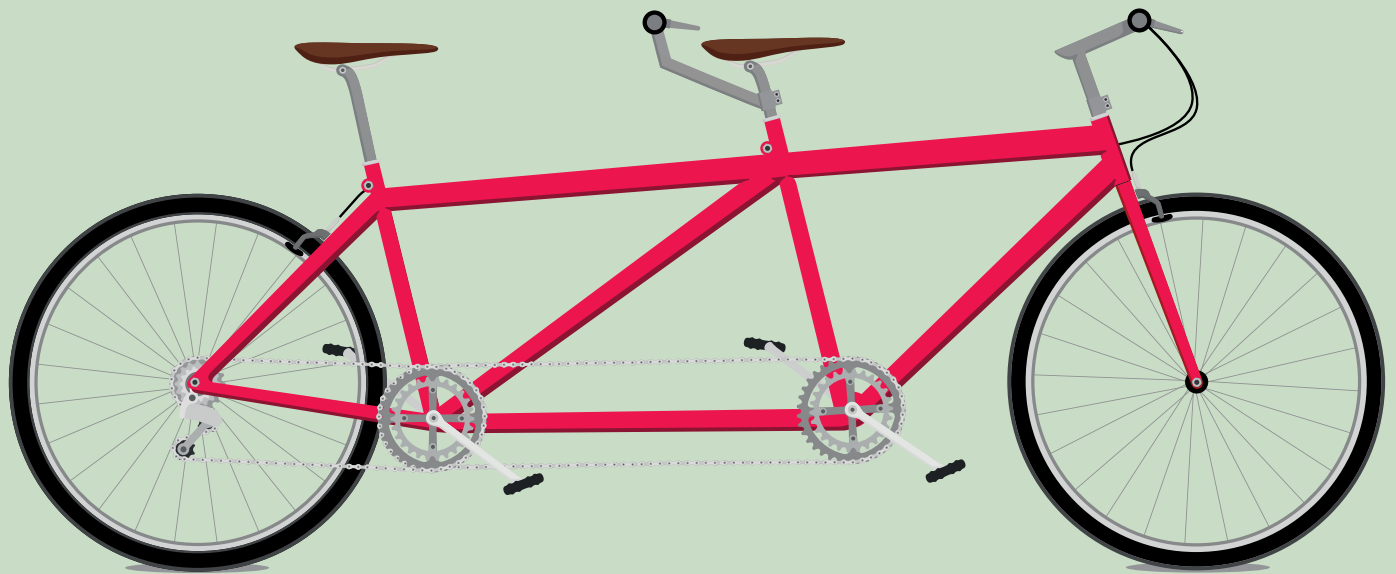# Enabling people to live well

Fresh thinking about collaborative approaches to care
for people with long-term conditions

Original research
May 2013

Acknowledgements

Authors	Organisations	Corresponding author
Vikki A Entwistle	Health Services Research Unit, University of Aberdeen	Vikki.Entwistle@abdn.ac.uk
Alan Cribb	Department of Education and Professional Studies, King's College London	

Contents

Health Foundation commentary

Everybody seems to be talking about collaboration, co-production, mutuality and partnership. These concepts underpin the four UK nations' health policies for those who live with one or more long-term condition – almost one in three of the population.

Yet there remains a significant gap between the aspiration of more collaborative care – in which patients and clinicians work in partnership, with patients supported to determine and achieve their quality of life goals – and the reality of many patients' experience. Collaboration remains largely confined to policy papers, academic research, health service seminars and improvement programmes such as Co-creating Health, the Year of Care and People Powered Health.[1] These have shown that the rhetoric can become a reality but have also demonstrated the attitudinal, behavioural and system barriers to change.

The Health Foundation wants to understand why practice has not followed aspiration as widely and consistently as hoped, so as to enable health services to take the steps required to close the gap between them. This report brings fresh insights to this question.

In the report, Professors Entwistle and Cribb argue that, while the ways people describe collaborative approaches to healthcare can be helpful in indicating how care could be delivered differently, they can also be counter-productive. Current descriptions may be limiting the uptake and effectiveness of more collaborative ways of working. The authors find that the ways in which improvement efforts are focused may actually be detrimental to their goal of improving collaborative working between patients and health professionals. For example, in concentrating on working with patients to set health goals, such as stopping smoking or reducing blood glucose levels, clinicians can forget the broader purposes and benefits of collaborative working such as developing a more supportive relationship between patients and clinicians.

The authors also argue that the desire to see healthcare professionals and patients as equal partners risks paying insufficient attention to appropriate differences between their roles, responsibilities, sources of authority and accountabilities. They suggest that, in seeking to support a patient's self-efficacy and activation, the familial, social, economic and cultural constraints on their lives can be neglected.

---

1 Co-creating Health: www.health.org.uk/cch
   Year of Care: www.diabetes.nhs.uk/year_of_care;
   People Powered Health: www.nesta.org.uk/assets/features/people_
   powered_health

Making care truly person-centred requires radically different ways of thinking. The authors reflect on clinicians' and patients' experiences and draw on ideas from development economics and social justice. Thinking in terms of people's capabilities focuses our attention on the role of health services in supporting people to develop and utilise their potential. Thinking in terms of people's relationships focuses our attention on how family and social networks can support or constrain that potential. Together, they can help us understand and potentially overcome some of the barriers to more collaborative care. Capabilities approaches and relational thinking may provide the firm foundation for collaborative working that is needed to inform the design of services, professional education and quality improvement strategies.

The authors don't shy away from some of the tensions at the heart of collaborative working, raising important though neglected questions for debate.

For example, if it is the patient who determines what matters to them, what are the boundaries for health services in supporting them to achieve their goals? Some medicines can be bought over the counter but access to others is controlled by clinicians. Personal health budgets enable patients to spend healthcare money in new ways to achieve goals which the patient decides: this may involve the patient directly determining what healthcare providers do.

Perhaps an effective approach to supporting people living with long-term conditions might draw upon models from elsewhere in health services. For example, palliative care focuses on symptom management and rehabilitation, which supports patients in regaining functions they need to pursue their own life.

Other tensions raised go to the core of healthcare professionalism in a 21st century health service. Traditionally, professionalism has been seen as a quality of the technical expertise of the individual clinician. But the analysis in this report suggests that expertise could be situated in the ability to engage in a reciprocal relationship of respect, trust and mutuality that supports patients to develop and utilise their potential. Thinking about relationships shows us that the health encounter has intrinsic value (it has value as it is a good in and of itself) as well as instrumental purpose (it has value because it helps achieve something else of value). It also encourages us to think about the trade off between providing continuity of care and offering continuity in our relationships.

While this report focuses on approaches that can support people with long-term conditions to live well, relational theories of autonomy and capabilities approaches could provide a framework for thinking about the role of health services more broadly.

This report reminds us that if we are to see truly collaborative healthcare, we will need not only those mechanisms of change with which we are familiar – leadership, training, measurement, incentives – but also conversation and space that enables people to understand, reflect upon and reconsider their purpose, attitudes, behaviours and roles. Healthcare will be advanced if we move beyond seeing patients as independent and free agents who act solely on the basis of reason. It will be enhanced when health services recognise that patients are people who, like all of us, are socially interdependent, culturally formed, with competing desires and values yet who can, with support that helps them unleash their potential, achieve their quality of life goals.

The ideas explored in this report suggest fresh ways of thinking about how patients and clinicians can work together in a meaningful partnership. Thinking in terms of capabilities and relational autonomy will not resolve tensions between patient and clinician priorities, but these concepts can facilitate much-needed discussion.

The Health Foundation will continue to support innovative research that advances our knowledge and understanding of the complex dynamics between person-centred care and quality improvement in healthcare. We are excited to be funding four new research projects in this area, including supporting the authors of this report to develop their work to consider further the practical implications and application of capabilities thinking and relational autonomy in healthcare in the UK. We look forward to sharing our learning with you in due course.

Adrian Seiff
Assistant Director
The Health Foundation

Executive summary

This report is the product of a project that considered ideas about how clinicians can work collaboratively with people with long-term conditions.

Using a combination of philosophical analysis and discussions with clinicians and patients experienced in collaborative approaches to managing long-term conditions, the project:

– critically analysed the ways that collaborative approaches are currently characterised, and

– started to examine what goes on in practice when clinicians and patients work together in ways they appreciate as meaningfully collaborative.

Our critical analysis is presented with reference to two summary characterisations (models) that compare 'collaborative' with 'traditional' approaches to care. These were:

– Bodenheimer and colleagues' comparison of traditional and collaborative care in chronic illness

– the Health Foundation's characterisation of clinician–patient interactions.

We also considered a definition and measure of 'patient activation' that is increasingly used in efforts to encourage and assess collaborative approaches. We reflected on these models, definition and measure, and the assumptions that lie behind them, the ambiguities that they tend to leave unresolved and the implications of what they emphasise.

We then explored several potentially useful shifts in thinking.

Critical analysis of current ideas

The summary characterisations (models), along with the notion of 'patient activation', point to a direction of travel that reflects an intention to respect patients' autonomy as well as promote the effectiveness, efficiency and sustainability of services. They cover a number of domains. For example, Bodenheimer's model indicates a shift from relationships in which professionals are the experts, who tell patients what to do, to relationships in which professionals are experts about disease, patients are experts about their lives, and expertise is shared. The Health Foundation's model indicates a shift from traditional interactions, in which the teaching of information and skills is based on the clinician's agenda, to collaborative interactions, in which patients and clinicians share their agendas and collaboratively decide what information and skills are taught.

However, summary characterisations have limitations. They must present ideas quite generally if they are to have broad relevance and appeal. The absence of detail can obscure their implications for 'real world' practice.

We also identified more specific concerns with current ideas about collaborative approaches. These related to three main areas:

– interactions and status differences between clinicians and patients

– goal setting

– 'patient activation'.

Interactions and status differences between clinicians and patients

Shifts from traditional to collaborative approaches are often portrayed as changes in divisions of labour between clinicians and patients. These changes are linked to shifts in the distribution of:

– knowledge, skills or expertise

– contributions to, and responsibilities for, condition management.

They are associated with more equality between clinicians and patients in these domains. In practice, however, there are important differences between clinicians and patients and their roles, responsibilities and accountabilities. When clinicians are asked to work in partnership with patients, their concerns about their roles, responsibilities and accountabilities must be considered if guidance about collaborative approaches is to be useful.

Patients and clinicians also identified important aspects of collaborative relationships that are obscured by the task orientation of current ideas about collaborative working. These include recognition of mutual humanity, respect and support.

Goal setting

Current models of collaborative approaches present goal setting as a key activity in which patients should play a lead role. While a sense of purpose and attentiveness to patients' agendas are important, differences between patients' and clinicians' values and priorities generate tensions in goal setting that current models do not address.

Focusing on goals for patients' condition management can also obscure a broader purpose of collaborative working – namely the provision of opportunities for patients to experience supportive relationships with healthcare professionals. It will not often be appropriate to set explicit goals for such experiences and, although such relationship support is important, it is usually neglected in healthcare evaluations.

'Patient activation'

'Patient activation' is defined in terms of patients' knowledge, skills, confidence and motivation to manage their condition and collaborate with healthcare providers. It encompasses the idea of patients' self-efficacy (confidence in their ability) that features in some models of collaborative approaches to care.

These issues are important. However, there are limits to the knowledge and skills people can realistically acquire, to how much they can contribute to condition management, and to what responsibility they can realistically take on.

A narrowly cognitive and strongly individualistic interpretation of patient activation risks neglecting the material and social realities of people's lives and the constraints these can impose on their activation and management of their long-term conditions. Attention to social realities is important both to ensure health services are appropriately responsive and to address social inequalities in the determinants of health and wellbeing.

Also, patient activation is currently measured in ways that emphasise clinical recommendations for health and that can fail to recognise patients' motivation to improve other aspects of their wellbeing and lives.

Potentially helpful shifts in thinking

As well as critically analysing specific concerns about current models of collaborative approaches to long-term condition management, we reflected on clinicians' and patients' accounts and considered how ideas from philosophical literature might help articulate key insights from these. We considered how this could address some limitations of current models and their conceptual underpinnings. We drew mainly on work concerning:

a. relational theories of autonomy and other personal attributes

b. capabilities approaches to thinking about quality of life.

Relational theories of autonomy and other personal attributes take account of how people are influenced, supported and constrained by their social and cultural environments and relationships. Capabilities approaches to thinking about quality of life focus on the genuine opportunities that people have (or don't have) to be and do the kinds of things that it matters that they can be and do.

Ideas from these approaches can suggest fresh ways of thinking about collaborative approaches to the management of long-term conditions. Our key observations about how they can address the concerns identified above are summarised overleaf. The headings reflect some of the shifts in emphasis that these approaches suggest.

Relationships between clinicians and patients

Relational theorising, including about capabilities, can help us look beyond the ways that clinicians and patients work on particular tasks. It encourages attention both to the deeper and more subtle aspects of clinician–patient relationships, and also to the potential significance of those relationships for who patients are able to be and what they are able to do – as they use health services and more generally. Such consideration can help explain what is wrong with some examples of practice that conform to current models of collaborative approaches but that experienced patients and clinicians do not recognise as adequately or appropriately collaborative.

Relational thinking suggests ways of recognising and talking about the experiences of collaborative approaches that patients and clinicians value but that are not clearly reflected in current models. For example, it suggests that clinicians' commitments and practical contributions to an ethos of healthcare as a cooperative enabling endeavour might sometimes be more important than questions of who does what in terms of identifying problems, setting goals and implementing tasks.

The broader purposes of collaboration and healthcare

Capabilities approaches invite us to look beyond health state outcomes. By supporting the identification of the range of things that it can matter that people with long-term conditions can be and do, such approaches could facilitate the development of flexible frameworks for considering both the kinds of goals that patients might set and the broader purposes of healthcare (and collaborative approaches to it) that current models tend to neglect. Thinking in terms of capabilities offers conceptual resources to facilitate much-needed discussions about both possible tensions between patients' and clinicians' priorities for long-term condition management and possible disagreements about the scope of support that health services should provide. Relational theorising also helps us think how healthcare (and collaborative approaches) influence patients' capabilities.

Capabilities approaches distinguish between capabilities and demonstrated functionings. This distinction might help identify ways of enabling people to manage their long-term conditions without imposing inappropriately normative behavioural demands.

The recognition that a person's capabilities are interconnected and that they can be more or less secure could usefully inform the prioritisation of capability development for resilience.

Enabling patients and addressing contexts

Capabilities thinking can be related to some important ideas behind current interests in patient activation, enablement and empowerment. Problematic tendencies to adopt narrowly cognitive and strongly individualistic interpretations of these concepts could be countered by attention to the broad range of capabilities that can matter and the relational understanding that capabilities are situationally and socially shaped.

Relational theorising about capabilities encourages an emphasis on services that respond flexibly to individuals. It reminds us that:

- features of health service provision and relationships with clinicians are fundamentally significant for what patients can be and do within consultations as well as beyond

- standardised approaches to communication and interaction will not ensure similar capabilities or capability gains for all patients

- the material and social circumstances of people's lives can shape their knowledge, confidence, skills and motivation as well as their self-management behaviours.

Future directions

This project demonstrated in principle that (a) relational theorising and (b) capabilities approaches can support fresh thinking about current collaborative approaches to care. Further work is now needed to develop and investigate applications of this thinking for quality improvement. This could include practice development and empirical research work to investigate where, how and in what ways the ideas outlined in this report could be put to effective use, given existing cultural norms and service constraints.

Chapter 1:
Introduction, aims and approach

Introduction

This report is the product of a project that was designed to explore and illustrate how philosophical thinking can support healthcare quality improvement.

The project considered the ways clinicians work to help people with long-term conditions. It focused on ideas about 'collaborative' approaches to the management of these conditions.

The rationale behind the project reflected two broad concerns. First, we were aware that collaborative approaches to the management of long-term conditions have not been adopted in practice as widely and consistently as many policy leaders and quality improvement advocates have hoped for. Second, we had a nascent sense that limitations in the ways of thinking about collaborative approaches that underpin current efforts to promote them might be relevant to understanding the gap between aspiration and practice. We fully appreciated that there can be many practical obstacles to translating 'ideals' into routine healthcare, but we also suspected that some of the ideas that are used to discuss collaborative approaches might themselves be problematic.

We were therefore keen to look more carefully at:

– how ideas about collaborative approaches are currently expressed

– how current ideas relate to the complexities of practical attempts to adopt them

– how well current ideas reflect what is good about collaborative approaches.

Using a combination of philosophical analysis and discussions with clinicians and patients experienced in using and promoting collaborative approaches to managing long-term conditions, the project:

– critically analysed the ways that collaborative approaches are currently characterised

– started to examine what goes on in practice when clinicians and patients work together in ways they appreciate as meaningfully collaborative.

Our critical analysis is presented with reference to two summary characterisations (models) that compare 'collaborative' with 'traditional' approaches to care.[1,2] We also considered a definition and a measure of 'patient activation'[3] that are increasingly used in efforts to encourage and assess collaborative approaches (all of these are presented in Chapter 3). We reflected on:

– the assumptions that lie behind the models and the definition and measure of patient activation

– the ambiguities that they tend to leave unresolved

– the implications of what they emphasise.

Our discussions with clinicians and patients took place during two day-long knowledge exchange events.

The critical analysis and discussions enabled us to move beyond our vague sense of unease to identify more specific concerns about current ideas on collaborative approaches. To further illustrate how philosophical thinking might help to address the concerns that we identified, we drew on philosophical literature that we had previously found useful to address similar concerns about ideas regarding shared decision making and patients' experiences of healthcare delivery.[4-7]

The literature that we drew on concerned:

a. relational theories of autonomy and other personal attributes[8]

b. capabilities approaches to thinking about quality of life.[9,10]

Our hope at the outset was that something valuable could be gained by bringing together insights derived from philosophical analyses of practice and from the academic literature on relational theories and capabilities. Over the course of the project, we were delighted with the fruitfulness of the interactions between philosophy and experiences of practice.

