per cent of the population had at least one long-term condition and 23 per cent had two or more (Barnett *et al* 2012). Most people aged over 65 had multi-morbidities, but the onset of multi-morbidity occurred 10–15 years earlier among those living in deprived areas; people in these areas were also more likely to experience mental health problems alongside physical illness or disability than people in more affluent areas.

The total number of people with a long-term condition in England is projected to be relatively stable over the next 10 years, but the number of people with multiple conditions is projected to rise to 2.9 million in 2018, from 1.9 million in 2008 (Department of Health 2012a).

A growing body of evidence underscores the importance of effective self-management of long-term conditions (Epping-Jordan *et al* 2004). People who are more 'activated' (that is, who recognise that they have an important role in self-managing their condition and have the skills and confidence to do so) experience better health outcomes (Greene and Hibbard 2012). With effective support and education, evidence shows that these skills can be developed and strengthened, even among those who are initially less confident, less motivated or have low levels of health literacy (Hibbard and Greene 2013).

The **Chronic Care Model**, which has influenced health policy around the world, stresses the need to transform health care for people with long-term conditions from a system that

is largely reactive – responding mainly when a person is sick – to one that is much more proactive, and focuses on supporting patients to self-manage (Wagner 1998). This assumes an active role for patients, who are encouraged to become both more knowledgeable about factors affecting their condition and more actively involved in decisions about their care. It is also based on a conviction that local communities have multiple resources that can be mobilised to help people live healthier and more fulfilled lives.

People with long-term conditions are managing their health on a daily basis, but they may need additional help to develop their confidence in fulfilling their role as a self-manager. This may include support to enhance their ability to manage their tests or medicines, to make changes to their lifestyle or to cope with the emotional and social consequences of living with a long-term condition (Corbin and Strauss 1988). Primary care teams that are willing and able to signpost their patients to appropriate support, including community resources, can do much to improve the quality of people's lives (Diabetes UK 2011).

The call for a more person-centred, better co-ordinated approach to managing care for people with long-term conditions has been embraced by numerous advisory bodies, advocacy groups, governments and international agencies. For instance, National Voices – a coalition of more than 140 UK health and social care charities – developed a first-person narrative to explain what the gold standard of care looks like. This requires making the patient perspective (or that of the service user) the organising principle of integrated care, and can be summarised as follows: 'I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me' (National Voices 2013).

A report by the Richmond Group of Charities and The King's Fund (2012) outlined the service components needed to achieve this:

- patients engaged in decisions about their care
- supported self-management
- co-ordinated care
- prevention, early diagnosis and intervention
- emotional, psychological and practical support.

These demands have not fallen on deaf ears in Whitehall. The government's [Mandate](#) for NHS England requires it to 'ensure the NHS becomes dramatically better at involving patients and their carers, and empowering them to manage and make decisions about their own care and treatment' (Department of Health 2012b). This includes the aspiration that everyone with a long-term condition, including those with mental health problems, should be offered a personalised care plan that reflects their preferences and agreed decisions.

Building the house of care

While there is now a consensus on the need to transform the model of care for people with long-term conditions, up until now there has been less clarity about the specific changes required. Many integrated care pilot schemes have been launched, most of which share the same goal – a new service delivery system that leads to better outcomes for specific groups of patients (Nuffield Trust and The King's Fund 2013; Roland *et al* 2012; Newbould *et al* 2012; Burt *et al* 2012; Bardsley *et al* 2013; Nuffield Trust and Imperial College London 2013). But few of these have succeeded in transforming the relationship between patients and clinicians. The management and care of long-term conditions still tends to be seen as the clinician's responsibility rather than a collaborative endeavour with active patient involvement and effective self-management support.

The house of care metaphor was devised to help those working in primary care adapt the chronic care model to their own situation. It explicitly places the patient at the heart of the delivery system. Its key elements are as follows.

- People with long-term conditions are central to the process. They are supported by health and social care professionals to express their own needs and decide on their own priorities through a process of information-sharing, shared decision-making and action planning.
- Self-management support and the development of collaborative relationships between patients and professionals are at the heart of service delivery. This shifts the focus onto the roles and responsibilities of patients as well as professionals, and the systems that are needed to support them to fulfil these roles. The ultimate aim is that people should have the knowledge, skills and confidence to manage their condition effectively in the context of their everyday life.
- Tackling health inequalities is a central aim of the house of care. The number of long-term conditions and their burden falls disproportionately on people with poor health literacy and those in lower socio-economic groups. Tools, skills training and ongoing support must be available to identify those who find it harder to engage with health issues and may need extra support to do so.
- The house of care delivery system aims to ensure that each individual is involved in a unified, holistic care planning process with a single care plan. A common set of relevant skills and processes reduces the burden of training.
- Quality assurance of the philosophy, core approach and skills required is essential to ensure that implementation builds on relevant evidence and experiential knowledge, which is consistently applied.
- Care planning is the gateway to personalisation and/or personal health budgets.

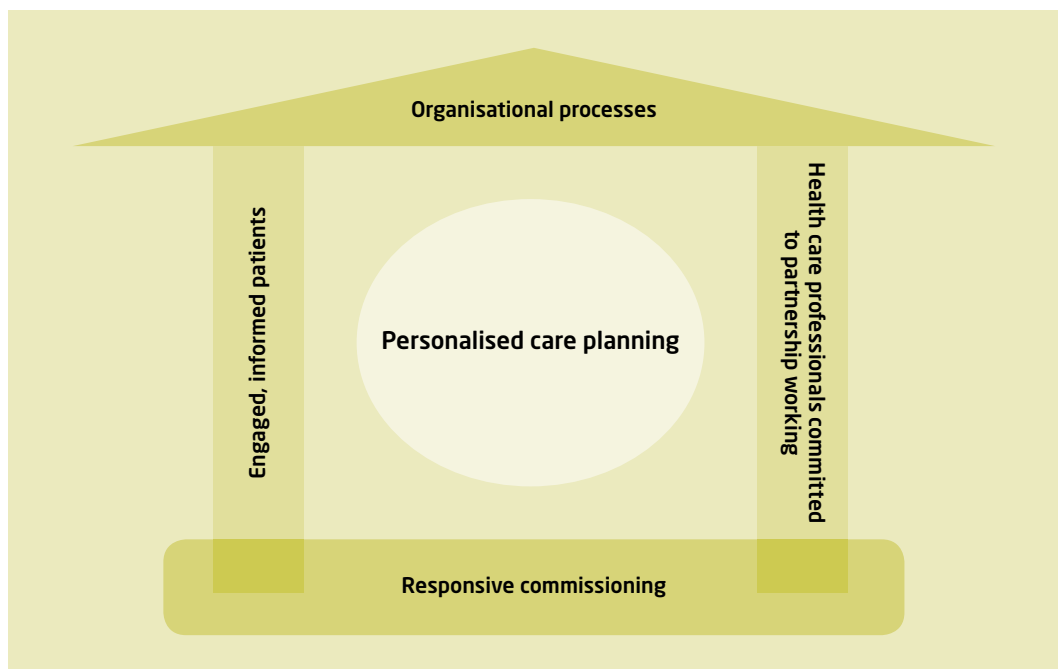
In 2007, Diabetes UK and the Department of Health launched an ambitious pilot project to explore ways of introducing and embedding this new type of delivery system into routine care for people with long-term conditions, using diabetes as an exemplar (Diabetes UK *et al* 2011). The starting point was to get primary care staff to model new types of collaborative conversations, encouraging patients to articulate their needs, decide on priorities, agree goals, and jointly develop a plan for achieving these. The ultimate aim was to develop a robust, systematic and reproducible approach, transferable to any setting and for people with any long-term condition or more than one condition, while also ensuring that each person received a uniquely personalised service.

