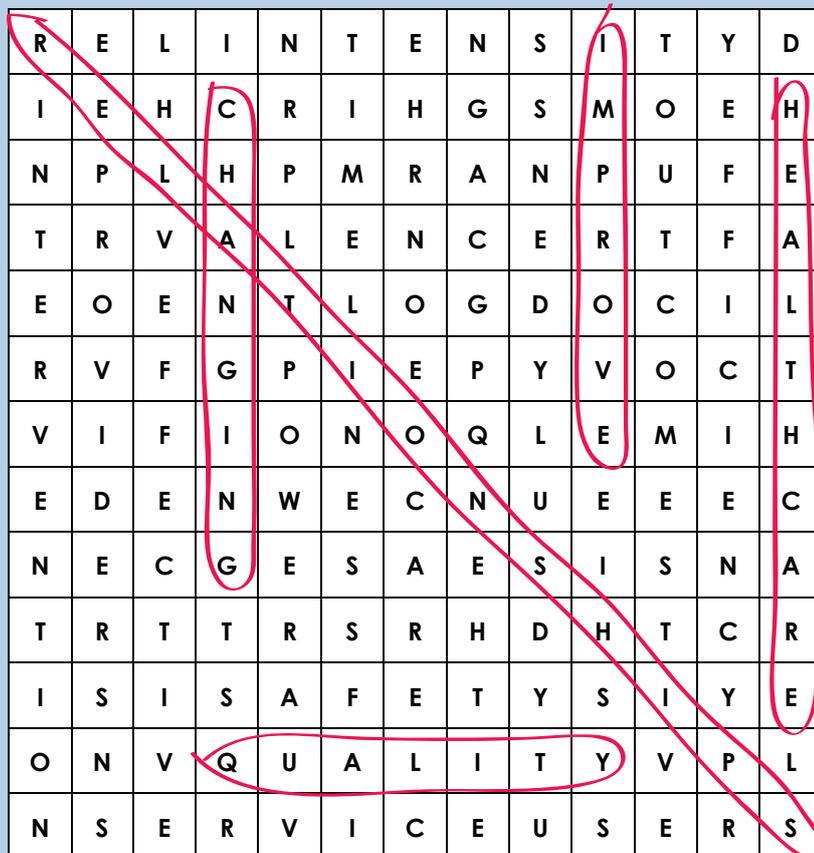


The puzzle of changing relationships

Does changing relationships between healthcare
service users and providers improve the quality of care?



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Health Foundation commentary

At the Health Foundation, we want a more person-centred healthcare system. By this we mean one that supports people to make informed decisions about, and successfully manage, their own health and care – including choosing when to let others act on their behalf. A person-centred system would deliver care that is responsive to people’s individual abilities, preferences, lifestyles and goals.

This requires a change in behaviour and mindset from patients and clinicians, supported by a system that puts patients at its heart. Such a system requires different roles for healthcare providers and patients, and different relationships between them.

Such a system would not simply be more person-centred; we believe it also has the potential to improve other dimensions of the quality of care. For example, where people are better able to self manage, they are more likely to adhere to mutually agreed treatment, increasing effectiveness. Where people are able to access and interact with their health records they are able to be more alert to the risk of errors, improving safety.

We commissioned this review of the evidence to understand how different relationships between patients and providers can impact – positively and negatively – on the quality of care. People encounter numerous relationships in their interactions with health services. We chose to focus the review around the seven relationship changes that we are testing as part of our Closing the Gap through Changing Relationships improvement programme. This £4m programme, in which seven teams are working on projects that aim to change the relationship between people and health services, was launched in 2010.

This report provides a snapshot of the evidence that relates changed relationships to changes in quality. What we learn is that the evidence is patchy and sometimes contradictory. This is perhaps unsurprising given the novel and wide range of interventions the researchers studied. It is also in part a reflection of the fact that in existing research attention is paid to process rather than to relationships: the interactions between interventions, relationships and quality have been poorly conceptualised, rarely described and most probably not even considered in terms of either their direct or indirect impact.

So, given that others have tended not to prioritise this in the past, why is it important to better understand the nature of relationships between patient and healthcare providers? Many of the ways in which healthcare is delivered limit people’s ability and opportunity to take an active role in their health and healthcare. We need to understand how the current professional–patient relationship creates and sustains this type of dependency if we want to change it. The report’s authors hypothesise that many of the interventions studied may impact on the relationship in a positive way through enhancing patients’ confidence and knowledge, and re-balancing the power dynamic. These hypotheses would benefit from further testing in the future.

The research explores the literature on conceptual frameworks for understanding relationships more generally. Disaggregating relationships into dimensions and factors that explain quality in healthcare can help understanding of whether and how a given intervention can lead to a change in a given relationship and potentially changes in the quality of care. It underlines the need for there to be a stronger underlying theory of how interventions – such as new roles, new technologies and a new emphasis on supporting patients – impact upon relationships and, as a consequence, on healthcare outcomes.

The report also emphasises the fact that the relationship between health professionals and patients is affected by the context in which the interactions are taking place – whether shaped by local and national system priorities, the distinct professional identities of different clinical communities, or the patient’s social circumstances.

So, creating a truly person-centred health system isn’t simply about changing the direct interactions with healthcare. We need to have a more sophisticated understanding of the type of relationships that are most likely to facilitate high quality care and we need changes at many levels. Sometimes this might mean changing an existing and established relationship, such as that between patient and GP, but on other occasions it may mean adding a new and complementary relationship into the mix, for example by providing peer support.

In exploring the evidence around some innovative approaches to improving quality this report highlights exciting opportunities to transform healthcare. Equally, it points to the need for those designing, managing and commissioning health services to think carefully about how their favoured intervention mediates, or is mediated by, relationships and how it might lead to the change they want to see. This will help ensure that the most appropriate intervention is selected and then implemented in a way that is most likely to achieve the desired outcome.

We hope that both the framework and the evidence in this report will, with further research and development, be valuable in informing:

- better policy
- better service commissioning and planning
- a professional identity built around relationships as well as around tasks
- a research agenda that focuses far more attention on providing the evidence of how changing roles and relationships can raise quality.

The Health Foundation will continue to support work that seeks to enable people to take a more active role in their health and healthcare so that we can learn how this can best be done and what effect it has. We will be commissioning a suite of original research looking at the patient–clinician relationship which will provide us with new knowledge on the conceptual underpinnings of more person-centred relationships in healthcare. We will also continue to invest in improvement programmes that test and demonstrate how person-centred care can become the heart of day-to-day health services.

Adrian Sieff
Assistant Director
The Health Foundation

Executive summary

Encouraging improvement through changing the relationships between healthcare service users and providers is a key area of work for the Health Foundation.

This report aims to contribute to the understanding of how changing relationships impacts on the quality of care. It does this through:

- firstly, reviewing the conceptual and theoretical literature on relationships between service users and providers
- secondly, exploring the extent to which a chosen set of interventions correlate with the conceptual evidence, and their likely impacts on the quality of care.

Given the potentially large number of approaches that are suited to effecting a change in relationships in healthcare there was a need to narrow the scope of the review presented here. We therefore focused on a set of interventions that are currently being tested within projects that form part of the Health Foundation's Closing the Gap through Changing Relationships programme. These interventions are:

- patient self-administration of medication
- patient access to online health records
- addressing complaints about care received
- involving women in decision making in antenatal care
- use of peer support workers in healthcare
- improving healthcare services for homeless patients
- shared decision making in child/adolescent mental healthcare.

Using a rapid evidence assessment, we sought to (i) assess whether and how these types of interventions impact on the quality of care, and (ii) consider the specific relationship change that the given intervention is seeking to bring about and how this relationship change may be linked to improvements in quality of care. We considered six domains of care quality: effectiveness, safety, person-centredness, timeliness, efficiency and equity.

The evidence of how interventions to change relationships impact the quality of care is patchy and sometimes contradictory

We find that evidence of impact on quality of care varied widely, in line with the range of interventions studied, consequently providing different insights into different domains of quality. Within each type of intervention, the range of approaches also varied, thus making an overarching conclusion difficult. Importantly, the range of interventions studied in the empirical literature does not necessarily map on to the interventions that guided our searches. This is because the main interventions and approaches tested within the Health Foundation's projects, as described above, tended to be innovative or comparatively novel and in some cases related empirical evidence is still emerging. We therefore expanded our searches to also include interventions that were comparable to the main approach tested by the project in question.

We find that for each of the interventions reviewed the majority of studies examined measures of effectiveness, followed by measures of person-centredness and, to a lesser degree, efficiency and equity. Measures of safety and timeliness were less frequently studied, which may, to a certain extent, reflect the applicability of that dimension to the intervention in question.

There was a fairly robust level of evidence of **effectiveness** for patient self-administration of medications, the use of peer support workers in mental healthcare and interventions to improve services for homeless people. However, conclusions will have to be drawn in the context within which the interventions were implemented. For example, in studies examining patient self-administration of medications, available evidence suggests that it may provide an appropriate and effective alternative to supervised administration for some patients and conditions, while being less suitable and potentially inappropriate for others, for example, those with more chaotic lifestyles.

For other types of interventions studied here, the evidence of effectiveness tended to be more mixed. Thus, some studies found that the given intervention led to improved outcomes but others did not. Sometimes improvements were observed for a select set of measures only, for example process measures such as regular measurement of blood pressure, but not clinical outcomes.

Evidence of impacts on **person-centredness** tended to be more mixed across studies and interventions. This reflects, to a great extent, the wide range of measures considered under the heading of centredness, reflecting, in turn, the multidimensional nature of this concept. For example, studies of interventions to improve services for homeless people produced mixed findings, with some reporting improvements on measures such as being treated with respect, while evidence of impacts on measures such as self-esteem were less consistent. In contrast, studies of peer support workers consistently tended to report improvements for both recipients and peer support workers, including increased levels of knowledge, confidence and/or the ability to make decisions among the former, and enhanced confidence and self-esteem among the latter.

Efficiency and equity were less frequently studied. In relation to efficiency, this is most likely a reflection of the challenges of measurement, which is not well advanced. Consequently, where efficiency is being assessed, this typically refers to cost savings, as shown in studies examining case management interventions for people with high use of the emergency department.

Where equity was studied, available evidence tended to show a certain degree of consistency within categories of interventions, for example, in relation to patient self-administration of medications and access to online health records. Here, several studies highlighted the potential for increasing inequity, with those belonging to ethnic minorities or living in poorer neighbourhoods less likely to enrol in schemes that offer online access to health records. Similar to what was observed for self-administration of medication, it is likely that those enrolling in related programmes are more engaged

in self-managing their condition already and that electronic personal health records in their current form merely support or enhance what they would have done in any case, implying the need for better targeting of related interventions to fully exploit their potential.

The quality domains **safety** and **timeliness** were frequently not considered as distinct measures of quality. This may, in part, reflect that these domains have limited applicability to the interventions under study, as noted earlier, or else, as evidence is still emerging for a number of interventions, these measures have yet to receive attention.

Associations between changed relationships in healthcare and quality of care are rarely made explicit

A second step of the evidence review sought to consider the specific relationship change that interventions reviewed are seeking to bring about and how this relationship change may be linked to improvements in quality of care. Yet studies rarely described how a given intervention is expected to change a given outcome directly or indirectly, for example, through a change in relationships. Indeed, in the majority of cases, studies reviewed here did not explain how the intervention was related to changes in relationships and how this can be linked to changes in quality.

Although direct reference to changing relationships was rarely made in studies reviewed here, it may be hypothesised that most interventions studied can impact the relationship between the service user/patient and professional providers through enhancing the confidence and knowledge of service users and so re-balancing the power dynamic. This effect may be direct, through for example enabling access to health information, or mediated by support workers or case managers as in the case of peer support interventions and interventions aimed at improving services for homeless people. The nature of the relationship will vary, however, with those involving support workers acting as a ‘mediator’ or proxy between the service user and the wider service. This is likely to enhance the trust between the service user and the health service and, potentially, increase the cooperation dynamic.

Several of the interventions reviewed have aimed to involve the patient or service user through, for example, providing access to electronic health records or information on options on prenatal testing, or mode of delivery, in the case of antenatal care. The impact on quality of care was mixed. There is a need to take a more user-centred approach that involves end users of such systems in all stages of system design and implementation.

The mechanisms underlying interventions need to be better understood and to be explicit about how they expect to change outcomes

This report set out from the premise that a given intervention has direct and indirect impacts on the quality of care or on changed relationships, or both. We were able to identify evidence, albeit sometimes contradictory, for impacts on quality of care. Studies reviewed rarely made explicit reference to interventions' impacts on relationships. Indeed, in most cases, studies rarely described the mechanism by which the intervention that was tested or reviewed was expected to achieve the outcome(s) measured. Where a change in a relationship was assumed to form the pathway by which a given intervention was expected to impact on the quality of care, this was largely implicit. Such understanding of assumptions regarding causal mechanisms is, however, necessary to identify the links between the intervention and changed relationships. Failure to clarify the underlying theory of how a given intervention is expected to change outcomes will limit the utility of existing research. It also fails to challenge the tendency to use simplistic evaluation approaches that often provide little insight into why a particular outcome has occurred. There is a need to better understand the underlying mechanisms to enable conclusions to be drawn in relation to causal pathways and the effectiveness of such interventions.

Part 1: Overview and discussion

Chapter 1:

Overview and discussion

1.1 Context

Encouraging improvement through changing the relationships between healthcare service users and providers is a key area of work for the Health Foundation.

The way in which changing relationships contribute to improving care quality is not well understood. However, understanding the nature of relationships in healthcare is especially relevant within the ongoing structural and policy reforms of the health and social care systems in England, and the UK more broadly. The notion of ‘no decision about me, without me’¹ illustrates the renewed emphasis, in the English National Health Service (NHS), on the importance of both public input into health services and individual involvement in care decisions.²

Relationships between people and health services have been categorised in different ways. For example, Donabedian (1980) emphasised the key function of the relationship between the service user and the service provider, forming the core of good quality care.³ His conceptualisation considers the social and psychological components of this interaction, highlighting the importance of involving the service user in the decision-making process as a means to enhance the quality of care.⁴

A growing body of evidence has demonstrated how patient engagement in treatment decisions and supporting self-management of conditions can lead to more appropriate use of health services and may lead to better health outcomes. However, the precise benefits will vary according to the conditions involved.⁵⁻⁷ Beyond the individual clinical encounter, arrangements at the organisational level form important components of effective care delivery, as they relate to care coordination in particular.⁸ Indeed, service users value the coordination of their care, seeing it as an important component of overall quality,⁹ especially when they have chronic health problems and complex needs.^{10,11}

Over the past decade, policy makers have also increasingly advocated the active engagement of service users and the wider public in strategic decision making.¹² This has been viewed as a necessary means to increase health systems’ responsiveness to the legitimate expectations of the population. However, the benefits of public involvement in measurable outcomes for decision making and policy remain inadequately understood.¹³

While enhancing active service user engagement at the various levels of healthcare delivery has an attractive and logical appeal as a means to enhance the quality of care and overall responsiveness of healthcare systems, defining what is needed remains a challenge. This is due to the varied and complex nature of relationships and interactions at each level.¹⁴ The nature and scope of change required will be determined by service user needs and preferences and providers’ ability and willingness to engage in change, which in itself can pose considerable challenges. There is a need to better understand the features of relationships between service users and providers so as to inform an understanding of whether, and to what extent, a change in these relationships will contribute to improved care quality.

Aims and objectives

This report aims to contribute to the understanding of how changing relationships impacts on the quality of care. It does this through:

- firstly, reviewing the conceptual and theoretical literature on relationships between service users and providers
- secondly, exploring the extent to which a chosen set of interventions correlate with the conceptual evidence, and their likely impacts on the quality of care.

Given the potentially large number of approaches that are suited to effecting a change in relationships in healthcare there was a need to narrow the scope of the review presented here. We therefore focused on a set of interventions that are currently being tested within projects that form part of the Health Foundation's Closing the Gap through Changing Relationships programme.

About this report

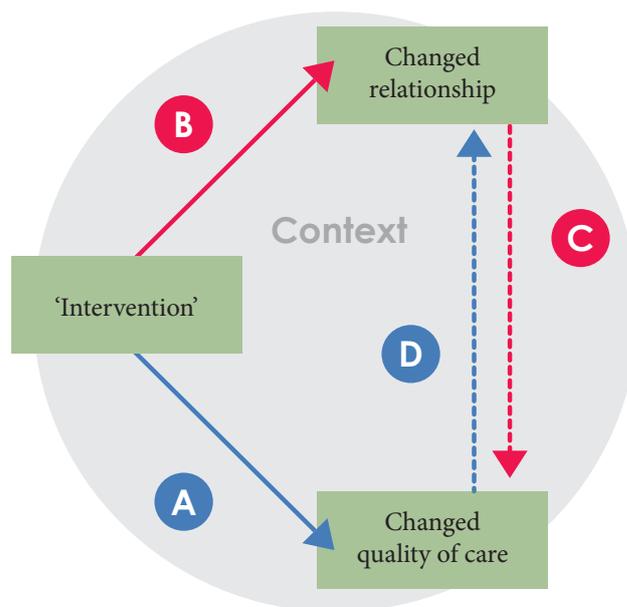
This report is divided into two parts. Part 1 provides an overview of the findings and discusses their implications. We begin, in section 1.2, by describing a conceptual framework linking interventions, relationships and quality of care that will guide the discussions presented in this report. We then provide a summary overview of the main findings of our review of the conceptual and theoretical literature on relationships between service users and providers in healthcare (section 1.3), followed by a brief overview of a select set of interventions that guided the evidence review. These interventions were selected deliberately in an attempt to focus the report: interventions considered are based on projects that are being implemented within the Health Foundation's Closing the Gap through Changing Relationships programme as a means to change relationships in healthcare (section 1.4). Focusing on this subset of interventions, section 1.5 provides a summary overview of the evidence base of whether and how these interventions impact on the quality of care delivered, followed by a reflection on the extent to which we can link this evidence to changed relationships in healthcare (section 1.6). We close with a brief section on lessons learned from the conceptual and empirical evidence reviewed here (section 1.7). Part 2 of the report presents the full reviews of the conceptual literature of relationships in healthcare (chapter 2) and of the empirical evidence of whether interventions seeking to change relationships in healthcare improve the quality of care (chapter 3).

1.2 Linking interventions, relationships and quality of care: a framework

This section describes a conceptual framework linking interventions, changed relationships and changes in components of care quality; it will form the basis for discussions presented in this report. It sets out from the basic premise that a given intervention may have direct and indirect impacts on quality of care and/or effect changed relationships (Figure 1). We conceptualise 'intervention' broadly as an activity aimed at modifying processes, behaviour and/or setting, recognising that a given activity might address these simultaneously, on a spectrum ranging from single to complex interventions.

For example, the introduction of a clinical guideline for the management of a given chronic condition in primary care may require the clinician to undertake regular assessments of physiological measures for the early detection of complications while at the same time requiring active engagement with the patient, for example, to define treatment goals.

Figure 1: Conceptual linkage between interventions, changed relationships and quality of care



The framework set out in Figure 1 identifies four principal conceptual linkages. Solid arrows indicate that the aim of the intervention is explicitly to bring about a change in quality of care (pathway A) or a change in a relationship (pathway B). Dotted lines indicate an indirect association (pathways C and D). Thus, pathway A illustrates how an intervention may impact directly on the quality of care through, for example, improving clinical outcomes, such as controlling blood pressure or reducing mortality, and/or by impacting the patient's experience of a given service. An intervention can also be targeted to change the relationship between a service user and the service (pathway B). This changed relationship may then lead to changed quality (pathway C). An example of this would be interventions aimed at changing the way service users and providers communicate, which may result in the service user experiencing greater satisfaction with the encounter.¹⁵ Equally, a given intervention might impact directly on the quality of care and, in doing so, also influence the nature of the relationship (pathway D). Returning to the example of a clinical guideline mentioned earlier, this may mean that through engaging the patient in setting treatment goals, the patient might develop a more trusting relationship with the provider. In practice, however, the interconnection between the three components is likely to be much more complex.

The work presented in this report sought to review the evidence in support of the (hypothesised) linkages between a given intervention and changed quality of care, mediated by changed relationships (pathways B and C). However, as we shall see below, much of the empirical evidence that is available tends to focus on the ‘intervention–changed quality of care’ nexus (pathway A), often with a prioritisation of health outcomes. Some evidence also relates to the ‘changed relationship–changed quality of care’ nexus (pathway C). In contrast, evidence supporting the ‘intervention–changed relationships–changed quality of care’ nexus (pathways B and C) is rare. This is mostly because the theory underlying a given intervention on whether and how it is expected to effect a change in relationships and how this change then translates into changed quality is typically not made explicit. Alternatively, the intervention may not follow a pathway through changed relationships at all (pathway A only).

It is important to note that the framework presented here is highly simplified. Thus, when examining the potential linkages between interventions, changed relationships and changed quality of care, or any two of these elements, it will be important to recognise that these do not take place in isolation but are influenced by, and reflect back on, the specific context in which they take place, and the ways in which this affects the potential links between them. Furthermore, for the purposes of the framework, we considered ‘changed relationship’ and ‘changed quality of care’ as separate. However, a changed relationship may constitute a dimension of care quality in itself, as illustrated by the notion of ‘person-centred care’, which we will discuss below.

1.3 Conceptualising relationships in healthcare

In this section we summarise the key findings from our review of the conceptual and theoretical literature on relationships between service users and providers. We drew on a range of academic disciplines, including communication and business theory, medical anthropology, medical sociology, economics and psychology, to enable multidimensional understanding of the conceptual underpinnings of ‘relationships’. We describe how relationships are defined and by whom, how they are characterised through various frameworks, and what concepts and contextual factors impact their quality. The full-length review is available in Part 2 of this report (chapter 2).

At the outset it is worth noting that within medical sociology there has been a long-standing focus on the interactions between providers, typically doctors, and patients or service users. However, much of the

discussion dates to the 1970s and earlier, with lack of progress towards the development of a theoretical framework for the understanding of the contemporary professional–patient relationship.¹⁶ In this context it should be noted that more recent literature has moved away from the notion of the ‘patient’ to that of a service user and we aim to use the latter term throughout the report. At the same time, it will not always be possible to ‘avoid’ the notion of the patient, in particular when referring to some of the earlier seminal work in this field, and we will therefore use the terms alongside each other.

In the context of our review, we drew mainly on a conceptualisation proposed by Wish (1976)¹⁷ as a guide to organise and map our findings. Arguing from an interpersonal, psychological perspective, Wish (1976) identified four primary relationship dimensions as attributes by which to characterise different types of relationships.¹⁷ The dimensions are conceptualised as being bidirectional in nature: each exists as a spectrum on which a relationship can be placed. This is further illustrated in Figure 2.