This report presents a critical analysis of some prevailing ideas about collaborative approaches to the management of long-term conditions. It also indicates some of the ways that ideas about social relationships and capabilities might helpfully refresh thinking about the ways clinicians work with people with long-term conditions. Given the small scale and exploratory nature of the project, we can present only a preliminary outline and illustration of the potential implications of these ideas. We also stress that relational theories of autonomy and other personal attributes, and capabilities approaches to thinking about the quality of life, are not the only bodies of philosophical literature that can offer useful insights.

However, we hope you will agree that this report:

– highlights questions about collaborative approaches to care that are important for policy and practice

– offers an agenda of concerns and suggestions that warrant consideration and further investigation

– illustrates the kind of value that could be derived from applying philosophical insights and approaches to other aspects of health and social care policy in the future.

If the report gives you useful 'food for thought' and encourages you in your efforts to improve healthcare, we will be satisfied.

Project aims and approach

The project aimed to:

– use philosophical analysis and experience-based insights to theoretically 'unpack' and critique prevailing ideas about how clinicians (can or should) work collaboratively with people with long-term conditions

– consider how prevailing ideas might be refreshed and made more useful for policy and practice, including by drawing on insights selected from philosophical literature on relational theories of autonomy and on capabilities approaches to assessing quality of life.

We stress that we were and are broadly sympathetic to the ideas that in general:

– it is better for people to be able to do more rather than less to manage their long-term conditions in ways that improve their health and quality of life

– clinicians can play important roles in enabling people to manage long-term conditions.

Our concern was and is to identify scope to improve service provision by improving the thinking that underpins the ways that clinicians are encouraged to relate to patients over the management of their conditions. We were and are wary of the view that any one particular way of relating to patients might be best in all circumstances. Similarly, we were and are concerned about potentially problematic implicit assumptions and value judgements that lurk within some accounts of how clinicians should relate to patients.

We used a combination of philosophical analysis and discussions with clinicians and patients experienced in using and promoting collaborative approaches to managing long-term conditions. Our approach involved a range of activities. We:

– read and reflected critically on a selection of policy documents and clinical–academic papers about 'co-production' and collaborative approaches to the management of long-term conditions

– listened (during two knowledge exchange events) to what clinicians and people with long-term conditions who were experienced in collaborative approaches told us about their experiences, evaluations and hopes for their working relationships and the management of long-term conditions

– used what we heard, together with insights from relational understandings of autonomy and the capabilities approach, to help reflect on the strengths and limitations of both prevailing thinking and possible new ways of thinking about collaborative approaches to the management of long-term conditions

– sounded out 'introductions' to relational understandings of autonomy and the capabilities approach among the Health Foundation staff, clinicians

and people with long-term conditions who attended the knowledge exchange events. We also discussed our initial ideas about their implications for thinking about the management of long-term conditions.

The two knowledge exchange events that were crucial to the 'listening' and 'sounding out' components of our project were both hosted by the Health Foundation.

Participants were clinicians and people with long-term conditions who had experiences of (and in some cases worked to promote) more collaborative approaches to the management of long-term conditions, as well as people working for or with the Health Foundation on projects associated with changing relationships in healthcare. An outline of the events is provided in Box 1.

Box 1: Outline of knowledge exchange events

Knowledge exchange event 1

Session 1: Sharing experiences of co-creating health

After a welcome and introductions, we asked clinicians and patients to describe, from their own experiences, 'good' examples of 'collaborative' approaches in the management of long-term conditions. We acknowledged that there were various ways of labelling these approaches. In this session we encouraged a descriptive focus on what happened in collaborative clinician–patient interactions and what they were like for participants.

Session 2: Identifying the key issues in practice

In this session we adopted a more analytic focus. We asked clinicians and patients what they thought was good about collaborative approaches, and what concerns they had (or had heard others express) about them. We then asked them to discuss what was different about collaborative approaches. For example, as clinicians, how did their current collaborative approaches differ from what they had been trained to do? Or, as patients, how did the encounters they experienced as being collaborative differ from other encounters?

Sessions 3 and 4: Introducing and reflecting on ideas from philosophy

We presented and discussed key ideas from relational theories of autonomy and from capabilities approaches to thinking about quality of life.

Knowledge exchange event 2

Session 1: How philosophy can challenge practice: what it can (and cannot) offer

We introduced some thoughts about philosophy and how it can (and cannot) contribute to quality improvement in healthcare. We used a discussion about the division of domestic labour to illustrate how philosophical reasoning can help us to ask better questions and develop clearer understandings of practical problems. We also highlighted the 'resource' of ideas and analyses provided by philosophical literature.

Session 2: What's different about 'co-production'? Initial ideas

We presented some initial ideas about revising current characterisations of collaborative approaches to care using a notion of 'extended repertoires' of goals and forms of interaction. Discussion of these ideas highlighted the difficulty of providing an adequate characterisation within the kind of framework that contrasts 'traditional' and 'collaborative' processes.

Session 3: Philosophical treasure or fool's gold?

Participants formed small groups to discuss the plausibility and usefulness of a series of short statements relating to collaborative approaches to healthcare. This session highlighted the limitations of summary characterisations.

Session 4: Discussion

In the final session we discussed where the project had taken us so far, and what we should reflect on and attend to in writing this report to help spread our learning.

What philosophy can (and cannot) offer

Policy makers today often look to the sciences, including the social and psychological sciences, for support, but they look to philosophy rather less often. This is perhaps because requirements for 'evidence-based' policy making reflect and encourage a strong focus on questions about effectiveness or, in crude terms, 'what works?' Questions about what works, for example to address particular problems or to achieve particular aims, are very important and they do need to be addressed by empirical research. But they are not the only questions that we need answers to, not least because they are themselves underpinned by an often questionable range of assumptions, values and arguments.[11,12] Sometimes it is simply not clear whether or in what sense something is a problem, what would count as an improvement to a situation and how we should determine whether a particular intervention would be well justified.

Philosophy is an activity of questioning, analysing and debating key features of the world and of the conceptual, theoretical and value frameworks through which we make sense of these. Philosophical activity can tackle questions about anything, but it often involves discussing and debating fundamental questions about the nature of reality, knowledge and values. This might sound rather abstract and potentially irrelevant, but philosophical thinking can be applied to very concrete problems and can have important practical implications in many key domains. For example, in a debate about the place of alternative therapies or complementary medicines in healthcare provision, we might question:

– whether the kinds of entities or qualities that particular healthcare traditions refer to (such as yin and yang or crystal resonances) exist

– whether and how we can have knowledge of these

– whether and why we should value particular therapies or services

– whether and why we might be justified in recommending them to our loved ones or agreeing to fund them from general taxation.

Philosophy can make very important contributions to the development of policy and practice by checking and improving the quality of our understanding and reasoning.[13] It can be compared to a (sometimes annoying) critical friend who asks uncomfortable questions about the assumptions we are making and whether we know what we are doing or talking about.

And like the best of critical friends, philosophy can make very constructive contributions by helping to develop better answers to questions about what matters and why.

To take an everyday example, imagine a conversation about the ways in which housework is divided. It might start with a question: 'What is the right gender balance in the division of domestic labour?' Then someone might ask whether gender is a relevant consideration at all. Someone else might suggest we should think instead about 'What should be the criteria for considering whether arrangements for sharing domestic work within a household are fair?' This kind of discussion allows us to examine the assumptions, values and arguments that are embedded in our questions, 'common-sense' answers and everyday practices. Through reflection, analysis, dialogue and debate we can 'test' the strengths and weaknesses of our current thinking, identify alternative ways of thinking and so develop a more critically informed and reflective understanding of what is at stake.

Careful reasoning can often be supported by discussion among people who bring different experiences and ideas to the table, as long as they are willing to listen to and learn from each other, and are committed to finding good ways of thinking about things. Interactive reasoning processes can help us all move towards positions where we see the issues differently, are asking more useful questions and providing more defensible (less bad) answers.

In one sense, as the example of the conversation about housework illustrates, the activity of philosophy can be broadly continuous with some of the discussions we have in everyday life. In another sense, it is a more technical, specialist, professional activity. Some people work (usually in academic contexts) as philosophers, and they publish their work in books and peer-reviewed journals to help progress their discipline, as well as knowledge more generally. Our day-to-day philosophical activities can often be supported by both the well honed processes and the products (usually publications) of this professional activity.

– The **disciplines, techniques and rigour of philosophical analysis** can be particularly useful for checking the robustness of arguments for and against particular positions. They urge and help us to critically examine assumptions and values, and to test the logic that underpins our own and others' claims. They can support constructive debate and promote the formulation of better alternatives.

– The **published philosophical literature** provides an opportunity to participate as if in dialogue with great thinkers of the past and present. It is an exceptionally rich source of concepts, arguments and approaches to understanding the world.

Philosophy has limitations of course. It can improve our thinking, and the ideas it generates and refines can in some senses be highly influential. However, policy makers who want to change the world to reflect even their most philosophically robust ideas will usually need to look beyond philosophy as well. For example, empirical evidence about communication and the promotion of change can also be important for the development of strategies for achieving practical influence.

We hope that this report will illustrate something of the potential value of both day-to-day and academic philosophy for healthcare policy and practice.

About this report

The report is organised as follows. Having introduced the project's rationale, aims and approach in this first chapter, in Chapter 2 we provide some introductory background to:

– the current policy interest in more collaborative approaches to public service provision, including healthcare in general

– long-term health conditions and the interest in collaborative approaches to their management.

In the first part of Chapter 3 we introduce the two summary characterisations (models) of collaborative approaches and the definition and measure of patient activation that serve as examples of current thinking about collaborative approaches. In the second part of Chapter 3 we present a critical analysis of some of the ideas that are embedded in – or sometimes taken from – this current thinking.

The critical analysis draws on our discussions with clinicians and patients with practical experience of collaboration. It recognises that summary characterisations of collaborative approaches, and the notion of patient activation, can be useful as signposts towards a direction of travel that we have reason to believe is, in general terms, appropriate for healthcare. However, it also highlights a number of specific concerns. These concerns tend to confirm our initial suspicion that if the ideas reflected in current models of collaborative approaches are promoted as if they are sufficient guides for good practice 'everywhere', or are built into 'measures' that are used uncritically to evaluate practice, they are unlikely to achieve the kinds of healthcare improvement that they are intended to support.

In Chapter 4 we briefly introduce key ideas from philosophical writings on:

– relational theories of autonomy and other personal attributes

– capabilities approaches to thinking about the quality of life.

We then consider how these ideas might be used to help address some of the concerns and questions raised in Chapter 3 about prevailing ways of characterising collaborative approaches to care. Chapter 4 highlights some of the shifts in emphasis and novel possibilities that a relational, capabilities-based view of enabling people to live well with long-term conditions could offer for thinking about key issues relating to collaborative approaches to care.

Chapter 2:
Background

In this chapter we provide some introductory background to:

– the current policy interest in more collaborative approaches to public service provision, including healthcare in general

– long-term health conditions and the interest in collaborative approaches to their management.

Collaborative approaches in public service provision

The idea of 'collaborative working' is now well established in a range of policy contexts.[14] A variety of terms are used (for example, 'partnership working', 'co-production', 'assets-based service provision'), and different issues are emphasised in different settings. However, the underlying idea represents something much more significant than a series of policy fads. Several major social trends have converged on the idea that it can be helpful to think of public services and the staff responsible for delivering them as working with people and helping people to help themselves rather than as simply doing things to and for them.

The basic argument is that if service providers recognise and develop people's potential to help themselves, they both show those people more respect and potentially achieve more – for the people themselves and for society more generally. In contrast, if service providers offer only 'professional' fixes for needs or problems, and if people must continue to present needs or problems if they are to continue to be eligible for help, service provision will tend to perpetuate needs and problems and will miss opportunities to harness people's own potential to improve things.[14]

Ideas such as partnership, participation or involvement, and the recognition of service users' own 'assets' (not just material resources) are applied at the levels both of communities or groups and of individuals. This project focused on the level of individuals: we were primarily concerned with the ways clinicians work with people with long-term conditions to address their particular issues. This report does not, therefore, consider the involvement of communities or service users more collectively in the design and redesign of services.

Interest in collaborative approaches to healthcare at an individual level has been stimulated by a combination of concerns about (previously) prevailing approaches and recognition of opportunities arising from technological development and social change.

One persistent concern over the past half century has been that clinicians often behave towards patients in ways that seem excessively paternalistic. In response to this concern, respect for patients' autonomy emerged as a key principle of healthcare ethics.[15] Related (broader) concerns about a lack of respect and compassion in the delivery of care have prompted the development of notions of patient- or person-centred care. These notions emphasise the importance of treating patients as unique and whole human beings (rather than treating diseased body components), and of ensuring that care is oriented to serve the needs of patients rather than the convenience and interests of clinicians or service provider organisations.[16-18]

Another persistent concern has been that of continually rising demand for healthcare, fuelled not only by changes in population demographics and technological developments that increase the scope of what can be done about health issues, but also by supply-side drivers and cultural changes that raise expectations.[19]

Recognition of the issues of expectations, and of the fact that people vary in the values that they attach to different kinds of healthcare interventions and outcomes, has led to interest in efforts to ensure that patients are informed in ways that make them confident enough to decline interventions when more is not necessarily better, and more generally to share in decision making about their care.[20,21]

There has also been a growing recognition that many patients (or their family members) could – and would like to – do more in terms of contributing to their healthcare than health services tend to recognise or encourage.[22] Possibilities for patients and families to contribute have increased as information and communication technologies have rendered information that was once the preserve of the professionally qualified much more widely accessible, and as healthcare technologies have become smaller, more portable, simpler to use and cheaper, and so more amenable to home use.[23]

All these concerns and developments – and others not mentioned in this brief overview – have prompted attempts to ensure that healthcare provision somehow better respects people's interests in living their lives on their own terms, and recognises and facilitates their efforts to participate in, or contribute to, their care. In addition to efforts to improve the quality of their healthcare experiences, they have supported the representation of patients as more autonomous, active and empowered citizens or consumers,[22-26] and highlighted the ways in which patients can and should be valued as 'assets' and active partners in healthcare.[22,26]

Many advocates believe that collaborative working between health service providers and those they serve can lead to improvements in the outcomes of services. Advocates can also increasingly point to improvements in cost-effectiveness – not least because of the huge potential to avoid the waste that can occur when services do not engage effectively and meaningfully with individual patients' particular agendas.[27-29]

Interest in collaborative working extends across the range of healthcare provision but there has been particular interest in the context of long-term conditions, where ideas about collaborative approaches have been developed with some particular emphases. We turn to these conditions now.

Long-term conditions and their management

Increasing numbers of people are living with at least one long-term health condition, such as asthma, dementia, diabetes, epilepsy, HIV/AIDS, Parkinson's disease, renal disease and some cancers.[30,31] Long-term health conditions are not curable: people must cope with them for the rest of their lives. Some of these conditions have a gradual onset and fluctuating symptoms, so clinicians and patients are often uncertain about diagnoses and prognoses. Long-term conditions have complex and dynamic implications (especially when they co-occur within one person). These implications can be hugely significant for many aspects of people's lives.[32,33]

Because long-term conditions generate a range of problems that can last (and change) over years and decades, people who have them can need various (and sometimes multiple) forms of care and support at different times. The rising prevalence of long-term conditions, and the sometimes unpredictable chronicity of the needs that they generate for care and support, raise important challenges for service provision and for societies more generally.[19,33,34]

In recent decades it has become increasingly clear to policy makers and service leaders that the kinds of services and approaches to healthcare that were developed to deal with more acute health problems are neither appropriate for the management of long-term conditions, nor sustainable into the future as these conditions come to account for an even greater proportion of demand for healthcare.[19,32-34] Strategies for improvement need to address a range of issues. For example, the widely cited Chronic Care Model advocates attention to features of healthcare systems (including delivery system design, clinical information systems and decision support) and communities (including policies and resources) and the kinds of support that both can offer for people to self-manage their conditions[34] (see www.improvingchroniccare.org).

The need to develop strategies to encourage and enable the people who have long-term conditions to self-manage those conditions is a common theme in policy and service development. Of course people have to 'manage' in some sense – they must get on and live with their conditions. And, of course, they are still likely to need some professional health service support. The key issues, then, are how well people manage – and manage to live with – their conditions, and how well services support them in this.

Attempts to encourage and enable people with long-term conditions to become more effective self-managers of those conditions have generally focused on two main strategies:

– Educational, training and peer-support programmes that are provided separately from clinical healthcare consultations. These vary in a number of respects. They cover different issues, with different aims, and for different combinations of patient groups. They are delivered via different media, in different organisational and community settings, and with varying (but usually little) connection to patients' usual clinical care.[35]

– Approaches to healthcare consultations in which clinicians put a strong emphasis on supporting people to manage their own conditions rather than encouraging people to rely on clinicians to manage those conditions for them. These approaches, which we are labelling 'collaborative', are sometimes encouraged by education and training programmes for healthcare professionals.[36]

Both strategies can be more or less integrated into larger programmes of health service redesign. This project focused on the adoption of collaborative approaches within healthcare consultations.

Chapter 3:
Collaborative approaches: current thinking

In this chapter we consider the ways that collaborative approaches to the management of long-term conditions are currently characterised and promoted to clinicians. We start by introducing two summary characterisations (models) of collaborative approaches and a definition and measure of patient activation that is increasingly used alongside them. These all serve as illustrative examples of current thinking.

We then present a critical analysis of some of the ideas that are embedded in, or can be taken from, these summary characterisations, definition and measure. Some of the concerns that we identify in this critical analysis are already well recognised and understood, at least in some quarters. Others are perhaps less so.