Evaluation of the pilot phase of the Year of Care programme revealed improvements in patients' experience of care and in self-care behaviour (Diabetes UK *et al* 2011). Professionals gained new knowledge and skills, leading to greater job satisfaction. Practice organisation, teamwork and productivity improved, and progress could be seen across relevant clinical indicators after two or three care planning cycles.

It quickly became apparent that embedding this new approach more widely would require fundamental changes to the organisation, delivery and commissioning of primary care. The metaphor of a house was used to describe the issues that each primary care team needed to address to make care planning possible (Figure 1).

The house of care reinforces the whole-system approach needed and acts as both a metaphor and an implementation checklist. As a metaphor, it emphasises the interdependence of each of the components, enabling the new style of clinical consultation. If one 'wall' is weak, the structure is not fit for purpose. As a checklist, it provides a reproducible mechanism to identify the essential processes and systems that

Figure 1 The house of care



promote awareness, engagement and clarity across clinical teams, stimulating reflection on the building blocks available locally and areas that may need prioritisation for improvement.

Personalised care planning is at the centre of the house. This is a collaborative process designed to bring together the perspectives and expertise of both the individual and the professional(s) involved in providing care, offering tailored personal support to develop the confidence and competence needed for effective self-management.

The two side walls of the house – engaged, informed patients and health care professionals committed to partnership working – are equally important. Patients may need extra encouragement to participate in a more active way than they are used to, so consideration needs to be given to preparing them for this new role. Staff need to understand this new way of working, value the contribution that each person can bring to their care and develop the skills to support self-management. Partnership working also extends to colleagues, as care for people with long-term conditions will increasingly be provided by multidisciplinary teams, both within general practice but also linking with wider community, social care and specialist staff.

The roof of the house represents the robust organisational systems that are essential to ensure efficient processes, including reliable systems for identifying and contacting patients with long-term conditions, flexible appointment systems that support linked contacts and allow for longer consultations when necessary, and record systems that can be used to document and share care plans, and for monitoring outcomes.

All this requires the firm foundation of a responsive local commissioning system. Care planning itself – and the systems and training needed to support it – must be explicitly commissioned; the menu of community groups and services must be developed, and a robust measurement system must be in place.

The house of care model provides a structure for transferring learning from site to site in a reproducible way, with each of its elements developed locally, based on local needs. The process of transfer is equally important, ensuring that cultural as well as

administrative components are reliably addressed. The critical success factors developed during repeated cycles of delivery and feedback provide the core of a quality-assured training and support programme.

We now describe each of the five components of the house in more detail, with examples of how they are being delivered in primary care settings, drawing on discussions with workshop participants and interviewees. We also explore some of the challenges likely to be faced when implementing this new delivery system, and our strategies for overcoming any barriers.

The centre of the house – personalised care planning

From the perspective of a person living with a long-term condition, the contacts they have with health and social care services make up only a very small proportion of their daily life. The larger part is spent managing their condition(s), drawing on their own resources and those available in the wider community – many of which can have a significant positive effect on outcomes (Horne *et al* 2013).

The few hours per year these individuals currently spend with health care professionals are often inadequately used to inform and support them or connect them with others who could provide support, representing both poor use of resource and a missed opportunity. Personalised care planning directly addresses this problem.

Collaborative personalised care planning aims to ensure that individuals' values and concerns shape the way in which they are supported to live with and self-manage their long-term condition(s). Instead of focusing on a standard set of disease management processes, this approach encourages people with long-term conditions to work with clinicians to determine their specific needs and express informed preferences for treatment, lifestyle change and self-management support. Then, using a decision coaching process, they agree goals and action plans for implementing them, as well as a timetable for reviewing progress. It is a continuous or cyclical process or pathway involving several steps (Figure 2).

Where care planning takes place, how frequently, with whom, and how each step is designed will vary according to local resources and individuals' needs. The important point is that care planning, implementation and review is a continuous process over a period of months or years, not a single one-off event.

It is acknowledged that having better conversations between clinicians and patients is not something that can be achieved without additional effort. Clinicians already have a structure for consultations 'hardwired' into their daily practice. Old habits die hard, so it is important to be clear about what exactly needs to change to implement this new way of working.

The biggest change for clinicians involves recognising that the information about the lived experience and personal assets that the patient brings to the care planning process is as important as the clinical information in the medical record; processes also need to be in place to help the clinician identify and include the patient's contribution. Once this is recognised, the subsequent stages happen more naturally – moving through a systematic process of sharing information, discussing options, setting goals and developing an action plan (Figure 3). But adopting this new approach requires clinicians to fundamentally reconsider their professional role – from working in a reactive system that treats people with long-term conditions when they become ill to working in a proactive system that supports those people to stay well. This means that clinicians need to work with patients in a different way, demanding new skills and knowledge and new ways of thinking, and involve themselves in new ways of working to ensure that the 'person's story' is effectively included.