Figure 2: Dimensions of relationships as presented by Wish (1976)¹⁷

Power	Symmetric	↔	Asymmetric
Valence	Cooperative	↔	Competitive
Intensity	Intimate	↔	Distant
Formality	Social	↔	Professional
NOTE: Valence principally refers to the level of negativity/positivity in behaviour and/or disposition			

The notion of power forms a core component in several models that have sought to characterise the physician–patient relationship in particular, arguing that the professional status of the doctor determines the role of the patient.¹⁸ This conceptualisation dates to the work of Parsons (1951),¹⁹ while Freidson (1970) pointed to the principal ‘conflict’ in the relationship, with doctors and patients having different agendas so the actual consultation is seen as a ‘competitive’ arena in which each party seeks out power with consequent potential for abuse of power.²⁰ In this interpretation, formal medical knowledge competes with the patient’s lay or ‘folk’ knowledge, with improvements in medical technology further reinforcing the power imbalance between physicians and patients.¹⁶ Although this work has remained fundamental to our understanding of the interaction between the patient and the health professional,²¹ more recent work has explored the role of the physician in terms of the emergence of a ‘new professionalism’ in response to changing contextual factors such as politics, societal or generational change, and advances in technology and the capabilities of medicine.²²

While the literature directly addressing the physician–patient relationship has frequently focused on issues around power and status, Wish’s (1976) framework provides a means to further disaggregate components of relationships within overarching dimensions to aid better understanding of the factors that may impact on relationship quality.¹⁷ The majority of factors identified in our conceptual review were synonymous with one of the four dimensions described by Wish (1976) or else could be seen to be associated with the dimension as a subsidiary concept, through influencing where that relationship might be placed on the spectrum of that dimension. For example, above we pointed to the notion of conflict highlighted by Freidson (1970).²⁰ ‘Conflict’ may thus be interpreted as a concept impacting the valence dimension of a relationship. We explored these subsidiary concepts as identified from the literature relating to each of the relationship dimensions. This is further depicted in Figure 3 and we briefly summarise our main observations below.

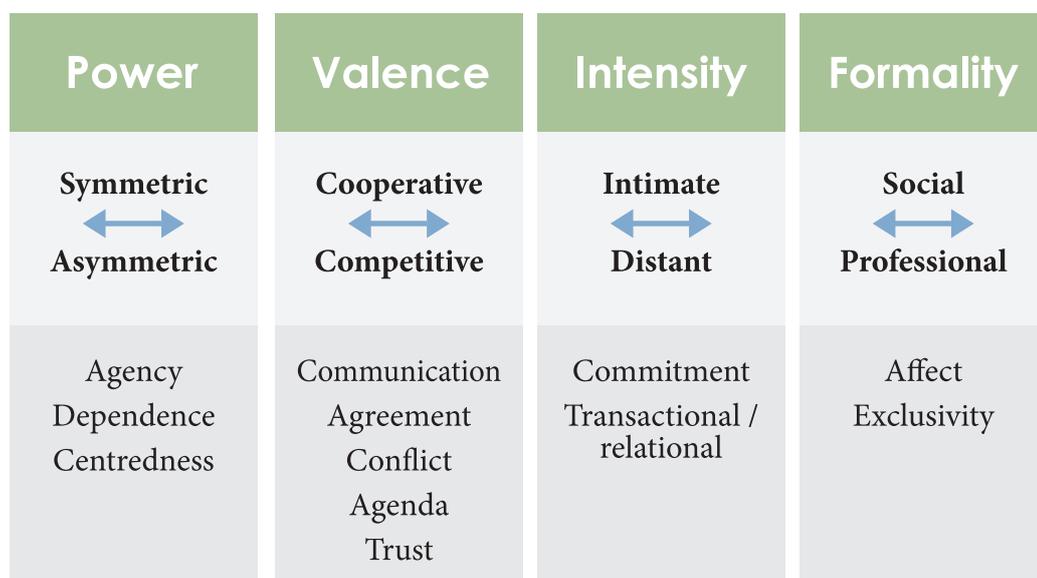
Within the **power** dimension we identified notions of agency, dependence and centredness as core concepts. Centredness has emerged as an increasingly important concept in healthcare.²³ While seen to be at the core for the delivery of high-quality care, ‘patient-centredness’ has been interpreted as a multidimensional concept itself, with Mead and Bower (2000)²⁴ arguing that patient-centred medicine ‘promotes the ideal of an egalitarian doctor–patient relationship’ (p1089), so building on the very concept of the power dynamic in the relationship, with related notions identified as user involvement, negotiation, concordance and patient empowerment.^{24–26}

Valence refers to the nature of a relationship along a continuum from cooperative and friendly to competitive and hostile. This dimension can be further described by notions of communication as an important factor to enhance service user satisfaction and relationship quality.^{27–29} It also points to the importance of the parties agreeing on the nature of the relationship as a means to improve patient experience and health outcomes.³⁰ Conversely, the presence of conflict will undermine relationship quality²⁸ as well as trust.

The **intensity** dimension is most frequently discussed in relation to commitment, which can involve a service user’s readiness for a relationship. An example is motivation to change behaviour and the willingness of a physician to tailor their approach to a service user’s preferences. Potter and McKinlay (2005) examined the nature of provider investment in the relationship in terms of being lateral (for the here and now) or longitudinal (for the longer term).¹⁶ They found high levels of both lateral and longitudinal investment to be associated with higher quality relationships.

Finally, in relation to the dimension of **formality**, Kaplan *et al* (1989) highlighted the notion of ‘affect’ in provider–service user interactions to be associated with health outcomes.¹⁵ Fainzang (2002)³¹ also pointed to the impact of service users withholding information about diagnosis from others, which can lead to a closer bond between the professional and the patient, in particular in relation to highly stigmatised but invisible conditions. Here, a link is created between the provider and the service user because they share the secret of the diagnosis.

Figure 3: Conceptual framework for relationships in healthcare



Disaggregating relationships into their various dimensions and factors that may explain their quality will help to better understand whether and how a given intervention may lead to a change in a given relationship and, potentially, changes in the quality of care. However, it is important to note that relationships in healthcare, and indeed in any setting, do not exist and evolve in isolation but are strongly influenced by the context(s) within which they take place. This includes the structure of the wider health system and the policies governing the interactions (eg regulation, organisation, funding), alongside factors that influence the service user and service provider as individuals, for example the service user's social status or access to other support networks, or a provider's attitude towards 'patient-centredness'. References to these contextual factors surfaced throughout our review, the most common being those of culture and historical/political changes. Any framework aiming to analyse relationships will need to take account of contextual factors in order to understand influences on relationship quality.

1.4 Changing relationships in healthcare: example interventions

The preceding section has illustrated the multidimensional nature of relationships in healthcare, pointing to a potentially large number of approaches that are suited to effect a change in relationships in healthcare. Against this background there was a need to narrow the scope of the review presented here.

We therefore focused on a select set of interventions that are currently being tested within projects that form part of the Health Foundation's Closing the Gap through Changing Relationships programme.³² As part of this programme, which seeks to transform the dynamic between people who use health services and those who provide them, seven projects are being tested that address relationships within the healthcare system. Each consists of a set of interventions that are considered to be best suited to the types of relationships that they seek to change, as well as to the organisational and social context in which these relationships occur. Table 1 provides a summary overview of these 'example' interventions, describing the main components by which they seek to effect a change in relationships. These interventions formed the basis of a rapid evidence assessment, presented in sections 1.5 and 1.6 below, which sought to (i) assess whether and how these interventions impact on the quality of care and (ii) consider the specific relationship change that the given intervention is seeking to bring about and how this relationship change may be linked to improvements in quality of care. For the purposes of this review, we further abstracted the interventions as described in Table 1 to better capture the available evidence.

We recognise that the interventions considered here target specific areas in healthcare only and, through abstracting principal mechanisms underlying interventions described in Table 1 further, we only provide selected insights into what is complex in nature. At the same time, the key observations of the rapid evidence assessment presented in sections 1.5 and 1.6 can be seen to provide a first step towards a better understanding of the extent to which changing relationships between service users and providers improve the quality of care.

1.5 Reflections on the evidence base: how do selected interventions improve the quality of care?

This section presents a high level summary of key observations of a review of the evidence of whether and how a select set of interventions (described in Table 1) impact on different dimensions of quality of care. We considered six dimensions of care quality: effectiveness, safety, person-centredness, timeliness, efficiency and equity.³³ The full review is presented in Part 2 of this report (chapter 3).

Across all interventions, or groups of interventions, reviewed here, evidence of impact on quality of care varied widely, in line with the wide range of interventions studied, consequently providing different insights into different dimensions of quality. Within each type of intervention, for example patient access to online health records or self-administration of medication, the range of interventions also varied, thus making an overarching conclusion difficult. Importantly, the range of interventions studied in the empirical literature does not necessarily map as directly as we would have anticipated to the seven interventions that guided our searches. This is because main interventions and approaches tested within the Health Foundation's projects as described above tended to be innovative or comparatively novel and in some cases related empirical evidence is still emerging. We therefore expanded our searches to also include interventions that were comparable to the main approach tested by the project in question.

Table 2 summarises the main observations of the evidence review of associations between interventions and quality of care in its various dimensions. Bearing the limitations of the review in mind (see Part 2, section 3.1 for further detail), we find that for each of the interventions reviewed the majority of empirical studies examined measures of effectiveness, followed by measures of person-centredness and, to a lesser degree, efficiency and equity. Measures of safety and timeliness were less frequently studied, which may to a certain extent reflect the applicability of that dimension to the intervention in question.

Table 1: Example interventions tested as part of the Health Foundation’s Closing the Gap through Changing Relationships programme³²

Health Foundation projects tested within the Closing the Gap through Changing Relationships programme	Interventions reviewed in this report
<p>Supporting patients in managing their own dialysis within a hospital environment</p> <ul style="list-style-type: none"> - Training and support for haemodialysis patients to self-administer treatment and make choices about where to receive care (eg patient education and engagement) - Training and support for nurses to enable an active partnership with patients 	<p><i>Patient self-administration of medication</i></p>
<p>Patient access to online health records and the functional use of those records</p> <ul style="list-style-type: none"> - Supporting GP practices to provide record access to patients - Supporting patients to understand and use records - Patients use records and associated technology for communication with practice 	<p><i>Patient access to online health records</i></p>
<p>Using patient complaints as a driver for improvement within a hospital environment</p> <ul style="list-style-type: none"> - Employing ‘patient champions’ from the community - Convening ‘expert panels’ to review a selection of complaint processes and outcomes each quarter - Complaints survey for patients/carers - ‘Digital stories’ – inviting patients to share the experience through writing a narrative, to be shared with staff for training purposes 	<p><i>Addressing complaints about care received</i></p>
<p>Putting women at the centre of antenatal care</p> <ul style="list-style-type: none"> - Improving information for women - Ensuring continuity of care - Responding to women who are anxious - Improving conversations between women and clinicians 	<p><i>Involving women in decision making in antenatal care</i></p>
<p>Use of peer support workers in mental healthcare</p> <ul style="list-style-type: none"> - Training, recruitment and employment of peer support workers - Specific interventions to promote person-centredness - Peer support workers have time dedicated to improve quality and enhance service user and carer experience, and are trained and supported to do so 	<p><i>Use of peer support workers in healthcare</i></p>
<p>Compassionate healthcare for homeless patients</p> <ul style="list-style-type: none"> - ‘Care navigators’ with experience of homelessness to assist staff in understanding what patients need and assist patients in knowing where else to get help - Developing a toolkit (training programmes, materials, processes, guidance, job descriptions) to share good practice and learning between sites - Clinician education/sensitivity training - Stronger links to external organisations; better connections between primary and secondary care to form a care pathway for homeless people; better tracking of regular attendees 	<p><i>Improving healthcare services for homeless patients</i></p>
<p>Shared decision making in child/adolescent mental healthcare</p> <ul style="list-style-type: none"> - Information dissemination to patients on condition and treatment options available - Shared decision making between young people and care staff regarding (i) key problems and goals, (ii) treatment course, (iii) progress reviews 	<p><i>Shared decision making in child/adolescent mental healthcare</i></p>

Given the wide variation in the methods used to assess interventions, the range of interventions itself and the range of populations or health concerns studied under each intervention heading, it was not possible to quantify the evidence of outcomes where these were measured. Instead, we attempted to rate qualitatively the strength of evidence for each of the quality domains under each intervention heading using study design and number of studies reporting the quality domains in question as a guide, as shown in Table 2.

In summary, we find a fairly robust level of evidence of effectiveness for patient self-administration of medications, the use of peer support workers in mental healthcare and interventions to improve services for

homeless people. However, conclusions will have to be drawn in the context within which the interventions were implemented. For example, studies examining patient self-administration of medications tended to show evidence of improved clinical outcomes and/or patient experience or, where a comparison strategy was used, outcomes that were comparable to usual care. Only one trial in a population of drug users found supervised administration to be more effective than self-administration.³⁴ This suggests that while self-administration may provide an appropriate and effective alternative to supervised administration for some patients and conditions, it may be less suitable and potentially inappropriate for others, for example, those with more chaotic lifestyles.

Table 2: Summary overview of associations of interventions and quality of care

Intervention (total number of studies)	Type and number of studies	Effectiveness	Safety	Person-centredness	Timeliness	Efficiency	Equity
Patient self-administration of medication (9)	RCT/other controlled: 5 Observational: 4	+	+	+	+	+/-	-
Patient access to online health records (15)	RCT: 3 (Systematic) review: 6 Observational: 6	+ (process) o (outcomes)	+	+/-	not reported	+	-
Addressing complaints about care received (7)	<i>Observational: 7 Total: 7</i>	<i>Studies generally assessed 'quality' as an input, that is they considered the usefulness of complaints data to identify quality problems; there was little direct empirical evidence on the impact of the intervention under study on quality of care</i>					
Involving women in decision making in antenatal care (6)	RCT: 2 Review: 1 Observational: 3	+/-	not reported	+	not reported	not reported	not reported
Use of peer support workers in healthcare (17; mental health: 6; other: 11)	RCT/other controlled: 7 (Systematic) review: 5 Observational: 5	+ (mental health) +/- (other)	not reported	+	not reported	not reported	+
Improving healthcare services for homeless patients (8)	RCT: 4 Systematic review: 1 Observational: 3	+	not reported	+/-	not reported	+	not reported
Shared decision making in child/adolescent mental healthcare (6)	RCT: 2 Systematic review: 3 Observational: 1	+/-	not reported	+	not reported	not reported	not reported
NOTE: + (some) evidence of improvement in outcome of interest; +/- mixed evidence (improvements, no change, deterioration); o no change/difference; - (some) evidence of worsening in outcome of interest. RCT = randomised controlled trial							

For other types of interventions studied here, the evidence of effectiveness tended to be more mixed: the intervention was shown to lead to improved outcomes in some studies but not others, or improvements were observed for a select set of measures only. Examples include process measures such as regular measurement of blood pressure, while clinical outcomes did not change significantly, such as in the case of patient access to online health records. This inconsistency can be explained, in part, by the heterogeneous nature of studies reviewed, both in the quality and type of intervention studied. Furthermore, for selected studies, it was not possible to isolate the impacts of the intervention under review where it was implemented as part of a wider strategy.

Evidence of impacts on person-centredness tended to be mixed across studies and interventions. To a great extent this reflects the wide range of measures considered under the heading of centredness, in turn reflecting the multidimensional nature of this concept.³⁵ For example, studies of interventions to improve services for homeless people produced mixed findings, with some reporting improvements on measures such as being treated with respect, while evidence of impacts on measures such as self-esteem were less consistent. In contrast, studies of peer support workers consistently tended to report improvements for both recipients and peer support workers, including increased levels of knowledge, confidence and/or the ability to make decisions among the former, and enhanced confidence and self-esteem among the latter.

Measures of efficiency and equity were less frequently studied. In relation to efficiency, this likely reflects the challenges of measurement, which is not well advanced. Thus, while efficiency relates to value for money, development has so far focused on effectiveness and cost indicators, with little combination of the two.³⁶ Consequently, where efficiency is being assessed this typically refers to cost savings, as shown for studies examining case management interventions for people with high use of the emergency department.

Where equity was studied, available evidence tended to show a certain degree of consistency, for example in relation to patient self-administration of medications and access to online health records. Here, several studies highlighted the potential for increased inequality, with those belonging to ethnic minorities or living in poorer neighbourhoods less likely to enrol in schemes that offer online access to health records. Similar to what was observed for self-administration of medications, it is likely that those enrolling in related programmes are more engaged in self-

managing their condition already and that electronic personal health records in their current form merely support or enhance what they would have done in any case, implying the need for better targeting related interventions to fully exploit their potential.

1.6 Reflections on the evidence base: how are changed relationships linked to changes in the quality of care?

A second step of the evidence review sought to consider the specific relationship change that the interventions reviewed have the potential to effect and how this relationship change may be linked to improvements in quality of care and, specifically, which dimensions of quality of care. At the outset it is important to note that studies rarely described how a given intervention was expected to change a given outcome directly or indirectly, for example through changes in existing healthcare relationships. So, perhaps not surprisingly, the majority of cases studies reviewed here did not explain how the intervention was related to changes in relationships and how this can be linked to changes in quality. Indeed, we had to infer such associations from studies reviewed.

Failure to clarify the underlying theory of how a given intervention is expected to change outcomes has been discussed in some depth in relation to patient access to electronic health records. For example, Black *et al* (2011), in a review of systematic reviews of the impact of eHealth on the quality and safety of healthcare, noted the limited utility of existing research and the tendency to use simplistic evaluation approaches that often provide little insight into why a particular outcome has occurred.³⁷ They highlighted the need to better understand the underlying mechanisms to make it possible to draw conclusions in relation to causal pathways and the effectiveness of such interventions.

Several studies reviewed here noted the potential for personal health records to increase levels of patient empowerment and, by implication, so contribute to balancing the power dynamic between the patient and the provider. However, the term 'empowerment' tends to remain poorly defined in many studies, encompassing different notions such as self-efficacy or degree of control, and it is frequently not made explicit how electronic personal health records are expected to increase empowerment.³⁸ Greenhalgh *et al* (2009) noted how, in the context of electronic patient records, lack of agreement on how efficacy, or empowerment, should be defined and measured will further complicate the interpretation and usefulness of evidence thus produced.³⁹ It should be noted, however, that instruments to assess 'empowerment' have been tested

in the context of peer and self-management support, for example suggesting how such interventions have the potential to empower patients or service users to play a more active role in their own care.⁴⁰ Repper and Carter (2011) further presented evidence of the potential of such schemes to increase self-efficacy, engagement and increased social networks.⁴¹

Although direct reference to changed relationship was rarely made in studies reviewed here, it may be hypothesised that most interventions studied can impact the relationship between the service user/patient and professional providers through enhancing service users' confidence and knowledge and so re-balancing the power dynamic. This effect may be direct, for example through enabling access to health information, or mediated by support workers or case managers, as in the case of peer support interventions and interventions aimed at improving services for homeless people. The nature of the relationship will vary, however, with those involving support workers providing a 'mediator' or proxy between the service user and the wider service, which is likely to enhance the trust between the service user and the health service and, potentially, increase the cooperation dynamic. In relation to peer support work a key notion that was mentioned is that of hope, where those with lived experience of a given condition provide a form of role model to the service user, to help them cope with their condition. This might benefit the cooperation dynamic (a notion that is part of the intensity dimension) of the relationship between the service user and the health professional, as well as the commitment invested by the two parties.⁴²

Several of the interventions reviewed here have aimed to involve the patient or service user, for example through providing access to electronic health records or information on options on prenatal testing, or mode of delivery in the case of antenatal care. The impact on quality of care was mixed. Several authors have highlighted how electronic personal health records might reflect a failure to actively engage the patient in the design of such systems and support them in their use.⁴³⁻⁴⁵ A more user-centred approach is needed that involves end users of such systems in all stages of system design and implementation.³⁸ However, such an approach will require good understanding of the 'theory of change' underlying the involvement of the end user and the assumed changes that will result. Such understanding will also be vital to inform decision making on the implementation of related interventions.

1.7 What have we learned?

This report sought to contribute to the understanding of whether and how changing relationships between service users and providers impacts on the quality of care. It aimed to do so through reviewing the conceptual and theoretical literature on relationships between service users and providers, and through exploring the extent to which a select set of interventions currently being tested within the Health Foundation's Closing the Gap through Changing Relationships programme are likely to impact on the quality of care.

Our review of the nature of relationships in healthcare and links between relationships and quality of care, as summarised in section 1.3 (also Part 2, chapter 2), suggests that the interaction between these two elements has not previously been examined in any great detail. Our rapid assessment of the empirical evidence of interventions that are hypothesised to effect the quality of care through a new or changed healthcare relationship, as presented in section 1.5 (also Part 2, chapter 3), suggests that (i) the evidence of impacts of these interventions on the quality of care is patchy and sometimes contradictory, and (ii) different (types of) interventions emphasise different domains of care quality, making an overarching conclusion difficult.

Disaggregating impacts on the six quality of care domains, drawing on those defined by the Institute of Medicine (2001), provided a useful starting point for understanding the various impacts of the different interventions reviewed here.³³ However, it has remained a challenge to link these domains to the conceptual literature on relationships between people and health services.

There are two main reasons for this. First, as outlined in section 1.2, we set out from the premise that a given intervention has direct and indirect impacts on the quality of care or on changed relationships, or both. While we were able to identify, albeit sometimes contradictory, evidence for the former, studies reviewed rarely made explicit reference to the latter. Indeed, in most cases, studies rarely described the mechanism by which the intervention that was tested or reviewed was expected to achieve the outcome(s) measured. Where a change in relationship was assumed to form the pathway by which a given intervention was expected to impact on the quality of care, this was largely implicit, through mention of concepts such as 'empowerment', 'control', 'confidence' and others. In some cases, these concepts were assessed empirically but most often they were not. Even where they were measured, the mechanism by which these dimensions were assumed to impact

care quality was not described. Such understanding of assumptions regarding causal mechanisms is, however, necessary to identify the links between the intervention and changed relationships. If we believe that concepts such as empowerment (however defined) are at the core of the change, we also need to understand how this will (potentially) impact on quality.

Second, our conceptual review of the nature of relationships in healthcare and links between relationships and quality of care drew on a framework developed from a psychological perspective in the context of interpersonal relationships.¹⁷ The four primary relationship dimensions, as identified by Wish (1976), provided a useful framework for organising the conceptual and theoretical literature on relationships in healthcare.¹⁷ However, when aiming to map these dimensions and related concepts to the empirical evidence, where it was possible to infer that a link exists between relationships and quality of care, this tended to focus on the power dimension and, specifically, person-centredness. The latter is considered a quality domain in itself, for example as proposed by the Institute of Medicine (2001),³³ suggesting that, in this case at least, the distinction between ‘relationship’ and ‘quality’ may be somewhat arbitrary and difficult to operationalise.

Importantly, however, we have not been able to fully map the four dimensions identified by Wish (1976) to the various interventions reviewed here.¹⁷ To a great extent this reflects the lack of detail (or perhaps even consideration) in interventions being reported on in the published literature regarding the underlying mechanism, or ‘theory of change’, by which a given impact is to be achieved. However, it also suggests how the Wish framework may provide a useful guide to inform the theory of change of a given intervention that seeks (implicitly or explicitly) to impact the quality of care through changed relationships. Good theoretical understanding of how a given intervention causes change and of the links within the causal chain (‘theory of change’) is important for establishing a causal relationship between the intervention and measured effects. Such understanding will also help in the identification of the potential contextual factors that are likely to impact on the intervention, particularly in complex settings.⁴⁶ This could make it easier to understand why a given approach may be suited to achieving the desired outcome.