In Chapter 4, we will introduce some constructive suggestions to help address some of the limitations we identify in the critical analysis presented in this chapter.

The broad collective term 'collaborative approaches' has been used to signal an interest in both:

– the scope people have to participate actively and be influential within formal healthcare encounters about long-term conditions

– the action people take to manage their conditions outside their formal healthcare encounters.

Since our primary aim is to inform thinking about how clinicians work with patients, we concentrate here on what goes on within formal healthcare encounters. We give some consideration to how clinicians might recognise and support what people do to manage their conditions as they go about their daily lives. However, we do not focus in detail on people's experiences of managing their conditions outside formal healthcare encounters.

A variety of terms are used to refer to what clinicians do (or what it is hoped they will do) when they work with people with long-term conditions. The ideas that they will give 'support for self-care' or 'support for self-management' reflect a concern that they will help patients to do well what they need to do outside their formal healthcare encounters. 'Self-care' has been variously defined over the years.[37] Some authors draw distinctions between 'self-care' (usually referring to anything people do to promote any aspect of their health) and 'self-management' (usually referring more narrowly to what people do to control the impact of their long-term conditions),[38] but the terms are often used interchangeably. The idea of 'care of the self' is also sometimes used to encourage attention to what people do for themselves in domains other than health, for example to develop and manage their personal identity.[38] However, the idea that clinicians might give 'support for care of the self' in this sense is not widely used.

Other terms that are quite commonly used include: 'collaborative approaches to care' and the 'co-creation of health'.[1,2] Terms such as 'shared decision making' and 'concordant prescribing', which are used beyond the context of long-term conditions, can also be relevant, as can the variously defined, but usually somehow overarching, 'person-centred care', 'patient-centred care' and other near-synonyms.[16-18,21,40-42]

The different terms stress different issues and suggest different kinds of questions. For example, 'collaborative care' does not present the clinician as the key support for the main actor in the more obvious way that 'support for self-management' does. It also does not imply that 'health' is the main or only goal of care in the way that 'co-creating health' does. The particular connotations of any of these terms can vary across audiences.

The emphases that the particular terms imply, and the questions they generate, can be variously reinforced and answered when the terms are defined and the topics they refer to are discussed. Although they are in some senses only words or labels, the terms that feature in policy documents, professional education materials and discussions about practice can all influence how clinicians and patients think about and experience their interactions with each other, as well as issues in the management of long-term conditions.

Current ideas: focal examples

As previously explained, we developed our critical analysis of current ideas with particular reference to:

– two summary characterisations (or models) that compare 'collaborative' with 'traditional' approaches to the management of long-term conditions

– a definition and a measure of 'patient activation' that are increasingly used to assess patients' readiness for collaboration and/or effective condition management (and thus to evaluate collaborative approaches).

We introduce these now.

Two models of collaborative approaches

A summary characterisation (model) of collaborative care that Thomas Bodenheimer and his colleagues developed[1] is provided in Box 2, and a model of collaborative interactions that the Health Foundation developed subsequently[2] is provided in Box 3.

Both of these models contrast collaborative approaches with approaches that are presented as more traditional or conventional. They portray shifts in a number of domains or dimensions, including what patients and clinicians do to deal with health conditions, and how they interact and relate to each other.

Box 2: Bodenheimer and colleagues' comparison of traditional and collaborative care in chronic illness

Issue	Traditional care	Collaborative care
What is the relationship between patient and healthcare professionals?	Professionals are the experts who tell patients what to do. Patients are passive.	Shared expertise with active patients. Professionals are experts about the disease and patients are experts about their lives.
Who is the principal caregiver and problem solver? Who is responsible for outcomes?	The professional.	The patient and professional are the principal caregivers; they share responsibility for solving problems and for outcomes.
What is the goal?	Compliance with instructions. Non-compliance is a personal deficit of the patient.	The patient sets goals and the professional helps the patient make informed choices. Lack of goal achievement is a problem to be solved by modifying strategies.
How is behaviour changed?	External motivation. The patient makes changes to please the physician.	Internal motivation. Patients gain understanding and confidence to accomplish new behaviours.
How are problems identified?	By the professionals, eg changing unhealthy behaviours.	By the patient, eg pain or inability to function, and by the professional.
How are problems solved?	Professionals solve problems for patients.	Professionals teach problem-solving skills and help patients in solving problems.

Source: Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. *The Journal of the American Medical Association* 2002; 288(19): 2469-2475.

We have chosen these models as good examples of summary characterisations of what is involved in collaborative ways of working. In the second half of this chapter, in 'Critical analysis of current ideas' on page 12, we will discuss some limitations of these summary characterisations, and suggest that they can contribute to uncertainties and problems in practice. We stress, however, that while it is important to maintain a critical attitude, we do not wish to say that these kinds of summaries cannot be useful as preliminary pointers to a general direction of travel, nor that the examples that we focus on are the ones most in need of criticism.

Definition and measure of patient activation

For over a decade, the idea that people with long-term conditions need to be 'activated' with the skills, knowledge and motivation to participate as effective members of their healthcare teams and contribute effectively to the management of their conditions has featured strongly in discussions about health policies.[3,34] The idea behind patient 'activation' is thus a very important and powerful one. Similar and closely related ideas, including for example about 'patient enablement', 'patient empowerment' and 'patient engagement', also feature in policies intended to promote patient safety, and efforts to respect patients' autonomy and improve their experiences of care.[22,42]

Judith Hibbard and colleagues developed a particular conceptualisation of patient activation for people with long-term conditions:

Those who are activated believe patients have important roles to play in self-managing care, collaborating with providers, and maintaining their health. They know how to manage their condition and maintain functioning and prevent health declines; and they have the skills and behavioural repertoire to manage their condition, collaborate with their health providers, maintain their health functioning, and access appropriate and high quality care.[3:p1010]

They used this definition to underpin their Patient Activation Measure.[3] The Patient Activation Measure includes questions that relate to beliefs about active roles, confidence and knowledge to take action, taking action, and staying the course under stress. A shorter version of the Patient Activation Measure, versions for particular clinical settings, and translations into languages other than English have also been published.[43-45]

Box 3: The Health Foundation's characterisation of patient–clinician interactions

Traditional interactions		Collaborative interactions
Information and skills are taught, based on the clinician's agenda	→	Patient and clinician share their agendas and collaboratively decide what information and skills are taught
There is a belief that knowledge creates behaviour change	→	There is a belief that one's confidence in the ability to change ('self-efficacy'), together with knowledge, creates behaviour change
The patient believes it is the clinician's role to improve health	→	The patient believes that they have an active role to play in changing their own behaviours to improve their own health
Goals are set by the clinician and success is measured by compliance with them	→	The patient is supported by the clinician in defining their own goals. Success is measured by an ability to attain these goals
Decisions are made by the clinician	→	Decisions are made as a patient–clinician partnership

Source: The Health Foundation. *Co-creating health (briefing paper)*. London: The Health Foundation, 2008.

Respondents to the Patient Activation Measure are asked to indicate their agreement with statements such as:[3]

– Taking an active role in my own healthcare is the most important factor in determining my health and ability to function (Q2)

– I know the lifestyle changes like diet and exercise that are recommended for my health condition (Q6)

– I am confident that I can take actions that will help prevent or minimise some symptoms or problems associated with my health condition (Q8)

– I have made the changes in my lifestyle like diet and exercise that are recommended for my health condition (Q16)

– Maintaining the lifestyle changes that are recommended for my health condition is too hard to do on a daily basis (Q22).

The Patient Activation Measure is increasingly used for a number of purposes, including:

– to identify the level of activation that particular patients have achieved (to help tailor interventions to support them, and to monitor progress in activation at an individual level)

– to assess and compare levels of patient activation in different populations and over time

– to evaluate interventions or practices intended to promote collaborative working, self-management, and so on.[46–50]

As with the summary models of collaborative care, we will look critically at some aspects of the definition of patient activation and uses of the Patient Activation Measure. Again, however, we stress that the concept of patient activation reflects some important ideas, and the Patient Activation Measure is not necessarily the measure most in need of criticism. The point is that they need to be interpreted critically and used carefully if they are to support, rather than undermine, efforts to promote appropriate and meaningfully collaborative approaches to care for people with long-term conditions.

Critical analysis of current ideas

In this section we discuss a number of concerns about the thinking that is embedded in, or sometimes taken from, the summary characterisations of collaborative approaches and the definition and measure of patient activation that we have just presented. Our critical analysis, developed by philosophical questioning, draws heavily on the discussions we had with clinicians and patients during the knowledge exchange events.

We start by exploring the kinds of problems that can arise with generalisations about many topics. These problems – concerns that the summary characterisations both 'go too far' and 'don't go far enough' – derive from limits to the ways that summary characterisations can reflect the complexities of the 'real world'.

We then look at some more specific concerns, focusing particularly on issues to do with:

– interactions and status differences between clinicians and patients

– goal setting

– patient activation.

Problems of generalisation

Going too far (some features are not appropriate in all situations)

The two models of collaborative approaches presented above are, intentionally, **summary** signpost-type indicators of a general direction of travel. As summaries, they highlight some aspects of shifts from broadly traditional to broadly collaborative approaches. But by highlighting these aspects as key, they almost inevitably downplay other aspects.

Summaries that attempt to characterise complex social practices, and particularly to compare the practices associated with different time periods, places or populations, need to work in generalisations. This almost inevitably means that they have limitations because they cannot reflect the different emphases and nuances that might be important in diverse real-world situations and cases.

Long-term conditions and the technologies that are available to help manage them vary significantly. They can have quite different implications for people's lives and for their potential to contribute to their own healthcare. Health service provision also tends to vary across conditions and, of course, healthcare organisations and their norms of delivery, and clinicians

and their usual ways of working, vary and evolve over time. In addition, healthcare practice is complex in the sense that it is multi-faceted and involves dynamic networks of interactions.

All this makes it difficult to characterise traditional or current approaches to the management of long-term conditions without caricaturing them. It also cautions against offering over-generalised universal recommendations about what is desirable in practice. Given the diversity of patients and circumstances, some variations in practice will be needed to ensure that all patients are appropriately cared for and supported.

As you think through the issues reviewed in this report, it might be helpful to keep in mind people with a range of different conditions, and in a range of social circumstances. The brief descriptions in Box 4 might help as a starting point. More detailed examples and personal stories can be found on a number of websites, including, for example, HealthTalkOnline (www.healthtalkonline.org).

Discussions at our knowledge exchange events confirmed that there is scope to critique the two illustrative characterisations of collaborative care because the ideals they present are not applicable in all cases. More particular issues are discussed below.

The complexity of healthcare interactions cautions us (as the authors of the two summary characterisations do) against viewing the 'traditional' and 'collaborative' approaches that they portray as representing two dichotomous categories with no middle ground.

The diversity of patients and circumstances similarly makes it unwise to assume that the notions of 'traditional' and 'collaborative' will always map directly and straightforwardly on to judgements of 'bad' and 'good'. While the view that collaborative approaches are generally better seems defensible, it is important to leave enough room for a discussion of when, where and why they might not be.

Box 4 Examples of people living with long-term conditions

– Ms A, a well educated and ambitious business woman in her mid-50s, 'got to grips with' her type 2 diabetes very quickly after it was diagnosed. She is adept at monitoring her blood glucose levels and manages to keep these within or very close to recommended levels most of the time. Ms A has recently had two hypoglycaemic emergencies for which she could identify no warning signs or triggers.

– Mr B is a retired manual worker in his early 70s who has chronic obstructive pulmonary disease (COPD) and heart failure. He doesn't say or ask much in his healthcare consultations, mainly because he is trying to avoid letting on to his doctors or nurses that he cannot read the leaflets that they have given him about these conditions. Mr B seems to have lost interest in things and has been struggling to look after himself since his wife died a few months ago.

– Mr C has had two major psychotic episodes, one before he went to university and the other soon after completing his postgraduate degree. Now in his mid-20s, his second statutory treatment order is almost due for review. Mr C believes that he is now better and wants to come off medication, get out of hospital and pursue a career as a teacher. His psychiatrist thinks the condition is probably chronic and is not sure whether Mr C has adequate insight into this.

– Ms D, a woman in her 30s, lost her job recently after being unable to work for 12 months because of (medically unexplained) pain and extreme fatigue. She has consulted with a number of specialists but not found them particularly helpful. Both she and her GP recognise that he has no medical intervention that will cure her, but her monthly 'touching base' with him is now one of the few social contacts she sustains.

– Mr E, a man in his 40s, has been living with a relapsing-remitting form of multiple sclerosis for 12 years. He has been able to earn a bit of money by helping out in his father-in-law's business as and when he can. He has noticed a marked worsening of his energy and mobility over the past 12 months and his neurologist has just diagnosed 'progression' to a secondary progressive form of multiple sclerosis.

Not going far enough (giving an inadequate account of what is required)

Summaries that aim to present a vision for a large-scale shift to a better state of affairs must present ideas in ways that have broad relevance and appeal. They might need to be amenable to various interpretations in order to secure widespread general support. This means that some ambiguity is in some senses a good thing.

However, the ambiguity that can be helpful for communicating the gist of a big idea and for securing a general consensus that the idea is appropriate often obscures important differences of understanding and opinion. Summary characterisations can leave scope for potentially problematic disagreements between policy makers, managers, clinicians, patients or researchers (in any combination) about what counts as a collaborative approach, about how collaborative approaches should be implemented, and about how we might know whether, to what extent and how appropriately collaborative approaches have been achieved.

The possibility that the summaries don't go far enough in terms of specifying what is needed for (or what matters in) collaborative approaches to care is evident in three observations.

– First, several participants in our knowledge exchange events noted that when they introduced ideas about collaborative approaches, some clinicians claimed quite sincerely that they were already using them. These clinicians' descriptions of their practice, however, did not fit with what our participants thought should count as collaborative. The clinicians could interpret their practice as consistent with summary descriptions of collaborative approaches while it fell short of our participants' (implicitly more demanding) interpretations.

– Second, our participants further reflected that some clinicians only really 'got' the idea of what collaborative approaches entailed when they observed examples of these approaches in practice (or role play). Simply giving clinicians the kinds of summary characterisations that we have been considering was apparently not always sufficient to convey what our participants thought was required for meaningfully collaborative care.

– Third, summary characterisations or descriptions of collaborative approaches to care can fail to differentiate between more and less appropriate attempts on the part of clinicians to 'involve' patients in aspects of their care. Several researchers have found that some clinicians manage patients' scope for involvement in a controlling or limiting sense. For example, they might discuss how and when particular treatments are used but not whether and why those treatments will be used, or even whether and why any treatment is necessary.[40,51] These kinds of limitations in the ability of models to differentiate between more and less appropriate approaches to care can leave scope for healthcare professionals to moralise and manipulate patients. This could ultimately tend to devalue ideas about collaborative approaches to care.

The summary characterisations also have limitations because they make a common and often useful simplification by considering only one clinician and one patient in a 'dyad', rather than the whole network of family, friends, multiple clinicians and services within and through which patients move. By missing out the myriad of multi-layered details that make up and shape the contexts of healthcare, they can more clearly draw attention to the key changes that are being advocated when collaborative approaches are proposed. However, if we want to understand the challenges of, and constraints on, achieving that change in practice, we must consider these details carefully.

Our considerations so far have brought us to a point where we suggest the following.

– While there is clearly something important and helpful in the ideas that have motivated the advocacy of collaborative approaches, summary characterisations of these approaches currently have some significant limitations. (Although the summary characterisations that we reproduced above were both accompanied by helpful explanatory discussion and comment in their original presentations,[1,2] these still leave a number of questions and ambiguities unaddressed.)

– If collaborative approaches are to be promoted effectively in practice, the characterisation of these approaches needs to be improved to make it easier for clinicians to recognise what is most different and important about them. (Participants in our knowledge exchange events were also keen that this be done without denigrating clinicians whose claims to be using collaborative approaches 'already' would effectively be denied.)

More specific concerns

We now turn to some more specific issues. As noted in Chapter 1, as we considered the ideas presented in the summary characterisations of collaborative approaches in a bit more detail, our intention was to examine some of the:

– assumptions that lie behind these characterisations

– ambiguities that they leave unresolved

– implications of what they emphasise.

We present the interlinked concerns that emerged from this activity under three headings:

– Interactions and status differences between clinicians and patients

– Goal setting

– Patient activation.

In each case we identify issues that might warrant more attention than they have been given in summary characterisations of collaborative care to date.

Interactions and status differences between clinicians and patients

In large part, shifts from traditional to collaborative approaches are portrayed as changes in what we will call the 'division of labour' between clinicians and patients. For example, Bodenheimer and colleagues answer their own questions about how problems are identified and solved in traditional and collaborative approaches primarily in terms of who identifies and solves problems. They give more of the tasks to patients in collaborative approaches. The Health Foundation's characterisation notes that in collaborative interactions, goals are set by the patient with support from the clinician, rather than by the clinician, and decisions are made as a partnership.

The changes in divisions of labour that feature in current thinking about collaborative approaches are linked to shifts between the two parties in terms of the balance or distribution of:

– knowledge or expertise

– contributions or influence and responsibility for condition management.

To some extent, these changes are associated with particular ways of thinking about patients as more activated – discussed in 'Patient activation' on page 21. They also, however, reflect an interest in seeing clinicians and patients as somehow more equal than they have been seen in more traditional approaches.

We turn now to look critically at these ideas about equality, or reductions in the status differences of clinicians and patients. We focus first on the domains of:

– knowledge or expertise

– contributions or influence and responsibility.

We will then highlight some other forms of equality – and other valued features of relationships – that were alluded to by participants in our knowledge exchange events.

Differences in knowledge and expertise

From the 'traditional' starting position of clinicians having more knowledge or expertise than patients, and assuming we do not want to reduce clinicians' knowledge and expertise, the difference between them can be reduced in two main ways.