Figure 2 Care planning – a cyclical process

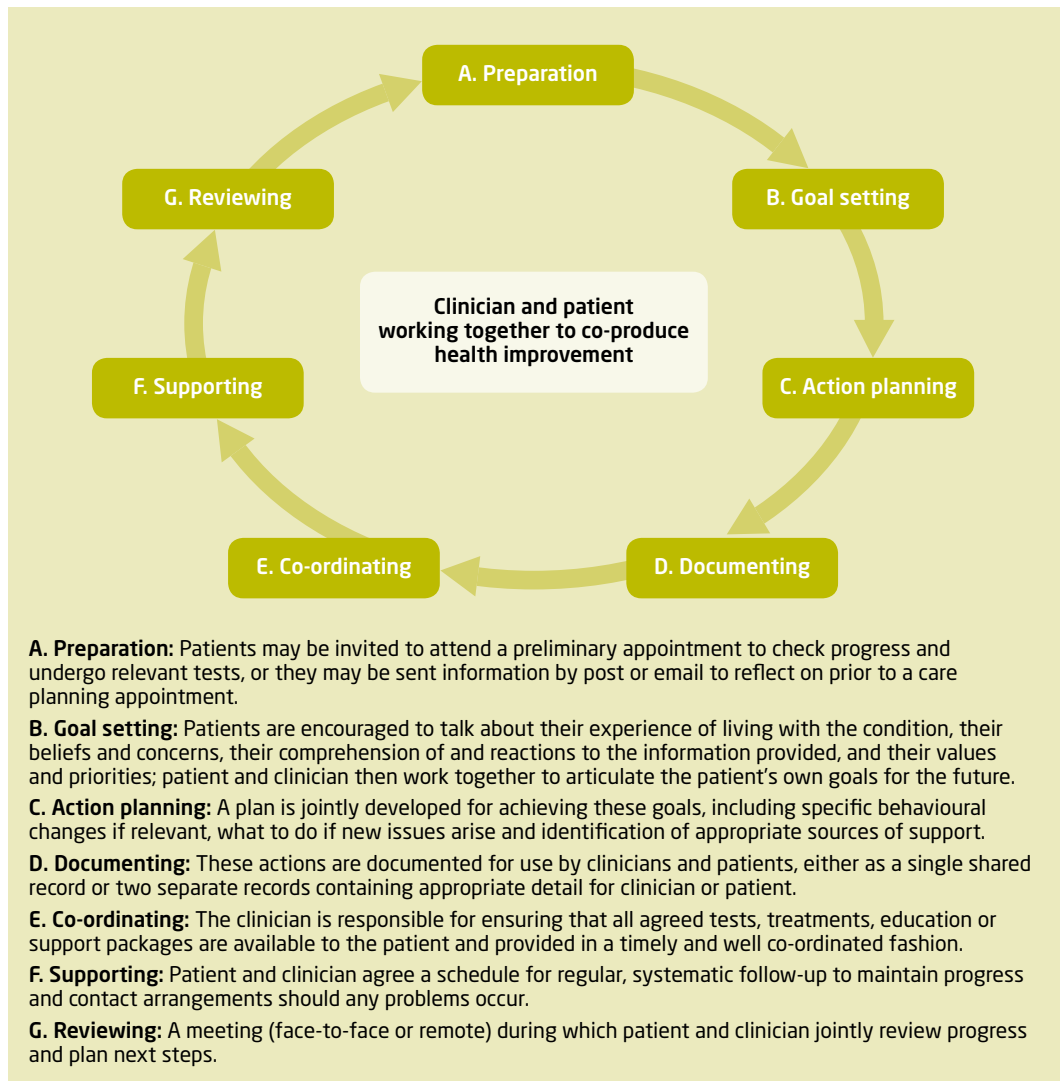
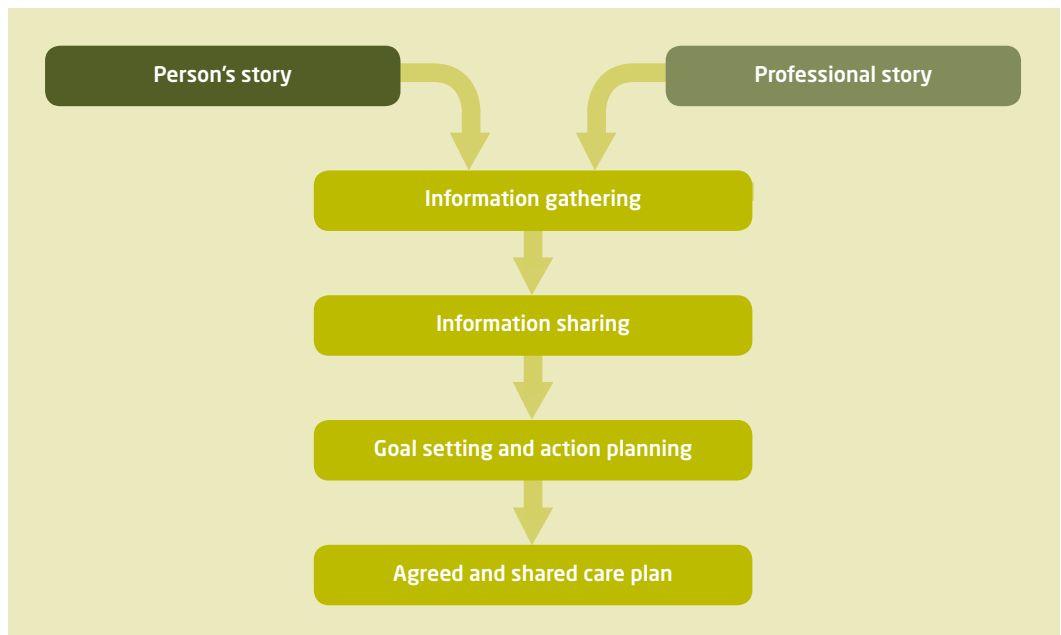


Figure 3 The new consultation – a systematic approach



Practitioners with experience of using a collaborative approach to care planning emphasised the importance of giving each individual the right amount of time for a consultation, and the benefits of a common approach for those with single or multiple long-term conditions. In some places, care planning is now being used to signpost people to community resources and support and as a first step in designing their personal health budgets.

Clinicians often complain that time pressures get in the way of providing the type of personalised care they would like to be able to deliver. Our informants described contrasting ways of dealing with this problem. For some, it involved careful prioritisation so that the person's most important issues were focused on first, with planned follow-up consultations to deal with secondary issues. For others, it meant offering longer consultations for those who needed them, in the belief that this approach makes the whole pathway more efficient.

The right consultation for each patient

Practices involved in the Year of Care programme offered longer appointments for care planning consultations for people with a long-term condition. Most often 20 minutes was sufficient, especially when tests and examinations were performed in advance. A risk stratification approach enabled some to offer 30–40 minute appointments when greater needs were identified.

Nurses took responsibility for consultations with patients whose health condition was relatively straightforward, while GPs dealt with those who had multi-morbidities or more complex problems.

Those who had embraced this way of working wanted more specific help to support those of their colleagues who were struggling to adapt their consultation styles. They also wanted advice on how to help those patients who were finding adopting effective self-management skills and making lifestyle changes especially difficult.

Where care planning had been introduced relatively easily for a single condition such as diabetes, participants reflected on the challenge of doing this at scale if every individual with a long-term condition were to be included, particularly those with mental health issues and learning disabilities.

Participants and interviewees remarked on the extra administrative complexity of organising care planning for people with multiple long-term conditions. While it proved challenging to bring together all the clinical issues for each individual with multiple conditions into one holistic care plan, the potential benefits of doing so were immense.

Many of those we talked to commented on the difficulty of knowing just what was going on in consultations, and whether the way clinicians and patients worked together had really changed. There was a strong demand for better ways of measuring patients' experiences and patient-reported outcomes, so that progress can be carefully monitored.

While in each case an example of success existed somewhere, there can be little doubt that the introduction of care planning on the scale envisaged will require significant changes across primary care practice as a whole.

Integrated health and care planning

Community health teams are using care planning with people with complex problems, linking them to support services in the community. Training in how to do this has been successfully adapted for integrated health and social care teams. This approach has been used for people with cardiovascular conditions, those with chronic obstructive pulmonary disease, and among older people with multiple conditions.

Care planning offers both a personalised solution for each individual and a means of identifying the variety of support needs in a local area. It achieves person-centred co-ordinated care by:

- linking support for self-management with high-quality clinical care
- co-ordinating health and social care across boundaries and teams
- signposting to community resources, where appropriate.

More profoundly, care planning becomes the pivot that transforms a reactive model of care, treating patients when they are sick, into a proactive one that aims to help people keep active and well for as long as possible.

The left wall of the house – engaged, informed patients

Most people want to take more control of their health and would like to be informed and involved in discussions about how to manage any conditions they may have. Patients may not expect to play a leading role in managing their health and reaching shared decisions with health care professionals, so taking active steps to prepare them for this new way of working can be helpful.

While the overall care planning process is cyclical, the need to ensure individual engagement in each care planning ‘conversation’ led to the key idea of a two-stage process. This involves: (1) actively seeking out the person’s views and providing them with personalised information in the form of prompts, decision aids and reflective sheets; and (2) building in time to reflect and discuss with family and friends before the consultation itself.

The sharing of information in the ‘two-stage’ consultation was highly valued. This means the conversation starts with both parties being better informed. For some, this involved collating and sending out test results and explanations, as in the original diabetes pilot; for others, signposting to tailored information prescriptions or patient decision aids that focus on a planned area of discussion helped to prepare patients for an active role in the care planning process. Patients are encouraged to come with a list of issues or concerns they would like to discuss with the health professional. This can then be used to set the agenda for the care planning consultation.

Agenda setting

Bolton Primary Care Trust worked with the Design Council to develop a set of 40 agenda cards that patients could use to describe how they feel about having diabetes. These helped to bring out the hidden dimensions of the challenges of self-care and allowed clinicians to spend less time on diagnosis and more time on co-developing and agreeing a care plan.