Part 2: Review of the evidence

Chapter 2:

Review of conceptual literature on relationships in healthcare

In this chapter we report on our review of the conceptual and theoretical literature on changing relationships between service users and providers in healthcare. Specifically, the review sought to explore how relationships between service users and healthcare providers are conceptualised and how the quality of these relationships can be related to quality of care. We begin by briefly outlining the methodological approach to this work, followed by defining ‘relationship’ and presenting an overview of models of the relationship between healthcare professional and service user as proposed by different scholars. These models are used to inform our understanding of the nature of this relationship and the key influences that have been identified to impact relationship quality. We then present these influences in the form of associated concepts and processes using a multidimensional framework, as identified from an interpersonal, psychological perspective. We conclude by embedding findings into the wider context of changing roles within healthcare and the overall environment for healthcare organisation and delivery.

2.1 Methods

In conceptualising the nature and scope of relationships between service users and providers, our emphasis was on understanding the theoretical underpinnings of relationships rather than synthesising empirical (quantitative and qualitative) evidence of change of such relationships. This approach precluded use of a traditional systematic literature review; instead we took an iterative approach, principally based on a network search to identify scholarly work of relevance to the topic under review. We applied a variation of the ‘systematic snowball process’ that builds on a non-keyword-based reviewing process as proposed by Contandriopoulos *et al* (2010).⁴⁷

We drew on a range of academic disciplines to enable multidimensional input into the conceptual underpinnings of ‘relationships’. We considered communication and business theory, medical anthropology, medical sociology, economics and psychology; however, theories and concepts relating to psychology and interpersonal relationships surfaced throughout.

Within each of the disciplines, we identified documents considered to have made an important contribution to the understanding of the nature of relationships, either directly relating to healthcare, or transferable to healthcare settings. Although we did not consider evidence of change of a given relationship itself at this stage, we sought to identify components and processes considered relevant for maintaining high quality relationships. The identification of what we considered ‘seminal’ contributions from these bodies of literature (disciplines) was by consensus among the research team. Although we acknowledge that this approach may have risked omitting a relevant body of work, the interlinked nature of the disciplines that we have selected was likely to reduce this possibility.

Following identification of relevant seminal work, we pursued a network approach to identify documents that cited these papers, using key themes and issues as extracted from the original paper and following up references from cited papers and other work by the same authors. This type of search allows for newly found concepts and emerging ideas to be incorporated into the review.⁴⁸ Additionally, we obtained documents suggested by reviewers to be especially relevant. We included work that (i) focused on relationships at the individual or organisational level within various fields/disciplines but with relevance to the healthcare setting; and (ii) provided theoretical or, where appropriate, empirical evidence on the processes involved in developing or maintaining these relationships. We

should reiterate that this review does not represent a synthesis of the empirical evidence in the field; rather, empirical evidence was considered as a means to illustrate a given aspect of a relationship.

To provide a preliminary framework for findings, analysis of work retrieved was guided by four primary relationship dimensions as identified by Wish (1976) to describe interpersonal relations.¹⁷ These four dimensions can be characterised as follows.

- **Power symmetry/asymmetry:** refers to the inherent power dynamic of a given relationship, stretching from symmetric (eg colleagues or close friends) to asymmetric (eg teacher–student). Others have also described power asymmetry, variously terming it as the dominant/submissive or equal/unequal nature of relationships.⁴⁹
- **‘Valence’ (cooperation vs competition):** describes the nature of a relationship along a continuum from cooperative and friendly to competitive and hostile. Teammates, for example, could be placed at one end of the spectrum, whereas a prisoner/guard relationship could be placed at the other.
- **Intensity (level of interdependence):** refers to the frequency of interactions, depth of relationship (intimacy) and commitment of both parties, stretching from intimate to distant, with an example for the latter being a waiter and restaurant patron.⁵⁰
- **Formality (social vs professional nature):** characterises whether the relationship is ‘social’ (eg friends or siblings), or ‘work-related’ (eg teacher–student).⁵¹

As indicated above, Wish (1976) conceptualised the dimensions as having a bidirectional nature, where each exists as a spectrum on which a relationship can be placed.¹⁷

In reviewing the work identified, we used these dimensions as broader categories within which to map associated concepts. Searches were complemented with regular discussion of emerging findings within the research team.

2.2 Relationships in healthcare: the literature and discourse

Although the doctor–patient relationship has been a topic of interest in academic medical and psychology literature since the 1950s,⁵² the link between quality of the relationship and quality of care has not often been explicitly addressed.

Defining ‘relationships’

The literature on ‘relationships’ in general variously refers to notions of interaction, encounter and relations. The Oxford English Dictionary defines a relationship as a ‘connection formed between two or more people or groups based on social interactions and mutual goals, interests, or feelings.’⁵³ Szasz and Hollender (1956), writing in the 1950s, asserted the concept of a relationship in medicine to be novel, defining it as an ‘abstraction, embodying the activities of two interacting systems’ (p586).⁵⁴ In healthcare contexts the term ‘relationships’ has traditionally been reserved for the doctor–patient interaction,⁵² although more recently the term has been broadened to refer more generally to the healthcare professional or provider and patient. The Medical Subject Headings (MeSH) system, as employed by the biomedical bibliographic database PubMed, defines professional–patient relations simply as ‘interactions between health personnel and patients’, subsuming physician–patient relations, nurse–patient relations and dentist–patient relations.⁵⁵

Potter and McKinlay (2005) noted that applying the term ‘relationship’ to the (contemporary) doctor–patient interaction may be misleading, however, as it inappropriately describes the actual experience.¹⁶ Indeed, it is argued that this ‘relationship’ would more appropriately be described as an ‘encounter’. Gutek *et al* (2000) contend that in an ‘encounter’ the service provider and the customer (here, patient) do not expect to interact with each other in the future whereas in a (service) relationship the ‘customer’ expects to interact again with the same service provider in the future and the two become interdependent.⁵⁶ Similarly, management communication theory conceptualises the customer–seller relationship from relational versus transactional perspectives, with the seller aiming to move the relationship towards a long-term and ‘relational’ exchange.²⁸ Although the concept of the patients as a ‘customer’ is a contested analogy,⁵⁷ the ways in which customer–seller (as an individual or organisation) relationships work as exchange partnerships provides another perspective from which to view patient–provider relationships.

In classic economics literature, individuals and organisations are assumed to pursue interactions that they expect will maximise their own utility (or satisfaction), and relationships are assumed to follow this underlying maxim.^{58,59} From this perspective, ‘ideal’ relationships facilitate functioning of a competitive market. Transferability of this conceptualisation to the healthcare context has been challenged, however, because of the distinct characteristics of the healthcare setting, including the presence of altruism as a motivating factor for healthcare providers, the vulnerability caused

by illness precluding patients from making rational decisions, or healthcare itself being an ‘experience’ good (sometimes referred to a ‘credence’ good) in that its worth can only be judged through individual experience or by a belief in its intrinsic value.^{60,61} However, the exchanges that take place within the healthcare system can be seen to resemble market exchanges in principle, and the incentives that affect actors within a market may well impact these actors and their relationships.

Wish (1976) referred to relationships from an interpersonal, psychological perspective. Although not defining the term directly, he used descriptors such as ‘bidirectional’ and ‘dyadic’, which emphasise the importance of two sources of input and their dual influences on the character of the relationship.¹⁷ This implies that in conceptualising relationships between users and providers of healthcare services, it will be essential to explore multiple points of view. In addition, each group, and individuals within it, needs to be seen in the context of a myriad of other relationships and influences that have a bearing on the specific relationship between them and the ways in which each party conceptualises and acts out this relationship. As relationships comprise recurring encounters where roles are performed,⁶² in practice, therefore, conceptualising relationships will require an understanding of the ‘underlying assumptions about the nature of social reality and human action.’⁶³ This also includes understanding of the ways individuals negotiate their position vis-à-vis other parties.

2.3 ‘Models’ of the physician/health professional–patient relationship

Before characterising relationships in healthcare as identified from the review work undertaken in this project, it may be useful to provide an overview of various conceptualisations of the physician/health professional–patient relationship that have been proposed in the literature so as to inform our understanding of the nature of such relationships and key influences that have been identified to impact their quality. We do not attempt an exhaustive review of all the work in this area but focus on selected models that we identified as helpful for further conceptualising relationships in the healthcare context.

Since its formation, medical sociology has focused on the interactions between providers, typically doctors, and patients. However, much of the discussion dates to the 1970s and earlier, with little further advancement on the professional–patient literature since then.¹⁸ Similarly, Potter and McKinlay (2005) noted lack of progress towards the development of a theoretical framework for the understanding of the contemporary professional–patient relationship.¹⁶

In an early attempt to describe relationships in the medical setting, Szasz and Hollender (1956)⁵⁴ distinguished the following three models of the physician–patient relationship, which were principally classified according to the power balance between the two parties.

- The **activity–passivity model** refers to a model in which the physician (active) does something to the patient (passive). This model is not considered as an interaction *per se*; it originates from the treatment of emergencies in which treatment takes place without the patient’s contribution.
- The **guidance–cooperation model** describes a situation in which the patient seeks help for a given issue and is ready and willing to cooperate while placing the physician in a position of power – as a guide they will ‘obey’. There is a possibility for the physician to exploit the situation. This model would be most common for situations such as infection processes.
- The **model of mutual participation** is based on the notion of the two parties having approximately equal power, being mutually interdependent and engaging in activity that will be satisfying to both. In this model the physician helps the patient to help themselves; it would apply to chronic illnesses.

According to Szasz and Hollender (1956), the activity–passivity and the guidance–cooperation models are essentially based on the (traditional) notion of the physician holding power and control of the situation, while the model of mutual participation was considered as ‘essentially foreign’ (p588) to medicine.⁵⁴ They further noted that the three models were not to be interpreted as ‘in competition’, with one being superior (however defined) to another; instead each model was to be seen as a type of therapeutic relationship that will be appropriate in some situations or contexts but not in others. Furthermore, the type of relationship might change, for example, from active–passive to guidance–cooperation to mutual participation as the patient recovers. This implies that the physician will have to adapt their behaviour and attitude to complement the patient’s emergent needs while different specialties might approach the same situation (symptom, disease) differently. Here the authors made a link to the quality of care (‘good medicine’), highlighting issues around satisfaction of either party (it cannot be concluded that anything which satisfies is ‘good’) and agreement between the physician and the patient on the outcome, as without such agreement ‘it is meaningless to speak of a therapeutic relationship’ (p589).⁵⁴

Balint's early work (1957)⁵² on the physician–patient relationship in primary care has been important in conceptualising relationships between general practitioners (GPs) and their patients, and might be seen to be broadly in line with Szasz and Hollender's (1956) 'model of mutual participation'.⁵⁴ Balint discussed the need for psychotherapeutic approaches in general practice in order to facilitate doctor–patient relationships that are seen by both parties as being positive, emphasising the need for GPs to rely on more than just 'common sense' in diagnosing and addressing patients' psychological ailments.⁵² Balint viewed the relationship between GPs and their patients as a 'mutual investment company', the 'joint capital' of which is increased by the GP's choice of a successful therapy, whether that is physical, pharmacological or psychological (p292).⁵² Where the 'company' is dissolved (the relationship is terminated for the best outcomes), the 'most important assets' – the successful treatment to date – should be saved.

Veatch (1972)⁶⁴ proposed four models of professional–lay relationships in medicine, essentially based on the moral aspects of the interaction.⁶⁵

- The **engineering model** views the physician as an applied scientist (a 'power broker who has medical knowledge'⁶⁵) who mechanically provides care.
- The **priestly model** likens the relationship to fatherhood or a parent–child relationship in which the physician is the locus of decision making for the benefit of the patient.
- The **collegial model** assumes a collegial relationship between the physician and the patient, in which both pursue the common goal of 'eliminating the illness and preserving the health of the patient' (p7).⁶⁵
- The **contractual model** assigns rights and responsibilities to both parties and there is a 'real sharing of decision making' on the premise of trust and confidence.

Similar to the categorisation proposed by Szasz and Hollender (1956),⁵⁴ the approach by Veatch (1972)⁶⁴ (and, indeed, Freidson (1970)²⁰ – see below) very much rests on the distribution of power between the two interacting parties, assuming that as patient or lay knowledge increases, the relative power imbalance between the physician and the patient decreases.

Building on Veatch (1972), Emanuel and Emanuel (1992) described four models of this relationship that may occur in practice.⁶⁶

- **Paternalistic:** The physician makes decisions on behalf of the patient, acting as the patient's guardian. Patient autonomy is conceptualised as assent to the physician's decision.

- **Informative:** The physician provides information and all available facts to the patient; the patient then determines the course of action according to their values.
- **Interpretive:** The patient is uncertain about their values, and the physician assists the patient in elucidating these patient-held values.
- **Deliberative:** The patient is open to development of their values, and the physician instructs on desirable values.

The authors emphasised that patient autonomy has a role in all four models, but is conceptualised differently in each.

More recently, Potter and McKinlay (2005) developed a framework ('theoretical rubric') for examining and structuring contemporary physician/provider organisation–patient relationships.¹⁶ It defines the relationship along 'longitudinal' and 'lateral' dimensions. Longitudinal is used to describe investments made by the provider in order to facilitate long-term interaction (eg monitoring, maintaining key personnel contacts), while lateral investments describe the efforts made to address the needs of the patient at a particular point in time, assessing laterally (eg patient history and social situation) as well as when there are acute health needs. The authors argue that both are necessary for a successful relationship, although sole changes in behaviour of physicians or patients in order to enable these investments are unlikely to be sufficient. Instead they emphasise that change is needed to reduce pressures and constraints of the organisational context within which the doctor–patient encounter takes place. We discuss the influences of context in later sections.

The nurse–patient relationship

It is important to reiterate that the models and frameworks described in the literature overwhelmingly refer to the physician–patient relationship. However, Dougherty and Tripp-Reimer (1985) made a strong case for conceptualising the relationships between nurses and patients separately from those between patients and doctors.⁶⁷ They point to the biomedical model as underlying doctors' practice, which is concerned with the diseased body, while nursing is concerned with what they refer to as 'human responses' to actual and potential health problems. Relationships of patients or service users with nurses are often of a different nature from those with doctors; according to Dougherty and Tripp-Reimer (1985), nurses work to promote wellbeing in the ill as well as in those who could be biomedically defined as being well or free from disease.⁶⁷

2.4 Characterising relationships in healthcare

The brief overview of models of the professional–patient relationship in the preceding section sought to understand how existing work has conceptualised relationships in healthcare. It highlighted how the notion of power in particular transcends existing models. Medical sociology has constructed the doctor–patient relationship as a ‘social model’ based on respective power, knowledge and status of the two parties. The professional status of the doctor determines the role of the patient.¹⁸ This conceptualisation dates to the work of Parsons (1951) who was the first to examine the relationship as part of his analysis of illness as social deviance, and to form the notion of the ‘sick role’. This is a temporary state, which exempts patients from normal social obligations while obliging them to seek help and follow medical advice to improve.¹⁹ The doctor in turn exerts a control function to manage the threat imposed by the sick patient on social order, and so assumes a stabilising function. In this relationship, the patient is a passive recipient of care who responds to medical authority. Freidson (1970), in contrast, pointed to the principal ‘conflict’ in the relationship, with doctors and patients having different agendas so the actual consultation is seen as a ‘competitive’ arena in which each party seeks out power with potential for abuse of power.²⁰ In this interpretation, formal medical knowledge competes with the patient’s lay or ‘folk’ knowledge, with improvements in medical technology further reinforcing the power imbalance between physicians and patients.¹⁶

Parsons’ work has been challenged on grounds of its medico-centric approach, with the development of the notion of the role of the patient in a rejection of the medical model (eg Illich (1974)⁶⁸), the limited applicability of the ‘sick role’ to chronic illness,⁶⁹ alongside widening of the definitions of illness to incorporate the concept of risk – people becoming patients on the basis of a risk profile that may result in future disease.^{18,70} However, contemporary debate has reinterpreted Parsons’ work as remaining fundamental to the understanding of the interaction between the patient and the health professional.^{71,72}

More recent work has explored the role of the physician as the emergence of a ‘new professionalism’ in response to changing contextual factors such as politics, societal/generational change and advances in technology and the capabilities of medicine.²² Christmas and Millward (2011) considered the effect of these changes on the doctor–patient relationship, identifying a decrease in paternalism as the most notable impact. Reasons for this change included:

- a moral rejection of paternalism in line with societal change
- the transformation of medical knowledge from something possessed only by doctors to something accessible by anyone
- a greater awareness that doctors are ‘merely individuals and are not perfect’, leading to a greater willingness to question them
- growing evidence that subjective experiences of the patient can have substantive impacts on health outcomes
- increasing emphasis on the patient’s role as an active partner in care.²²

While the literature directly addressing the physician–patient relationship has often focused on issues around power and status, as described above, it may be useful to further disaggregate components or dimensions of relationships to aid better understanding of the factors that may impact relationship quality. As noted earlier, here we use Wish’s (1976) framework, which identified four relationship dimensions (power, ‘valence’ (here referred to as cooperation/competition), intensity and formality¹⁷), as a framework for presenting factors found to have an impact on a relationship’s quality. The majority of those identified in our review were synonymous with one of these dimensions or could be seen to be associated with the dimension as a subsidiary concept, through influencing where that relationship might be placed on the spectrum of that dimension. For example, Kaplan *et al* (1989) described greater patient sense of control to be associated with satisfaction with care.¹⁵ ‘Control’ (or sense of control felt by either party) can be seen as a concept impacting the power dimension of a relationship. In what follows, we explore the subsidiary concepts relating to each of the relationship dimensions.

We should note that many of the concepts that characterise relationships and their quality are likely to impact more than one dimension. Indeed, Wish (1976) noted that the distinction between the four dimensions is not clear-cut; for example the ‘democratic’ nature of a relationship could be placed within both the power and cooperation/competition (valence) dimensions.¹⁷ In what follows, we discuss how our literature search findings on relationships in healthcare can be situated in the four dimensions of relationships in Wish’s (1976) framework.

Power: symmetry vs asymmetry

Agency

In the context of healthcare, the power relationship is strongly associated with the concept of ‘agency’, or how much one party must or is permitted to act on behalf of another. Agency in healthcare has been the focus of a considerable body of work on the doctor–patient relationship, specifically regarding assumptions surrounding choice and information exchange,⁵⁹ and whether rational decisions can be expected during illness.⁵⁸ Scott and Vick (1999) refer to previous definitions of a ‘perfect’ agent as ‘one who makes the same decisions that the patient would have made if the patient possessed the same information and expertise as the agent’.⁵⁸

Information (or knowledge) symmetry, between doctor and patient, and doctor and payer, has been considered to be a major factor impacting an agent’s ability to act, either on behalf of another party or in their own interest (see also cooperation/competition, below).⁷³ Furthermore, broader system features, such as physician payment, may affect the way physicians as agents may (be willing to) act and whether or not patients perceive the relationship between themselves and the provider (organisation) to be one of a competitive nature with conflicting objectives.⁷⁴ This observation relates to the ‘double-agency’ interpretation of the dual role of providers in that they represent the interests of their patients to payers (eg communicating what treatments are required and need to be paid for), while also representing the interests of the payer (eg treatment decisions for individual patients simultaneously serve as decisions on allocation of local and national health system resources). Depending on the system context and reimbursement modalities, providers have an incentive to keep care costs at a minimum, although where providers are paid on a fee-for-service basis the incentive is to increase activity while also ensuring that the medical needs of their patients are satisfied appropriately.⁷³

Dependence (also intensity)

Dependence describes a situation whereby one or both parties do not have a choice of whether or not to enter into the relationship. Examples include young children and their parents, or in the case of economics, monopoly or monopsony; a consumer only has one choice of provider, for example in rural areas where service provision is limited, or a provider has only one choice of consumer, for example pharmaceutical companies wanting to provide reimbursable medication to NHS patients can only contract with the NHS as a purchaser. In the case of non-healthcare service providers and their consumers, Palmatier *et al*

(2006) found consumer dependence to be relatively ineffective as a facilitator to improving relationship quality.²⁸

Regarding the doctor–patient relationship, Balint’s work highlighted a form of hidden dependence, in which the patient becomes dependent on the consultation itself as a healing measure.⁵² This hypothesis assumes that patients receive psychological benefit from the relationship with the doctor, from reassurance and advice given at the consultation. Balint (1957) further noted that this form of dependence gave doctors and patients responsibility to uphold the quality of the relationship (as defined by both parties) as a mutual investment.⁵²

Centredness (also cooperation/competition)

A growing body of work has evolved over the past decades around centredness as an increasingly important concept in healthcare.²³ While seen to be at the core of the delivery of high-quality care, the definition of ‘patient-centredness’ has remained elusive, however, with little consensus on its actual meaning.²⁴ Importantly, centredness itself has been interpreted as a multidimensional concept, with Mead and Bower (2000) identifying five dimensions to further describe patient-centredness: the biopsychosocial perspective, ‘patient-as-person’, sharing power and responsibility, a therapeutic alliance, and ‘doctor-as-person’. They argued that patient-centred medicine ‘promotes the ideal of an egalitarian doctor–patient relationship’ (p1089),²⁴ so building on the very concept of the power dynamic in the relationship, with related notions identified as user involvement, negotiation, concordance and patient empowerment.^{25,26}

Lee and Garvin (2003) highlighted how physicians can exercise power in the consultation through use of professional or expert language, which may act as a barrier for patients to express their lay views.²⁶ The consultation can be seen as a monologue, with the physician talking at the patient most of the time, or a dialogue between the physician and the patient. Kaplan *et al* (1989) noted that consultations characterised by more conversation led by the patient, relative to the physician, were associated with better clinical measures and patient-reported health outcomes.¹⁵ Trummer *et al* (2006) reported improved patient outcomes when clinicians were taught to use a more patient-centred communication style.⁷⁵ Other perspectives characterised the concept of centredness along the symmetry of input into the consultation – patient experience versus doctor expertise, and its balance.⁷⁶ Evidence from a small number of studies found patient-centredness to be associated with patient satisfaction and adherence to treatment.^{77,78}

Doctors' and patients' perceptions of their own power in the relationship were shown to impact their interactions and feelings about its quality. For example, Street *et al* (2007) noted that doctors' perceptions of a patient influenced their consultation style, with more patient-centred consultations occurring with patients who were perceived by doctors to be better communicators, who were more satisfied overall, and more likely to adhere.⁷⁸ Additionally, patient-perceived ability to complain⁷⁹ and, outside the immediate healthcare context, consumer-perceived provider expertise²⁸ were found to be associated with higher relationship quality from the patient/consumer perspective.