– By recognising that patients can develop more of the scientific or biomedical kinds of knowledge about their condition than traditional models of care (and many clinicians) give them credit for, and enabling patients to do this.[52]

– By recognising that patients have different kinds of knowledge to healthcare professionals, and regarding these different kinds of knowledge as somehow of equal value to the scientific/biomedical kinds. (Typically, patients are seen to have experiential knowledge of what it is like for them to live with their condition, and knowledge of themselves, their lives and what matters to them.)[53]

There is something significant in both of these possibilities, but in practice some differences in knowledge or expertise between clinicians and patients are likely to persist. The extent of the differences will, of course, vary considerably and in a dynamic way given the variable implications of long-term conditions, the diversity of people involved, and the long time frames and courses of activity over which salient knowledge and expertise might develop.[52] For example, we might contrast:

– people with conditions that are and are not associated with impairments in cognitive functioning

– people who are more and less educated

– people who are more and less able to access various sources of informational, emotional and social support

– people who have had more and less time to come to terms with their diagnosis.

In addition, we suggest that there is a need to avoid pushing ideas about the extent of patients' knowledge of their own lives and selves too far. People do not have fixed and uncomplicated identities and sets of values, preferences and goals.[54] And their values, preferences and goals, even if expressed and recognised, do not always make it 'obvious' what the best course of action is.[6] It is not unusual for people to have conflicting views and desires, or to struggle to understand themselves and be clear about what matters most to them. The fact that some patients can clearly and confidently identify and articulate goals and preferences cannot be extrapolated simply to mean that all patients can (all of the time). Also, the fact that some patients can do something does not logically imply that all patients will or should do it.

This suggests that policy makers, service managers, clinicians and researchers should continue to recognise, respect and engage with differences in knowledge and expertise – as well as forms of parity – within as well as between groups of patients and clinicians.

Differences in contributions or influence and responsibility

The term 'partnership' features quite often in the advocacy of collaborative forms of care. It not only implies that two or more people are operating together, but also that there is less of a hierarchy between them than might be suggested by other descriptors of social relationships. This is further emphasised when the adjective 'equal' is added and the talk is of 'equal partnership'.[14]

Collaborative approaches in large part reflect a concern to move away from the idea that doctors tell and patients do as they are told. In so doing they aim for a somehow more equal status between healthcare professionals and patients in terms of contribution, influence and responsibility.

Bodenheimer and colleagues present a shift from a traditional view of the clinician as the principal caregiver, problem solver and person with (implicitly sole or full) responsibility for outcomes, to a view of the patient and clinician as (implicitly both or joint) principal caregivers who share responsibility both for solving problems and for outcomes.

The Health Foundation's characterisation emphasises a shift from a traditional view in which patients believe that it is their clinicians' role to improve health to a view in which patients believe that they have an active role to play in changing their own behaviours to improve their own health. The Health Foundation's characterisation also presents patients as potentially influential in deciding what information and skills they are taught.

The language of 'collaboration', 'partnership', 'equality' and 'shared responsibility' has many positive connotations and reflects values that are widely endorsed. However, there may still be very good reasons for continuing to attend to differences between clinicians and patients in terms of their contributions or influence and responsibilities.

Healthcare professionals have socially sanctioned authority over some domains of action, including the prescribing of prescription-only medicines. They also have lines of accountability to their employers and professional bodies as well as to their particular patients. Clinicians' sources of authorisation and forms of accountability are different from those of patients, and clinicians are often concerned about their particular responsibilities when they are asked to work in partnership with patients.[40,55] If the advocacy of collaborative relationships is to be consistent with social reality – and useful in practice – it will be important that these differences are not obscured.

It will also be important to acknowledge that the kinds of contributions that patients can make, the kinds of influence they can have, and the kinds of responsibility they can be given can vary according to a number of factors. In particular, some conditions are less amenable to modification by patients' behaviours than others. For some progressive conditions, there are currently no known ways by which patients can influence health state indicators – especially biomedical or narrowly functional ones.

Experience-based comments about equality in clinician–patient relationships

When participants in our knowledge exchange events described examples of healthcare that they had experienced as collaborative, they mentioned or alluded to aspects of relationships that went beyond ideas to do with the division of labour and shifts in the balance of knowledge or expertise and contributions, influence or responsibility. Issues relating to knowledge or expertise and contributions, influence or responsibility were not completely absent from their descriptions and reflections, but neither were they identified as the features of relationships that most significantly differentiated more from less meaningfully collaborative forms of care.

Participants' experience-based accounts and analyses put much more emphasis on interpersonal attitudes, or how clinicians and patients are disposed towards each other, than the summary characterisations of collaborative care do. They referred, for example, to changes in 'the whole dynamic of relationships' leading to significantly more openness. They particularly stressed the importance of healthcare professionals being genuinely interested in patients, being prepared to be surprised by patients, seeing opportunities to learn from and with patients and, more generally, taking patients seriously.

Participants highlighted the value of patients being able to access and develop what social scientists might call a secure trust[56] in healthcare professionals who listened, were aligned with patients as they struggled with their condition, who could hear patients sympathetically when they needed to say that they just wished the condition would go away, and who could help them maintain perspective, 'contain' the condition and cope. They also highlighted the importance of patients being able to work with healthcare professionals with whom they could be themselves, not have to worry about overcoming potential stereotype prejudices, and not have to work hard to present an acceptable face.

When participants in the knowledge exchange events alluded to equality in relationships, they were often talking about respect or even more broadly about humanity. For example, a patient talked about realising, in a more collaborative encounter, that 'the doctor was human too'. Similarly, a doctor reflected on her recognition of a difference between the way that she usually talked with patients and the way she had talked to a non-medical family friend about a health problem that they had mentioned.

In other words, experience-based discussions about contrasts between collaborative and more conventional approaches reflected reductions in hierarchies in terms of the possibility of more mutually engaged, respectful and reciprocal relations between clinicians and patients. What was talked about was not just a matter of allowing 'soft' and 'touchy-feely' concerns into healthcare encounters: participants were referring to different ways of seeing and being with each other. These ways of seeing and being with each other could reflect and support a significant shift from some current practice. They could be related to fundamental questions about professionalism and the purposes of healthcare.

The moves towards more mutual respect and the kinds of partnership working that knowledge exchange participants highlighted could occur despite the persistence of some (complex) differentials in knowledge or expertise and contributions, influence or responsibility. But attention to issues of knowledge or expertise, contributions, influence and responsibility could still be significant for the deeper senses of equality. Notably, clinicians' recognition and cultivation of patients' knowledge, expertise, contributions, influence and responsibility in the management of their long-term conditions (including in the context of activities such as collaborative goal setting) could serve in part to signal that they care about and respect patients and engage with them on the basis of their mutual humanity.[57,58]

As we will see in the next section, this point about what might be regarded as the 'side effects' of task-oriented communication is not always explicitly recognised when patient-led goal setting is advocated in summary characterisations of collaborative approaches to care.

Before we move on, however, we want briefly to highlight the paradox that this section reflects. When collaborative approaches to care are thought of in terms of new divisions of labour and distributions of attributes such as knowledge, expertise, influence and responsibility, attention is drawn to questions of who does and who has what, and the separateness of clinicians and patients is emphasised. The processes and experiences of collaboration, and of relationships within social units, tend to be obscured. This paradox may contribute to some of the concerns about the obscuring of key features of relationships, mentioned above in 'Problems of generalisation' on page 12.

Goal setting

As noted above, the two summary characterisations that we are considering both regard goal setting as a key activity in the management of long-term conditions. Both also present a shift in the 'division of labour' for goal setting as a key feature of the shift from traditional to collaborative approaches.

Interest in the idea that patients, rather than clinicians, should lead goal setting can reflect a number of beliefs and commitments. These include:

– health services should be responsive to diverse individual patients and their particular needs

– health services should encourage and enable people with long-term conditions to manage those conditions

– what patients want from healthcare, and what they value and prioritise in terms of the management of their condition, might differ from what health services and clinicians are set up to provide and support

– people are often more motivated and more likely to achieve goals that they have set for themselves than goals that have been imposed on them by others.

In general terms, these beliefs and commitments seem important and likely to command a broad consensus. However, it is not immediately obvious either how they all hang together or that patient-led goal setting is necessarily the best – or even always a good – way of reflecting them in practice.

A few linked questions can highlight something of the complexity and need for caution about patient-led goal setting. We will explore two particular issues shortly, but encourage you first to reflect at least briefly on these questions for yourself – perhaps keeping a range of patients in mind as you do so (see, for example, Box 4 on page 13).

– Why is it important to shift the division of labour in goal setting from clinicians to patients, and what might be the risks and costs of doing so?

– Is it always helpful, and practical, for patients to think explicitly about goals (especially specific, measurable, achievable, realistic and time-defined (SMART) goals) and to assume responsibility for setting them?

– What kinds of goals might patients be inclined to set, and how and why might these differ from the kinds of goals that clinicians might be inclined to set?

– What kinds of 'support' is it appropriate for clinicians to give patients during their goal setting processes? How is clinicians' support for goal setting differentiated from clinicians' goal setting?

– Are there limits on the kinds of goals that can be considered appropriate or legitimate?

– Are clinicians or health services practically and ethically bound to work towards whatever goals patients set?

– Are there any overarching goals, or broader purposes that need to be kept in mind over and above any specific goals set by individual patients?

We do not propose to answer all these questions, but we assume that your own reflections will lead you to agree that the promotion of patient-led goal setting

is likely to need some qualification, and that its implications need careful consideration. We focus here on two particular issues:

– the possibility of tension between patients' and health services' or clinicians' goals (or more general aspirations) for healthcare and condition management

– the possibility that a focus on explicit, patient-led goal setting can obscure the purpose of collaborative approaches to healthcare.

Potential tensions between patients' and clinicians' goals

As already noted, proposals to shift the division of labour in goal setting from clinicians to patients can reflect a recognition that what patients want from healthcare, and what they aspire to in terms of condition management, might differ from what health services and clinicians are oriented to give.

The idea of patient-led goal setting opens up the possibility of a shift away from professional- and service-led agendas (which are often assumed to be conventionally biomedical) towards agendas that cover a broader range of concerns that patients might have about their conditions and about the implications of their conditions for their quality of life. It also opens up the possibility of agendas that are more personalised in the sense that they reflect what matters specifically to particular patients, rather than what might matter generally to (most) people with similar conditions.

The 'management' of long-term conditions can be understood as being oriented towards different kinds of ends. For example, we might think in terms of:

– 'biomedical management' oriented to monitor and control disease progression and to limit the risk of disability and death (for example, for people with diabetes, efforts to keep blood glucose levels within recommended limits to reduce the risk of peripheral neuropathy and its complications)

– the broader management of the unwelcome impact of the condition and its treatment on the person's life (for example, for people with recurrent migraine the prescription and use of medications that can limit the severity and duration of activity-limiting symptoms; or for people on long-term anticoagulant medication, the use of self-monitoring technology that can reduce the need to schedule and travel to multiple healthcare appointments)

– the still broader business of living as well as possible according to one's own values and reasons while having the condition (for example, for a person with unexplained pain or fatigue, persisting to complete a project of personal significance; for someone with mobility difficulties, sustaining visits to a much-loved elderly relative; or for someone with newly diagnosed epilepsy, overcoming a fear of stigma to participate in a personally valued social activity).

In practice, clinicians, as well as patients, often recognise that these ends are interlinked and not always easy to distinguish. Disease progression and disability will, in many cases, increase the level of intrusion of a condition into a person's life. However, the mapping is not necessarily always direct and linear. For example, a person with diabetes may be able to keep their blood glucose levels tightly controlled (managing their condition well in a way that reduces disease progression and limits the risk of disability and death) but only by sticking to very rigid daily routines that limit their possibilities for enjoying impromptu and more adventurous social activities.

The relative emphasis that is put on the different kinds of ends could appropriately vary across situations, and 'good' condition management will probably support progress towards all of these kinds of ends. Clinicians and patients might see a need to work towards several ends concurrently, balancing them together and perhaps shifting emphases over time (including with the progression of patients' conditions) and across healthcare settings. The different kinds of ends, however, suggest different possibilities for collaborative working and they pose different challenges for clinicians and for patients.

A number of health policies and features of the way that healthcare is organised are geared to support what we are calling biomedical management. For example, there are clinical guidelines, service standards and performance assessment and financial reward systems that promote the regulation of blood glucose levels in people with diabetes. Of course, some health services and clinicians, most obviously those associated with palliative care, are less concerned about disease progression and quite routinely attend to symptom management and seek to alleviate the negative implications of treatments. And some health services and clinicians, most notably those associated with rehabilitation, aim more broadly to support people to function in ways that allow them to pursue their own particular life projects. But tensions can and do arise quite often when the realities and priorities of patients' lives are not well aligned with professional and service norms.

These tensions are, in part, linked to the professional responsibilities and accountability of clinicians that are built in to legal and policy frameworks and the structures and processes of healthcare organisations. These 'systems features' have not been fundamentally changed to fit with the advocacy of more collaborative working, and the norms embedded within them can tend to work against the adoption of collaborative approaches to care.

This means that to implement collaborative approaches, it will not suffice to simply 're-programme' clinicians to overcome their traditional 'conditioning' to take responsibility for deciding on courses of action and then hold themselves fully accountable for what happens to patients. The social organisation of healthcare provision presents more complex challenges. Serious attention needs to be paid to clinicians' multiple accountabilities, the sometimes inconsistent pressures that these generate, and the ways in which clinicians can experience them as deterrents to or constraints on patient-led goal setting and more collaborative working more generally.

While it seems appropriate to give individual patients at least some scope to influence the kinds of ends that they pursue for themselves and the ways that healthcare helps them towards those ends, it also seems appropriate to put some boundaries around the kinds of ends that clinicians and health services support and the means by which they do this. For example, we might expect health services to help an athlete to manage their long-term condition in ways that facilitate their participation in elite level sport, but not to take over – or even ensure – the provision of sport-specific coaching, kit or opportunities to participate in major competitions.

Yet questions about what health services and clinicians should do when patients' goals are not consistent with generally recommended biomedical indicators or health-related behaviours, and questions about how the roles and responsibilities of health services and clinicians should be circumscribed for people with long-term conditions, have been relatively neglected.

Current characterisations of collaborative approaches to care might be contributing both to the obscuring of the potential tensions that are created by the promotion of patient-led agenda or goal setting, and to the neglect of questions about the purposes and scope of healthcare and about the responsibilities and accountability of clinicians. This is in part because biomedical agendas and professional and service norms are to some extent embedded within these characterisations, with the assumption that these

biomedical agendas and professional or service norms will or can persist despite the introduction of patient-led agenda or goal setting.

Because the proposed shift to patient-led agenda or goal setting has been presented as a change in who does something, rather than as the introduction of a new activity, its implications have perhaps been assumed to be less far-reaching than they might be. But a change in who does the agenda or goal setting in healthcare also changes the activities themselves, because it changes the ways in which they are linked to other activities, including by virtue of the different concerns of the actors involved.[59] The shift can therefore be practically problematic in ways that go beyond questions of whether people can understand and execute a few tasks in isolated abstraction from the rest of their activities and roles.

Current models of collaborative approaches seem to retain some commitment to a conventional (implicitly biomedical) agenda, and to favour goals that are oriented to promote this even though they promote patient-led agenda or goal setting. For example, Bodenheimer and colleagues hope that *Ideally, patients …[will] come to agree with their physician's delineation of the problem'* and set goals addressing unhealthy behaviours.[1] The Health Foundation's characterisation envisages patients believing that they have an active role to play in changing their own behaviours *'to improve their own health'*.[2] This, and the goal of co-creating health, are ambiguous because the term 'health' can notoriously be used to pick out both narrow, disease-relative biomedical concerns and much more open-ended concerns related to positive personal wellbeing. The Patient Activation Measure (which we discuss further in 'Patient activation' on page 21) assesses patients' self-rated knowledge, skills and confidence to adhere to clinical recommendations relating to their condition(s).[3]

Potential tensions between particular patients' priorities and the more general goals of healthcare systems will not be easy to resolve, either for clinicians (who in their daily work are potentially pulled in two directions by the imperatives of collaborative care as currently presented) or at a more collective or societal level. While aspects of human life other than health very often matter to patients and can be widely recognised as valuable,[60] health services are intentionally oriented to improve health, and the pursuit of biomedical markers will often be helpful in addressing health issues, although it might sometimes (especially by some means) clash with the pursuit of other ends that matter.

We are not aiming to resolve these tensions here – although we will highlight some possibilities for thinking them through in the next chapter. Our main concern in this section has been to draw attention to some important uncertainties and ambiguities about the scope and purpose of healthcare that the promotion of patient-led agenda setting can raise. These uncertainties and ambiguities have been relatively neglected in discussions about collaborative care, but warrant careful thought and debate.

The idea introduced with collaborative approaches to care that agenda and goal setting should be undertaken by patients at an individual level paradoxically makes the need for an explicit public discussion about the boundary between what does and does not fall within the remit of health services more urgent.

Potential to obscure an important purpose of collaborative working

The second main issue that we want to raise in relation to the strong emphasis that current characterisations place on goal setting is the possibility that this emphasis tends to obscure the intrinsic value of collaborative working.

It is possible to argue that the value of collaboration is at least in part intrinsic. To illustrate this, we invite you to imagine that you have decided to spend time tomorrow with a friend. If we were to ask you 'What is the goal of you spending time with your friend?' you might think the question a little odd, but you could probably answer by telling us about an activity you plan to do (such as watch a film or go shopping). If, however, we were to ask you 'What is the goal of the friendship?' you might find the question more problematic because it seems somehow to miss the point. Friendship is valuable in its own right and we don't have to think of it as having any further goals or purposes to recognise that. You might well 'get something out of' your friendships (and more obviously out of your planned activities with friends) but the purpose and value of friendships cannot be adequately captured by questions that assume that their value is instrumental for something else.