Primary care teams have developed a number of pre-consultation tools, including questionnaires, reflection sheets and patient decision aids for consultations where specific decisions have to be made.

Decision support

The [Pennine MSK Partnership](#) is a service set up in conjunction with NHS Oldham to provide an integrated care pathway for people with musculoskeletal problems. The team is led by two GPs with an interest in rheumatology, and a nurse consultant.

Referral to the team triggers access to specially designed decision aids that tell patients about different options for managing their condition, and the pros and cons of each option. This prepares them for an active role and encourages shared decision-making.

A number of evidence-based patient decision aids are now freely available on websites such as [NHS Choices](#) and [Patient.co.uk](#).

Collaborative care planning is not confined to primary care; secondary care clinics can make good use of it too.

Care planning in secondary care

Care planning using a two-stage process is now established in routine diabetes outpatient clinics and specialist insulin pump clinics for people with diabetes in [Nottingham City Hospital](#). Specialist staff and health care assistants as well as patients are enthusiastic about the improved teamwork that has resulted from working and training together in this new way.

Some patients may need additional support to enable them to become effective self-managers. This might include referral to structured education programmes, such as [DESMOND](#) for type 2 diabetes, or six-week generic self-management courses such as those run under the auspices of the [Expert Patients Programme](#). Such courses can help people to develop practical skills and strategies for dealing with the emotional and psychological impact of living with a long-term condition.

In addition to the educational impact of courses, many patients value the social support gained from meeting other people who are living with a long-term condition. Referral to community or self-help groups can serve the same function. Self-help groups have the added advantage of being user-controlled and not time-limited.

Outside a care planning format, other approaches to encourage effective involvement have been developed, including record access schemes such as [Patients Know Best](#), or social marketing campaigns such as [Ask 3 Questions](#) (see box on p 12), both of which are designed to legitimise the patient's role as an active partner or co-producer in managing their health.

Social marketing

Practices in Newcastle and Cardiff involved in the Health Foundation's **MAGIC** (Making Good Decisions in Collaboration) project and those involved in the **Right Care Shared Decision Making** programme distributed leaflets encouraging patients to ask three questions about their treatment:

- What are my options?
- What are the pros and cons of each option for me?
- How do I get support to make a decision that's right for me?

These were accompanied by a **video** in which patients talked about how they used these questions to understand their care and get more involved. The video could be accessed on Newcastle Hospital website and was played in practice waiting areas.

Various strategies have been used to encourage patient participation, including making information available about care planning and how people can be involved (either by letter or using display screens in waiting rooms), and engaging the wider community, local champions and faith groups.

People told us that the greatest barrier to getting these approaches more widely adopted was negative attitudes on the part of health professionals. Health and social care professionals may also be unaware of local community and self-help resources and their potential benefits. However, experience at a number of sites demonstrated that these attitudes could be overcome, given the right support and training. Many primary care sites and CCGs have produced directories of community resources to aid information exchange and referral.

The right wall of the house – professionals committed to partnership working

Health care professionals who do things *with* people rather than *to* them can achieve so much more, but this is not sufficiently emphasised in most training programmes. On first hearing about the collaborative partnership approach required for personalised care planning, many clinicians say 'we do that already'. However, those who attend development workshops or training courses quickly learn that there are things they can improve on. Often they find that their usual consulting style is not as collaborative as they thought it was.

Recognising the central role of patients in the day-to-day self-management of their conditions, and the professional's role in supporting each patient to develop the knowledge, skills and confidence to be an expert self-manager, is the first step to professional engagement.

Clinicians need to learn to practise a consulting style that is curious, supportive and non-judgemental, which uses problem-solving and coaching techniques, and contains the following elements (Coulter and Collins 2011):

- developing empathy and trust
- negotiating agenda setting and prioritising
- sharing information
- challenging and re-attributing unhelpful beliefs
- communicating and managing risk

- supporting deliberation
- summarising and feeding back
- developing action plans collaboratively
- documenting agreed actions
- providing practical and emotional follow-up support.

Judicious use of role play, feedback, self-assessment and lay involvement in skills workshops can help to create those ‘light bulb’ moments that are the important first step towards developing new attitudes and a commitment to learning new skills. Training together as a team or with specialist colleagues can provide an environment that is conducive to change and improves partnership working with colleagues too. The good news is that once professionals are engaged in shared decision-making with patients and actively supporting them in self-management, they often describe it as a better way of working. Positive feedback from patients in the form of questionnaire responses reinforces the benefits of adopting the approach.

Developing care planning skills

Newcastle West Clinical Commissioning Group has provided care planning training for GPs across all their 18 practices as part of a **People Powered Health** project. The Year of Care programme team adapted the training to cover mental health issues because these tend to get forgotten when staff focus on physical health.

Role play and interactive DVD exercises were used to create the ‘light bulb’ moments when participants realise that, contrary to what they think about involving patients in their care, they are not ‘doing it already’.

Effective leadership from professional bodies will be key to embedding the type of culture change that is needed if personalised care planning is to become the norm. Until recently, these bodies were disappointingly slow to adopt a leadership role in this area; but a few colleges and professional societies have begun to lead the way.

Clinical leadership

The **Royal College of General Practitioners** has announced that care planning is a quality marker of best practice in the 21st century. It is embarking on an ambitious programme to embed care planning across general practice, starting with the creation of communities of practice (each involving 6 to 12 general practices) working on specific clinical conditions. Ultimately, the aim is to develop a model that works for patients with multi-morbidities and ensures that the competencies to deliver care planning are incorporated and assessed in professional training.

Meanwhile, the **Royal College of Physicians** has appointed a fellow in shared decision-making with a remit to introduce the concept to each of the college’s specialist societies and their members, and to share good practice.

Numerous courses are now available for clinicians as well as patients, covering a wide variety of competencies relevant to the management of long-term conditions, but these are of variable quality. Courses that combine a challenge to traditional attitudes and behaviours with providing a safe environment in which to practise new skills and identify the type of procedures and system changes that are needed have had a strong impact on professional behaviour.

Quality assurance

The **Quality Institute for Self Management Education & Training (QISMET)** is an independent body that sets standards and certificates providers of training in self-management, patient education and self-care. QISMET certification covers all aspects of managing and running high-quality education programmes. It is currently developing standards for self-management support services.

The roof of the house – organisational processes

Many of the primary care teams involved in the Year of Care programme found that they needed to adapt their clinic infrastructure and working practices. Some made significant changes to the way the workforce was deployed, with more support for administrative and task-based roles to free up clinical staff for the longer consultations that were needed.

The ability to record, analyse and use information in new ways is another key aspect in making the system work efficiently, ensuring that patients receive the right level of support. For primary care teams, this means knowing their practice population and ensuring that they have the capacity to identify people who should be invited to attend for care planning consultations. This may involve reviewing and upgrading IT systems in a number of respects: to check contact details; for risk stratification and identification; to merge results into personalised letters; to facilitate the administration of linked appointments; to send out prompts, test results, information prescriptions or decision aids; to record patients' goals; and to ensure that summaries and plans are available in written as well as electronic form, for use by patients as well as clinicians.

Participants reported numerous successes in solving practical issues in specific areas such as coding, putting decision aids on the web, developing recall systems and 'navigators', and using measurement routinely. This provides considerable experience on which to build a sophisticated suite of support tools.

IT systems

Practices in Kirklees, West Yorkshire, tested IT templates that enable individuals' goals and action plans to be incorporated into the clinical record alongside traditional test results. This demonstrated the potential to stimulate practice improvement as well as feed into local commissioning plans for community support.