Valence: cooperation vs competition

Communication

Authors in various disciplines referred to the association between physician/seller communication skills and patient/service user satisfaction and relationship quality.^{27-29,58,59} Skills found to have particularly strong associations with satisfaction were information giving, interpersonal sensitivity and partnership building.^{27,29} Two studies showed that, in describing experience of primary care consultations, patients value (in order of importance) being made to feel comfortable talking to the doctor and understanding the doctor's explanations; here, the quality of information was found to be more important than quantity.^{58,59}

Agreement on nature of relationship

Compatibility between parties regarding objectives and values, and agreement on the role of each party within the relationship were mentioned throughout the literature as facilitators to perceived relationship quality.^{28,50} Emanuel and Emanuel (1992) and Jahng *et al* (2005) highlighted the importance of agreement on the degree of patient involvement within the physician-patient relationship.^{30,66} Jahng *et al* (2005) further noted that congruent views between the patient and clinician in relation to preferences for patient involvement were related to higher patient satisfaction, adherence and improved health outcomes.³⁰ Satisfaction was highest when both parties desired collaboration. Quill (1983) proposed four assumptions that underlie an implicit contract between patients and physicians: each party has unique responsibilities; the relationship is consensual, not obligatory; both the physician and the patient must be willing to negotiate; and each party must gain something from the encounters.⁷⁶

Conflict

As mentioned earlier, Freidson (1970) highlighted the principal 'conflict' between physician authority and patient autonomy in the relationship.²⁰ The presence of conflict in a relationship was found by Palmatier *et al* (2006) to be stronger as a negative impact on relationship quality than any positive facilitating factor, and the authors noted that conflict may undermine the effect of any strategy or intervention aiming to develop facilitators.²⁸

Perception of the other party and the other party's agenda (also conflict)

Perceptions of the other party's nature and intentions were identified as important factors impacting relationship quality, although references to this concept were found mostly in literature outside healthcare. For example, Palmatier *et al* (2006) and Crosby *et al* (1990) found perceived similarity and perceived seller expertise to have the greatest impact on relationship quality as experienced by the customer.^{28,80} Palmatier *et al* (2006) also noted that perceived relationship investment (eg time, effort, resources invested by seller) increased customer satisfaction with the relationship.²⁸ The authors further noted that when an individual evaluates another individual they make stronger, quicker and more confident judgements than when they evaluate a group. This may have implications for interventions targeted at the patient-clinician relationship versus the patient-provider organisation relationship.

Trust (also intensity, formality)

Although the concept of trust between two parties arose throughout the literature as an underlying feature of relationship quality, and can arguably impact multiple relationship dimensions, it appeared to be most commonly discussed in relation to the competitive or cooperative nature of a relationship. Mechanic and Meyer (2000) noted that patients develop trust in their physician based on familiarity and the impact of physician interpersonal skills, such as the extent to which the patient feels listened to.⁸¹ Other factors found to influence trust in a relationship were the level of provider expertise experienced by the consumer, perceived improvement in provider 'relationship investment' and repeated interactions.²⁸ Repeated interactions provide a context that facilitates and enhances development of trust and lasting cooperation; conversely, single encounters may limit the extent to which trust and stable cooperation can be established.⁸² Palmatier *et al* (2006) noted that trust is both built and lost more quickly at organisational level than in individual-level relationships.²⁸

Iacobucci and Ostrom (1996) also highlighted the notion of perceived risk or uncertainty by either party, which can impact quality of relationships between service users and providers; indeed, in the business theory literature, 'trust' is often found to be the antidote to risk.⁵⁰

Intensity: intimate vs distant

Commitment

The 'intensity' of a relationship can be impacted by how committed both parties are to the relationship and its quality. Palmatier *et al* (2006) defined commitment as an 'enduring desire to maintain a valued relationship'.²⁸ In healthcare this concept can involve a patient's readiness for a relationship, for example motivation to change behaviour on the patient's part and willingness to tailor their approach to a patient's preferences on the part of the physician.

Transactional vs relational nature of relationship

As noted earlier, the management literature describes short-term exchanges and longer-term relationships as 'transactional' versus 'relational'. This concept is referred to in relation to securing returning customers and promoting brand loyalty.²⁸ In relation to healthcare, Potter and McKinlay (2005) examined the nature of provider investment in the relationship as being lateral (for the here and now) or longitudinal (for the longer term).¹⁶ They found high levels of lateral and longitudinal investment to be associated with higher quality relationships.

Formality: social vs professional

Iacobucci and Ostrom (1996) argued that the formality dimension may have particular relevance for relationships in the management context, but can also be applied to individual relationships regarding their emotional or intellectual nature.⁵⁰

Affect (or expressed emotion by either party)

Kaplan *et al* (1989) highlighted that positive and negative 'affect' in physician-patient interactions are associated with improved health outcomes as a result of functional assessment and patient-reported assessments.¹⁵ Negative affect included emotions and behaviours such as anger, tension, impatience, strain, misgivings, stammering, nervous laughter, frustration, anxiety and self-consciousness.

Exclusivity (also intensity)

In an interesting note on the role of secrecy in the doctor-patient relationship, Fainzang (2002)³¹ pointed out that patients keeping information about diagnosis from others can lead to a closer bond between physician

and patient. For example, in the case of HIV diagnosis and other potentially highly stigmatised but invisible conditions, a link is created between the doctor and the patient because they share the secret of the diagnosis. Fainzang (2002) discussed how this element of secrecy in the relationship is distinct from lying, which can also be a characteristic of doctor-patient relationships; secrecy here is seen as 'a means of protecting the patient so that he does not suffer from the fact that others know this information' (p122).³¹

2.5 Contextual factors impacting relationships

Relationships in healthcare, and indeed in any setting, do not exist and evolve in isolation but are strongly influenced by the context(s) in which they take place. This includes the structure of the wider health system and the policies governing the interactions (eg regulation, organisation, funding), alongside factors that influence the patient and physician as individuals, for example, the patient's social status or access to other support networks or a physician's attitude towards 'patient-centredness'. References to these contextual factors surfaced throughout our review, the most common being those of culture and historical/political changes. Any framework aiming to analyse relationships will need to take account of contextual factors in order to understand influences on relationship quality.

The role of culture

Culture is defined differently depending on the context and discipline within which it is being discussed or applied.⁸³ An anthropological focus on 'culture', while it is somewhat intangible, can be broadly described as drawing attention to the way things are formulated and conceptualised as a matter of practice or technique. People's values are based on their ideas about the world; conversely, ideas shape how people think and react.⁸⁴ Culture is seen as being inherent in all actors, rather than just in managers, elites or others in positions of superior power (eg medical professionals vis-à-vis health service users), and all actors are therefore able to bring about cultural change in their interactions with each other. Strathern (1997)⁸⁴ and Lock and Nguyen (2010)⁸⁵ noted, however, that it is necessary to apply the concept of culture universally to all groups. Therefore in a healthcare setting 'culture' should not only be applied to patients as a way of explaining away those of their actions that do not comply with the medical professionals' expectations but should equally be used to examine the ways in which health professionals act. They should also make clear which ideas about the world they are drawing on in encounters or relationships with patients.

Fischer (2007) highlighted how thinking about culture when assessing relationships between healthcare providers and users helps to ‘make visible differences of interests, access, power, needs, desires and philosophical perspectives’, which can all have an impact on the perceived quality of these relationships by those involved.⁸⁶ At the same time, while context is important, where relationships appear to be problematic or of low quality, a focus on the distinct context or culture should not be used as an ‘excuse’ for ignoring potentially more important issues, such as the differences mentioned above.

Health interventions that are designed to improve the quality of care have tended to rest on the disease model of health,⁸⁷ stemming from the western, biomedical approach that is focused on the cure of a specific disease. Singer and Baer (2007) stressed the importance of broadening this approach, as a focus on the nature of relationships is intended to do, to enable better understanding of ‘sickness’, its conceptualisation and experience by those affected, their support networks, and how the social and cultural context influences and shapes health-related beliefs and practices.⁸⁸

The changing healthcare context

Approaches to healthcare and associated patterns of behaviour have changed as a reflection of the changing burden of disease from acute to chronic, and this has influenced the nature of relationships between healthcare providers and users of healthcare.

Chronic illness confronts patients with a spectrum of needs that requires them to alter their behaviour and engage in activities that promote physical and psychological wellbeing, to interact with healthcare providers and adhere to treatment regimens, to monitor their health status and make associated care decisions, and to manage the impact of the illness on physical, psychological and social functioning.⁸⁹ There is a changing balance in the degree of professional and patient involvement in care, with many chronic conditions requiring significant participation by informed patients, calling for support from healthcare providers to inform and enable patients to self-manage their illness. This may also necessitate an ongoing collaborative process between patients and professionals to optimise long-term outcomes.⁹⁰ Partly as a consequence of these developments, alongside requirements to standardise clinical processes as a means to reduce variation in healthcare and medical error and performance measurement, the patient-provider relationship has become more diverse and multifaceted, and ‘less paternalistic’.⁷⁰

Chapter 3:

Rapid assessment of the empirical evidence on interventions and quality

This chapter provides an overview of the findings of a rapid assessment of the empirical evidence of a select set of interventions, building on seven projects that are currently being tested within the health services as part of the Health Foundation's Closing the Gap through Changing Relationships programme.³² Specifically, we sought to explore whether and how the intervention under consideration impacts on the quality of care as defined by the Institute of Medicine (2001),³³ and to consider the specific relationship change the given intervention is seeking to bring about and how this relationship change may be linked to improvements in quality of care.

Table 1, overleaf, is reproduced from Part 1 (page 7), listing the seven Foundation projects that guided the identification of core interventions to be reviewed here.

The quality domains considered were those proposed by the Institute of Medicine (2001),³³ further adapted by the Health Foundation:⁹¹ effectiveness, safety, person-centredness, timeliness, efficiency and equity.

We begin by briefly outlining the general approach taken, followed by a description for each intervention of results of the literature searches, a summary overview of the empirical evidence of associations of the given intervention with domains of quality of care, and a discussion of the likely impact of the relationship change that a given intervention aims to produce and its impact on the quality of care.

Table 1: Example interventions tested as part of the Health Foundation’s Closing the Gap through Changing Relationships programme³²

Health Foundation projects tested within the Closing the Gap through Changing Relationships programme	Interventions reviewed in this report
<p>Supporting patients in managing their own dialysis within a hospital environment</p> <ul style="list-style-type: none"> - Training and support for haemodialysis patients to self-administer treatment and make choices about where to receive care (eg patient education and engagement) - Training and support for nurses to enable an active partnership with patients 	<p><i>Patient self-administration of medication</i></p>
<p>Patient access to online health records and the functional use of those records</p> <ul style="list-style-type: none"> - Supporting GP practices to provide record access to patients - Supporting patients to understand and use records - Patients use records and associated technology for communication with practice 	<p><i>Patient access to online health records</i></p>
<p>Using patient complaints as a driver for improvement within a hospital environment</p> <ul style="list-style-type: none"> - Employing ‘patient champions’ from the community - Convening ‘expert panels’ to review a selection of complaint processes and outcomes each quarter - Complaints survey for patients/carers - ‘Digital stories’ – inviting patients to share the experience through writing a narrative, to be shared with staff for training purposes 	<p><i>Addressing complaints about care received</i></p>
<p>Putting women at the centre of antenatal care</p> <ul style="list-style-type: none"> - Improving information for women - Ensuring continuity of care - Responding to women who are anxious - Improving conversations between women and clinicians 	<p><i>Involving women in decision making in antenatal care</i></p>
<p>Use of peer support workers in mental healthcare</p> <ul style="list-style-type: none"> - Training, recruitment and employment of peer support workers - Specific interventions to promote person-centredness - Peer support workers have time dedicated to improve quality and enhance service user and carer experience, and are trained and supported to do so 	<p><i>Use of peer support workers in healthcare</i></p>
<p>Compassionate healthcare for homeless patients</p> <ul style="list-style-type: none"> - ‘Care navigators’ with experience of homelessness to assist staff in understanding what patients need and assist patients in knowing where else to get help - Developing a toolkit (training programmes, materials, processes, guidance, job descriptions) to share good practice and learning between sites - Clinician education/sensitivity training - Stronger links to external organisations; better connections between primary and secondary care to form a care pathway for homeless people; better tracking of regular attendees 	<p><i>Improving healthcare services for homeless patients</i></p>
<p>Shared decision making in child/adolescent mental healthcare</p> <ul style="list-style-type: none"> - Information dissemination to patients on condition and treatment options available - Shared decision making between young people and care staff regarding (i) key problems and goals, (ii) treatment course, (iii) progress reviews 	<p><i>Shared decision making in child/adolescent mental healthcare</i></p>

3.1 Methods

We carried out a systematic search of the published literature on the empirical evidence of the main interventions described in Table 1, using the bibliometric database PubMed. We identified studies using a set of MeSH terms specific to the intervention under consideration and in combination with the Institute of Medicine quality domains (either the MeSH term ‘quality of health care’ or single terms). Where MeSH terms were not appropriate or applicable we used free text combinations. For example, ‘peer support work’ is currently not identified as a distinct concept within the PubMed MeSH database; in such cases we used text combinations describing the intervention under review. Selection of free text search terms built on detailed descriptions of the interventions as obtained from project sites’ progress reports, including the logic models developed by sites to inform individual projects. Given the wide range of interventions considered, the overall structure of searches was discussed within the research team and search strategies were reviewed to ensure consistency in approach across intervention types. Details of the search terms and strategies used for each intervention are presented in the Appendix.

A principal inclusion criterion was study design, prioritising original experimental and quasi-experimental designs as well as systematic reviews, although observational designs were also considered where appropriate. Studies were only considered for inclusion if they provided evidence of associations between the intervention and quality of care. We excluded editorials, letters and commentaries. Studies in languages other than English were also excluded, as were those that provided insufficient detail on analyses undertaken. We did not apply limits on publication date. Further detail of inclusion and exclusion criteria is provided for each intervention reviewed below and in the Appendix.

Titles and abstracts were screened for eligibility for inclusion. Studies considered eligible were retrieved where possible and scrutinised further for inclusion or exclusion in the review. References in studies considered eligible were followed up where appropriate. Searches and title/abstract screening were led by one of three researchers on the team and cross-validated by a senior researcher. Eligible studies were analysed by extracting data according to a common template, including information about the stated study objective, study design, description of intervention and population under study, methodological approach, outcome measure(s) and key findings. It was beyond the scope of this review to undertake a systematic assessment of the quality of included studies. However, where appropriate and relevant, we comment on potential quality

concerns such as (small) sample size, lack of detail on methodology, or lack of definition of concepts studied.

We further included a commentary noting whether and how the intervention under study was found to be related to any of the domains of care quality described below, as well as the type of relationships that were involved and how the quality of the relationship was impacted by the intervention. This information typically had to be inferred by the researchers, as frequently studies did not make these associations explicit.

In line with the Institute of Medicine’s definition of quality³³ and with other work,⁹²⁻⁹⁴ we operationalised the six domains of quality of care as:

- **effectiveness:** captures clinical effectiveness, ie the extent to which a service or intervention achieves the desired result(s) or outcome(s); and patient experience, ie the extent to which the patient perspective and experience of a service is measured and valued as an outcome of service delivery
- **safety:** the extent to which healthcare processes avoid, prevent and ameliorate adverse outcomes or injuries that stem from the processes of healthcare itself
- **person-centredness:** the extent to which services involve service users; provide them with information to support their decision-making; are responsive to their needs and expectations; and are respectful of privacy, confidentiality and differences between service users
- **timeliness:** the extent to which services are accessible in a timely manner
- **efficiency:** the relationship between a specific product (output) of the healthcare system and the resources (inputs) used to create the product
- **equity:** the extent to which the distribution of healthcare and its benefits among a population is fair; implies that, in some circumstances, individuals will receive more care than others to reflect differences in their ability to benefit or their particular needs.

Boundaries between these domains of quality are not clear-cut, however, in particular for distinguishing patient experience as a measure of effectiveness or of person-centredness, as we will see below. It should further be noted that measures of efficiency in the field of quality of care are not well developed.³⁶ While efficiency relates to value for money, available measures tend to reflect costs of care only and studies reviewed here typically present the latter.

3.2 Patient self-administration of medication

The initial search aimed to identify studies on support for self-management of treatment as tested within the Foundation's projects (see Table 1); however, this did not yield any returns. We therefore refined the search, focusing on patient self-administration of complex medication treatment in any setting, which yielded 1,806 records. We excluded studies describing non-pharmacological interventions, an intervention that was administered by a carer and not the patient, or an intervention concerned with general self-management, including chronic conditions such as diabetes and asthma that also involve self-administration of medication. One paper was excluded as insufficient detail was provided on data analysis. We identified nine studies as eligible for inclusion, including three randomised controlled trials (RCTs),^{34,95,96} one pragmatic randomised crossover trial,⁹⁷ one cost-effectiveness analysis of an RCT⁹⁸ and four observational studies.^{99–102}

Interventions studied included the self-administration of anticoagulation therapy,^{95–98,101} C1-inhibitor concentrate for the prophylaxis and treatment of severe angioedema¹⁰⁰ and antiretroviral therapy.³⁴ Two observational studies examined self-administration programmes in a hospital setting.^{99,102}

Associations of the intervention with quality of care

Effectiveness

The majority of studies examined the effectiveness of the intervention, generally pointing to improved clinical outcomes and/or patient experience or, where a comparison strategy was used, outcomes that were comparable to usual care.^{34,95–101} For example, Fitzmaurice *et al* (2005), in a multicentre RCT of patient self-management of oral anticoagulation treatment in general practice in the UK, found therapeutic control to be similar to that among patients receiving usual primary care management.⁹⁶ Self-managed patients with poor control at baseline were further shown to improve control significantly, from 45% to 55%, which was not seen in the control group, suggesting self-administration of oral anticoagulation to be at least as effective as routine care for a sizeable proportion of patients. This was supported by a cost-effectiveness analysis undertaken alongside the trial, which demonstrated that mean total quality-adjusted life years (QALYs) after 12 months was slightly higher in the intervention group although the difference from the control group was statistically not significant (mean difference: 0.009; 95% confidence interval (CI) –0.012, 0.030).⁹⁸ A linked retrospective matched control study further found that patient self-management of oral

anticoagulation outside trial conditions was as clinically effective as routine UK care, again demonstrating similar levels of therapeutic control between the intervention and control group after 12 months.¹⁰¹ However, the sample size was small (intervention: 38 patients; control: 40) and there were concerns about the representativeness of intervention patients.

In a randomised crossover trial of a very small sample of patients (n=11) from one family practice in British Columbia, Canada, Grunau *et al* (2011) found patient self-management of warfarin therapy to be equally effective for therapeutic control as in standard care.⁹⁷ Observed improvements in patient satisfaction were not statistically significant. However, findings of the study cannot easily be generalised because of the small sample size and need to be interpreted with caution. Grantham *et al* (2006) examined the feasibility of a self-medication programme in a nursing convalescent unit in a large metropolitan teaching hospital in Australia.⁹⁹ Involving a convenience sample of medical and surgical patients (n=220), the intervention differentiated three levels of nurse involvement in medication. At the end of the six-month study period, about 45% of patients had remained at level 1 (medication administered by a nurse) while 29% had achieved level 3 (self-administration). Among those responding to a survey (16%), all reported high satisfaction with the programme, suggesting that self-medication may be an effective alternative to usual medication administration for selected patients.

Conversely, Altice *et al* (2007), in a RCT of a community intervention of directly administered antiretroviral therapy of HIV-infected drug users recruited from HIV clinics in Connecticut, USA (n=88), found the intervention to be more effective than self-administered therapy (n=53).³⁴ At six months, a significantly greater proportion of those in the intervention group had achieved the primary outcome (HIV-1 RNA level reduction or achievement of HIV-1 RNA < 400 copies/mL) than in the control group, at respectively 70.5% and 54.7% (p=0.02). Those in the intervention group further showed a significantly greater improvement in CD4 cell counts. These and the earlier findings described above seem to suggest that while self-administration may provide an appropriate and effective alternative to supervised administration for some patients and conditions, it may be less suitable and potentially inappropriate for others, for example, those with more chaotic lifestyles.

Safety

Safety was a commonly analysed quality domain in six studies reviewed here, measured as the number or rate of adverse events^{95–97,100} or medication errors.^{99,102} Patient self-administration was generally found to be as safe

as or safer than usual care. For example, Phelan *et al* (1996), reporting on a self-administration of medication programme in a hospital setting in New York based on a review of medication administration errors over a four-year period, showed that the medication error rate was lower for self-administration than usual care (3.06 per 10,000 medication orders vs 4.01).¹⁰² The pilot study of a self-medication programme in a nursing convalescent unit by Grantham *et al* (2006) reported that two staff medication errors had occurred during the trial period but no patient-initiated medication errors.⁹⁹ However, historical data during the six months preceding the study showed one medication error, making it difficult to interpret observed findings.

Levi *et al* (2006), in an observational study of self-administration of C1-inhibitor concentrate among a total of 43 patients with angioedema in the Netherlands, did not observe any serious adverse effects over the 3.5-year follow-up period although a small proportion reported self-limiting adverse events such as dizziness after injection.¹⁰⁰ Fitzmaurice *et al* (2005), in their RCT of patient self-management of oral anticoagulation treatment in general practice in the UK, found the rate of serious adverse events in the intervention group to be similar to that seen in the control group (2.8 per 100 patient years vs 2.7/100; $p=0.89$).⁹⁶ This suggests that self-management of anticoagulation treatment may provide a safe strategy. In summary, available evidence seems to indicate that self-administration of medication can be safe although the small sample size of several studies included in this review limits the generalisability of findings.

Person-centredness

A small number of studies considered this domain of care quality and found interventions to have a positive impact or no impact when compared with professional administration of medication. For example, Grunau *et al* (2011) reported that 10 out of the 11 patients included in their study preferred self-management to standard care and would elect to continue with this strategy following study completion.⁹⁷ Fitzmaurice *et al* (2002), in a small randomised trial of patient self-management of oral anticoagulation, highlighted patients' reports on knowledge, self-empowerment and self-efficacy while also noting anxiety, but the direction of these reports (eg an increase compared with the control group) was not clear.⁹⁵

Timeliness

Timeliness was an important domain for one intervention for patients with attacks of angioedema, as self-administration allowed for more rapid access to treatment than usual care.¹⁰⁰ Here, the time between onset of attack and initiation of relief or complete resolution of symptoms was found to be reduced by the intervention.

Efficiency

Mixed impact was reported in relation to efficiency. The cost-effectiveness analysis of patient self-management of anticoagulation by Jowett *et al* (2006) estimated the overall healthcare cost of the intervention to be significantly higher than usual care, at £417 (95% CI £394, £422) and £122 (£103, £144) respectively.⁹⁸ While this finding suggests that the intervention may not be cost-effective overall, the analyses further showed that costs over one year to the patients were lower for those in the intervention arm (£46 (£43, £49) vs £57 (£54, £61)), which, alongside increased convenience, points to a possible benefit of this approach for a selected group of patients. Higher costs of the intervention compared with routine care were also demonstrated in related studies by the same group of researchers.^{95,101} The feasibility study by Grantham *et al* (2006), while not assessing costs of the intervention directly, noted that the self-medication programme for inpatients increased reported staff workload overall because of the time spent on patient education.⁹⁹ At the same time, staff also reported improved confidence of nursing staff about their knowledge base of medicines, with suggestions of potential (time) savings related to patient discharge.