We are not saying that clinicians and health services exist primarily to befriend people, but we do want to stress that one of the kinds of value that can inhere in collaborative healthcare relationships is more akin to the value that inheres in friendship than to the value that derives from the activities that friends engage in or the tangible achievements of those activities.

Support for the idea that collaboration between clinicians and people with long-term conditions can have intrinsic value was evident in our discussions with people with positive experiences of collaborative working. It is also supported by other accounts of what matters to patients about healthcare delivery. People's experiences of feeling respected, cared about, trusted and supported feature strongly in what they think matters about healthcare delivery,[5,61] and they value feeling that clinicians are aligned with them or 'on the same side'.[57] Collaborative approaches to care offer patients the potential to experience supportive relationships with clinicians – to experience and benefit from 'support'. Similar kinds of things can be said about 'respectful' relationships or 'respect'.

The intrinsic value of more collaborative working between clinicians and patients perhaps only becomes evident when we think how relationships themselves are, and can be experienced as, valuable. But we are less likely to think about this if our thoughts about collaboration are directed to questions about who contributes what to particular activities (such as goal setting) and to the outcomes that they achieve (such as improved health status).

There are at least two concerns here.

– First, when goal setting is seen as integral to collaborative approaches, and attention is directed to the question of who does it, the collaboration is seen either as a context or as an instrumental means for achieving something else.

– Second, some of the important purposes that collaboration can serve are not appropriately expressed as explicit goals.

There is a strong culture within health policy circles at present of thinking in a fairly linear way about processes and outcomes. This encourages a tendency to think about collaborative approaches to care as processes and health or broader indicators of wellbeing as outcomes. Of course, it can be important to remember that the ways in which clinicians communicate and work with patients have a range of consequences, but we need to additionally recognise the substantial intrinsic value of patients feeling valued, respected and supported within collaborative partnerships if we are not to miss a large part of the point of the shift towards a collaborative approach.

One way of keeping alive the idea that the point of working in partnership might **be** the partnership could be to introduce collaborative approaches to care with an emphasis on personal support as well as on health or wellbeing 'consequences' as an organising purpose. However, it is important to bear in mind the danger that if the intrinsic benefits of collaborative working are highlighted, this might lead to them being 'translated' into the language of goals. There is no reason to suppose that it is helpful to incorporate the intrinsic benefits of collaborative working or the promotion of personal support explicitly within goals that are discussed and agreed by particular clinicians and patients. The experience of partnership might in some senses be an appropriate goal for clinicians to bear in mind, but its achievement is not readily measurable and, furthermore, in many circumstances discussing the experience of partnership as a goal for members of the potential partnership risks undermining the possibility of achieving it.

Patient activation

Collaborative approaches to the management of long-term conditions can place more demands on patients (as well as on clinicians) than traditional approaches. For example, they can assign patients more tasks, expect them to develop and use more knowledge and expertise, and hold patients more responsible for outcomes. Not surprisingly then, there has been significant interest in the idea that patients need to be activated (and that health services need to help activate them) to play their part.

The emphasis on activating patients has a firm basis in valid and important concerns, but caution is needed to ensure that people's legitimate ongoing needs for care from health services are not neglected in the drive to have them do more to help themselves. In particular it is important not to assume that all patients can be activated to the highest levels. For many people with long-term conditions there will be important limits to the extent to which they can be activated to take on the management of their condition(s), and these limits will not be the result of 'shortcomings' in their motivations or moral choices. For example, people with some long-term conditions and/or a history of very limited education might struggle to acquire the range and levels of knowledge and skills required to interpret and take the initiative to respond to fluctuations in their condition. People with some long-term mental health problems and people with intellectual disabilities may – in different ways – need ongoing support with medication management.

We will not dwell on this issue further. Rather we think it is important to consider the way patients and their attributes are sometimes conceptualised within ideas about patient activation. The assumptions that are made about what more people can be enabled to do to help themselves – within their healthcare encounters and beyond – need to be checked carefully.

The definition of patient activation presented above encourages attention to patients' beliefs about their role in condition management, their knowledge about their condition (including how to prevent declines) and their skills and behavioural repertoires for collaborating with clinicians, managing their condition and maintaining their health functioning. The notion of patient activation also encompasses ideas about patients' self-efficacy (confidence in their ability) that features in many discussions about collaborative approaches to care, and questions about confidence feature prominently in the Patient Activation Measure.

On this account, patient activation seems to be understood primarily as a cognitive characteristic of individuals – one that is relatively stable (a person 'has' a level of activation that they are assumed to take with them through different health and healthcare scenarios), but to some degree changeable (because effective support for self-management is intended to increase patients' levels of activation).

This emphasis seems to reflect and invite a view of patients as largely independent agents (albeit agents whose knowledge, skills, confidence and motivations to act can be enhanced). The Patient Activation Measure relies on patients' self-reports of what they believe and consider themselves able, confident and motivated to do. The questions are asked without reference to particular healthcare situations. They do not attempt directly to assess how health services or clinicians might have contributed to what they believe or consider themselves able, confident and motivated to do.

The strong cognitive and individualistic emphasis of some presentations of patient activation risks reflecting and fostering a neglect of the importance of both clinician–patient relationships and the material and social realities of people's lives.[62] The social arrangements (including cultural norms) within some health services and clinician–patient relationships can work against patients' activation. For example, consultations are sometimes constructed in ways that leave little scope for patients to have a say,[63] and the ethos in some services renders patients and family members fearful to speak up even when they have concerns about their safety.[64]

The material and social realities of many people's lives can impose significant constraints on their abilities to manage and live well with long-term conditions. Several studies of people's experiences of managing long-term conditions have highlighted how people with fewer social and material resources in particular are often unable to act as collaborative approaches might advocate.[65,66]

Attention to social realities, including those that operate within healthcare, is important both to ensure health services are appropriately responsive to people and their particular needs, and to address social inequalities in the determinants of health and wellbeing.

The particular cognitive and individual behavioural emphasis of the definition and measure of patient activation could also foster neglect of other key aspects of patients' 'management' of their conditions. Although they draw attention to patients' confidence and motivation for condition management for health improvement, they do not consider the broader senses in which patients feel able to cope with their condition(s). As a means of evaluating clinicians' support for patients' self-management, the Patient Activation Measure is unlikely to detect, for example, the kind of difference a supportive clinician might have made to how a patient feels about themselves – within the clinician–patient partnership or beyond. Yet for some long-term conditions in particular, this kind of difference can be quite significant for the person's (and others') sense of how they are doing.

Questions also need to be asked about the normative aspects of current ways of thinking about patient activation. Patients' motivation, which is treated as a key part of activation, can be understood and assessed in ways that are more or less tied to (and therefore judgemental about) particular goals. People might be differently motivated to act to promote different aspects of their health and broader quality of life. As discussed in the previous section, questions arise about how any discrepancies between what they are motivated to do and what health services or clinicians would prioritise feature in assessments of their motivation.

Patient activation is often understood and currently measured in ways that prioritise clinical recommendations for health over other aspects of quality of life. This probably reflects the normative judgements that were built into the established definition and measure presented above because of the way they were developed. The authors of the definition explain that they developed it by considering what it would take for people to become effective and

informed managers of their health and care. They examined literature that investigated what kinds of skills, knowledge, motivation and confidence are needed to manage long-term conditions 'successfully', and apparently focused on particular health status outcomes as indicators of success.[3]

Some discussions of patient activation can also be criticised for being unduly naïve about the extent to which patients can benefit from – and the extent to which their autonomy is respected by – the promotion of gains in knowledge and skills for condition management, together with the kinds of opportunities to exercise them that would be offered within collaborative approaches to care as they are currently described. The concern arises because of the ways current ideas neglect the values and norms that are embedded within patients' social contexts. Patients (and clinicians) come to healthcare encounters with the 'baggage' of habits, expectations and preferences that have been strongly shaped by their socio-cultural exposures. These can pertain to what goes on within and beyond healthcare encounters, and they will not be easily adjusted or adapted by information provision and skills-based training.

A note about contrasts

Before turning to resources from the philosophical literature that could help us think further about some of the concerns we have outlined in this chapter, we reflect a little on why the summary characterisations are as they are. Apart from the sheer necessity of some kind of simple 'signpost' style accounts for communicating policy directions, we want to mention and note some implications of two reasons for the prevalence of these kinds of division or labour- and process-oriented characterisations of collaborative approaches to care.

First, presentations involving two columns with parallel entries facilitate direct comparisons and contrasts between traditional and new (in this case collaborative) approaches. This can, of course, be helpful to show people who are familiar with traditional approaches what kinds of differences are envisaged. But it also means that the characterisations of both approaches must be constructed using broadly the same domains. The risk when presentations of new approaches are made by considering parallels with traditional approaches is that more elements of a traditional mindset get 'carried across' into the characterisation of the new approaches than is helpful. In the case of characterisations of collaborative approaches to care, a sometimes implicit continuing emphasis on narrowly biomedical health goals might be one of these elements.

Second, it is relatively difficult to talk concisely and authoritatively about the subtle, deeper and intrinsically valuable aspects of relationships that we have suggested are neglected in current characterisations of collaborative approaches. In environments where health policy leaders and clinicians have been trained (especially with the rise of 'evidence-based' approaches) to think in terms of entities that can be precisely described, replicated and measured, it is not obvious how, for example, to:

– present a view of relationships as something more than a practical interaction between two fundamentally separate individual agents

– talk about the 'ends' of healthcare for patients in ways other than either standardised biomedical outcomes or the goals that an individual patient chooses to specify

– recognise and represent individual patients and their possibilities for agency as in part constituted by their contexts

– appeal to the 'humanity' of patients or to the idea of 'moral equality'.

In the next chapter, we introduce ideas from the capabilities approach and relational understandings of autonomy that we think are among the conceptual and theoretical resources that can help to meet some of these challenges. They will not provide 'magic' solutions, and they are not the only conceptual-theoretical resources available,[39,60,67] but we believe they have potential that is worth investigating.

Chapter 4:

Enabling people with long-term conditions to live well: potentially helpful shifts in thinking

In this chapter we first briefly introduce ideas from philosophical literature about:

– relational theories of autonomy and other personal attributes

– capabilities approaches to assessing the quality of human lives.

We indicate some of the ways that these ideas have already been found to be useful for thinking about healthcare policy and ethics. We then illustrate how relational theorising and ideas about capabilities suggest fresh ways of thinking about clinical support for people with long-term conditions. We focus particularly on how they can help address some of the concerns identified in Chapter 3 about the tendencies of current characterisations of collaborative approaches to care to:

– focus on task-oriented interactions and status differences between clinicians and patients to the neglect of the deeper features and significance of relationships

– emphasise goal setting to the neglect of broader considerations of the purposes of healthcare and collaboration in condition management

– emphasise patient activation in a strongly individualistic way to the neglect of broader considerations of social circumstances.

Relational understandings of autonomy and other personal attributes

What is autonomy and how can clinicians 'respect' it?

The concept of personal autonomy is often invoked in calls for clinicians to work more collaboratively with people with long-term conditions and to support their self-management of those conditions. Personal autonomy is associated with ideas about being one's own person, developing and following one's own life plan, and acting in accordance with one's own reasons and values.[8,68] Living autonomously is contrasted with living under other people's control and/or acting under influences that work against one's own best reasons and values.

Personal autonomy is widely valued. Concern that it can be undermined by paternalistic healthcare practices led to the development of the ethical principle that clinicians (and health services) should respect patients' autonomy.[15]

However, when people have tried to say more precisely what personal autonomy is, or to explain just how anyone can have it, the concept has proved quite difficult to pin down.[69] Conventional ideas about what clinicians need to do to respect patients' autonomy have recently been subject to important criticisms.

Early attempts to specify the conditions and characteristics of personal autonomy focused strongly on the 'internal' psychology of individuals. One, for example, suggested (albeit in more technical language) that a person was acting autonomously if they were acting on desires that they had confirmed

(to themselves) that they wanted to have.[70] These early attempts were strongly criticised by philosophers who recognised that people are inevitably and often deeply influenced by their socialisation and social circumstances.[69] Theories of autonomy that focus on 'internal' psychology can fail to take adequate account of the various and complex ways that socialisation and social relationships can affect people's beliefs, desires and values, and of the fact that people may not always be aware of these influences. They can lead to people being wrongly classed as acting autonomously when they are acting under significant social pressure.[8]

Conventional ideas about what clinicians need to do to respect autonomy have focused on decisions about healthcare interventions and stressed that clinicians should respect individual patients' autonomous choices.[15] Autonomous choices are conventionally defined as choices that are made deliberately, by competent patients with sufficient understanding and sufficient voluntariness or independence from the influence or control of clinicians or others.[15] This focus has tended to restrict thinking about autonomy to a limited range of patients (those deemed competent as decision makers) and situations (those which are recognised as decision junctures).[71] It has also tended to obscure the value (or even legitimacy) of some important forms of professional support for patients' decision making.[4,6,40]

Relational accounts of autonomy and their advantages for healthcare

A number of philosophers have subsequently developed accounts of autonomy that:

– better reflect the various ways that socialisation and social relationships can influence people

– can help overcome the limitations of the conventional focus on, and thinking about, how clinicians can respect patients' autonomy.

These accounts, which are collectively known as relational accounts, 'emphasise the role that background social dynamics and power structures play in the enjoyment and development of autonomy'.[72] They also recognise 'the ways in which, as agents, our practical identities and value commitments are constituted in and by our interpersonal relationships and social environment'.[73: p519] Two examples are briefly summarised in Box 5.

Box 5: Two examples of relational accounts of autonomy

Diana Meyers suggested that we should understand personal autonomy as the possession and exercise of skills related to self-discovery, self-direction and self-definition, and the use of these skills to achieve an integrated but dynamic authentic self. She stressed that the 'repertoire of skills that make up autonomy competency' are developed through socialisation (for example under the influence of parents and teachers) and then shaped by social experience in a broad range of interactions.[72]

More recently, Catriona Mackenzie proposed that we should understand a person's autonomy not just as a matter of them having a sense of who they are and of what matters to them, but also as a matter of them having a sense of themself as the legitimate source of normative authority over their life. This sense, which is associated with attitudes of self-respect, self-trust and self-esteem, is developed and sustained in part by other people's recognition of the person's claim to normative authority. It is therefore also dependent on social attitudes and other people's behaviours towards the person. Mackenzie builds on this point to argue that clinicians might be obliged to promote patients' capacities for autonomy, including if necessary by working to shift patients' attitudes so that they can see themselves as a source of normative authority over their lives.[73]

Relational accounts of autonomy arguably have several advantages in comparison to the conventional emphasis of thinking about how clinicians can respect patients' autonomy. These advantages include the following.

– They offer scope to include people who are not deemed competent as decision makers within the protection of an ethical principle of respect for autonomy.[8]

– They can acknowledge the importance of, and give in principle legitimation to, clinicians' interventions to support patients' autonomy as well as their efforts purely to respect it in a 'hands off' kind of way.[6,73]

- They encourage us to look behind and beyond decision situations in which patients are (or might be) presented with options relating to their healthcare, and to see a broader range of ways in which health services can constrain or undermine patients' autonomy. This includes, for example:

  - how the option sets that are offered to patients sometimes omit or obscure valid and potentially valued options[55]

  - how health service norms can become unnecessarily oppressive or at least unduly restrictive of patients' behaviour[74,75]

  - how clinicians who are dismissive of patients' reports or concerns can limit patients' potential for autonomy[7,76]

  - how clinicians who fail to attend to difficulties that patients might have enacting their own plans for health-related behaviour change can be missing opportunities to support and respect those patients' autonomy in their life beyond healthcare encounters.[77]

The practical value of relational accounts of autonomy is to some extent independent of their philosophical merits, and it is not necessary to agree with all aspects of any particular account to find it helpful to think about the various ways in which a patient's autonomy can be affected by different aspects of healthcare as well as by their other relationships and broader social situations.

Relational thinking about other personal attributes

The kinds of concerns that relational theorists have expressed about 'internal' psychological accounts of autonomy can also be relevant to some prevailing ways of thinking about other personal attributes – including 'activation' and others that feature in thinking about collaborative approaches to healthcare.

In recent decades, philosophers and theorists working in a variety of domains have raised concerns that some of the ways of thinking about people that are incorporated within influential philosophical ideas and cultural ideals are based on untenable assumptions and have unacceptable implications.

The details vary but many critiques centre on conceptions of people that assume that they are all free agents who act without any dependence on others and primarily on the basis of reason, which they use, for example, to transcend cultural norms and work out what is the right thing to do (if we are talking about

ethics) or to prioritise their desires and maximise their desire satisfaction or utility (if we are talking about psychology or economics). These conceptions of people as self-sufficient and narrowly rational actors are not always explicit, but they lurk within academic, policy and popular discourse on a wide range of topics.

Critics point out the following.

- It is unrealistic and inappropriate to view most people as unconstrained by their bodies or broader material contexts, able to act unencumbered or unaided by interpersonal relationships, and isolated from broader social structures and norms.[8,72]

- A complex range of influences on, and experiences of, self and identity are salient to moral judgement and action.[77]

- Unrealistically narrow idealisations of persons are problematic not only because they reflect and encourage limited understandings: they have also been (often unintentionally) a source of oppression.[68]

The proposed 'relational' solutions or re-conceptualisations of people and their attributes also vary, but in general terms they seek to take seriously and incorporate in a more thoroughgoing way the diverse range of people's lived experiences as:

- vulnerable to bodily change, fragility and limitations

- exposed to a variety of more and less readily identifiable social and cultural influences

- socially interdependent, entwined in networks of relationships with others

- having complex and sometimes competing sets of desires, demands and so on

- not fully self-transparent (not having complete insight, for example, into what motivates them)

- having to participate in, or find a way through, unchosen as well as chosen situations and events.