People at the top of the long-term conditions pyramid (Figure 4) – those with complex needs who have the highest risk of needing more intensive care and support – tend to be high users of both health and social care. In many places, they have to undergo multiple assessments by different health and social care professionals who do not communicate with each other. Integrated record systems, data-sharing and pooled budgets are the basic building blocks of a more joined-up system that should provide less fragmented care.

Data-sharing

Cumbria Partnership NHS Foundation Trust has made significant investments over three years to build robust IT systems that allow data-sharing. As a result, 90 per cent of their general practices and community services now use the same system. Clinical information can be shared across the local health economy, and it is also possible to link with social care data.

However, despite these successes, IT issues remained the biggest challenge for participants, after professional engagement.

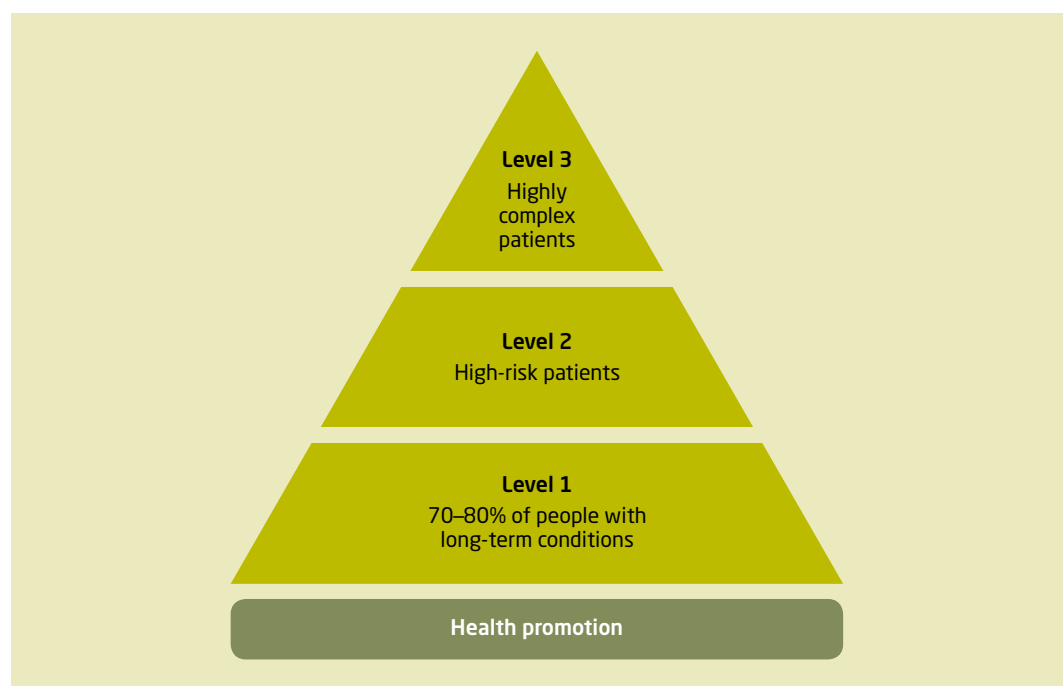
Risk stratification and case-finding systems use a combination of hospital and primary care data to predict the likelihood of hospital admission, but some of our informants felt that linking in social care data would produce a more complete picture of what is going on across their locality. This might enable commissioners to integrate care and target resources more accurately. The gold standard would be fully interoperable systems that allow data to be shared between different local services.

A basic issue for many of those we spoke to was how to ensure that the administrative and recording functions to support care planning were incorporated as standard in electronic health record systems; no one had achieved this completely.

The foundations of the house – responsive commissioning

Many commissioning bodies see considerable potential for improving efficiency by reducing demand for unscheduled hospital admissions and accident and emergency (A&E) attendances. Primary care trusts (PCTs) and now CCGs are making extensive use of predictive modelling tools to identify needs and target people at high risk of hospital admission in an attempt to control costs – focusing on the top of the long-term conditions pyramid (Figure 4).

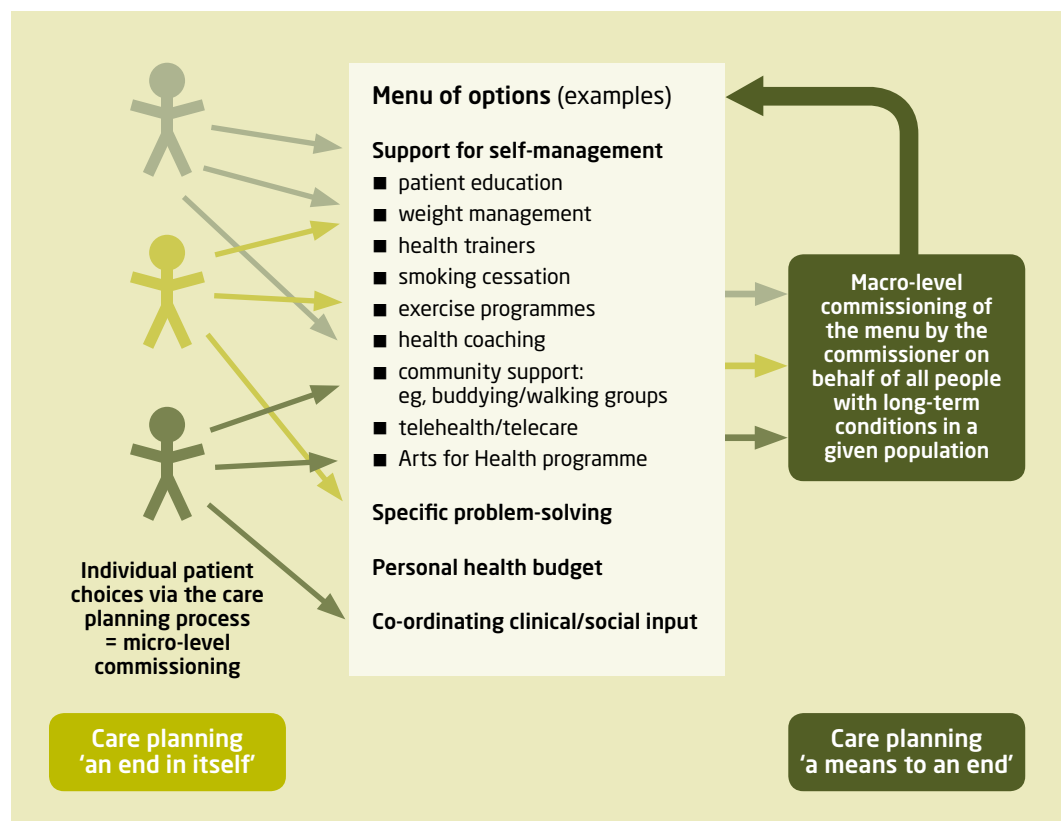
Figure 4 Matching support to needs



A high-risk approach can be a good place to start; frail older people in particular and those approaching the end of their lives have an important need for special support in their own right. But since these groups comprise a relatively small proportion of the local population, targeting a much wider group with preventive care and self-management support is probably a better way to achieve benefits that are measurable across a local health economy (Roland and Abel 2012). A comprehensive strategy for *all* people with long-term conditions based on a common approach is what concerns us here.

The house of care model integrates personalised care planning for individuals with responsive commissioning for populations. Individual needs and choices identified during the care planning process (micro-level commissioning) are aggregated to provide a local commissioning plan (Figure 5). In this way, commissioners can match services to their population as well as to each person.