Equity

Studies reviewed here did not explicitly examine equity in relation to the intervention analysed. In their trial of directly administered antiretroviral therapy of HIV-infected drug users, Altice *et al* (2007) found that, in a population with historically poor levels of adherence, the use of directly administered medication did improve it.³⁴ This suggests that, in this particular group, self-administration might increase inequity. Likewise, the work by Fitzmaurice *et al* (2002, 2005) suggests that self-administered anticoagulation therapy may be appropriate for a selected group (of highly motivated patients) only.^{95,96} This group may not necessarily have the most to benefit from since they are more likely to show better adherence; the authors highlighted the need for further work to better understand differential participation in such programmes.

Linking to changes in relationships

Studies examining interventions involving the self-administration of medication rarely explicitly mentioned changes in relationships. At the outset it is important to note that self-administration interventions reviewed here focused on a small set of conditions or patient groups only, and the nature and dimension of the relationship affected is likely to vary with the condition and patient group concerned. For example, one study that showed self-administration to be inappropriate for a particular group of patients (drug users) may have been successful because of the potential

relationship between the patient and the care worker.³⁴ Grantham *et al* (2006) found that nurses reported greater knowledge of medication education as a result of the intervention, which may have led to closer relationships with patients.⁹⁹

However, given that, by their very nature, the interventions reviewed aim for less frequent contact of patients with health professionals, this is likely to have implications for the patient–provider relationship. Self-administration might increase levels of empowerment among patients, as hinted at by Fitzmaurice *et al* (2002),⁹⁵ and so, potentially, (re-)balance the patient–professional dynamic along the power continuum from an asymmetric to a more symmetric relationship. At the same time, in shared-administration interventions, the cooperation dynamic alongside the intensity of the relationship may come more into play, in particular where vulnerable patient groups are concerned. It is conceivable that levels of trust and investment in the relationship on the part of the provider form the precondition for high-quality outcomes.

3.3 Patient access to online health records

We sought to identify studies of interventions that provide patients with electronic access to their own medical records along with support to enable them to understand, navigate and use their data. This yielded a total of 2,380 records. Studies that did not focus on patient use of records (eg their focus was on the use or outcomes of electronic health records by health professionals), described eHealth technology other than the personal use of electronic health records, or the intervention involved one-way communication only (eg patient reminders to attend appointments) were excluded. One paper was excluded because of insufficient detail on study methodology. We identified 15 studies as eligible for detailed review. These included three randomised controlled designs,^{43,44,103} six (systematic) reviews^{37, 104–108} and six observational studies.^{45,109–113}

Interventions considered targeted persons with chronic disease,^{43,44,103,108} tobacco dependence¹⁰⁵ or the general (patient) population.^{37,45,104,106,107,109–113} At the outset it is important to note that the terminology and scope of interventions used varies widely, stretching from giving access to doctors' visits or office notes,¹¹³ to electronic personal health records that permit patients to input data themselves to inform the development of a care plan.⁴⁴

Associations of the intervention with quality of care

Effectiveness

Six studies considered measures of effectiveness, including process measures and clinical outcomes measures as well as patient satisfaction, although the evidence was mixed.^{43,44,103,105,107,108} For example, Holbrook *et al* (2011), in a RCT of shared electronic vascular risk decision support in 49 primary care practices in Ontario, Canada, found process measures such as assessment of blood pressure or lipids to be significantly improved in the intervention group (mean process composite 14.08 vs 9.49, $p < 0.001$).¹⁰³ In contrast, outcomes such as blood pressure or cholesterol levels as well as quality of life at one year did not differ significantly between intervention and control groups. Similarly, a randomised controlled study of online personal health records for type 2 diabetes in 11 primary care practices in Massachusetts, USA, found that a significantly higher proportion of patients in the intervention group had their diabetes treatment regimen adjusted after one year compared with a control group that also used personal health records but did not receive tailored decision support (53% vs 15%, $p < 0.001$).⁴⁴ However, there were no significant differences in risk factor control between the two groups. Improved process measures were also shown for patients participating in a pilot randomised trial of a web-based online medical record for patients with congestive heart failure, with a higher level of adherence to medical regime after 12 months than a control group (adherence score 85 vs 78, $p = 0.01$).⁴³

This relative lack of evidence of effect was confirmed by two recent reviews of the value of electronic personal health records or patient portals for chronic disease management, which also included the studies described above, highlighting the overall dearth of good quality evidence in this area.^{107,108} Tenforde *et al* (2011) further noted that electronic personal health records are typically introduced as part of a broader intervention that includes additional care tools, so making it difficult to isolate the effects of the individual components.¹⁰⁸ Similarly, a systematic review of the impact of electronic medical records as a means to enhance the delivery of effective treatment of tobacco dependence in primary care settings failed to identify sufficient evidence of such an effect or, indeed, impacts on smoking cessation.¹⁰⁵

Safety

Safety was rarely addressed explicitly in the context of electronic personal health records. The pilot RCT of a web-based online medical record for patients with congestive heart failure by Ross *et al* (2004) noted that no adverse effects had been observed as a consequence

of the use of the system.⁴³ Where safety was mentioned, this was typically referred to in the context of potential or perceived impacts. For example, a qualitative study of perceptions of personal health records using focus groups at four family medicine practices in Iowa, USA, noted a concern among physicians about accuracy of information and that such a system might facilitate narcotic abuse.¹¹² In their review of cost indicators associated with electronic records, Gallego *et al* (2010) highlighted a range of non-monetary benefits arising from reduced adverse drug events, reduced errors and reduced use of laboratory tests.¹⁰⁶ However, these findings rested on one study only¹¹⁴ and their generalisability to patient access to electronic health records remains unclear.

Person-centredness

Eight studies considered measures that could be described as, or constituted elements of, person-centredness, but evidence of effect was mixed.^{37,43,103,104,107,110,111,113} Holbrook *et al* (2011), in their RCT of shared electronic vascular risk decision support, found that patients receiving the intervention had significantly higher odds of rating their continuity of care to have improved (odds ratio (OR) 4.18, 95% CI 3.04, 5.76), as did their self-rated ability to improve their vascular health (OR 3.07, 95% CI 2.37, 3.99).¹⁰³ An exploratory qualitative study of perceptions of personal health records of 10 patients aged 60 years and older at a tertiary hospital in Sydney, Australia, highlighted the importance patients attributed to the greater level of control provided by such a system.¹¹⁰ This finding of the value of greater control was supported by a recent patient and physician survey study of giving patients electronic access to their doctors' notes in primary care practices in three US states.¹¹³ However, that study elicited attitudes of individuals before they joined the programme that would enable such access and it remains to be seen whether this anticipation of greater control will materialise.

Indeed, a recent review by Ammenwerth *et al* (2011) of the benefit of patient portals noted that available evidence does not (yet) support the notion that such systems enhance patient empowerment.¹⁰⁷ Similarly, a narrative review of the impact of electronic medical records on patient–doctor communication during the consultation noted that while their use was frequently shown to have a positive impact on information exchange, it also raised the possibility for such systems of negatively influencing patient-centredness, for example by means of restricting time spent talking because of the requirement for the doctor to enter data into the electronic record.¹⁰⁴ However, that study examined doctors' use of electronic means more generally and it is not clear whether and how these

findings are generalisable to patient access to their records. In their pilot RCT of an online medical record for patients with congestive heart failure, Ross *et al* (2004) observed a trend for higher levels of patient satisfaction with the doctor–patient communication, while the intervention did not improve self-efficacy levels above those in the control group (self-efficacy score 91 vs 85, $p=0.08$).⁴³

Timeliness

Studies reviewed did not examine associations of interventions with timeliness of care.

Efficiency

Three studies explored associations with indicators of efficiency.^{37,106,109} Zhou *et al* (2007) assessed efficiency indirectly by studying the impact of patient access to an electronic health record with secure patient–physician messaging on service utilisation in primary care in one large managed care organisation in the USA.¹⁰⁹ Using a retrospective cohort and matched-control design, it found a significant decline in annual office visit rates among those who had signed up to the online system: 10.7% (0.25 visits per member per year) compared with a fall of 3.7% (0.08 visits) among controls ($p<0.003$). Registered users also had a smaller increase in documented telephone contacts (16.2% vs 29.9%, $p<0.01$). A systematic review by Black *et al* (2011), although concerned with the impact of electronic health records in general, as opposed to patient access, noted anecdotal evidence on improved organisational efficiency with some empirical evidence of time efficiency for some staff, alongside improved data quality (legibility, completeness and comprehensiveness).³⁷ There are limited data on empirically measured costs, with work by Gallego *et al* (2010), which examined cost indicators related to electronic health records more generally, pointing to savings in relation to billing through reduced errors or resulting from unnecessary testing.¹⁰⁶

Equity

Equity issues associated with patient access to electronic health records or personal health records were noted in several studies.^{43–45,108,110,112,113} Roblin *et al* (2009), in a two-year cohort study of personal health records in a managed care organisation in Georgia, USA, found that African Americans were significantly less likely to register with the online system (30.1%) than white Americans (41.7%) (hazard ratio (HR) 0.652, 95% CI 0.549, 0.776).⁴⁵ There was also a significant educational gradient within both groups, with those with higher educational levels more likely to register, as were persons with baseline access to the internet. Evidence of, or the potential for the development of,

such a digital divide was also noted by Grant *et al* (2008) whose randomised trial of online personal health records for type 2 diabetes found that people who were older, belonged to ethnic minorities or lived in poorer neighbourhoods were less likely to enrol in the study.⁴⁴ Similar concerns were raised by Ross *et al* (2004) in their pilot study of access to online medical records for patients with congestive heart failure.⁴³ Tenforde *et al* (2011) highlighted that existing evidence of the impact of electronic personal health records remains of limited representativeness of the general population in terms of internet access and health literacy.¹⁰⁸ Thus, taking full advantage of the potential benefits of personal health records requires better understanding of barriers to access to reduce the risk of widening health and healthcare inequalities.⁴⁵

Linking to changes in relationships

Interventions that provide patients with access to their medical records aim to enable them to better understand their medical condition(s) and prescribed treatment(s): the expectation is that patients will thereby develop greater interest and confidence in becoming more active in treatment planning and self-management. Yet studies reviewed here that examined such interventions rarely noted how this might be linked to (changed) patient–provider relationships. It is important to note that several studies reviewed here focused on electronic health records in general and it is often not clear to what extent these involved direct patient access. Where direct patient engagement is lacking there may be a risk of reducing the quality of the relationship, as highlighted by Shachak and Reis (2009) and Black *et al* (2011), with the individual encounter perceived as becoming less personal with the intrusion of a computer in the consultation.^{37,104}

Several studies noted the potential for personal health records to increase levels of patient empowerment and, by implication, so contribute to balance the power dynamic between the patient and the provider. However, the term ‘empowerment’ tends to remain poorly defined in many studies, encompassing different notions such as self-efficacy or degree of control, and it is frequently not made explicit how electronic personal health records are expected to enhance empowerment.³⁸ Improved communication has been suggested as one route into increasing empowerment, by means of enabling patients to express preferences and contribute important information to the consultation. In addition to potentially contributing to (re-)balance the patient–professional dynamic along the power continuum, improved patient satisfaction with the doctor–patient communication may have the effect of making the two parties feel that they are ‘on the same team’ and so shifting the cooperation–competition dynamic.

Importantly, several authors have also highlighted that an informed patient is not necessarily a healthier patient¹⁰⁷ and the current lack of robust evidence of the effect of electronic personal health records on outcomes might reflect failure to actively engage patients in the design of such systems and support them in their use.^{43–45}

3.4 Addressing complaints about care received

Our search aimed to identify studies that focused on institutional processes for addressing complaints by patients or their advocates about care received, and the association of these processes with the quality of care. We used a combination of broad sets of free text terms, including ‘complaints’ and synonyms of ‘complaint’ included in MeSH terms such as ‘dissent and disputes’; this yielded a total of 8,177 records. Studies of interventions describing the nature of complaints processes more generally and single case studies were excluded. Our prime focus was complaints initiated by patients or their advocates, but we also included studies that considered complaints filed by healthcare professionals where these concerned the quality of patient care. A total of seven observational studies were identified as eligible for inclusion.^{115–121}

At the outset it is important to note that studies retrieved by our search are conceptually different from those reviewed in sections 3.2–3.3 and 3.5–3.8 in that in the present section ‘quality’ forms an input. This means that studies generally assessed the usefulness of complaints data to identify quality problems; there was little direct empirical evidence on the impact of the intervention under study on quality of care. The majority of studies focused on processes and procedures in single hospitals or nursing homes,^{115–117,119,121} while two studies examined complaints issued within a process implemented at a national level in one country (New Zealand).^{118,120} All studies drew on analyses of complaints data with a major focus on describing the nature and content of complaints, alongside the characteristics of those issuing complaints, rather than examining the impact of providing for a (formal) complaint process. This is reflected in our review below.

Associations of the intervention with quality of care

Effectiveness

We did not address measures of effectiveness as defined for the purposes of our review in studies of complaints processes.

Safety

The majority of studies that examined complaints processes found them to be triggered by concerns about safety; typically, safety was conceptualised as an input rather than an outcome of the intervention in question. For example, Bismark *et al* (2006) analysed the characteristics of patients in New Zealand who complained to an independent health ombudsman following experience of adverse events in a public hospital.¹¹⁸ They found that in one year (1998), 0.4% of adverse events had led to a complaint (3/850). Patients or their advocates were 11 times more likely to complain following serious permanent injuries and 18 times more likely to complain as a result of a death.

At the organisational level, Troyer and Sause (2011), in an analysis of complaints data from the North Carolina state certification agency and Ombudsman from 2002 to 2006 against nursing homes, found that the majority of complaints filed related to issues around quality of care (40%), in particular safety, such as inadequate hygiene or supervision and negligence.¹²¹ Likewise, Anderson *et al* (2000), who analysed all complaints filed in one year by, or on behalf of, older patients in one teaching hospital in southern Australia, found that about half the complaints (1.44 complaints per 1,000 occasions of service to older people aged 65 years and older (95% CI 1.19, 1.69)) were attributable to failures in treatment such as absence of due care, inappropriate treatment, wrong diagnosis or medication errors.¹¹⁶ As with other studies reported here, the authors noted how complaints could provide important pointers to improve care quality although they do not provide evidence of the extent to which this was subsequently taken up.

One possible exception is a study by Griffey and Bohan (2006), which involved a retrospective descriptive analysis of complaints received through a formalised process in the emergency department of an academic tertiary care centre in Boston, USA, in 2002.¹¹⁹ Of a total of 53 complaints received from healthcare professionals (one-third of all complaints during one year), the majority were related to errors in diagnostic work-up, delay or lack of doctor notification or inappropriate patient admission, transfer or discharge. This study also examined the impact of the complaints process, noting how, overall, 19% of complaints had led to formal peer review, and two to changes informing quality improvement and 'customer' service in the hospital. However, the nature and outcome of the reported peer review and quality improvement were not described.

Person-centredness

Similar to safety described above, components of person-centredness typically served as a trigger for complaints rather than an outcome of the intervention

in question. Components of person-centredness commonly noted included poor communication or communication failures, staff attitudes and lack of attention, inadequate or delayed information, and undignified service.^{115,116,120,121} For example, a retrospective review of 100 investigations by the New Zealand Health and Disability Commissioner that had been made available online found that in 48.7% of cases, complaints related to communication with the medical practitioner under investigation.¹²⁰ The study by Anderson *et al* (2000) of complaints among elderly patients in one hospital in Australia highlighted concerns around poor attitudes of treating staff (32 out of 71 complaints) or communication breakdown (19/71).¹¹⁶ In a study of long-term care Ombudsman complaint data from one state's 261 nursing homes in the USA, Allen *et al* (2006) reported that most of the 3,302 complaints filed between 1998 and 2000 related to concerns around the care process, including abuse, neglect and exploitation or restraints, and involving 8.6–9.6 complaints per 100 beds, compared with 2.89–3.52 per 100 complaints related to administrative procedures.¹¹⁵ The impact of these processes on quality of care was not described.

Timeliness

Where timeliness was discussed, it was typically related to the timely resolution of complaints brought¹²⁰ but with little empirical evidence on impacts on outcomes.

Efficiency

Studies reviewed did not explore associations of the interventions with efficiency of care.

Equity

Studies of patient complaints in New Zealand in particular highlighted how particular population groups are less likely to file a formal complaint following experience of adverse events. Thus Bismark *et al* (2006) demonstrated that the odds of complaining were significantly lower among older patients (OR 0.2, 95% CI 0.1, 0.4), for those of Pacific ethnicity (OR 0.3, 95% CI 0.1, 0.9) or for those who lived in the most deprived areas (OR 0.3, 95% CI 0.2, 0.6).¹¹⁸ This finding points to considerable inequalities in access to, and use of, complaints processes, and requires better understanding of the barriers that prevent people from participating in this process.

It is important to note that this is partly compensated for by a higher number of relatives or patient advocates complaining on behalf of patients, for example as shown by Anderson *et al* (2000) (73% of cases)¹¹⁶ and Allen *et al* (2006) (approximately 60% of cases).¹¹⁵ In their study of complaints made to

the long-term care Ombudsman regarding nursing homes in one state in the USA, Allen *et al* (2006) also found that men were more likely to report technical, impersonal and legalistic issues than women, who were more likely to express concerns about personal care and socio-emotional or environmental issues.¹¹⁵ The authors noted that this is likely to reflect, in part, differential preferences for, and perceptions of, the quality of care received, while also pointing to evidence of inequitable treatment that requires further investigation.

Linking to changes in relationships

All studies reviewed here used complaints data to examine the nature of concerns about the quality of care and to assess the profile of those filing complaints, most frequently reporting on the quality domains safety, person-centredness and equity. The majority of studies noted how complaints data can be used to inform quality improvement, but they provided little direct empirical evidence on how the complaint process itself impacted on the quality of care. An example would be satisfaction with the complaints process but this was typically not measured in the studies included.

Studies did not comment directly on how (formal) complaints procedures influence the relationships between service users and healthcare providers. A number of studies related specifically to complaints filed by family members or other advocates on behalf of patients, typically in nursing homes and hospitals.^{115,116,121} From the evidence presented in the studies reviewed, it is conceivable that providing the opportunity to issue a complaint is aimed at rebalancing the power relationship towards the service user side, in particular where vulnerable groups, such as the elderly in nursing homes, are concerned. Furthermore, given that most cases in which service users or their advocates filed a complaint were prompted by (gross) failure in the quality of care provided, the notion of conflict and, potentially, loss of trust may come into play, and complaint processes might aim to counteract this.

However, whether such processes indeed succeed in doing so will be influenced by the expected outcomes of a complaint. Existing evidence suggests that those lodging a complaint often do so to ensure that reported incidents are not repeated, implying corrective action such as system change, or as a means to obtain information or disclosure.^{122,123} Thus, complaint handling that does not allow for change or provide explanation is unlikely to meet patients' expectations and, by implication, affect the quality of the relationship.

3.5 Involving women in decision making in antenatal care

We aimed to identify studies that focused on enabling women to make decisions about their antenatal care. The initial searches returned 7,401 records. Studies were excluded if they did not refer to the role of women in decision making, focused exclusively on healthcare providers' clinical decision making in antenatal care, or focused only on developing country contexts that were not comparable to developed country contexts. Six studies were included: two RCTs,^{124,125} one structured review¹²⁶ and three observational studies, of which two were linked.¹²⁷⁻¹²⁹

Studies analysed interventions aimed at improving communication processes¹²⁶ and providing information on prenatal testing^{124,125} or on mode of delivery.¹²⁷⁻¹²⁹

Associations of the intervention with quality of care

Effectiveness

Rowe *et al* (2002) carried out a structured review of 11 controlled trials aimed at improving communication between healthcare professionals and women in maternity care.¹²⁶ The authors reported that the majority of these trials did not find statistically significant differences in health outcomes in the intervention group. Outcomes considered included clinical outcomes such as anxiety levels and maternal depression, as well as patient experience, measured as satisfaction with the care provided. Two of the trials reviewed by Rowe *et al* (2002)¹²⁶ showed significantly lower levels of anxiety at 20-weeks' gestation in the intervention group compared with the baseline state as a result of more information being made available to women in a variety of formats.^{124,125} Outcomes considered by some or all of these controlled trials spanned a wide range of factors related to clinical effectiveness and women's experience of care.

Safety

Studies reviewed did not explore associations of the interventions with safety of care.

Person-centredness

Rowe *et al* (2002) suggested that the impacts on patient-centredness were positive in that women reported feeling more in control and better informed.¹²⁶ For example, women who were provided with more information about antenatal testing in a variety of formats reported that they had received better information and understood it better, but no data were presented regarding the effect size.¹²⁵

Karlström *et al* (2011) studied the experiences of pregnancy and childbirth of 693 Swedish women based on their preferred and actual mode of delivery.¹²⁸ They found that although their preference had been fulfilled, women who had preferred and also delivered by Caesarean section were less likely to be satisfied with the decision-making process than most women who delivered vaginally. This highlights potential shortcomings in the way women's decisions are being informed. These findings are supported by those of Emmett *et al* (2007), who carried out a pilot study of two computer-based decision aids (an information programme and a decision analysis programme) designed to help women decide whether to give birth by Caesarean section or vaginally.¹²⁷ This study found that women generally considered the decision aids to be useful as an additional source of information about the risks and benefits of the two delivery options. This was also discussed in a later quality study of health professional views on computer-based decision aids.¹²⁹

Timeliness

Studies reviewed did not explore associations of the interventions with timeliness of care.

Efficiency

Studies reviewed did not explore associations of the interventions with efficiency of care.

Equity

Studies reviewed did not explore associations of the interventions with equity of care.

Linking to changes in relationships

Studies reviewed here tended to focus on the impact on clinical outcomes of changes in the provision of antenatal care such as anxiety and maternal depression, alongside women's satisfaction with changes to services. There was no explicit discussion of potential or achieved impacts on relationships between women and providers of antenatal care, as this was not a reported focus of any of the studies reviewed here.