The kinds of attributes that need to be understood relationally include a broad range of capabilities that can matter to people. We consider these in the next section.

Capabilities: what matters for the quality of human lives

The capabilities approach is an approach to thinking about the quality of human lives. It can be linked to ideas that have a long history in philosophy, but it has emerged much more recently in writings about human development and social justice as a way of considering how advantaged or disadvantaged people are.

Two leading authors, Amartya Sen and Martha Nussbaum, have developed different variants of the capabilities approach, and many others are now actively engaged in clarifying and refining accounts of it, as well as applying it in practice. The key features that we summarise here can be recognised in most descriptions of the approach,[9,10,79] and for ease of reading, we talk in general terms. For those with a particular interest, however, we note that in this report we lean more towards Sen's writings than Nussbaum's. This is because we are interested in the value of a range of capabilities that might be identified as important by different groups of people and in particular circumstances, and we are interested in considering the possession of capabilities above minimum threshold levels.

The main concepts of the capabilities approach are 'functionings' and 'capabilities'.

- **Functionings** are doings or ways of being, such as preparing meals, being literate, working as a teacher, or being a respected member of a community.

- **Capabilities** are the real freedoms, opportunities or powers that people have to achieve particular functionings.

The key idea of the capabilities approach is basically that what makes for good lives is having capabilities for valued functionings. The approach simply encourages us to think, when we are considering the quality of people's lives, about the extent to which they are genuinely free and able to be and do what it matters that they are able to be and do.

There are several features of the capabilities approach that we wish to highlight because they can be helpful for thinking about collaborative approaches to healthcare.

The capabilities approach offers a space for consideration of what matters to people

The capabilities approach offers a broad evaluative space with potential for structured but flexible consideration of what matters to people. It offers scope for thinking very broadly about people's quality of life because it can matter that we are able to be and do a wide range of things.

There are important and linked questions that must be answered when using the capabilities approach to develop evaluative frameworks.

- Which functionings should count as 'valued', and so which capabilities should be considered or assessed?

- Who should decide this, and how?

These questions are still subject to much debate. Good arguments can, however, be made for both more general and more personal considerations being brought to bear on judgements about what it matters that someone is able to be and do, especially when thinking about the quality of life above very basic levels.

Capabilities for some functionings can be recognised as widely valued because they are deemed essential for human flourishing and/or are foundational for many other capabilities. These 'basic' or 'central' capabilities might include capabilities to be well nourished, literate and be socially respected. Other, usually more specific, capabilities might be valued (or valued very strongly) by, or for, a relative minority of people.

Evaluative exercises conducted for different purposes might appropriately focus on different sets of capabilities.

The capabilities approach emphasises personal freedom

The capabilities approach emphasises the importance of personal freedom. Its proponents have usually been careful to avoid imposing particular (especially narrow) ideals on everyone. Several features of the approach support the maintenance of this emphasis. In particular, the distinction between capabilities and functionings, and the emphasis on capabilities in the assessment of advantage (especially above basic thresholds) supports a recognition that often it is important not only that someone is able to do something, but also that they can be left free not to do it.

Recognition that capabilities are socially shaped

Consistent with the relational thinking that we introduced in the previous section, the capabilities approach has been developed with recognition that a person's capabilities are dynamically shaped by interactions between that person and their environment. Physical geography, legal arrangements, social policies, cultural norms, material resources and interpersonal relationships are all taken seriously as potential influences on a person's capabilities.

Some capabilities depend very heavily on social relationships, at interpersonal and/or broader levels. For this reason, the persistence (or security)[80] as well as the development of a person's various capabilities can be socially shaped, so capabilities can be understood as not fully within a person's control. For example, a person who develops some capabilities for negotiation in the safe confines of a support group for people with

long-term conditions might find themself lacking those capabilities in a consultation with a clinician who is determined to stick to a particular agenda and conclude the consultation promptly. A person's capability to be a respected member of their local community depends on the attitudes of other community members towards them, which may in turn depend on cultural stereotypes and behavioural norms as well as on the behaviours of the person concerned.

Because it treats a person's capabilities as socially shaped and (at least in part) situationally constituted, the capabilities approach is said to incorporate a relational, rather than an individualistic, ontology of persons and their capabilities.[81]

Capabilities are dynamically interconnected

Functionings and capabilities can be specified at different levels (for example, capability to work, capability to work as a surgeon, capability to perform a particular complex operation). They are often interconnected in a range of ways (for example, a capability to read can support a capability to navigate an unfamiliar town using signposts, to study, and to hold down many kinds of jobs).

A person might need a cluster of component capabilities to ensure a more complex capability. For example, the capability to prepare a meal for one's family depends on being able to access food and tools for cooking it, having knowledge and skills, interpersonal proximity and a position within the family from which socio-cultural norms allow the development and exercise of food preparation responsibilities. These ideas are potentially very useful for thinking about capabilities for managing long-term conditions, and also about priorities for support for the development of capabilities.

Similar input does not guarantee similar capability development

The concept of 'conversion factors' is often used in writings about the capabilities approach. Conversion factors are the things that affect how readily a person can convert particular resources, forms of support or basic capabilities into (other) valued capabilities. For example, a person who is unable to walk but has a wheelchair that they can use to get around will not be able to 'convert' the resource of their wheelchair or their (generally) enhanced capability for mobility into

a capability to participate in civic life if all the buildings in their town, including those where civic meetings are held, are only accessible via steps.

An insistence that each person counts

The capabilities approach takes individual human beings as the ultimate concern of moral thinking. Its proponents usually insist that a problematic shortfall in one person's capabilities cannot be compensated by particularly high levels of capabilities in others. This contrasts with approaches sometimes used in healthcare that evaluate interventions on the basis of their average effects.

The capabilities approach is starting to be used for work on health and social care policy and services, particularly to consider issues of justice in healthcare.[82,83] Several researchers have recognised that what people say matters to them about what services achieve for them can usefully be understood in terms of capabilities,[84] and are developing capabilities-based outcome measures for service evaluation purposes.[85-87] Capabilities thinking has also been used to help explain why features of the way healthcare is delivered can be so important,[5] and to refresh thinking about the concept of person-centred care, including to ensure that it can be relevant for people with limited cognitive capacity.[41]

We now turn to consider more closely how capabilities thinking and relational understandings of autonomy and other personal attributes might help address the concerns about current thinking on collaborative approaches to the management of long-term conditions that we identified in Chapter 3.

Potential contributions of relational and capabilities-based perspectives

Both the capabilities approach and relational understandings of autonomy and other attributes of persons encourage careful consideration of the ways patients can be supported (or not) by clinicians (as well as by others, and by their broader environments) to manage and live well with their long-term conditions. They can offer new perspectives on some practically significant issues. They can also suggest a language and conceptual–theoretical framework that might help make more visible some of the valuable insights that were incorporated in what patients and clinicians told us of their practical experiences but that are not well reflected in current characterisations of collaborative approaches.

In what follows we pick up the key concerns from Chapter 3 relating to:

1. interactions and status differentials between clinicians and patients

2. goal setting

3. patient activation.

We discuss these under three 'parallel' headings that reflect some of the shifts in emphasis that relational and capabilities-based perspectives suggest:

1. relationships between clinicians and patients

2. the broader purposes of collaboration and healthcare

3. enabling patients and addressing contexts.

The issues considered under these three headings are interlinked, and we acknowledge some overlap between the sections.

As noted in Chapter 1, what we present here is only an initial exploration of the possibilities that might be developed using relational thinking and the capabilities approach. We regard what we offer as an agenda of ideas for further consideration rather than a fully worked-through treatise on the topic. Some suggestions for further development of this work are outlined at the end of the chapter.

Before we proceed, we stress that it is not necessary to accept the 'whole' of either any particular relational theory of autonomy or any particular version of the capabilities approach to make the kind of use that we are suggesting could be made of the ideas about relationality or the concept of capabilities. We are assuming only that:

– capabilities for many valued functionings can be considered among what matters for quality of life

– each person's capabilities for valued functionings matter

– capabilities, including those for autonomy and for particular personal identities, are in large part socially shaped and constituted.

We would also like to summarise some of the implications that, we suggest, relational theories and a capabilities approach have for understanding people and, in particular, for the assumptions about people that it is appropriate to adopt. They highlight:

– the diversity of people, and that people can be thought of as differentiated by the particular sets of capabilities that they value and that they have[88]

– the importance of understanding that people's valuation and 'possession' of particular capabilities are to some extent socially (including situationally) dependent (in other words, people's capabilities are not all fully in their own control)

– people's identities are not wholly individual or separate but are also in part socially constituted.

As we turn to think about collaborative approaches to care, then, it is worth remembering that relational and capabilities-based perspectives encourage us to recognise that when people work with others, it is not just what they achieve as the outcome of particular tasks that is 'co-created', but key aspects of the characteristics that we often think of as particular or personal to them. These include aspects of their identities and some of their capabilities (and 'activation') to work collaboratively and on particular self-management tasks.

Relationships between clinicians and patients

Relational theorising about how autonomy and other personal attributes are constituted encourages us to consider what features of relationships are significant for what people can do and who they can be. It invites us to ask, for example, what it is about relationships that matters for how respected and supported people are, and for which particular personal characteristics and identities they can (be seen to) have. Relational theorising prompts us to look, for example, not only at the ways that clinicians and patients divide up particular tasks and work together on those, but also at the deeper and more subtle aspects of their relationships.

Relational theorising treats clinician–patient relationships not just as a context for important activities, and not just as instrumentally important combinations of actors. Because it treats these relationships as fundamentally implicated in – even constitutive of – patients' experiences, relational theorising can help illuminate the **intrinsic** value of 'collaboration' and 'partnership'.

Relational theorising can also help us to acknowledge and understand the significance of the 'ways of seeing and being with each other' that participants in our knowledge exchange event alluded to as key. People experience their personal status and identity within relationships. The fine-grained aspects of the ways

clinicians relate to (or **are** with) patients can reflect and communicate their attitudinal orientations to them. Their ways of being and relating signal how they regard and 'position' patients. These ways of being and relating can thus shape how a patient experiences being treated (or not) as, for example, a valued and respected fellow member of the human community, a moral equal, and someone who not only has particular interests but who is a source of normative authority over their life.

Of course, what patients bring to their relationships with clinicians also has implications for the shaping of those relationships. The links between participants' capabilities and the relationships they participate in can be understood as dynamic, two-way interactions. As we will discuss further in 'Enabling patients and addressing contexts' on page 35, both the participants and their interpersonal relationships also need to be understood as dynamically shaped by their broader social contexts and by other relationships that the participants are engaged in.

Although all participants will contribute somehow to the shaping of their relationships, the structural features of healthcare provision, patients' likely future needs for professional clinical expertise, and prevailing social norms mean that clinicians are usually more readily able than patients to influence their relationships. Patients' capabilities to experience 'good' (for example, respectful and supportive) relationships are therefore at least to some extent dependent on clinicians. This idea is reflected by the fact that patients who have experienced effective and supportive collaboration with one clinician can find themselves lacking the capability for such collaboration in subsequent encounters with different clinicians.

People who generally have fewer or limited capabilities, for example because of the knock-on implications of intellectual disability, poor education, or significant material deprivation, are perhaps even less likely than most to drive the shaping of clinical relationships that can enhance their capabilities.

Relational thinking about capabilities has useful potential for the development of ideas about how clinicians can respect the humanity of people who generally have fewer or more limited capabilities. It can be used to help identify ways of treating them as morally significant agents while still paying appropriate heed to their particularities.[41] For example, if a person has limited capabilities to reason about something, clinicians can still treat them in ways that recognise what capabilities they do have. They can also strive to

develop those capabilities further (and certainly not to undermine them) in any interaction that involves reasoning with (or relating to) them.

Recognition of the intrinsic value and broad implications of good and supportive clinician–patient relationships could be seen as an argument in support of the continuity of relationships over and above the kind of informational and condition-management continuity[89] that might be experienced within a series of encounters with coordinated healthcare professionals. Certainly some capabilities to experience supportive relationships, to develop secure trust and to exercise autonomy can only be developed over time, especially in people whose past experiences give grounds to lack trust, and/or in whom autonomy capabilities are not generally well established. Relationship continuity can thus be very important. However, there is also substantial scope for enhancing the quality of more short-term or 'one-off' relationships if we are alive to their intrinsic and not just their narrowly instrumental value.

Patient–clinician relationships are, of course, not the only relationships that matter for patients' capabilities, for example, to develop and maintain self-respect, to have identities that they value and to exercise autonomy and agency. These relationships can, however, be particularly important. For some people with long-term conditions, clinical encounters are a significant part of their lives and they can significantly moderate how people's self-respect, identity, autonomy and agency are affected by their long-term conditions. For example, the ways in which healthcare professionals communicate and relate to people with conditions that are potentially stigmatising, especially when they are first diagnosed, could be quite influential on their capabilities to develop identities that they are comfortable with as people with those conditions.[7,90]

The broader purposes of collaboration and healthcare

The ultimate goal of healthcare for people with long-term conditions is arguably, in general terms, to help them live well with those conditions. The capabilities approach suggests a particular way of thinking about what it means to live well with long-term conditions: it encourages reflection on the questions of whether and to what extent people with long-term conditions are able to be and do what it matters that they can be and do.

Consideration both of what it **matters** that people are able to be and do, and of what they actually **are** able to be and do, will typically incorporate some consideration of issues relating to health. The capabilities approach can,

however, represent quite a re-orientation of thinking for anyone who has been used to considering and assessing quality of life largely in health-related terms.

Some things that are conventionally thought of as health issues can also be quite readily thought of in terms of capabilities or functionings. We might talk, for example, about capabilities to avoid or to treat pain, to walk or otherwise get around, and to experience emotions without being blighted by severe anxiety. And although advocates of the capabilities approach sometimes talk of a capability to be healthy, or a capability to be free of malaria or other (usually preventable) diseases,[9] other health issues, especially those that are discussed in terms of biomedical markers or diagnostic labels, do not translate so obviously and directly into capabilities. (Their links to capabilities become more obvious if we ask about their consequences or implications.)

More significantly for this report, there are various capabilities for valued functionings that are unlikely to be considered as health issues. These include, for example, capabilities for employment, capabilities for political and social participation, and a cluster of capabilities that can be associated with the notion of being recognised and treated 'as a person' (including capabilities for autonomy and capabilities to experience respect and compassion).[41] The conceptual relationships between health and capabilities are the subject of ongoing philosophical investigations[83,91] that we will not examine here. Rather, we will continue to focus on the question of which capabilities can be associated with living well with long-term conditions.

The precise content of any list of capabilities that might be identified as valuable for a good quality of life for people with long-term conditions will depend on how and by whom the list is constructed, and which of various possible ways are chosen to describe and group particular capabilities. The relative importance or value attached to any particular capability is also likely to vary, both across groups of people with different kinds and combinations of conditions and across individuals with different conceptions of what is a good life for them.

This project was not designed to develop a formal list of capabilities of importance for people with long-term conditions, but we can offer some initial thoughts about the kinds of capabilities that might feature on such a list, and the implications these might have for healthcare provision in general, and for collaborative approaches in particular.

The capabilities associated with living well with long-term conditions can be specified at various levels and grouped in different ways. Picking up on the idea we introduced in Chapter 3 that the 'management' (including self-management) of long-term conditions can be understood as being oriented towards different kinds of ends, we might, for example, consider:

a. capabilities to manage long-term conditions in ways that reduce disease progression and limit the risk of disability and death

b. capabilities to manage, more broadly, the unwelcome impact of long-term conditions and their treatment on daily life

c. capabilities for the still broader business of having a life that is experienced as valuable.

And, although they could be considered within the above categories, given the focus of this report it might also be helpful to think particularly about:

d. capabilities to access and 'manage' healthcare (including support to help develop and sustain the capabilities in sets a, b and c)

e. capabilities to experience supportive healthcare relationships

f. capabilities associated with being recognised and treated by others 'as a person'.

Sets d and e, and e and f, are closely interlinked.

As with any applications of capabilities approaches to particular policy issues, or to evaluations of particular kinds of service, further work is needed to identify which particular capabilities should be cultivated and/or assessed. Questions might be asked, for example, about the following.

– Which of these capabilities matter (most) to whom and why?

– How are they linked?

– Which is it realistic to expect to develop, to what extent, in what time frame, with what kinds of support?

– Which can health services impact on (positively or negatively)?

– Which matter and can potentially be enhanced by healthcare providers, and which (if any) should healthcare providers focus on for other reasons?

These questions could be tackled in a variety of ways. We do not aspire to provide a full set of answers here, but offer some initial thoughts about how consideration of capabilities might contribute to thinking about:

– the scope of health service provision

– the ways that clinicians can support people with long-term conditions

– the quality of healthcare.

Thinking about the scope of health service provision

The question of which valued capabilities it should be the business of health services to positively support is an important one. Saying that healthcare activity is ultimately oriented to improve quality of life does not entail believing that health services should do everything that could possibly be done to improve quality of life, however quality of life is defined. As the example of the elite athlete in Chapter 3 illustrated, it seems inappropriate to expect health services to optimise everything that could appear on any list of capabilities that might be valued by people with long-term conditions.

It is beyond the scope of this project to resolve debates about the purpose and boundaries of healthcare, but we hope that what we have said so far illustrates that the capabilities approach offers significant conceptual and theoretical possibilities for clarifying and taking these debates forward. In particular, capabilities thinking invites us to identify and lay out the broad range of potential purposes or implications of healthcare in terms of (capabilities for) valued functionings. In principle, it allows us to attend to everything that it matters that people can be and do. This can help us to consider multiple possible purposes and implications of healthcare within a common framework, and one that avoids us having to count everything that is good as health or, alternatively, having to pit health against not health.[60]

As we look down the above list (from a to f), the capabilities referred to are both less readily associated with health and less usually seen as things that it is the business of healthcare to address. The capabilities in sets a and b are arguably the ones that policy makers and clinicians have tended to focus on when thinking about health service support for people's self-management of their long-term conditions – although they have not generally thought of them in terms of capabilities.