Figure 5 From care planning to population commissioning



The support needs identified during the care planning process may not be confined to those normally supplied by traditional health services; community and self-help groups can often provide the type of support to people with long-term conditions that statutory services tend to ignore (Diabetes UK 2011). Examples include cookery classes to help those struggling to eat a healthy diet, gardening projects to encourage physical exercise, volunteer befriending schemes to combat social isolation and loneliness, advice centres, and peer-led self-help groups.

This type of 'social prescribing' depends on staff having good knowledge of what services are available in their local community. Mapping local community groups and services into electronic health directories to facilitate signposting and referral is an important component of the house of care.

In some places, community health trainers are being commissioned to offer direct information and support where needed (*see box*).

Community health trainers

HealthWORKS Newcastle has recruited and trained local people to work as community health trainers, providing a variety of support services for people with long-term conditions. For example, health trainers help patients attending the lipid clinic at Newcastle's Royal Victoria Infirmary to improve their lifestyle by linking advice and practical support around smoking, stress, diet, alcohol, physical activity and obesity.

Other community health champions, based in local primary schools, are working with parents to tackle priority issues such as child health and obesity.

Encouraging self-help

Self Help Nottingham has more than 30 years' experience of supporting self-help groups for people with various long-term conditions in Nottingham and across the rest of England.

In addition to helping more than 200 groups to get established, including finding funding, organising publicity and campaigning, they provide training courses for staff in the principles and practice of shared experience and self-care support.

They are also working with CCGs, local authorities and voluntary organisations, helping them to create supportive environments for self-help groups and to systematise self-care support provided by self-help groups and the third sector.

Aggregating the support needs identified by individuals into a commissioning plan for a locality requires robust electronic records and systems for data-sharing. It also requires the identification of a portfolio or menu of local services for people to choose from and a willingness on the part of commissioners to fund non-traditional services. This might include a wide variety of options, from telehealth to peer support, depending on local requirements (Diabetes UK 2011).

Recent evidence suggests that encouraging greater emphasis on anticipatory care, better support for self-management and better use of community assets could create greater value at lower cost than is possible with the current fragmented network of services. Nesta, a UK charity that promotes innovation, has estimated that this could produce savings of around £4.4 billion per year if fully implemented (Morioka *et al* 2013). The evaluation of the Personal Health Budgets pilots found that a personalised approach had significant positive effects on patients' quality of life and emotional wellbeing (Forder *et al* 2012).

However, these optimistic conclusions were not reflected in the findings of several other recent studies of self-management support (Bardsley *et al* 2013; Kennedy *et al* 2013; Bucknall *et al* 2012; Fan *et al* 2012). This may be because specific components – for example, patient involvement in goal setting and action planning – were not given sufficient priority in the evaluated programmes, or it may be due to the difficulties inherent in implementing the type of whole-system change that we believe is necessary.

At a local level, the importance of human factors cannot be overstressed. Disappointing results from some telehealth schemes underline the folly of assuming that the answer lies simply in the provision of more technical tools and kit, or relying on single interventions without taking account of the local context and the need for system change (Steventon *et al* 2012). Care planning should be monitored to check that it is being practised as intended, and commissioners will need to ensure that the menu of care and support services is relevant and up to date. The importance of a systematic process to sustain this and to link the whole model together, in the form of steering groups and practice facilitators, cannot be overemphasised.

The NHS is awash with small-scale improvement initiatives, but care planning and self-management support needs to be implemented across multiple organisations covering much wider geographical areas if it is to make a real impact. Success depends on building effective local partnerships between NHS, social care, public health and community organisations and, where necessary, provision of appropriate support from NHS England and other national bodies.

CCGs will need to be ambitious if they are to change traditional ways of working and realise the benefits in terms of better outcomes and greater value for money. Our informants assured us that many organisations are keen to raise their game in this way, and there are several examples of ambitious strategic plans that are in the process of being implemented.

Investing for change

Cumbria Clinical Commissioning Group has committed £1 million per year over the next three to five years to fund training and skills development for the care of people with long-term conditions, including improvement collaboratives, train the trainers programmes, pathway development, capacity-building, and management support for change and innovation.

Developing integrated systems

Kent County Council aims to provide anticipatory care for people at the highest risk by integrating health and social care. The local authority is working closely with NHS organisations to apply integrated health and social care assessment and personalised care planning, using mechanisms such as pooled budgets, integrated practitioners, integrated personal health and social care budgets, patient-held records and linked data systems.

Monitoring progress

Use of appropriate metrics for monitoring progress is essential in any quality improvement programme, and the house of care model is no exception. The methods may include obtaining systematic feedback from patients using validated questionnaires to check that they are being involved in developing their care plans. Once there is agreement on goals and these are linked to reliable measures, then incentives can be put in place to encourage improvements. Many of the groups we spoke to had struggled to find locally appropriate measures that could be easily applied, analysed and fed back.

Metrics to incentivise improvements

The **Personal Health Budgets** pilot sites agreed to measure the effects of budget-holding on bio-medical markers and hospital admissions. No changes were observed in the clinical indicators, but admission rates reduced significantly and patients' quality of life and emotional wellbeing improved (Forder *et al* 2012).

Measurement was also an important feature of **AQuA's Shared Decision Making project**, where several patient questionnaires were used to monitor progress, none of which was entirely satisfactory. Those involved in the **MAGIC** programmes in Newcastle and Cardiff developed special codes that were incorporated into EMIS software packages to monitor shared decision-making consultations.

In some cases, Quality and Outcomes Framework (QOF) scores may be sufficient. For example, Tower Hamlets practices were delighted to find that they moved from the bottom of the league table for diabetes care to very near the top after introducing care planning.

The purpose of personalised care planning is to ensure that people with long-term conditions are given personalised support to develop the knowledge, skills and confidence they need to effectively manage their health. Several instruments have been developed to measure these attributes, including the Patient Activation Measure (PAM) (Hibbard *et al* 2005), the Patient Enablement Instrument (PEI) (Howie *et al* 1998), the Patient Partnership in Care (PPIC) instrument (Powell *et al* 2009), the Self-Management Ability Scale (SMAS-30) (Cramm *et al* 2012), the Partners in Health (PIH) scale (Battersby *et al* 2003), the Patient Assessment of Chronic Illness Care (PACIC) (Schmittiel *et al* 2008) and the Consultation and Relational Empathy (CARE) measure (Mercer *et al* 2004), to name a few.

Commissioners may want to use indicators such as these to monitor the impact of this new way of working on population health. CCGs might also want to encourage their providers to focus on improving these metrics for people at low levels of activation or with low health literacy, thus driving the system to reduce health inequalities. Providers might make use of these or other similar measures to ensure that they are undertaking personalised care planning and self-management support to the highest possible standard. For example, measures of patient experience and decision quality can be used to check the extent to which the patient was informed about their options and involved in the care planning process.