There was some notion that interventions aimed at improving the communication between women and providers may enhance perceived levels of control and, by increasing levels of knowledge through information, also strengthen confidence, which may be seen to (re-) balance the power relationship. At the same time, as indicated by the work of Karlström *et al* (2011), the mode of communicating information will be of crucial importance in ensuring that service user experience is positive, which may otherwise undermine trust in the relationship, although this was not explored further in

their study.¹²⁸ In the context of providing information on antenatal screening, Yu (2012) highlighted the importance of healthcare providers understanding preferences and pre-existing knowledge, and how this might vary among different population groups, if information is to help women make informed decisions.¹³⁰

3.6 Use of peer support workers in healthcare

We sought to identify studies of interventions involving peers with a lived experience of a given condition who provide support to those affected by that condition. Initial searches, which included the term 'peer support' or 'peer support workers', returned a total of 1,934 titles. While the Health Foundation's project guiding this review targets employed peer support workers in mental health, we broadened our search to also include volunteer schemes in other health areas, as long as they involved one-to-one peer support among adults as part of service delivery. We excluded studies examining interventions involving peer support in self-management (although boundaries were not always clear-cut), assessing mutual support schemes or self-help groups, examining online peer support interventions, and those set in low-income countries. We identified 18 studies as eligible for inclusion. These included six RCTs,^{131–136} one randomised trial,¹³⁷ five (systematic) reviews^{41,138–141} and six observational studies.^{42,142–146}

Studies concerned the use of peer support workers in relation to mental health problems,^{41,131,133–135,139,140} examined peer support for breastfeeding^{132,136,141,144,145} or for economically disadvantaged first-time mothers more generally,¹⁴³ for renal disease^{42,137} and for cancer.^{138,142,146}

Associations of the intervention with quality of care

Effectiveness

The majority of studies examined the effectiveness of the intervention under consideration. Davidson *et al* (2006), reporting on four early studies that used a randomised controlled design to assess the effectiveness of case management provided by peers with a lived (and acknowledged) experience of mental health, found no differences in outcomes measured, such as psychiatric hospitalisations, functioning, disability or quality of life.¹³⁹ Only one study observed fewer hospitalisations for a subgroup of participants receiving services delivered by peers.¹³⁷ The authors pointed to the evolving nature of the approach as the likely reason for lack of observed impact. Indeed, in

a recent comprehensive review of the published and grey literature on peer support workers employed in mental health services, Repper and Carter (2011) found evidence for such schemes in reducing admissions among those with whom they work.⁴¹ This was confirmed in a controlled trial published the same year, which examined the use of salaried peer support workers to reduce recurrent psychiatric hospitalisations in Connecticut, USA.¹³⁵ It found study participants who were assigned a peer support worker (n=38) had significantly fewer re-hospitalisations than those in the control group (n=36) (0.89±1.35 vs 1.53±1.54; p=0.042). The number of hospital days was also significantly lower (10.08±17.31 vs 19.08±21.63 days; p<0.03). Dennis (2009) also reported positive impacts in a multisite randomised controlled trial of telephone-based peer (mother-to-mother) support for the prevention of postnatal depression in Ontario, Canada.¹³¹ It showed that, at 12 weeks, women in the intervention group had a significantly reduced risk of developing postnatal depression (relative risk reduction 0.46, 95% CI 0.24, 0.62). Furthermore, of the 221 women in the intervention group who received peer support, over 80% were satisfied with the service.

In contrast, a study of the effectiveness of home-based peer support in Alberta, Canada, which included maternal–infant interaction teaching for mothers with symptoms of postpartum depression, found significant differences for measures of symptoms of postpartum depression, favouring the control group.¹³⁴

A considerable body of work has emerged around the use of peer volunteers to support breastfeeding, summarised in two recent systematic reviews.^{140,141} For example, in a review of 17 trials, Jolly *et al* (2012) found that, compared with usual care, women allocated to peer support had a 15% significantly lower risk of not breastfeeding at follow-up (relative risk 0.85, 95% CI 0.77, 0.94), but when disaggregated by setting, low- and middle-income countries showed a greater effect than high-income settings.¹⁴⁰ Importantly, no significant effect on breastfeeding was observed in UK-based studies, which the authors explained with existing breastfeeding support mechanisms as part of routine postnatal healthcare. Ingram *et al* (2010), reporting on 11 studies, mostly set in the USA and the UK, found no evidence of universal peer support schemes to significantly enhance initiation of breastfeeding (relative risk 0.96, 95% CI 0.76, 1.22).¹⁴¹

Published evidence in the field of cancer points to moderate positive impacts of peer support, with Macvean *et al* (2008), in a systematic review of 28 studies, noting that while most studies pointed to beneficial effects for a range of outcomes such as pain, depression, anxiety or quality of life, empirical evidence

of effect was rarely presented and typically mixed.¹³⁸ Only one trial that was considered to be of high quality demonstrated significant improvement among the intervention group (depression).¹⁴⁷

Several studies also reported on the impact on peer support workers. For example, Murphy *et al* (2008), analysing peer-mentoring for first-time mothers in deprived communities in Belfast, Northern Ireland, noted moderately positive results of effectiveness for peer support workers, although the authors provided little detail of the impacts for those who received the intervention.¹⁴³ Brunier *et al* (2002), in a longitudinal study of renal peer support volunteers in Canada, found psychological wellbeing to have improved over a period of 12 months.¹⁴² Similar findings were reported for a breastfeeding peer support programme in Ontario, Canada.¹³²

In summary, the impact of peer support approaches appears to be varied and highly dependent on the nature and setting of a given programme. At the risk of simplification it may be argued that peer approaches in mental health settings appear to have a (small) overall positive impact on outcomes, with important exceptions, whereas in other areas the evidence is less consistent.

Safety

Studies reviewed did not examine associations of the interventions with safety of care.

Person-centredness

Several studies explored person-centredness, reporting impacts on both recipients and peer support workers. For example, Dennis (2010), in a cross-sectional study of women participating in a controlled trial of peer support for the prevention of postpartum depression in Ontario, Canada, found women to report high levels of positive relationship qualities such as trust (83.6%) and perceived acceptance (79.1%).¹³³ Likewise, in their qualitative study of kidney patients' experiences of receiving individual peer support in London, UK, Hughes *et al* (2009) found the peer approach to have given patients access to practical information about kidney disease, so enabling them to reach decisions about treatment.⁴² Also, peer support workers were seen to provide positive role models of coping with treatment for their disease, and increasing patients' sense of empowerment and agency. Increasing knowledge among recipients of a peer support intervention was also reported by Schafer *et al* (1998), in an earlier study of the use of volunteer peer counsellors to promote breastfeeding in a rural community in Iowa, USA.¹⁴⁵ They noted how women receiving the intervention (n=72) had significantly increased their knowledge

about breastfeeding and a healthy diet. Also examining the peer approach to promote breastfeeding, Dennis (2002) reported mothers to have increased their confidence and to have reached their breastfeeding goals.¹³²

The study by Dennis (2002) also noted positive impacts for peer support workers, who in response to a peer volunteer experience questionnaire (25/58) reported enhanced self-esteem and feeling empowered.¹³² Brunier *et al* (2002) also reported positive impacts, showing notable increases in personal growth and wellbeing for the peer support volunteers over time.¹⁴² Overall, available evidence generally seems to support a positive impact of peer support worker schemes on person-centredness and, in contrast to evidence of effectiveness, this seems to hold across different settings and target populations.

Timeliness

Studies reviewed did not examine associations of the interventions with timeliness of care.

Efficiency

Studies reviewed did not examine associations of the interventions with efficiency of care.

Equity

Equity was not explicitly discussed in studies reviewed here, except for those specifically targeting disadvantaged population groups. For example, in their review of the evidence of peer approaches for the initiation of breastfeeding, Ingram *et al* (2010) identified three high-quality studies that involved low-income women and that found antenatal peer support to significantly lower the relative risk for not initiating breastfeeding (relative risk 0.64, 95% CI 0.41, 0.99).¹⁴¹ In their study, Murphy *et al* (2008) worked with first-time mothers in deprived areas and identified some moderate positive findings.¹⁴³

Linking to changes in relationships

Interventions that use peer support workers or volunteers tend to rest on the assumption that people who have lived through a given experience may provide useful encouragement and informational, practical and/or emotional support to others facing similar situations, which may then lead to improved outcomes. For most of the interventions reviewed a new relationship was formed, mainly between the peer support worker or volunteer and the service user or patient. Studies reported variation in the effectiveness of such relationships, with most identifying benefits to service users and peer support workers, although impacts

varied across service areas (mental health, maternal and child health, renal disease, cancer) and settings.

Researchers studying peer support have proposed ways in which such approaches might operate to improve outcomes. Thus, Dennis (2003) suggested that peer support may decrease isolation, reduce the impact of stressors and increase sharing of health and self-management information,¹⁴⁸ and several studies reviewed here provide evidence for the latter.^{132,145} Peer support has also been suggested to empower patients or service users to play a more active role in their own care,⁴⁰ with Repper and Carter (2011) further presenting evidence of the potential of such schemes to increase self-efficacy, engagement and expanded social networks.⁴¹ Davidson *et al* (2006) conceptualised peer support in mental health to fall between a theoretical continuum with traditional self-help or mutual support groups at one end and consumer-run drop-in centres at the other.¹³⁹ In either case, they argued, peers maintain essentially reciprocal relationships. Peer support work, as reviewed here, however, is conceptualised as involving one or more people ‘who have a history of mental illness and who have experienced significant improvements in their psychiatric condition offering services and/or support to other people with serious mental illness who are considered to be not as far along in their own recovery process’ (p444).¹³⁹

Against this background it may be hypothesised that peer approaches can impact the relationship between the service user/patient and professional providers through enhancing service users’ confidence and knowledge and so re-balancing the power dynamic. Furthermore, peer support approaches may contribute to forming greater connections between patients/service users and the health system, with the peer support worker serving as a proxy between the two. As the patient/service user develops trust in the peer, we can presume that through the peer’s connection to the health system, the patient’s trust in the system would grow as well, increasing the cooperation (vs competition) dynamic of the relationship.

3.7 Improving healthcare services for homeless patients

Our search sought to identify interventions that employed formerly homeless ‘care navigators’ to assist staff in understanding what patients need and patients on where to get help. The PubMed searches returned a total of 1,924 records, of which eight were considered eligible for inclusion in the review. These were four RCTs,^{149–152} one systematic review¹⁵³ and three observational studies.^{154–156}

Studies reviewed here examined impacts of case management for frequent users of emergency departments,^{150,153,154} and of interventions to improve treatment adherence among homeless patients.¹⁵¹ Two studies analysed interventions involving formerly homeless peers,^{151,155} although roles were tied into case management programmes and in one study were not independently assessed.

Associations of the intervention with quality of care

Effectiveness

All eight studies considered here explored intervention effectiveness, in terms of process (eg utilisation) or outcomes (eg clinical outcomes, satisfaction). Redelmeier *et al* (1995), examining an intervention that involved trained volunteers as contacts for homeless adults in the emergency department in Ontario, Canada, found increases in satisfaction with care and a decrease in repeat visits to the emergency department by those in the intervention group (relative reduction 28%, 95% CI 14, 40).¹⁴⁹ The average number of visits per month was also significantly reduced among those receiving the intervention compared with those receiving usual care (0.43 vs 0.65, $p=0.018$). Okin *et al* (2000), using a before–after design, examined the effects of intensive case management on hospital service use among those frequently attending emergency departments in San Francisco, USA, including tracking patients and accompanying them to appointments ($n=53$).¹⁵⁴ They found that the intervention reduced problem alcohol and drug use by 22% and 26% respectively ($p=0.05$) as well as homelessness (–57%, 95% CI –73%, –42%). These findings were confirmed in a subsequent controlled study involving the same setting. Thus, Shumway *et al* (2008) demonstrated how case management was associated with statistically significant reductions in psychosocial problems common among frequent users ($n=252$), including homelessness, alcohol use and financial need, in a group receiving the intervention compared with a control group receiving usual care.¹⁵⁰ These observations were underlined by a more recent systematic review of the effectiveness of interventions targeting frequent users of emergency departments.¹⁵³ Other work reported improved outcomes among a group of homeless persons with severe and persistent mental illnesses assigned to an intervention combining community-based clinical treatment, intensive case management and advocacy in Baltimore, USA.¹⁵² These included significantly greater improvements in symptoms and self-rated health at two and six months. Morse *et al* (1997) reported similar findings.¹⁵⁶

Tulsky *et al* (2000) examined the effectiveness of financial incentives (\$5 for twice-weekly treatment) or of a peer health adviser on treatment adherence among a population of homeless adults with tuberculosis in California, USA.¹⁵¹ They showed that adherence in the monetary incentive arm was significantly greater (71%, 95% CI 59%, 86%) than in the peer health adviser arm (42%, 95% CI 29%, 61%) or the usual care arm (45%, 95% CI 31%, 64%). Completion at six months was significantly better in the monetary incentive group than in the two other groups combined (OR 2.57, 95% CI 1.11, 5.94), reflecting the specific constraints of this group.

In summary, studies reviewed provide evidence of how different interventions involving intensive case management may be suited to improve outcomes for homeless patients with different needs. There is limited evidence for the effectiveness of peer support mechanisms although, as the study by Tulsky *et al* (2000) suggests, this is likely to depend on the setting within which such approaches are being implemented.¹⁵¹ Nyamathi *et al* (2001) reported similar observations in a study comparing peer-mentored and nurse-case-managed programmes for HIV risk reduction among homeless women.¹⁵⁵

Safety

Studies reviewed did not examine associations of the interventions with safety of care.

Person-centredness

Four studies examined associations with person-centred elements of care, such as empathy or respect. For example, in their trial of trained volunteers as contacts for homeless adults, Redelmeier *et al* (1995) found patients receiving the intervention to be twice as likely to report that they were treated with courtesy and respect as those receiving usual care (77% vs 35%) and to acknowledge the ability of staff to make them feel comfortable (75% vs 29%), although levels of feeling informed about tests and procedures did not differ between the two groups.¹⁴⁹ In the review of interventions targeting frequent users of emergency departments, Althaus *et al* (2011)¹⁵³ reported some evidence of positive impact on patient-centredness, although this was limited to one retrospective cohort study set in Australia, which reported increased levels of community care engagement among those receiving case management.¹⁵⁷ Others failed to identify significant effects of different support schemes for homeless people to enhance measures of patient-centredness such as increased self-esteem,¹⁵⁶ although lack of evidence may simply indicate that standard care sufficiently meets the needs of the vulnerable groups studied, as for example highlighted by Nyamathi *et al* (2001) in their study of HIV risk-reduction programmes for homeless women in California, USA.¹⁵⁵

Timeliness

Studies reviewed did not explore associations of the interventions with timeliness of care.

Efficiency

Three studies examined the cost-effectiveness of case management, reported to reduce emergency department costs while improving or maintaining social and clinical outcomes.^{150,154} For example, in their randomised trial of case management approaches to frequent users of emergency departments, Shumway *et al* (2008) reported that statistically and clinically significant reductions in psychosocial problems were achieved at a cost similar to that of usual care.¹⁵⁰ Okin *et al* (2000) examined the impact of case management by social workers on homeless patients' use of the emergency department. They reported that after 12 months the median number of visits had decreased from 15 to 9 ($p < 0.01$) while median emergency department costs had decreased from \$4,124 to \$2,195 ($p < 0.01$); likewise, median medical inpatient costs had decreased from \$8,330 to \$2,786 ($p < 0.01$).¹⁵⁴ In their trial of community-based clinical treatment, intensive case management and advocacy (assertive community treatment (ACT)) for homeless people with severe and persistent mental illnesses, Lehman *et al* (1997) did not report cost savings; the intervention group used fewer resources than a control group, including fewer psychiatric inpatient days (35.4 vs 66.9, $p = 0.01$) and fewer emergency department visits (0.8 vs 2.0, $p = 0.009$), implying cost savings, although this would have to be set against the costs of implementing the intervention, which was not a focus of that study.¹⁵²

Equity

Studies reviewed did not explore associations of the interventions with equity of care.

Linking to changes in relationships

Interventions intended to improve care for homeless people aimed variously to reduce repeat emergency department visits, reduce drug and/or alcohol use, and improve clinical mental health symptoms, self-esteem and social outcomes (homelessness, insurance status, social security support, basic financial needs, need for a primary care practitioner).

Relationships in the context of interventions studied involved patient/service user–health and social care system,^{149–152,154–156} patient–volunteers¹⁴⁹ and patient–case manager/peer adviser.^{151,155} The link between improvements in care effectiveness and person-centredness for homeless patients seems likely to centre on the 'relationship' between the patient and the wider health and social care system, often through

an individual case manager. The case management role in these interventions served to increase the intensity of the relationship, while improved empathy and compassion in patient–provider interactions may impact the power dynamic, so enabling patients to feel more accepted by the health system. Both case management and increased empathy involve the cooperation–competition dynamic of the relationship in that by attempting to provide more of what these patients need individually, the system is working to make them feel as though providers are on their side rather than against them.

3.8 Shared decision making in child/adolescent mental healthcare

The intervention guiding the literature search seeks to disseminate information to patients regarding mental health conditions and treatment options, and to facilitate shared decision making between young people and care staff. Searches focused on the central aspects of the intervention underlying the project, namely shared decision making, adolescence and mental healthcare. However, studies focusing on adolescents with mental health conditions were rare and we therefore expanded the search to the wider theme of shared decision making while not undertaking a full review of all literature on this topic; such a review was commissioned by the Health Foundation and their report, *Helping people share decision making*, was published in June 2012. Our searches returned 364 records, of which six were considered eligible for inclusion in the review. Studies reviewed were two randomised controlled trials,^{158,159} three systematic reviews^{160–162} and one observational study.¹⁶³

Studies reviewed focused on impacts of elements of shared decision making (eg patient participation, information dissemination) in adolescent health or mental healthcare, frequently also involving their parents/carers.

Associations of the intervention with quality of care

Effectiveness

The four studies that examined intervention effectiveness found mixed impacts, with little robust evidence that shared decision making had identifiable impacts on clinical outcomes, while measures of patient experience may improve.^{159–162}

Lewis *et al* (2010) reviewed 19 studies to determine the effectiveness of different approaches to provide information or education to young people with epilepsy and their parents, including the use of information,

information needs and experiences, and facilitators and barriers to information exchange in healthcare settings for this group.¹⁶⁰ They highlighted some evidence that interventions delivered in an age-appropriate way increased young people's knowledge about epilepsy and a trend towards improved quality of life. Overall, however, they noted the lack of robust evidence on effective interventions, and whether impacts, where observed, are sustainable over time.

Campbell *et al* (2007) investigated the satisfaction of 80 college student patients with the care they received from healthcare providers in a college health centre in Virginia, USA.¹⁶³ The study found the degree of match between a patient's desired and actual levels of involvement in their care to be associated with greater satisfaction. In a systematic review of 35 randomised trials seeking to alter the interaction between service users more generally and practitioners within a consultation or clinical encounter, Griffin *et al* (2004) found that among six studies measuring disease processes, only two reported statistically significant benefits of interventions.¹⁶¹ Among eight studies that measured satisfaction as the principal outcome, three significantly favoured the intervention group. It is important to note that only one study reviewed by Griffin *et al* (2004) addressed adolescent mental health.¹⁶¹

Nieboer *et al* (2011) carried out an experimental study to assess the impact on 147 parents of young people with intellectual disabilities, who sought protected living arrangements (26.5%), assisted daily activities (58.5%) or both (15%) for their child, of providing only decision-support information compared with providing a combination of information and personal decision-making support on the choice process and on patients' satisfaction with care.¹⁵⁸ They found that while the forms of support impact on choices made, satisfaction with care did not change.

Safety

Studies reviewed did not examine associations of the interventions with safety of care.

Person-centredness

Person-centredness was explored as an outcome for four studies, in the form of perceived choice.^{158-160,163} Loh *et al* (2007) measured physician facilitation of patient involvement in the care for depression using the patient perceived involvement in care scale and a patient participation scale, and found improvements compared with usual care for depression.¹⁵⁹ The study by Campbell *et al* (2007) of college students found patients to report high competence at managing their own health outcomes (mean: 4.52 on a 6-point item

scale, standard deviation: 0.88), strongly desiring to be well informed by their healthcare providers regarding their condition.¹⁶³ However, neither study specifically considered involvement of young people in decision making.

Nieboer *et al* (2011) observed a positive impact on parents' choice process of providing decision-making support information combined with personal decision-making support, although the effects were not statistically significant.¹⁵⁸ They found that information provision interventions affected patient/carer choices and led to less frequent switching between providers. The types of information provided to parents were not all used, for example only 14% of intervention group 1 and 4.7% of intervention group 2 used the information website; however, parents did make use of counselling sessions where these were offered.

Timeliness

Studies reviewed did not examine associations of the interventions with timeliness of care.

Efficiency

Studies reviewed did not examine associations of the interventions with efficiency of care.

Equity

Studies reviewed did not examine associations of the interventions with equity of care.

Linking to changes in relationships

Shared decision making interventions reviewed here aim to bring the patient's experience into the consultation and, in doing so, may decrease the formality of the relationship while also balancing the power dynamic. However, the provider will need to understand the individual patient's desired level of involvement and take action to meet it.¹⁵⁸ This is likely to also increase the cooperation dynamic of the relationship.

Studies reviewed here generally tended not to be explicit about the nature of the relationships involved and the way they may be affected by interventions or how changing these relationships will lead to improved quality of care. The only exception is Nieboer *et al* (2011).¹⁵⁸ Drawing on Calnan and Gabe (2009)¹⁶⁴ and discussing parent/guardian choice of protected living arrangements, assisted daily activities or both for their children with intellectual disability, they suggest that the move to increase choice and provide more information to inform this choice has been a top-down process, based on healthcare providers' motivations, rather than on patients' or their advocates' desires. This conclusion

may be seen to support Calnan and Rowe's (2008) observation that healthcare users' exercising of choice tends to be determined by trust resulting from personal experiences rather than the provision of information by healthcare providers.¹⁶⁵ Loh *et al* (2007), while finding positive impacts of interventions to increase shared decision making, emphasised the need for further research to better understand the causal linkages to positive outcomes regarding patient participation and satisfaction.¹⁵⁹

3.9 Summary

We found the empirical evidence of an association between selected interventions reviewed here and domains of quality to be mixed. It was beyond the scope of this project to undertake an exhaustive review of the evidence on the interventions explored although it is important to note that high-quality studies tended to be rare or limited to selected settings only. The review presented here was limited to evidence published in the biomedical database PubMed only. Thus, studies made available through other means (such as monographs or reports) and not indexed by the National Library of Medicine were not captured. Furthermore, we restricted our searches to studies published in English. Therefore, we cannot assume that evidence presented in this rapid evidence review is comprehensive.

The main interventions and approaches tested within the Health Foundation's projects, as described in Table 1 (page 7, reproduced on page 24), tended to be innovative and/or comparatively novel and in some cases related empirical evidence is still emerging. Therefore, we expanded the search strategy to also include interventions that were comparable to the main approach tested by the project in question. This was, for example, the case for supporting patients in managing their own dialysis within a hospital environment. Here our review included a range of studies under the broad heading of self-administration of medication by patients. As a consequence, findings of the review may not be directly transferable, although they may provide valuable insights into understanding the principal mechanisms as they relate to quality of care domains impacted. Overall, the review sought to cover a complex set of very different interventions, requiring adaptation of search strategies and inclusion and exclusion criteria to optimise yield. This has meant that searches are not necessarily comparable across interventions under review, which will need to be kept in mind when considering the evidence presented here.

Associations between the interventions and the quality of care

Across all interventions or groups of interventions reviewed here, evidence of impact on quality of care varied widely in line with the wide range of interventions studied, consequently providing different insights into different domains of quality. Within each intervention category the range of approaches also varied, thus making an overarching conclusion difficult.

At the risk of oversimplifying what is inherently a complex set of findings, we sought to summarise the main observations of the evidence review of associations between interventions and quality of care in its various domains. Bearing in mind the limitations of the review, as outlined above, we find that for each of the interventions reviewed the majority of studies examined measures of effectiveness, followed by measures of patient-centredness, and, to lesser degree, efficiency and equity. Measures of safety and timeliness were less frequently studied which may, to a certain extent, reflect the applicability of that domain to the intervention in question. Given the wide variation in the methods used to assess interventions, the range of interventions itself and the range of populations or health concerns studied under each intervention heading, it was not possible to quantify the evidence of outcomes where these were measured. Instead, we attempted to rate qualitatively the strength of evidence for each of the quality domains under each intervention heading, using study design and number of studies reporting the quality domains in question as a guide. This is shown in Table 2 in Part 1 of this report (page 8), which we have reproduced overleaf.