As mentioned in Chapter 3, some services and clinicians also quite routinely help people with issues that can be associated with the capabilities in set c. This is the set that will attract more attention in debates about the scope

of health service provision, especially if the balance of service provision shifts more strongly towards providing for the needs of people with long-term conditions, if proposals to integrate health and social care provision are successful, and if the promotion of patient-led goal setting is sustained. But the opportunities for (or obligations of) service providers to positively support the development of some of the broad range of capabilities that would feature in set c are likely to be contested and will need careful consideration and discussion.

The 'boundary' between sets b and c is open to interpretation, in part because people might disagree about what counts as 'daily life', and in part because people's capabilities to have the kind of life that is experienced as valuable will often be shaped by other factors in addition to their long-term conditions. And because people's conceptions of a good life (and so of what it takes for them to experience their own life as valuable) vary, set c will probably include a range of more and less idiosyncratic capabilities. Opinion will be divided about which of these can be (reasonably and generally) recognised as valuable, and about which should be supported by health or other services.

The question of whether health services should help to develop more sophisticated capabilities that are valued by some but not all people is a version of a longstanding challenge in political philosophy: the question of how to deal with 'expensive tastes' when considering justice in distributions. Within the philosophical literature relating to the capabilities approach, questions are being asked about how much weight should be given to individually prioritised capabilities in relation to collectively agreed capability priorities, especially when what individuals prioritise might not be accommodated within collectively agreed priorities. Considerations of the remit of particular services and of how, and how well, they are funded will also be relevant to questions of which capabilities they should support.

The provision of meaningfully collaborative approaches to healthcare can itself be understood at least in part as a matter of positively cultivating the capabilities in sets d, e and f. We say a bit more below about the value of considering these capabilities.

Thinking about how clinicians support people with long-term conditions

Ideas from the capabilities approach can not only refresh thinking about questions about the scope of health services provision. They can also suggest new directions for thinking about the ways clinicians can work to support people with long-term conditions.

While there might be advantages to clinicians thinking about the broad range of patients' capabilities that they might help shape, as we suggested in our critique of the current emphasis on goal setting in Chapter 3, we do not think that it is necessarily appropriate for clinicians to focus only on those capabilities that patients explicitly articulate as goals. We also think that it may be inappropriate to make some valuable capabilities the focus of explicitly articulated goals.

When clinicians **are** discussing explicit goals with patients, the distinction between capabilities and functionings is potentially very useful – perhaps especially when clinicians want to promote capabilities to manage conditions in ways that are generally recommended to reduce disease progression and limit the risk of disability and death. A focus on securing and perhaps assessing capabilities rather than functionings could help avoid the oppressive imposition of professional or health service organisational values on individual patients.[92]

It might also be useful for clinicians to recognise that a cluster or network of component capabilities will often be needed to make up the complex capabilities for managing long-term conditions in all the disease-limiting, life-impact-limiting and broader living well senses (sets a, b and c). Exactly which capabilities are important and how they are connected will vary across long-term conditions and also within groups of people with the same long-term condition. Discussions between clinicians and patients about strategies for achieving condition-management capabilities might therefore need to explore a range of possibilities. Attention to people's particular 'conversion factors' and to the ways that capabilities are related could help inform their judgements about which capabilities should be attended to as priorities.

Attention to capabilities, and especially those in sets d, e and f, can also help us reflect the suggestion made in Chapter 3 that in some senses the purpose of clinicians working in partnership with patients is the partnership. If we accept the value of capabilities to access and manage healthcare, capabilities to experience supportive healthcare relationships, and capabilities associated with being recognised and treated by others 'as a person', then a case might be made that not all healthcare encounters need necessarily to focus strictly on the patient's health (especially not in a narrow, disease-relative sense). Attention to these capabilities can help us see that some important support might be going on even when clinicians are spending time with patients and **not** working directly towards capabilities in sets a, b or c.

When a relationship between a patient and a clinician arises because of the patient's long-term conditions, addressing those health conditions and (at least some of) the problems they present is a key purpose of that relationship. However, once the relationship is established, it may be appropriate – and important – for the clinician to be interested in a broader range of aspects of the patient's life, even if they are not responsible for attending to them directly in practical terms.

Although clinician–patient relationships must have something to do with the patient's long-term conditions (or health), it is hard to sustain good relationships if the focus of all encounters is always narrowly defined. Perhaps especially in the context of long-term conditions, relationships between clinicians and patients will fall short of what is possible if clinicians do not take a genuine interest in what matters to each patient for their broader quality of life. Put more strongly, if they do not take such an interest, clinicians risk undermining valued capabilities of types d, e and f.

In other words, as we suggested above in 'Relationships between clinicians and patients' on page 29, consideration of the implications of service provision for a range of valued capabilities might encourage a more nuanced consideration of what matters and why, and might help ensure that features of clinician–patient communication and relationships are taken seriously and as potentially of **intrinsic** value.

Ideas about service quality

If the purpose of healthcare is seen as the positive cultivation of particular capabilities, then the effectiveness of services will be judged at least in part in terms of its impact on those capabilities. The same applies to the purpose and evaluation of clinical support for, or collaborative approaches to, the management of long-term conditions.

But even if health services or collaborative approaches are not primarily oriented to positively develop all of the valued capabilities that contribute to quality of life, the fact that these capabilities contribute to (or part constitute) quality of life suggests that it will be important at least to ensure that services do not undermine them. The capabilities lens allows us to consider the undermining of any of these valued capabilities during healthcare provision as unwanted side effects of intervention, or even as safety shortfalls in service provision.

Attention to the ways in which services and clinicians can potentially undermine capabilities in sets e and f in particular can help explain what is going wrong in some of the instances in which clinicians claim to be using collaborative approaches but seem to be somehow falling short of the kinds of practice that are likely to be experienced as meaningfully collaborative by patients.

This point is illustrated in Box 6. Harm to patients' capabilities to experience treatment 'as persons' are perhaps more likely to be avoided, and meaningful approaches to collaboration more likely to be enacted, if services recognise, and staff are alert to, the importance of these capabilities.

Box 6: What goes wrong when clinicians claim to use collaborative approaches but control the agenda to pursue biomedical targets?

Sometimes clinicians who claim to use collaborative approaches 'involve' people with long-term conditions in discussions, for example about how and when they will take particular medications and/or adopt particular lifestyle changes, but seem somehow to fall short of what experienced advocates think matters for collaborative approaches. The good intentions of these clinicians need not be doubted, and what they do might be consistent with published models of collaborative approaches and with notions of patient activation. A few more details can start to reveal how they might fall short of more demanding aspirations.

Sometimes clinicians can be seen to be 'managing' patients' involvement to support the pursuit of biomedical treatment targets.[40,51] This can reflect a tenacious commitment to limit disease progression and reduce the risk of disability and death in the patient populations they take responsibility for. The clinicians might also express strong commitments to maintaining relationships with their patients for the benefit of their health: they hope that by 'chipping away' with reluctant patients they will eventually 'win them round' and convince them to act to limit disease progression and reduce risk.

Several authors have recognised that these clinicians effectively deny the patients a significant say in whether, and by what kinds of means, their conditions will be treated.[51] Although, in some senses, they might allow or enable patients to set their own goals, they only open up a very limited subset of intermediate goals for negotiation. Perhaps encouraged by policies and guidelines promoting healthcare 'effectiveness' according to 'evidence-based' standards they seem to see (and leave) little scope to reflect anything other than narrowly defined health goals, regardless of what the patients might want, reflecting their potentially broader conceptions of health and wellbeing.

Thinking in terms of relationally shaped capabilities can help us to take the analysis of these kinds of situation further and suggest what might be needed for a more ethically robust conception of collaborative care.

– First, clinicians who insist that patients behave in particular ways and/or achieve particular biomedical targets can be understood as insisting on the demonstration of particular **functionings**. They might be less prone to deny important patient freedoms if they were to shift their concern to that of ensuring that the patients had the capabilities for those functionings (and could make their own assessment of the value of those functionings).

– Second, it is not just the patients' scope to influence the identification and setting of goals for their own health and care that these clinicians are limiting. They are also likely to be restricting their patients' opportunities to experience a clinical relationship as supportive, and to be undermining their patients' capabilities for autonomy (including, for example, by potentially reducing their self-trust and sense of self-worth).

These clinicians might be strongly oriented to secure benefit for the patient, for example to reduce the risk of significant disability or premature death, but their approaches to 'involving' patients to secure that benefit might themselves be damaging to other valued aspects of the quality of people's lives. Overall, they might achieve less than could be achieved, and (perversely) even do more harm than good. In certain instances, a case might also be made, on the basis of the above ideas, that such clinicians are acting unjustly or unethically.

In current policy climates, there is significant interest in assessing (measuring) all aspects of service quality. The assessment of capabilities raises particular methodological challenges, but these are not necessarily insurmountable, and progress is being made to address them in healthcare and other contexts.

Enabling patients and addressing contexts

As we have noted previously, there is some resonance between the ideas behind the current interest in activating patients to enhance their management of their long-term conditions and the ideas built into the capabilities approach. However, the different emphases of the capabilities approach, especially when its relational ontology is highlighted, have some significant potential advantages for thinking about collaborative approaches to care.

We noted above that because the developers of the established definition and measure of patient activation relied on research evidence of what contributes to improvements in particular health status outcomes for people with long-term conditions, they built in particular norms and limited the potential applicability of the definition and measure to support thinking and assess the practice of patient activation. Thinking about patients' capabilities for valued functionings gives more scope to recognise that particular health norms are not always the only or the most important orienting purpose of healthcare for people with long-term conditions.

In this section, we highlight the potential advantages that the capabilities approach and relational theorising can offer efforts to implement meaningfully collaborative approaches because of the kinds of assumptions about people and their attributes that they embody and promote. In particular, we suggest that they could help to counter the problematic (and paradoxical) tendencies within some work to focus strongly on patients' cognitions, skills and individual behaviours, and to rely (usually implicitly) on assumptions that people can and do operate more or less as isolated individuals.

We start by considering how relational understandings of capabilities might suggest a need to expand thinking about and beyond patient activation. We will then comment briefly on the implications of this for thinking about – and addressing – patients' social contexts, including the social contexts of healthcare encounters.

Patient activation and more

The established definition and measure of patient activation draw attention to patients' knowledge, skills, confidence (or self-efficacy) and motivation. These are clearly important for patients' capabilities to manage both their long-term conditions and the support they might receive from health services and clinicians, and we do not want to imply otherwise.

Our concern about the strong normative emphasis that the established definition and associated measure place on particular aspects of health (and behaviours associated with those) could probably be overcome to some extent by revising them in the light of answers to questions about the domains of knowledge, skills, confidence, motivation and behaviour that matter for people's capabilities to manage and live well with their long-term conditions.

Ideas about confidence or self-efficacy could perhaps also be developed a bit further in other respects. The recognition that people need more than knowledge to be able to manage long-term conditions has been important for improving support for self-management in the past few decades. So again we stress that we are not suggesting that confidence or self-efficacy are irrelevant. What we do think is that they need to be understood relationally, and that they might usefully be integrated into broader thinking about relevant capabilities. For example, confidence or self-efficacy might be understood as:

– the perception someone has of their own capabilities

– a constituent of a capability (when the functioning in question is only achievable with a sufficiently positive self-perception).

In both cases, it might sometimes be appropriate to talk in more specific terms about confidence or self-efficacy for particular functionings and in particular kinds of situation.

It is also important to remember that other attributes can also matter for people's capabilities to live well with long-term conditions. Some of these might be seen to be covered by the broad categories of knowledge, confidence, skills, motivations and individual behaviours once the domains of these are expanded, but for now we will mention:

– people's (capabilities for) self-esteem, self-trust and recognition of themselves as a legitimate source of normative authority for their lives (which relational understandings suggest can be key for the development and exercise of personal autonomy)

– positive mood, or at least the absence of disabling depression (which is arguably likely to feature in many people's conception of a good life).

In addition, relational theorising usefully reminds us that patients' knowledge, skills, confidence and motivation, and other attributes, are not fully malleable and in the control of the patients themselves. Although we often think of them as attributes of persons (because individual people 'have them' in different forms and to differing extents), they are at least in part a dynamic product of the contexts in which people live and act.

Patients' social contexts (a): home and daily life

Relational theorising about people and their capabilities can prompt us to look behind and beyond people's knowledge, skills, confidence and motivation for self-management. It can help us to recognise and think how clinicians and others who seek to support them might attend to the material and social realities of people's lives and the implications of these for their capabilities to manage and live well with long-term conditions.

Attention to the past and present life circumstances of particular people with long-term conditions could help both clinicians and policy makers, service managers and researchers think more carefully and responsively about which capabilities these individuals value and can realistically acquire.

Relational theorising about autonomy highlights the ways in which people's beliefs, values and ideas about what it might mean to live well with long-term conditions are themselves likely to be socially shaped. Questions of whether, when and how services and clinicians (or others) might be justified in trying to shift these values and ideas (for example to raise people's aspirations about the kind of quality of life they would like to, and could, achieve) are notoriously difficult – but perhaps better recognised and grappled with than ignored. The key point to remember is that relational accounts insist that individuals should not be seen as if their potential for learning and action starts from a blank canvas.

It is also important to recognise that people will not necessarily be able to articulate what they value and want, or to anticipate the kinds of capabilities for self-management they might come to need. Clinicians might need to enable people to anticipate and prepare, rather than just react to what patients say they need and want.[52,66]

Relational theorising also tends to emphasise that if clinicians want to check the adequacy of support that they or others are giving patients to manage their long-term conditions, they will need to consider their patients' capabilities in their particular contexts. This is likely to require going beyond asking the kinds of questions that feature on the Patient Activation Measure, especially if patients might have reason to inflate their self-reports.

Consideration of **how** patients' capabilities are socially shaped and constituted is likely to be a practically fruitful form of enquiry, both for clinicians who aspire to collaborative approaches to condition management and for researchers and others who investigate practice with a view to informing quality improvement. Relational thinking suggests people's capabilities can be supported (or undermined) in a variety of ways by features of 'context'. Indeed, they suggest that context can part constitute some capabilities.

The idea of 'conversion factors' is a useful reminder that different people will need different kinds of support to manage and live well with their conditions, and this may depend heavily on features of their home and daily life situations.

All these ways of recognising the complex range of personal and social factors that can contribute to patients' capabilities to manage their conditions suggest that meaningful clinical support for these capabilities can be highly demanding of the creativity and skills of healthcare professionals. Effective clinical support is likely to require not just persistence and persuasive communication, but social and social–psychological awareness, and skills to facilitate and engage in collaborative and patient-context-specific problem solving (which will require attention to the particularities of the patient's life including from the person's own perspective).

Relational capabilities perspectives are not only important at the level of clinical practice encounters with particular individual patients. Both cumulatively, and by informing community-oriented and larger-scale interventions they could help contribute to efforts to attend to, understand and address social inequalities in healthcare, health and quality of life issues.

Patients' social contexts (b): healthcare encounters

It is important to recognise that health service structures and the particularities of healthcare encounters (including relationships with staff) are themselves influential contexts for patients. They can have significant implications for who patients can be and what they can do within them.

Features of healthcare provision have been shown to limit some of the very capabilities that healthcare policies want to activate patients to develop and exercise. For example, in the context of efforts to improve the safety of healthcare, patients are exposed to various educational messages that tell them to 'speak up' about any concerns that they have about their condition or care. In practice, however, patients' (and their family members') observations of the apparently uncaring attitudes of overstretched staff, their prior experiences of having their efforts to engage in discussions discouraged, and their fears that if they 'challenge' the staff they depend on then their future care will be jeopardised, can all limit their confidence and motivation (and broader capabilities) to 'speak up'.[64]

The potential for healthcare to undermine capabilities that healthcare policies seek to promote is perhaps greatest when we consider the capabilities we put in set f above, for example to feel respected and able to engage in healthcare relationships as moral equals.

Reflections on the ways in which previous healthcare encounters, as well as features of the current situation, might have shaped what patients are able to do and who they feel able to be have a number of implications. For example, they suggest that clinicians who are experiencing challenges with particular patients should think not just in terms of difficult patients but also in terms of difficult encounters – with patients whose behaviours might in part reflect previous experiences of poor (or non-collaborative) healthcare.[93]

Clinicians' contexts

Although the capabilities approach is used primarily to think about quality of life and the relative advantage or disadvantage people experience in their lives as a whole, it might also be fruitful to think about the capabilities that it matters that clinicians have for their professional roles – and the extent to which people working as clinicians have (or lack) capabilities that matter. Attention is, of course, already paid to clinicians' knowledge, skills and competencies, but this does not necessarily always reflect a recognition that clinicians' capabilities, like those of patients, are dynamic and socially and relationally shaped.

Legal and policy frameworks, professional norms and organisational structures and processes can all constrain what clinicians are able to be and do in particular clinical situations. Clinicians' capabilities can also be influenced by the particularities of the patients (and families) they are working with. Relational capabilities perspectives could thus be useful for analysing how

clinicians do and could work with people with long-term conditions. They could therefore help inform the development of training and support for clinicians, and of quality improvement efforts oriented to encouraging the adoption of collaborative approaches.

Suggestions for further work

Our exploration has further convinced us of the potential usefulness of ideas from the capabilities approach and relational thinking. However, many of the possibilities that we have outlined in a preliminary way will need further development if they are to be useful for professional education and quality improvement applications.

An agenda for further investigation and development work could include the following.

– Empirical work to examine which capabilities can matter, and why, to people with long-term conditions, and how these capabilities are shaped and could be enhanced via clinical (and other) support. It will be important to attend to the potentially different emphases that people with diverse and often multiple long-term conditions place on particular capabilities – in general and in the contexts of their healthcare encounters.