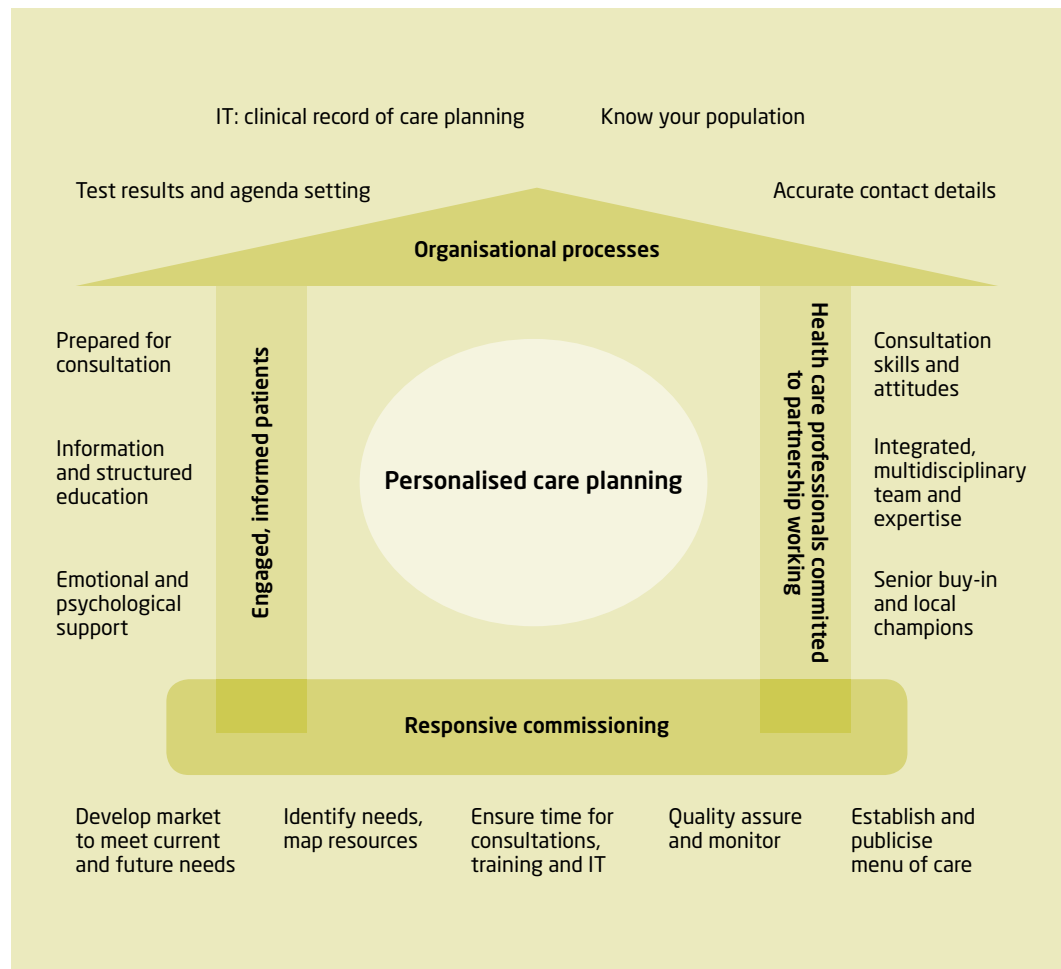
Putting all the components together

Local providers and commissioners need to ensure that all the components of the house of care are in place if the desired impacts are to be achieved (Figure 6). This will involve:

- acknowledging the philosophy and principles of systematic support for self-management (the driver of the delivery system)
- identifying accountable leadership
- identifying the population involved (risk stratification)
- identifying the capacity of individuals to engage in the necessary processes and supporting them to do so

- identifying the multidisciplinary teams involved and the roles and responsibilities of each team member in order to ensure that care is personalised and co-ordinated
- using available evidence-based and quality-assured training
- identifying robust metrics, data collection methods, analysis and feedback to drive improvement.

Figure 6 Putting all the components of the house of care in place



Overcoming barriers

Few of those we spoke to had managed to assemble all the various components needed for the house of care in one place. While a range of activities are being conducted with enthusiasm, they are often isolated efforts. There are also some national barriers that are preventing progress, for example, problems related to contracts and incentives in primary care, inflexible IT systems and a lack of agreed outcome measures.

It was often the case that where one primary care team was struggling with a particular component, another had found a solution. Ensuring that all components are in place is no easy task; but recognising the need to assemble them all in order to construct the house in its entirety is the key to effective delivery.

The momentum for this new way of working is taking hold across England. Some 3,000 practitioners in 26 communities have begun to introduce aspects of the house of care model via the Year of Care programme – an approach that links attitudes, skills and infrastructure. Systematic community support is generally less well incorporated and the patchy use of metrics, inflexible IT systems and limited ongoing support mean there is still much to do to capitalise on their enthusiasm for this ‘better way of working’.

However, since few sites have adopted the model in full, with all the components in place, we cannot yet be certain that it will deliver the desired results. Studies underline the need for caution before assuming that promising blueprints will reliably produce the expected outcomes. Yet the discussions and sharing of experience at the workshop organised by The King’s Fund generated a great deal of excitement. There was a general consensus among participants that a model that starts and ends with an improved patient–clinician partnership is worth adopting and should now be pursued with more vigour.

The time is therefore ripe for a renewed effort to deliver better care for people with long-term conditions. Patient organisations are calling for a new approach, and financial pressures on the NHS and social care require co-ordinated action to secure better value from limited resources. These pressures are especially acute in primary care, encouraging professionals to seek a different approach. The Department of Health’s [Mandate](#) and the [NHS Outcomes Framework](#) have set out the new direction for health and social care. CCGs now have both the incentive and the opportunity to move this agenda forward.

Change on the scale needed is not easy, especially when the main barriers involve aspects of organisational culture. Implementing the house of care challenges the way the workforce is developed and how training is organised and quality assured. There is a need not just for better metrics but for better use of those metrics. Current IT systems cannot cope with issues such as recording patients’ issues and goals, printing off personalised letters and care plans or gathering real-time feedback for clinicians.

Multi-morbidity – especially where people have complex mental as well as physical health problems – poses additional challenges, as the primary care [QOF](#), most clinical guidelines, and the most common IT systems and datasets are all structured around single conditions.

However, none of these problems is insurmountable. Co-ordinated action at both local and national levels could do much to overcome them.

The way forward

The preparation and discussion around The King’s Fund workshop provided a rich source of thinking to underpin a new strategy for helping people with long-term conditions. Participants focused on what needed to be put in place to make this a reality. Three main needs emerged: a clear narrative describing care planning and the infrastructure needed to support it (a gap that we hope has now been filled by this report); a ‘hub’ for disseminating this narrative, providing a source of support and co-ordinating activities; and a ‘coalition of the determined’, each contributing from their own perspective, building on the pledges they made at the event and ensuring that their activities are aligned with and support the joint endeavour.

Workshop participants and interviewees suggested various actions that could be taken by organisations at different levels in the system to help embed this way of working.

NHS England should:

- adopt and promote a compelling narrative so that everyone understands what is expected of them in respect of care planning for people with long-term conditions
- assist a national support unit or hub to help local sites, particularly helping them tackle any barriers they encounter
- ensure that the GP contract is aligned to support this approach and that its incentives reflect the importance of care planning
- model the care planning approach through specialist commissioning
- develop and test funding mechanisms that facilitate co-ordinated care, including the use of non-traditional services such as those provided by community or third sector organisations
- develop a set of measures that can be used across the system, including patient reported experience measures (PREMs) and patient reported outcome measures (PROMs), to be used for improvement as well as quality assurance
- liaise with suppliers of GP computer systems to encourage the development of care planning modules integrated into the main clinical record
- liaise with IT companies and others to encourage system interoperability to enable data-sharing across service boundaries and the inclusion of self-management capabilities and social care data in risk stratification
- be ready to de-commission poor-quality primary care services.