Table 2: Summary overview of associations of interventions and quality of care

Intervention (total number of studies)	Type and number of studies	Effectiveness	Safety	Person-centredness	Timeliness	Efficiency	Equity
Patient self-administration of medication (9)	RCT/other controlled: 5 Observational: 4	+	+	+	+	+/-	-
Patient access to online health records (15)	RCT: 3 (Systematic) review: 6 Observational: 6	+ (process) o (outcomes)	+	+/-	not reported	+	-
Addressing complaints about care received (7)	Observational: 7 Total: 7	<i>Studies generally assessed 'quality' as an input, that is they considered the usefulness of complaints data to identify quality problems; there was little direct empirical evidence on the impact of the intervention under study on quality of care</i>					
Involving women in decision making in antenatal care (6)	RCT: 2 Review: 1 Observational: 3	+/-	not reported	+	not reported	not reported	not reported
Use of peer support workers in healthcare (17; mental health: 6; other: 11)	RCT/other controlled: 7 (Systematic) review: 5 Observational: 5	+ (mental health) +/- (other)	not reported	+	not reported	not reported	+
Improving healthcare services for homeless patients (8)	RCT: 4 Systematic review: 1 Observational: 3	+	not reported	+/-	not reported	+	not reported
Shared decision making in child/adolescent mental healthcare (6)	RCT: 2 Systematic review: 3 Observational: 1	+/-	not reported	+	not reported	not reported	not reported
<p>NOTE: + (some) evidence of improvement in outcome of interest; +/- mixed evidence (improvements, no change, deterioration); o no change/difference; - (some) evidence of worsening in outcome of interest. RCT = randomised controlled trial</p>							

Accordingly, we find a fairly robust level of evidence of effectiveness for patient self-administration of medications, the use of peer support workers in mental healthcare and interventions to improve services for homeless people. However, conclusions will have to be drawn in the context within which the interventions were implemented. For example, studies examining patient self-administration of medications tended to show evidence of improved clinical outcomes and/or patient experience or, where a comparison strategy was used, outcomes that were comparable to usual care. Only one trial in a population of drug users found supervised administration to be more effective than self-administration.³⁴ This suggests that, while self-administration may provide an appropriate and effective alternative to supervised administration for

some patients and conditions, it may be less suitable and potentially inappropriate for others, for example, those with more chaotic lifestyles.

For other types of interventions studied here, the evidence of effectiveness tended to be more mixed: that is, the intervention was shown to lead to improved outcomes in some studies but not others, or improvements were observed for a select set of measures only, for example process measures such as regular measurement of blood pressure, but not clinical outcomes. This inconsistency can be explained, in part, by the heterogeneous nature of studies reviewed. Furthermore, in the case of selected studies, it was not possible to isolate the impacts of interventions that were related to patient access to electronic records as these tended to be implemented as part of a wider strategy.

Evidence of impacts on person-centredness tended to be more mixed than for effectiveness across studies and interventions. To a great extent this reflects the wide range of measures considered under the heading of centredness, in turn reflecting the multidimensional nature of this concept.³⁵ For example, in the case of patient access to online health records, there was some evidence of improved patient-rated continuity of care and self-perceived levels of control. Other studies did not support this notion, however, and it has been argued that research in the area of electronic health records and electronic personal health records has been challenged by inconsistent use of terminology, lack of consensus of common taxonomy and consequent poor referencing within bibliographic databases.³⁷ Similarly, studies of interventions to improve services for homeless people produced mixed findings, with some reporting on improvements on measures such as being treated with respect, while evidence of impacts on measures such as self-esteem were less consistent. In contrast, studies of peer support workers consistently tended to report improvements for both recipients and peer support workers, including increased levels of knowledge, confidence and/or the ability to make decisions among the former, and enhanced confidence and self-esteem among the latter.

In contrast to effectiveness and person-centredness, efficiency and equity were less frequently studied. In relation to efficiency, this probably reflects the challenge of measurement, which is not well advanced. Thus, while efficiency relates to value for money, development has so far focused on effectiveness and cost indicators, with little combination of the two.³⁶ Consequently, where efficiency is being assessed, this typically refers to cost savings, as shown for studies examining case management interventions for people with high use of the emergency department (section 3.7).

Where equity was studied, available evidence tended to show a certain degree of consistency within types of interventions, for example in relation to patient self-administration of medications. Here, available evidence highlighted that the intervention may be applicable to a select group of patients only. This could potentially increase inequities where only highly motivated patients who may not necessarily benefit the most are likely to take up the intervention. In summary, available evidence seems to indicate that self-administration of medication can be safe although the small sample size of several studies included in the review limit generalisability of findings. A risk of increased inequity was also noted for patient access to online health records. Here, several studies highlighted the potential for the development of a 'digital divide' with those belonging to ethnic minorities or living in poorer neighbourhoods less likely to enrol in schemes that offer online access to

health records. Similar to what was observed for self-administration of medication it is likely that those enrolling in related programmes are more interested in self-managing their condition already and that electronic personal health records in their current form merely support or enhance what they would have done in any case, implying the need for better targeting of related interventions to fully exploit their potential.

It may be worth noting that the quality domains 'safety' and 'timeliness' were frequently not considered as distinct measures of quality. This may, in part, reflect that these domains have limited applicability to the interventions under study, as noted earlier, or else, as evidence is still emerging for a number of interventions, these measures have as yet to receive attention. In this context it is interesting to note that the evidence on complaints procedures reviewed here tended to show that complaints frequently originate from safety concerns (section 3.4). However, while it is being recognised how complaints could provide important pointers to improve care, studies reviewed here rarely reported on whether this potential was subsequently taken up.

Associations between the interventions and relationships between people and healthcare providers

A second step of the evidence review presented here sought to consider the specific relationship change that the interventions are seeking and how this relationship change may be linked to improvements in quality of care (and specifically, which domains of quality of care). At the outset it is important to note that studies rarely described how a given intervention is expected to change a given outcome directly or indirectly, for example, through changing relationships. So in the majority of cases, and perhaps not surprisingly, studies reviewed here did not explain how the intervention was related to changes in relationships and how this can be linked to changes in quality. Indeed, we had to infer such associations from studies reviewed.

Failure to clarify the underlying theory of how a given intervention is expected to change outcomes has been discussed in some depth in relation to patient access to electronic health records. For example, Black *et al* (2011), in a review of systematic reviews of the impact of eHealth on the quality and safety of healthcare, noted the limited usefulness of existing research and the tendency towards simplistic evaluation approaches that often provide little insight into why a particular outcome has occurred.³⁷ They highlighted the need to better understand the underlying mechanisms to enable conclusions to be drawn in relation to causal pathways and effectiveness of such interventions.

Several studies reviewed here noted the potential for personal health records to increase levels of patient empowerment and, by implication, so contribute to balance the power dynamic between the patient and the provider. However, the term ‘empowerment’ tended to remain poorly defined in many studies, encompassing different notions such as self-efficacy or degree of control, and it is frequently not made explicit by which mechanism electronic personal health records are expected to increase empowerment.³⁸ Greenhalgh *et al* (2009) noted how, in the context of electronic patient records, lack of agreement on how efficacy, or empowerment, should be defined and measured further complicates the interpretation and usefulness of evidence thus produced.³⁹ Such understanding is necessary to enable making the link between the intervention and changed relationships, if we believe that empowerment (however defined) is at the core of the change, and how this will then (potentially) impact on quality. It should be noted, however, that instruments to assess ‘empowerment’ have been tested in the context of peer and self-management support in particular, suggesting how such interventions have the potential to empower patients or service users to play a more active role in their own care,⁴⁰ with Repper and Carter (2011) further presenting evidence of the potential of such schemes to increase self-efficacy, engagement and increased social networks.⁴¹

Although direct reference to changing relationships was rarely made in studies reviewed here, it may be hypothesised that most interventions studied can impact the relationship between the service user/patient and professional providers through enhancing the confidence and knowledge of service users and so re-balancing the power dynamic. This effect may be direct, for example through enabling access to health information, or mediated by support workers or case managers as in the case of peer support interventions and interventions aimed at improving services for homeless people. Indeed, the literature on peer support workers has made references to the (assumed) underlying (relationship) change somewhat more explicitly, suggesting how peer support may decrease isolation, reduce the impact of stressors and increase sharing of health and self-management information.¹⁴⁸

The nature of the relationship will vary however, with those involving support workers providing a ‘mediator’ or proxy between the service user and the wider service that is likely to enhance the trust between the two parties and potentially increase the cooperation dynamic. In relation to peer support work a key notion that was mentioned is that of hope: those with lived experience of a given condition provide a form of role model to the service user, to help them cope with their condition.¹⁶⁶ This might benefit the cooperation dynamic (a notion that is part of the intensity dimension) of the relationship between the service user and the health professional, as well as the commitment invested by the two parties.⁴²

It may be worthwhile noting that several of the interventions reviewed here which aimed to involve the patient or service user, for example through providing access to electronic health records or information on options on prenatal testing or mode of delivery in the case of antenatal care, yielded mixed results in terms of impact on quality of care. In relation to electronic personal health records several authors have highlighted how this might reflect a failure to actively engage the patient in the design of such systems or offer support in their use.^{43–45} Similar concerns were raised in relation to shared decision making concerning young people with mental health problems, highlighting the lack of consideration of service users’ preferences.¹⁵⁸ There is, therefore, a need to take a more user-centred approach that involves end users of such systems in all stages of system design and implementation.³⁸ However, such an approach will require good understanding of the ‘theory of change’ underlying the involvement of the end user and the assumed changes that will result. Such understanding will also be vital to inform decision making on the implementation of related interventions.

References and Appendix

References

1. Department of Health. *Equity and excellence: Liberating the NHS*. London: Department of Health 2010.
2. Department of Health. *Government response to the NHS Future Forum Report: Briefing notes on amendments to the Health and Social Care Bill*. London: Department of Health 2011.
3. Donabedian A. *The definition of quality and approaches to its management*. Ann Arbor, MI: Health Administration Press 1980.
4. Donabedian A. The quality of care: how can it be assessed? *JAMA* 1988;260(12):1743.
5. Coulter AJE. *The quality enhancing interventions project: Patient-focused interventions*. London: The Health Foundation 2006.
6. Zwar N, Harris M, Griffiths R, et al. *A systematic review of chronic disease management*. Sydney: Australian Primary Health Care Institute 2006.
7. Rijken M, Jones M, Heijmans M, et al. Supporting self-management. In: Nolte E, McKee M (eds) *Caring for people with chronic conditions: A health system perspective*. Maidenhead: Open University Press 2008:116-42.
8. Davies GP, Williams AM, Larsen K, et al. Coordinating primary health care: an analysis of the outcomes of a systematic review. *Med J Aust* 2008;188(8):65.
9. Calnan M, Hutten J, Tiljak H. The challenge of coordination: the role of primary care professionals in promoting integration across the interface. In: Saltman R, Rico A, Boerma W (eds) *Primary care in the driver's seat*. Maidenhead: Open University Press 2006:85-104.
10. Alazri MH, Neal RD, Heywood P, et al. Patients' experiences of continuity in the care of type 2 diabetes: a focus group study in primary care. *Br J Gen Pract* 2006;56(528):488.
11. Turner-Stokes L, Sykes N, Silber E, et al. From diagnosis to death: exploring the interface between neurology, rehabilitation and palliative care in managing people with long-term neurological conditions. *Clin Med* 2007;7(2):129-36.
12. Wait S, Nolte E. Public involvement policies in health: exploring their conceptual basis. *Health Econ Policy Law* 2006;1(02):149-62.
13. Conklin A, Morris ZS, Nolte E. *Involving the public in healthcare policy: An update of the research evidence and proposed evaluation framework*. Santa Monica, CA: RAND Corporation 2010.
14. Ploch T, Klazinga NS. Community-based integrated care: myth or must? *Int J Qual Health Care* 2002;14(2):91-101.
15. Kaplan SH, Sheldon G, Ware JE, Jr. Assessing the effects of physician-patient interactions on the outcomes of chronic disease. *Medical Care* 1989;27(3):S110-S27.
16. Potter SJ, McKinlay JB. From a relationship to encounter: an examination of longitudinal and lateral dimensions in the doctor-patient relationship. *Soc Sci Med* 2005;61(2):465-79.
17. Wish M. Comparisons among multidimensional structures of interpersonal relations. *Multivariate Behav Res* 1976;11(3):297-324.
18. Armstrong D. Conceptualising the patient. *J Health Serv Res Policy* 2002;7:245-7.
19. Parsons T. *The social system*. London: Routledge 1991(1951).
20. Freidson E. *Profession of medicine*. New York: Dodd Mead 1970.
21. Shilling C. Culture, the 'sick role' and the consumption of health. *Br J Sociol* 2002;53:621-38.
22. Christmas S, Millward L. *New medical professionalism: A scoping report for the Health Foundation*. London: The Health Foundation 2011.
23. Hughes JC, Bamford C, May C. Types of centredness in health care: themes and concepts. *Med Health Care Philos* 2008;11:455-63.
24. Mead N, Bower P. Patient-centredness: a conceptual framework and review of the empirical literature. *Soc Sci Med* 2000;51:1087-110.
25. Salmon P, Hall GM. Patient empowerment and control: a psychological discourse in the service of medicine. *Soc Sci Med* 2003;57:1969-80.
26. Lee RG, Garvin T. Moving from information transfer to information exchange in health and health care. *Soc Sci Med* 2003;56(3):449-64.

27. Duggan A. Understanding interpersonal communication processes across health contexts: advances in the last decade and challenges for the next decade. *J Health Commun* 2006;11(1):93-108.
28. Palmatier RW, Dant RP, Grewal D, et al. Factors influencing the effectiveness of relationship marketing: a meta-analysis. *J Mark* 2006;70(4):136-53.
29. Street Jr RL, Makoul G, Arora NK, et al. How does communication heal? Pathways linking clinician-patient communication to health outcomes. *Patient Educ Couns* 2009;74(3):295-301.
30. Jahng KH, Martin LR, Golin CE, et al. Preferences for medical collaboration: patient-physician congruence and patient outcomes. *Patient Educ Couns* 2005;57:308-14.
31. Fainzang S. Lying, secrecy and power within the doctor-patient relationship. *Anthropol Med* 2002;9(2):117-33.
32. The Health Foundation. Closing the Gap through Changing Relationships. 2012. www.health.org.uk/areas-of-work/programmes/closing-the-gap-through-changing-relationships/why-this-programme/ (accessed 4 May 2012).
33. Institute of Medicine. *Crossing the quality chasm: A new health system for the 21st century*. Washington, DC: National Academy Press 2001.
34. Altice F, Maru D, Bruce R, et al. Superiority of directly administered antiretroviral therapy over self-administered therapy among HIV-infected drug users: a prospective, randomized, controlled trial. *Clin Infect Dis* 2007;45:770-8.
35. Mead N, Bower P. Patient-centredness: a conceptual framework and review of the empirical literature. *Soc Sci Med* 2000;51(7):1087-110.
36. Hussey PS, De Vries H, Romley J, et al. A systematic review of health care efficiency measures. *Health Serv Res* 2009;44(3):784-805.
37. Black AD, Car J, Pagliari C, et al. The impact of eHealth on the quality and safety of health care: a systematic overview. *PLoS Med* 2011;8(1):e1000387.
38. Ennis L, Rose D, Callard F, et al. Rapid progress or lengthy process? Electronic personal health records in mental health. *BMC Psychiatry* 2011;11(1):117.
39. Greenhalgh T, Potts HWW, Wong G, et al. Tensions and paradoxes in electronic patient record research: A systematic literature review using the meta-narrative method. *Milbank Q* 2009;87(4):729-88.
40. Rogers ES, Teague GB, Lichenstein C, et al. Effects of participation in consumer-operated service programs on both personal and organizationally mediated empowerment: results of multisite study. *J Rehabil Res Dev* 2007;44:785-99.
41. Repper J, Carter T. A review of the literature on peer support in mental health services. *J Ment Health* 2011;20(4):392-411.
42. Hughes J, Wood E, Smith G. Exploring kidney patients' experiences of receiving individual peer support. *Health Expect* 2009;12(4):396-406.
43. Ross SE, Moore LA, Earnest MA, et al. Providing a web-based online medical record with electronic communication capabilities to patients with congestive heart failure: randomized trial. *J Med Internet Res* 2004;6(2).
44. Grant RW, Wald JS, Schnipper JL, et al. Practice-linked online personal health records for type 2 diabetes mellitus: a randomized controlled trial. *Arch Intern Med* 2008;168(16):1776.
45. Roblin DW, Houston TK, Allison JJ, et al. Disparities in use of a personal health record in a managed care organization. *J Am Med Inform Assoc* 2009;16(5):683-9.
46. Craig P, Dieppe P, Macintyre S, et al. *Developing and evaluating complex interventions: new guidance*. London: Medical Research Council; 2008.
47. Contandriopoulos D, Lemire M, Denis JL, et al. Knowledge exchange processes in organizations and policy arenas: a narrative systematic review of the literature. *Milbank Q* 2010;88(4):444-83.
48. Nutley S, Davies H, Walter I. *What is a conceptual synthesis? Briefing Note 1*. St Andrews: University of St Andrews Research Unit for Research Utilisation 2002.
49. Haslam N, Fiske A. Implicit relationship prototypes: investigating five theories of the cognitive organization of social relationships. *J Exp Soc Psychol* 1992;28(5):441-74.
50. Iacobucci D, Ostrom A. Commercial and interpersonal relationships: using the structure of interpersonal relationships to understand individual-to-individual, individual-to-firm, and firm-to-firm relationships in commerce. *Int J Res Marketing* 1996;13:53-72.
51. Lazarus ES. Theoretical considerations for the study of the doctor patient relationship: implications of a perinatal study. *Med Anthropol Q* 1988;2(1):34-58.
52. Balint M. *The doctor, the patient and his illness*. New York: International Universities Press 1957.
53. Oxford English Dictionary. Relationship. <http://www.oed.com/view/Entry/161816?redirectedFrom=relationships#eid> (accessed 25 September 2012).
54. Szasz TS, Hollender MH. A contribution to the philosophy of medicine. The basic models of the doctor-patient relationship. *Arch Intern Med* 1956;97:585-8.
55. PubMed. Professional-Patient Relations, Introduced 1968. <http://www.ncbi.nlm.nih.gov/mesh/68011369> (accessed 25 September 2012).
56. Gutek BA, Bennett C, Bhappu AD, et al. Features of service relationships and encounters. *Work and Occup* 2000;27:319-52.
57. Greener I. Towards a history of choice in UK health policy. *Sociol Health Illn* 2009;31(3):309-24.
58. Scott A, Vick S. Patients, doctors and contracts: an application of principal-agent theory to the doctor-patient relationship. *Scottish J Polit Econ* 1999;46(2):111-34.
59. Vick S, Scott A. Agency in health care: examining patients' preferences for attributes of the doctor-patient relationship. *J Health Econ* 1998;17(5):587-605.
60. Nelson P. Information and consumer behavior. *J Polit Econ* 1970;78(2):311-29.
61. Arrow KJ. Uncertainty and the welfare economics of medical care. *Am Econ Rev* 1963;53(5):941-73.
62. Goffman E. *The presentation of self in everyday life*. Garden City, NY: Anchor Doubleday 1959.
63. Lambert H, McKeivitt C. Anthropology in health research: from qualitative methods to multidisciplinary. *BMJ* 2002;325(7357):210.
64. Veatch R. Models for ethical medicine in a revolutionary age. *The Hastings Center Report* 1972;2:5-7.

65. Young JT. Illness behaviour: a selective review and synthesis. *Sociol Health Illn* 2004;26:1-31.
66. Emanuel EJ, Emanuel LL. Four models of the physician-patient relationship. *JAMA* 1992;267(16):2221-7.
67. Dougherty MC, Tripp-Reimer T. The interface of nursing and anthropology. *Ann Rev Anthropol* 1985;14:219-41.
68. Illich I. Medical nemesis. *Lancet* 1974(i):918-21.
69. Bury M. Chronic illness as biographical disruption. *Sociol Health Illn* 1982;4(2):167-82.
70. Boyer CA, Lutfey KE. Examining critical health policy issues within and beyond the clinical encounter. *J Health Soc Behav* 2010;51(1 suppl):S80-S93.
71. Shilling C. Culture, the 'sick role' and the consumption of health. *Br J Sociol* 2002;53:621-38.
72. Williams SJ. Parsons revisited: from the sick role to ...? *Health* 2005;9(2):123-44.
73. Blomqvist Å. The doctor as double agent: information asymmetry, health insurance, and medical care. *J Health Econ* 1991;10(4):411-32.
74. Wynia MK, Zucker D, Supran S, et al. Patient protection and risk selection. *J Gen Intern Med* 2002;17(1):40-7.
75. Trummer UF, Mueller UO, Nowak P, et al. Does physician-patient communication that aims at empowering patients improve clinical outcome? A case study. *Patient Educ Couns* 2006;61(2):299-306.
76. Quill TE. Partnerships in patient care: a contractual approach. *Ann Intern Med* 1983;98(2):228-34.
77. Hughes JC, Bamford C, May C. Types of centredness in health care: themes and concepts. *Med Health Care and Philos* 2008;11:455-63.
78. Street RL, Gordon H, Haidet P. Physicians' communication and perceptions of patients: is it how they look, how they talk, or is it just the doctor? *Soc Sci Med* 2007; 65:586-98.
79. Van der Geest S. Complaining and not complaining: social strategies of older people in Kwahu, Ghana. *Global Ageing* 2007;4(3):55-66.
80. Crosby LA, Evans KR, Cowles D. Relationship quality in services selling: an interpersonal influence perspective. *J Mark* 1990;54(3):68-81.
81. Mechanic D, Meyer S. Concepts of trust among patients with serious illness. *Soc Sci Med* 2000;51:657-68.
82. Tarrant C, Dixon-Woods M, Colman A, et al. Continuity and trust in primary care: a qualitative study informed by game theory. *Ann Fam Med* 2010;8(5):440-46.
83. Mannion R, Davies HTO, Marshall MN. *Cultures for performance in health care*. Maidenhead: Open Univ Press; 2004.
84. Strathern M. The work of culture: an anthropological perspective. In: Clarke A, Parsons E. (eds) *Culture, Kinship and Genes: Towards a Cross-Cultural Genetics*. Basingstoke: Macmillan Press Ltd; 1997.
85. Lock M, Nguyen V-K. *An anthropology of biomedicine*. Oxford: Wiley-Blackwell 2010.
86. Fischer MMJ. Culture and cultural analysis as experimental systems. *Cult Anthropol* 2007;22(1):1-65.
87. Kiefer CW. *Doing health anthropology: research methods for community assessment and change*. New York: Springer; 2007.
88. Singer M, Baer HA. *Introducing medical anthropology: a discipline in action*. Lanham MD: Altamira Press 2007.
89. Clark NM. Management of chronic disease by patients. *Annu Rev Public Health* 2003;24(1):289-313.
90. Nolte E, McKee M. (eds) *Caring for people with chronic conditions: a health system perspective*. Maidenhead: Open University Press; 2008.
91. The Health Foundation. Our approach: what is quality? 2012. www.health.org.uk/our-approach/what-is-quality/ (accessed 4 May 2012).
92. Klassen A, Miller A, Anderson N, et al. Performance measurement and improvement frameworks in health, education and social services systems: a systematic review. *Int J Qual Health Care* 2010;22(1):44-69.
93. Nolte E, Roland M, Damberg CL, et al. *Informing the development of a resource allocation framework in the German healthcare system*. Santa Monica: RAND Corporation; 2011.
94. Legido-Quigley H, McKee M, Nolte E, et al. *Assuring the quality of health care in the European Union*. Copenhagen: World Health Organization, on behalf of the European Observatory on Health Systems and Policies; 2008.
95. Fitzmaurice D, Murray E, Gee K, et al. A randomised controlled trial of patient self management of oral anticoagulation treatment compared with primary care management. *J Clin Pathol* 2002;55:845-9.
96. Fitzmaurice D, Murray E, McCahon D, et al. Self management of oral anticoagulation: randomised trial. *BMJ* 2005;331:1057-62.
97. Grunau BE, Wiens MO, Harder KK. Patient self-management of warfarin therapy. *Can Family Phys* 2011;57(8):e292-e298.
98. Jowett S, Bryan S, Murray E, et al. Patient self management of anticoagulation therapy: a trial based cost effectiveness analysis. *Br J Haematol* 2006;134(6):632-39.
99. Grantham G, McMillan V, Dunn SV, et al. Patient self-medication—a change in hospital practice. *J Clin Nurs* 2006;15(8):962-70.
100. Levi M, Choi G, Picavet C, et al. Self-administration of C1-inhibitor concentrate in patients with hereditary or acquired angioedema caused by C1-inhibitor deficiency. *J Allergy Clin Immunol* 2006;117(4):904-8.
101. McCahon D, Murray E, Jowett S, et al. Patient self management of oral anticoagulation in routine care in the UK. *J Clin Pathol* 2007;60(11):1263-7.
102. Phelan G, Kramer EJ, Grieco AJ, et al. Self-administration of medication by patients and family members during hospitalization. *Patient Educ Couns* 1996;27(1):103-12.
103. Holbrook A, Pullenayegum E, Thabane L, et al. Shared electronic vascular risk decision support in primary care: Computerization of Medical Practices for the Enhancement of Therapeutic Effectiveness (COMPETE III) randomized trial. *Arch Intern Med* 2011;171(19):1736.
104. Shachak A, Reis S. The impact of electronic medical records on patient-doctor communication during consultation: a narrative literature review. *J Eval Clin Pract* 2009;15(4):641-9.
105. Boyle RG, Solberg LI, Fiore MC. Electronic medical records to increase the clinical treatment of tobacco dependence: a systematic review. *Am J Prev Med* 2010;39(6):S77-S82.