– Methodological work to develop and examine the implications of different ways of assessing valued capabilities and identifying what health services contribute to these.

– Theoretical–philosophical work to further elucidate ways of relating capabilities to health and to quality of life.

– Theoretical–philosophical work to develop and examine potential justifications for different views about which capabilities health services should support. This would include addressing questions of how and to what extent the provision and prioritisation of health service support should be tailored to the particularities of individual patients.

– Theoretical–philosophical and empirical work to examine questions of when it is appropriate to aim to ensure capabilities and when to aim for (or insist on) the achievement of functionings.

– Public policy debate about the purpose(s) of healthcare for people with long-term conditions. Ideally, this will be ongoing and both informed by, and contributive to, the previously mentioned empirical, methodological and theoretical–philosophical work.

– Consideration of how thinking about clinicians' relationally shaped capabilities could inform developments in professional education and service development work. (This could be one way of addressing the need that has been recognised by the Health Foundation and others to attend to healthcare systems and the broader context in which healthcare professionals work.)

– Practice development and empirical work to investigate where, how and in what ways the ideas examined in this report could be put to effective use.

We will say just a little about the last point before closing. The discussions during our knowledge exchange events demonstrated that relational theories of autonomy and capabilities thinking had a strong resonance for a small group of clinicians and patients who had significant experience of meaningfully collaborative approaches in practice, and who were already committed to using these. However, it is not clear whether and how this thinking will resonate for clinicians who do not have that experience and commitment. The question of where and how the ideas that have been outlined could be put to effective use will therefore need some careful investigation. The answers might well vary across healthcare settings and for different healthcare professionals and patients.

We suggest that further work on the philosophical ideas could usefully be integrated with work on the issues of communication and practical change – investigating the possibilities of 'translation' between applied philosophy and healthcare policy and practice. The obvious challenges are how the kinds of ideas rehearsed here can be made more accessible and realised in practice given existing cultural norms and service constraints. In addition to the general issues of social and institutional change, some specific challenges come to the fore. For example, we will need to ask the following.

– Which aspects of the language of 'capabilities' or 'relational' thinking can work at an everyday level?

– How might ideas about capabilities and relationally constituted attributes have to be 'boiled down' or 'repackaged'?

– If simplifications are needed, how far are the potential contributions of the ideas diluted or lost in the process?

It is, of course, also important to remember that the same challenges face relational and capabilities thinking as faced the developers of the prevailing summary characterisations of collaborative approaches discussed in Chapter 3. The potency of ideas can easily be lost in translation and there is a tendency for 'new thinking', once it is made compatible with dominant agendas, to be incorporated in ways that simply reinforce existing models of practice. We state this not because we are pessimistic but rather because we are convinced of the potential real-world value of the analysis offered here and, for that very reason, we believe it is essential to be realistic about the challenges of translation.

References

1 Bodenheimer T, Lorig K, Holman H, Grumbach K. Patient self-management of chronic disease in primary care. *JAMA* 2002 Nov 20;288(19):2469-2475.

2 The Health Foundation. *Co-creating health (briefing paper)*. London: The Health Foundation, 2008.

3 Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health Serv Res* 2004 Aug;39(4 Pt 1):1005-1026.

4 Entwistle VA, Cribb A, Watt IS. Shared decision-making: enhancing the clinical relevance. *J R Soc Med* 2012 Oct;105(10):416-421.

5 Entwistle V, Firnigl D, Ryan M, Francis J, Kinghorn P. Which experiences of health care delivery matter to service users and why? A critical interpretive synthesis and conceptual map. *Journal of Health Services & Research Policy* 2012 Apr;17(2):70-78.

6 Cribb A, Entwistle VA. Shared decision making: trade-offs between narrower and broader conceptions. *Health Expectations* 2011 Jun;14(2):210-219.

7 Entwistle VA, Carter SM, Cribb A, McCaffery K. Supporting patient autonomy: the importance of clinician-patient relationships. *Journal of General Internal Medicine* 2010 Jul;25(7):741-745.

8 Mackenzie C, Stoljar N (eds). *Relational autonomy: feminist perspectives on autonomy, agency and the social self*. New York: Oxford University Press; 2000.

9 Sen A. *The idea of justice*. Cambridge, MA.: Belknap Press; 2009.

10 Nussbaum A. *Creating capabilities*. Cambridge, MA.: Belknap Press; 2011.

11 Flyvbjerg B. *Making social science matter*. Cambridge: Cambridge University Press; 2001.

12 Nutley SM, Walter I, Davies HTO. *Using evidence: how research can inform public services*. Bristol: The Policy Press; 2007.

13 Wolff J. *Ethics and public policy: a philosophical inquiry*. Abingdon: Routledge; 2011.

14 Boyle D, Harris M. *The challenge of co-production: how equal partnerships between professionals and the public are critical to improving public services*. London: NESTA; 2009.

15 Beauchamp TL, Childress JF. *Principles of biomedical ethics*. Fifth Edition ed. Oxford: Oxford University Press; 2001.

16 Mezzich J, Snaedal J, van Weel C, Heath I. Toward person-centered medicine: from disease to patient to person. *Mount Sinai Journal of Medicine* 2010 May-Jun;77(3):304-306.

17 Mead N, Bower P. Patient-centredness: a conceptual framework and review of the empirical literature. *Soc Sci Med* 2000 Oct;51(7):1087-1110.

18 Berwick DM. What 'patient-centered' should mean: confessions of an extremist. *Health Aff* 2009 Jul-Aug;28(4):w555-65.

19 Wanless D. *Securing our future health: taking a long term view*. London: HM Treasury, 2002.

20 Stiggelbout AM, Van der Weijden T, De Wit MP, Frosch D, Legare F, Montori VM, et al. Shared decision making: really putting patients at the centre of healthcare. *BMJ* 2012;344:e256.

21 Edwards A, Elwyn G (eds). *Shared decision-making in health care: achieving evidence-based patient choice*. Second edition. Oxford: Oxford University Press; 2009.

22 Coulter A. *Engaging patients in healthcare*. Maidenhead: McGraw-Hill; 2011.

23 Mol A. *The logic of care: health and the problem of patient choice*. Abingdon: Routledge; 2008.

24 Coulter A. *The autonomous patient: ending paternalism in medical care*. London: The Nuffield Trust; 2002.

25 Williamson C. *Towards the emancipation of patients: patients' experiences and the patient movement*. Bristol: Policy Press; 2010.

26 McGreevy M (ed). *Patients as partners: how to involve patients and families in their own care*. Oakbrook: Joint Commssion on Accreditation of Healthcare Organisations; 2006.

27 De Dilva D. *Helping people help themselves*. London: The Health Foundation, 2011.

28 Coulter A, Ellins J. Effectiveness of strategies for informing, educating, and involving patients. *BMJ* 2007 Jul 7;335(7609):24-27.

29 Øvretveit J. *Do changes to patient-provider relationships improve quality and save money?* London: The Health Foundation, 2012.

30 World Health Organization. *Non-communicable diseases country profiles 2011*. 2011.

31 Barnett K, Mercer SW, Norbury M, Watt G, Wyke S, Guthrie B. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *Lancet* 2012 Jul 7;380(9836):37-43.

32 Busse R, Blumel M, Scheller-Kreinsen D, Zentner A. *Tackling chronic disease in Europe: strategies, interventions, challenges*. The European Observatory on Health Systems and Policies. Observatory Studies Series No 20. 2010.

33 Holman H, Lorig K. Patients as partners in managing chronic disease. Partnership is a prerequisite for effective and efficient health care. *BMJ* 2000 Feb 26;320(7234):526-527.

34 Von Korff M, Gruman J, Schaefer J, Curry SJ, Wagner EH. Collaborative management of chronic illness. *Ann Intern Med* 1997;127(12):1097-1102.

35 Coleman K, Mattke S, Perrault PJ, Wagner EH. Untangling practice redesign from disease management: How do we best care for the chronically ill? *Annual Review of Public Health* 2009;30:385-408.

36 Wallace LM, Turner A, Kosmala-Anderson J, Sharma S, Jesusathan J, Bourne C, Realpe A. *Co-creating health: evaluation of the first phase*. London: The Health Foundation 2012.

37 Godfrey CM, Harrison MB, Lysaght R, Lamb M, Graham ID, Oakley P. Care of self - care by other - care of other: the meaning of self care from research, practice, policy and industry perspectives. *International Journal of Evidence Based Healthcare*, 2011;9:3-24.

38 Jones M, C., MacGillivray S, Kroll T, Zohoor A, Reza, Connaghan J. A thematic analysis of the conceptualisation of self-care, self-management and self-management support in the long-term conditions management literature. *J Nurs Healthc Chronic Illn* 2011 09;3(3):174-185.

39 Murray SJ. Care and the self: biotechnology, reproduction, and the good life. *Philos Ethics Humanit Med* 2007;2:6.

40 Cribb A. *Involvement, shared decision-making and medicines*. London: Royal Pharmaceutical Society; 2011.

41 Entwistle VA, Watt IS. Treating patients as persons: a capabilities approach to support delivery of person-centered care. *American Journal of Bioethics* 2013 (forthcoming).

42 Institute of Medicine. *To err is human*. Washington: National Academy of Medical Sciences; 2001.

43 Hibbard JH, Mahoney ER, Stockard J, Tusler M. Development and testing of a short form of the patient activation measure. *Health Serv Res* 2005 Dec;40(6 Pt 1):1918-1930.

44 Green CA, Perrin NA, Polen MR, Leo MC, Hibbard JH, Tusler M. Development of the Patient Activation Measure for mental health. *Administration & Policy in Mental Health* 2010 Jul;37(4):327-333.

45 Maindal HT, Sokolowski I, Vedsted P. Translation, adaptation and validation of the American shortform Patient Activation Measure (PAM13) in a Danish version. *BMC Public Health*, 2009; 9:209

46 Dixon A, Hibbard J, Tusler M. How do People with Different Levels of Activation Self-Manage their Chronic Conditions?. *The Patient: Patient-Centered Outcomes Research* 2009 Dec 1;2(4):257-268.

47 Hibbard JH, Cunningham PJ. How engaged are consumers in their health and health care, and why does it matter?. *Research Briefs* 2008 Oct(8):1-9.

48 Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Aff* 2013 Feb;32(2):207-214.

49 Greene J, Hibbard JH. Why does patient activation matter? An examination of the relationships between patient activation and health-related outcomes. *Journal of General Internal Medicine* 2012 May;27(5):520-526.

50 Hibbard JH, Greene J, Overton V. Patients with lower activation associated with higher costs; delivery systems should know their patients' 'scores'. *Health Aff* 2013 Feb;32(2):216-222.

51 Shortus T, Kemp L, Mckenzie S, Harris M. 'Managing patient involvement': Provider perspectives on diabetes decision-making. *Health Expectations* 2011 Jun 7.

52 Kukla R. How do patients know?. *Hastings Cent Rep* 2007 Sep-Oct;37(5):27-35.

53 Ziebland S, Wyke S. Health and illness in a connected world: How might sharing experiences on the internet affect people's health? *Milbank Q* 2012;90(2):219-249.

54 Epstein RM, Peters E. Beyond information: Exploring patients' preferences. *JAMA* 2009;302(2):195-197.

55 Wirtz V, Cribb A, Barber N. Patient-doctor decision-making about treatment within the consultation--a critical analysis of models. *Soc Sci Med* 2006 Jan;62(1):116-124.

56 Tarrant C, Dixon-Woods M, Colman AM, Stokes T. Continuity and trust in primary care: A qualitative study informed by game theory. *Annals of Family Medicine* 2010;8(5):440-446.

57 Wright EB, Holcombe C, Salmon P. Doctors' communication of trust, care, and respect in breast cancer: Qualitative study. *Br Med J* 2004;328(7444):864-867.

58 Mendick N, Young B, Holcombe C, Salmon P. Telling 'Everything' but not 'Too Much': The surgeon's dilemma in consultations about breast cancer. *World J Surg* 2011;35(10):2187-2195.

59 Engestrom Y. Activity theory and individual and social transformation. In: Engestrom Y, Miettinen R, Punamaki RL (eds). *Perspectives on activity theory*. Cambridge: Cambridge University Press; 1999. p. 19-38.

60 Powers M, Faden R. *Social justice: the moral foundations of public health and health policy*. New York: Oxford University Press; 2006.

61 Goodrich J, Cornwell C. *Seeing the person in the patient*. London: The King's Fund; 2008.

62 Taylor D, Bury M. Chronic illness, expert patients and care transition. *Sociology of Health and Illness*, 2007; 29:27-45.

63 Collins S, Drew P, Watt I, Entwistle V. 'Unilateral' and 'bilateral' practitioner approaches in decision-making about treatment. *Soc Sci Med* 2005 Dec;61(12):2611-2627.

64 Entwistle VA, McCaughan D, Watt IS, Birks Y, Hall J, Peat M, et al. Speaking up about safety concerns: multi-setting qualitative study of patients' views and experiences. *Quality & Safety in Health Care* 2010 Dec;19(6):e33.

65   Hinder S, Greenhalgh T. 'This does my head in'. Ethnographic study of self-management by people with diabetes. *BMC Health Serv Res* 2012;12:83.

66   Sinding C, Miller P, Hudak P, Keller-Olaman S, Sussman J. Of time and troubles: patient involvement and the production of health care disparities. *Health (Lond)* 2012 Jul;16(4):400-417.

67   Greenhalgh T. Patient and public involvement in chronic illness: beyond the expert patient. *BMJ* 2009;338:b49.

68   Friedman M. *Autonomy, Gender, Politics*. Oxford: Oxford Univ Pr; 2003.

69   Christman J. Autonomy in moral and political philosophy. In: Zalta EN (ed). *Stanford Encyclopedia of Philosophy* (http://plato. stanford.edu); 2003.

70   Frankfurt HG. Freedom of the will and the concept of a person. *Journal of Philosophy* 1971;48(1):5-20.

71   Sherwin S (ed). *The politics of women's health: exploring agency and autonomy.* Philadelphia: Temple University Press; 1998.

72   Meyers D. *Self, society and personal choice*. New York: Columbia University Press; 1998.

73   Mackenzie C. Relational Autonomy, Normative Authority and Perfectionism. *Journal of Social Philosophy* 2008 12/01;39(4):512-533.

74   Kukla R, Kuppermann M, Little M, Lyerly AD, Mitchell LM, Armstrong EM, *et al.* Finding autonomy in birth. *Bioethics* 2009;23(1):1-8.

75   Sherwin S, Winsby M. A relational perspective on autonomy for older adults residing in nursing homes. *Health Expect* 2011 Jun;14(2):182-190.

76   McLeod C. *Self trust and reproductive autonomy*. Cambridge MA: MIT Press; 2002.

77   Walker RL. Medical ethics needs a new view of autonomy. *J Med Philos* 2008;33(6):594-608.

78   Meyers DT. *Decentralizing Autonomy: Five Faces of Selfhood.* Cambridge: Cambridge Univ Pr; 2005.

79   Robeyns I. The capability approach. In: Zalta EN (ed). *Stanford Encyclopedia of Philosophy* (http://plato. stanford.edu); 2011.

80   Wolff J. *Disadvantage*. Oxford: Oxford University Press; 2007.

81   Smith ML, Seward C. The relational autonomy of Amartya Sen's Capability Approach. *Journal of Human Development and Capabilities* 2009;10(2):213-213-235.

82   Ruger JP. Shared health governance. *American Journal of Bioethics* 2010;11(7):32-45.

83   Venkatapuram S. *Health justice*. Cambridge: Polity Press; 2011.

84   Grewal I, Lewis J, Flynn T, Brown J, Bond J, Coast J. Developing attributes for a generic quality of life measure for older people: Preferences or capabilities? *Social Science and Medicine* 2006;62(8):1891-1901.

85   Al-Janabi H, Flynn TN, Coast J. Development of a self-report measure of capability wellbeing for adults: the ICECAP-A. *Qual Life Res* 2012 Feb;21(1):167-176.

86   Coast J, Peters TJ, Natarajan L, Sproston K, Flynn T. An assessment of the construct validity of the descriptive system for the ICECAP capability measure for older people. *Qual Life Res* 2008 Sep;17(7):967-976.

87   Coast J, Flynn TN, Natarajan L, Sproston K, Lewis J, Louviere JJ, et al. Valuing the ICECAP capability index for older people. *Soc Sci Med* 2008 Sep;67(5):874-882.

88   Davis JB. The capabilities conception of the individual. *Review of Social Economy* 2009;67(4):413-413-429.

89   Haggerty JL, Reid RJ, Freeman GK, Starfield BH, Adair CE, McKendry R. Continuity of care: a multidisciplinary review. *BMJ* 2003 Nov 22;327(7425):1219-1221.

90   Entwistle VA. Hurtful comments are harmful comments: respectful communication is not just an optional extra in healthcare. *Health Expectations* 2008 Dec;11(4):319-320.

91   Law I, Widdows H. Conceptualising health: Insights from the capability approach. *Health Care Anal* 2008;16(4):303-314.

92   Carter SM, Entwistle VA, McCaffery K, Rychetnik L. Shared health governance: the potential danger of oppressive 'healthism'. *American Journal of Bioethics* 2011 Jul;11(7):57-59.

93   Fiester A. The 'difficult' patient reconceived: an expanded moral mandate for clinical ethics. *Am J Bioeth* 2012;12(5):2-7.

The Health Foundation is an independent charity working to improve the quality of healthcare in the UK.

We want the UK to have a healthcare system of the highest possible quality – safe, effective, person-centred, timely, efficient and equitable. We believe that in order to achieve this, health services need to continually improve the way they work.

We are here to inspire and create the space for people to make lasting improvements to health services.

We conduct research and evaluation, put ideas into practice through a range of improvement programmes, support and develop leaders and share evidence to drive wider change.