Clinical commissioning groups and primary care teams should:

- use the resources and concepts that the delivery system provides to systematically re-design services and build their own house of care, actively working with local partners to share risks over the medium as well as the short term
- work with NHS England to help primary care shift from the current episodic approach to caring for patients with long-term conditions to an approach that is more anticipatory and planned
- be ready to challenge negative attitudes and encourage awareness of new ways of working in partnership with patients
- monitor the extent to which patients are engaged in decisions, have personalised care plans, and receive co-ordinated services and appropriate support for self-management
- ensure that good-quality training courses in care planning and self-management support are available and that staff are encouraged to attend them, with locum cover and back-fill funding when necessary
- recognise that provision of occasional ad hoc workshops or courses, however good, will not be sufficient to achieve measurable changes in practice; a more strategic approach is required
- agree common goals for care planning, as well as outcome measures, and provide analytical support and feedback
- actively work with health and wellbeing boards to ensure that a portfolio of commissioned and non-commissioned community or peer support is available and/or signposted to patients when necessary

- develop and make available directories of community services and other non-traditional self-care support services
- ensure that patient records are in good order and contact details are up to date
- work to ensure that local electronic health records are fit for care planning and share information with other organisations, including those in the community
- allow patients to access their electronic medical records and develop shared records for care planning.

Health Education England should:

- produce a new workforce development strategy for long-term conditions that is aligned with the components of the house of care and supports care planning
- ensure that the core competencies for care planning are related to service needs rather than professional roles
- ensure that primary care and the primary care workforce strategy are adequately represented in local education and training boards
- work with Royal Colleges, the General Medical Council, the Nursing and Midwifery Council, the Health and Care Professions Council and other standard-setting groups to ensure that collaborative care planning is a key component and is reflected in curricula
- work with Royal Colleges and specialist societies to strengthen clinical leadership in relation to care planning and systematic support for people with long-term conditions
- develop a quality assurance framework for training courses to support people with long-term conditions and work with training bodies to ensure that these are incorporated in relevant programmes
- develop the standards and quality criteria for training courses in shared decision-making, care planning and self-management support
- work with Royal Colleges and specialist societies to strengthen medical leadership in relation to personalised care planning for people with long-term conditions.

The Department of Health should:

- adopt and promote a compelling narrative so that all health and care professionals and organisations understand what is expected of them with respect to care planning for people with long-term conditions
- encourage the National Institute for Health Research, universities, Collaborations for Leadership in Applied Health Research and Care, Academic Health Science Networks and policy research centres to carry out relevant research into the effects of care planning, including evaluation of pilot projects.

Conclusion

The house of care model we have described here is a deliberate simplification of a complex delivery system with primary care as its cornerstone and personalised care planning at its heart, underpinned by the solid foundation of responsive commissioning. Each of the individual components of the model is being implemented in various primary and secondary care sites across England. Putting all the components in place at the same time has proved challenging, but everyone we spoke to was confident that a fully functioning house of care is perfectly feasible within the NHS right now, without needing radical system reform.

However, the projects we have described constitute bold initiatives led by pioneering individuals who are willing to take risks. It is unrealistic to rely on these leaders to make change happen across the board. It is high time that the barriers to implementing the full house of care model were swept away, making it much easier for everyone to do it – not just the heroes and heroines. The prize of well co-ordinated personalised care for everyone who needs it is within our grasp. Getting there will require a coalition of the determined, plus strong support at national as well as local levels.

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Appendix: Workshop participants and interviewees

Name	Job title	Organisation	Interviewed
Sponsors			
Dr Anna Dixon	Director of Policy	The King's Fund	
Dr Martin McShane	Director, Improving the quality of life for people with long-term conditions	NHS England	
Attended event			
Michael Adamson	Managing Director, Operations	British Red Cross	
Alison Austin	Head, Personal Health Budget Team	Department of Health	Yes
Elaine Bayliss	Programme Manager, National End of Life Care Programme	NHS Improvement	
Laura Boothman	Policy Manager	Arthritis Research UK	
Amanda Cheesley	Long Term Conditions Adviser	Royal College of Nursing (RCN)	
Dr Alf Collins	Clinical Associate	The Health Foundation	
Sarah Collis	Director	Self Help Nottingham	Yes
Prof Paul Corrigan	Management Consultant	Paul Corrigan	
Dr Angela Coulter	Visiting Fellow	The King's Fund	
Ciaran Devane	Chief Executive	Macmillan Cancer Support	
Dr Matthew Dolman	Chair, Clinical Operations Group	Somerset CCG	
Prof Chris Drinkwater	Professor	NHS Alliance	Yes
Prof Ray Fitzpatrick	Professor of Public Health and Primary Care	University of Oxford	
Prof Judith Hibbard	International Visiting Fellow	The King's Fund	
Dr Isabel Hodgkinson	RCGP Lead for Care Planning	The Tredegar Practice	Yes
Ruthe Isden	Public Services Programme Manager	Age UK	
Halima Khan	Director, Public Services Lab	Nesta	
Dr James Kingsland	National Clinical Lead	National Clinical Commissioning Network	
Dr Steven Laitner	National Clinical Lead for Shared Decision Making	Department of Health	
Nicola Levitt	Head of Strategy	Health Education England	
Dr Nick Lewis-Barned	Consultant Physician, RCP SDM Clinical Fellow	Royal College of Physicians (RCP)	Yes
Dr Johnny Marshall	Associate Director	NHS Confederation	
Prof Nigel Mathers	Vice Chair	Royal College of General Practitioners (RCGP)	Yes
Dr Ed Mitchell	Clinical Fellow	NHS England	
Dr Penny Newman	GP and Director of Integration	Colchester Hospital University NHS Foundation Trust	
Dr Alan Nye	Director	Pennine MSK Partnership Ltd	Yes
Luke O'Shea	Head of Patient Participation	NHS England	
Dr Linda Patterson	Clinical Vice President	Royal College of Physicians	
Jim Phillips	Director	Quality Institute for Self Management Education & Training (QISMET)	Yes
Dr Joanne Protheroe	Senior Lecturer in General Practice	Keele University	
Mat Rawsthorne	Fellow	Institute of Mental Health	
Don Redding	Policy Director	National Voices	
Sondra Roberto	Policy Manager	The Health Foundation	
Dr Sue Roberts	Chair, Year of Care Partnerships	Northumbria Healthcare Foundation Trust	
Lara Sonola	Researcher	The King's Fund	
Susan Summers	Head of Long Term Conditions	NHS England	
Prof Richard Thomson	Professor of Epidemiology and Public Health	Newcastle University	Yes
Anne Tidmarsh	Director of Older People and People with Disability	Kent County Council	Yes
Bridget Warr	Chief Executive	UK Homecare Association Limited (UKHCA)	
Jo Webber	Interim Director of Policy	NHS Confederation	
Jacquie White	Deputy Domain Director (Long-Term Conditions)	NHS England	
Dr Nina Wilson	National Clinical Fellow	NHS England	
Interviewed only			
Dr Hugh Reeve	Clinical Chair	Cumbria CCG	Yes

About the authors

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Sue Roberts is Chair of Year of Care Partnerships at Northumbria Healthcare Foundation Trust. Previously she was National Clinical Director for Diabetes and a consultant physician for 30 years in acute and long-term condition specialties. Sue pioneered structured and integrated diabetes care and prevention programmes for cardiovascular disease across North Tyneside and Northumberland and has designed services in acute medicine, gastroenterology, nutrition and health complications of alcohol. Sue helped to introduce rigorously evaluated structured education programmes for people with diabetes into the UK. She advises on the commissioning and delivery of patient-centred services for people with long-term conditions and the mainstream change that is needed to support and embed this. She is an honorary fellow of the Royal College of General Practitioners.

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Anna was previously Lecturer in European Health Policy at the London School of Economics and Political Science. In 2005–6 she was awarded a Harkness Fellowship in Health Policy by the Commonwealth Fund of New York. Before joining the Department of Health, Anna was Director of Policy at The King's Fund where she led work on health system reforms, regulation, patient choice, self-management of long-term conditions and the future of health and social care in England.

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