106. Gallego AI, Gagnon MP, Desmarts M. Assessing the cost of electronic health records: a review of cost indicators. *Telemed J E Health* 2010;16(9):963-72.
107. Ammenwerth E, Schnell-Inderst P, Hoerbst A. Patient empowerment by electronic health records: first results of a systematic review on the benefit of patient portals. *Stud Health Technol Inform* 2011;165:63-7.
108. Tenforde M, Jain A, Hickner J. The value of personal health records for chronic disease management: what do we know? *Fam Med* 2011;43(5):351-4.
109. Zhou YY, Garrido T, Chin HL, et al. Patient access to an electronic health record with secure messaging: impact on primary care utilization. *Am J Manag Care* 2007;13(7):418-24.
110. Forsyth R, Maddock CA, Iedema RAM, et al. Patient perceptions of carrying their own health information: approaches towards responsibility and playing an active role in their own health – implications for a patient-held health file. *Health Expect* 2010;13(4):416-26.
111. Reti SR, Feldman HJ, Ross SE, et al. Improving personal health records for patient-centered care. *J Am Med Inform Assoc* 2010;17(2):192-95.
112. Witry MJ, Doucette WR, Daly JM, et al. Family physician perceptions of personal health records. *Perspect Health Inf Manag* 2010;7(Winter):1d.
113. Walker J, Leveille SG, Ngo L, et al. Inviting patients to read their doctors' notes: patients and doctors look ahead. *Ann Intern Med* 2011;155(12):811-19.
114. Wang SJ, Middleton B, Prosser LA, et al. A cost-benefit analysis of electronic medical records in primary care. *Am J Med* 2003;114(5):397-403.
115. Allen P, Nelson H, Gruman C, et al. Nursing home complaints: who's complaining and what's gender got to do with it? *J Gerontol Soc Work* 2006;47(1-2):89.
116. Anderson K, Allan D, Finucane P. Complaints concerning the hospital care of elderly patients: a 12-month study of one hospital's experience. *Age Ageing* 2000;29(5):409-12.
117. Anderson K, Allan D, Finucane P. A 30-month study of patient complaints at a major Australian hospital. *J Qual Clin Pract* 2001;21(4):109-11.
118. Bismark M, Brennan T, Paterson R, et al. Relationship between complaints and quality of care in New Zealand: a descriptive analysis of complainants and non-complainants following adverse events. *Qual Saf Health Care* 2006;15(1):17.
119. Griffey R, Bohan J. Healthcare provider complaints to the emergency department: a preliminary report on a new quality improvement instrument. *Qual Saf Health Care* 2006;15(5):344-6.
120. Temelkovski S, Callaghan K. Opportunities to learn from medical incidents: a review of published reports from the Health and Disability Commissioner. *NZ Med J* 2010;123(1314):18-29.
121. Troyer JL, Sause WL. Complaints against nursing homes: comparing two sources of complaint information and predictors of complaints. *Gerontologist* 2011;51(4):516-29.
122. Bismark M, Dauer E, Paterson RDS, et al. Accountability sought by patients following adverse events from medical care: the New Zealand experience. *CMAJ* 2006;175:889-94.
123. Friele RD, Sluijs EM. Patient expectations of fair complaint handling in hospitals: empirical data. *BMC Health Serv Res* 2006;6:106. doi:10.1186/1472-6963-6-106.
124. Graham W, Smith P, Kamal A, et al. Randomised controlled trial comparing effectiveness of touch screen system with leaflet for providing women with information on prenatal tests. *BMJ* 2000;320:155-60.
125. Thornton JG, Hewison J, Lilford RJ, et al. A randomised trial of three methods of giving information about prenatal testing. *BMJ* 1995;311:1127-30.
126. Rowe RE, Garcia J, Macfarlane AJ, et al. Improving communication between health professionals and women in maternity care: a structured review. *Health Expect* 2002;5(1):63-83.
127. Emmett CL, Murphy DJ, Patel RR, et al. Decision-making about mode of delivery after previous caesarean section: development and piloting of two computer-based decision aids. *Health Expect* 2007;10(2):161-72.
128. Karlström A, Nystedt A, Hildingsson I. A comparative study of the experience of childbirth between women who preferred and had a caesarean section and women who preferred and had a vaginal birth. *Sex Reprod Health* 2011;2(3):93-9.
129. Rees K, Shaw A, Bennert K, et al. Healthcare professionals' views on two computer-based decision aids for women choosing mode of delivery after previous caesarean section: a qualitative study. *BJOG* 2009;116(7):906-14.
130. Yu J. A systematic review of issues around antenatal screening and prenatal diagnostic testing for genetic disorders: women of Asian origin in western countries. *Health Soc Care Community* 2012;20(4):329-46.
131. Dennis C, Hodnett E, Kenton L, et al. Effect of peer support on prevention of postnatal depression among high risk women: multisite randomised controlled trial. *BMJ* 2009;338:280.
132. Dennis CL. Breastfeeding peer support: maternal and volunteer perceptions from a randomized controlled trial. *Birth* 2002;29(3):169-76.
133. Dennis CL. Postpartum depression peer support: maternal perceptions from a randomized controlled trial. *Int J Nurs Stud* 2010;47(5):560-8.
134. Letourneau N, Stewart M, Dennis CL, et al. Effect of home-based peer support on maternal-infant interactions among women with postpartum depression: A randomized, controlled trial. *Int J Ment Health Nurs* 2011;20(5):345-57.
135. Sledge WH, Lawless M, Sells D, et al. Effectiveness of peer support in reducing readmissions of persons with multiple psychiatric hospitalizations. *Psychiatr Serv* 2011;62(5):541-4.
136. MacArthur C, Jolly K, Ingram L, et al. Antenatal peer support workers and initiation of breast feeding: cluster randomised controlled trial. *BMJ* 2009;338:b131.
137. Clarke GN, Herinckx HA, Kinney RE, et al. Psychiatric hospitalizations, arrests, emergency room visits, and homelessness of clients with serious and persistent mental illness: findings from a randomized trial of two ACT programs vs. usual care. *Mental Health Serv Res* 2000;2(3):155-64.
138. Macvean ML, White VM, Sanson-Fisher R. One-to-one volunteer support programs for people with cancer: A review of the literature. *Patient Educ Couns* 2008;70(1):10-24.
139. Davidson L, Chinman M, Sells D, et al. Peer support among adults with serious mental illness: a report from the field. *Schizophr Bull* 2006;32(3):443-50.
140. Jolly K, Ingram L, Khan KS, et al. Systematic review of peer support for breastfeeding continuation: metaregression analysis of the effect of setting, intensity, and timing. *BMJ* 2012;344.

141. Ingram L, MacArthur C, Khan K, et al. Effect of antenatal peer support on breastfeeding initiation: a systematic review. *CMAJ* 2010;182(16):1739-46.
142. Brunier G, Graydon J, Rothman B, et al. The psychological well-being of renal peer support volunteers. *J Adv Nurs* 2002;38(1):40-9.
143. Murphy C, Cupples M, Percy A, et al. Peer-mentoring for first-time mothers from areas of socio-economic disadvantage: a qualitative study within a randomised controlled trial. *BMC Health Serv Res* 2008;8(1):46.
144. Pistrang N, Jay Z, Gessler S, et al. Telephone peer support for women with gynaecological cancer: recipients' perspectives. *Psycho-Oncology* 2011. doi:10.1002/pon.2005.
145. Schafer E, Vogel MK, Viegas S, et al. Volunteer peer counselors increase breastfeeding duration among rural low-income women. *Birth* 1998;25(2):101-6.
146. Matthews B, Baker F, Hann DM, et al. Health status and life satisfaction among breast cancer survivor peer support volunteers. *Psycho-Oncology* 2002;11(3):199-211.
147. Weber BA, Roberts BL, Resnick M, et al. The effect of dyadic intervention on self-efficacy, social support, and depression for men with prostate cancer. *Psycho-Oncology* 2004;13(1):47-60.
148. Dennis CL. Peer support within a health care context: a concept analysis. *Int J Nurs Stud* 2003;40(3):321-32.
149. Redelmeier D, Molin JP, Tibshirani RJ. A randomised trial of compassionate care for the homeless in an emergency department. *Lancet* 1995;345(8958):1131-4.
150. Shumway M, Boccellari A, O'Brien K, et al. Cost-effectiveness of clinical case management for ED frequent users: results of a randomized trial. *Am J Emerg Med* 2008;26(2):155-64.
151. Tulskey JP, Pilote L, Hahn JA, et al. Adherence to isoniazid prophylaxis in the homeless: a randomized controlled trial. *Arch Intern Med* 2000;160(5):697-702.
152. Lehman AF, Dixon LB, Kernan E, et al. A randomized trial of assertive community treatment for homeless persons with severe mental illness. *Arch Gen Psychiatry* 1997;54(11):1038-43.
153. Althaus F, Paroz S, Hugli O, et al. Effectiveness of interventions targeting frequent users of emergency departments: a systematic review. *Ann Emerg Med* 2011;58(1):41-52.
154. Okin RL, Boccellari A, Azocar F, et al. The effects of clinical case management on hospital service use among ED frequent users. *Am J Emerg Med* 2000;18(5):603-8.
155. Nyamathi A, Flaskerud JH, Leake B, et al. Evaluating the impact of peer, nurse case-managed, and standard HIV risk-reduction programs on psychosocial and health-promoting behavioral outcomes among homeless women. *Res Nurs Health* 2001;24(5):410-22.
156. Morse GA, Calsyn RJ, Klinkenberg WD, et al. An experimental comparison of three types of case management for homeless mentally ill persons. *Psychiatr Serv* 1997;48(4):497-503.
157. Phillips GA, Brophy DS, Weiland TJ, et al. The effect of multidisciplinary case management on selected outcomes for frequent attenders at an emergency department. *Med J Aust* 2006;184(12):602.
158. Nieboer AP, Cramm JM, Meij B, et al. Choice processes and satisfaction with care according to parents of children and young adults with intellectual disability in the Netherlands. *J Intellect Dev Disabil* 2011;36(2):127-36.
159. Loh A, Simon D, Wills CE, et al. The effects of a shared decision-making intervention in primary care of depression: a cluster-randomized controlled trial. *Patient Educ Couns* 2007;67(3):324-32.
160. Lewis S, Noyes J, Mackereth S. Knowledge and information needs of young people with epilepsy and their parents: mixed-method systematic review. *BMC Pediatr* 2010;10(1):103.
161. Griffin SJ, Kinmonth AL, Veltman MWM, et al. Effect on health-related outcomes of interventions to alter the interaction between patients and practitioners: a systematic review of trials. *Ann Fam Med* 2004;2(6):595-608.
162. Joosten E, DeFuentes-Merillas L, De Weert G, et al. Systematic review of the effects of shared decision-making on patient satisfaction, treatment adherence and health status. *Psychother Psychosom* 2008;77(4):219-26.
163. Campbell TA, Auerbach SM, Kiesler DJ. Relationship of interpersonal behaviors and health-related control appraisals to patient satisfaction and compliance in a university health center. *J Am Coll Health* 2007;55(6):333-40.
164. Calnan M, Gabe J. The restratification of primary care in England. In: Calnan M, Gabe J, (eds) *The new sociology of the health service*. Oxon: Routledge 2009:56-79.
165. Calnan M, Rowe R. Trust relations in a changing health service. *J Health Serv Res Policy* 2008;13(suppl 3):97-103.
166. Schrank B, Bird V, Rudnick A, et al. Determinants, self-management strategies and interventions for hope in people with mental disorders: Sytematic search and narrative review. *Soc Sci Med* 2012;74:554-64.

Appendix:

Intervention-specific search strategies

The tables below show the search terms used for each of the seven interventions that are being tested as part of the Health Foundation's Closing the Gap through Changing Relationships programme and which formed the basis for our evidence review. We also show the total number of records retrieved from the combination of the search terms listed and the final number of relevant studies that were included in the review. Where relevant, the key intervention is italicised. The search strategy is described in detail in Part 2, section 2.1, including general inclusion and exclusion criteria. In the tables below, we show detail of the additional intervention-specific filtering that was applied.

Intervention 1: Supporting patients in managing their own dialysis within a hospital environment – *Patient self-administration of medication*

Specific inclusion criteria	Focus on: <ul style="list-style-type: none">- support for self-management of treatment- patient self-administration of medication in any setting- provision of support to patients to enable them to understand, navigate and use their data.
Search terms	<ul style="list-style-type: none">- (Staff-patient shared self management) OR- (Patient self-administration of treatment and 'patient participation' and 'quality of care')- (Patient self-administration of treatment and 'safety' [MeSH])- (Patient self-administration of treatment and effectiveness)- (Patient self-administration of treatment and 'patient-centered care' [MeSH])- (Patient self-administration of treatment and timeliness)- (Patient self-administration of treatment and 'efficiency, organizational' [MeSH])- (Patient self-administration of treatment and equity)
Total number of records retrieved	1,806
Filter	Excluding studies that: <ul style="list-style-type: none">- described non-pharmacological interventions- described interventions that were administered by a carer (not the patient)- described interventions concerned with general self-management (including the self-administration of medicines for common chronic conditions such as diabetes or asthma)- lacked methodological detail.
Number of records included in review	9

Intervention 2: Patient access to online health records and the functional use of those records – *Patient access to online health records*

Specific inclusion criteria	Focus on: <ul style="list-style-type: none"> - giving patients access to their own electronic medical records - giving patients support to enable them to understand, navigate, and use their data.
Search terms	<ul style="list-style-type: none"> - ('Electronic Health Records' [MeSH] AND 'Patient Participation' [MeSH]) AND 'Quality of Health Care' [MeSH] - ('Electronic Health Records' [MeSH] AND 'Patient Participation' [MeSH]) - Electronic Health Records [MeSH] - 'Health Records, Personal' [MeSH] AND 'Quality of Health Care' [MeSH] - 'Health Records, Personal' [MeSH] AND 'Patient Participation' [MeSH]
Total number of records retrieved	2,380
Filter	Excluding studies that: <ul style="list-style-type: none"> - did not focus on patient use of records (eg their focus was on the use or outcomes of electronic health records by health professionals) - described eHealth technology other than the personal use of electronic health records - involved one-way communication only (eg patient reminders to attend appointments) - provided insufficient detail on study methodology.
Number of records included in review	15

Intervention 3: Using patient complaints as a driver for improvement within a hospital environment – *Addressing complaints about care received*

Specific inclusion criteria	Focus on: <ul style="list-style-type: none"> - institutional processes for addressing complaints by patients or their advocates about care received - complaints filed by healthcare professionals concerning quality of care - the association of complaints processes with the quality of care.
Search terms	<ul style="list-style-type: none"> - 'Patient-centred care' [MeSH] AND 'complaint' [all fields] AND 'Quality of health care' [MeSH] - Complaint [all fields] AND 'Quality of health care' [MeSH] - Complaint [all fields] AND 'Quality of health care' [MeSH] AND 'hospital' [MeSH] - 'Patient-centred care' [MeSH] AND 'complaint' [all fields] AND 'Quality of health care' [MeSH] - 'Patient-centred care' [MeSH] AND 'Dissent and Disputes' [MeSH] AND 'Quality of health care' [MeSH] (additional, based on above) - 'Dissent and Disputes' [MeSH] AND 'Quality of health care' [MeSH] (additional, based on above) - 'Patient satisfaction' [MeSH] AND 'complaint' [all fields] AND 'Quality of health care' [MeSH] - 'Narration' [MeSH] AND 'complaint' [all fields] AND 'Quality of health care' [MeSH] - 'Patient advocacy' [MeSH] AND 'complaint' AND 'Quality of health care' [MeSH] - 'Story' [all fields] AND 'complaint' [all fields] AND 'Quality of health care' [MeSH]
Total number of records retrieved	8,177
Filter	Excluding studies that: <ul style="list-style-type: none"> - included interventions describing general complaints processes - were based on single case studies.
Number of records included in review	7

Intervention 4: Putting women at the centre of antenatal care – Involving women in decision-making in antenatal care

Specific inclusion criteria	Focus on: - enabling women to make decisions about their antenatal care.
Search terms	<ul style="list-style-type: none"> - ‘Patient-centered care’ [MeSH Terms] AND (‘Hospitals, Maternity’ [MeSH Terms] OR ‘antenatal care’ [All Fields]) AND ‘Quality of health care’ [MeSH Terms] - (‘Hospitals, Maternity’ [MeSH] OR ‘antenatal care’ [all fields]) AND ‘Quality of health care’ [MeSH] - (‘Co-design’ OR ‘Delivery of Health Care’ [MeSH Terms]) AND (‘Hospitals, Maternity’ [MeSH Terms] OR ‘antenatal care’) AND ‘Quality of health care’ [MeSH Terms] - ‘Empowerment’ AND (‘Hospitals, Maternity’ [MeSH] OR ‘antenatal care’ [all fields]) AND ‘Quality of health care’ [MeSH] - ‘Empowerment’ AND ‘Hospitals, Maternity’ [MeSH] OR ‘antenatal care’ [all fields] AND ‘Quality of health care’ [MeSH] - ‘Joint decision-making’ AND ‘Hospitals, Maternity’ [MeSH] OR ‘antenatal care’ [all fields] AND ‘Quality of health care’ [MeSH] - (‘Informed choice’ OR ‘information’) AND (‘Hospitals, Maternity’ [MeSH] OR ‘antenatal care’ [all fields]) AND ‘Quality of health care’ [MeSH] - (‘Patient relationship management’ OR ‘PRM’) AND (‘Hospitals, Maternity’ [MeSH] OR ‘antenatal care’ [all fields]) AND ‘Quality of health care’ [MeSH] ‘Information technology’ AND (‘Hospitals, Maternity’ [MeSH Terms] OR ‘antenatal care’) AND ‘Quality of health care’ [MeSH Terms] - Antenatal care [Title/Abstract] AND decision-making [Title/Abstract] - Antenatal care [Title/Abstract] AND empowerment [Title/Abstract]
Total number of records retrieved	7,401
Filter	Excluding studies that: <ul style="list-style-type: none"> - did not make reference to the role of women in decision making - focused exclusively on healthcare providers’ clinical decision making - focused only on developing country contexts that were not comparable to developed country contexts.
Number of records included in review	6

Intervention 5: Use of peer support workers in mental healthcare – *Use of peer support workers in healthcare*

Specific inclusion criteria	<p>Focus on:</p> <ul style="list-style-type: none"> - interventions involving peers with a lived experience of a given condition who provide support for those affected by that condition - employed peer support workers in mental health - volunteer schemes in non-mental health areas involving one-to-one peer support among adults as part of service delivery.
Search terms	<ul style="list-style-type: none"> - (Peer support work and ‘patient participation’ and ‘quality of health care’) - (Peer support workers and ‘patient participation’ and ‘quality of health care’) - (Peer support approach and ‘patient participation’ and ‘quality of health care’) - (Peer support workers and safety) - (Peer support workers and safety [MeSH]) - (Peer support workers and effectiveness) - (Peer support workers and ‘patient-centered care’ [MeSH]) - (Peer support workers and timeliness) - (Peer support workers and ‘efficiency, organizational’ [MeSH]) - (Peer support workers and equity) - (Peer support workers)
Total number of records retrieved	1,934
Filter	<p>Excluding studies that:</p> <ul style="list-style-type: none"> - examined interventions involving peer support in self-management (although boundaries were not always clear-cut) - assessed mutual support schemes or self-help groups - dealt with online peer support interventions - were set in low-income countries.
Number of records included in review	18

Intervention 6: Compassionate healthcare for homeless patients – Improving healthcare services for homeless patients

Specific inclusion criteria	Focus on: <ul style="list-style-type: none"> - the employment of formerly homeless ‘care navigators’ - ‘care navigators’ assisting staff in understanding what patients need - ‘care navigators’ assisting patients in understanding where to get help.
Search terms	<ul style="list-style-type: none"> - ‘Homeless Persons’ [MeSH] AND ‘Delivery of Health Care’ [MeSH] - ‘Homeless Persons’ [MeSH] AND ‘peer support’ - ‘Homeless Persons’ [MeSH] AND ‘Peer Group’ [MeSH] - ‘Homeless Persons’ [MeSH] AND ‘Education, Medical, Continuing’ [MeSH] - ‘Quality of Health Care’ [Majr:NoExp] AND ‘Homeless Persons’ [MeSH] - ‘Empathy’ [MeSH] AND ‘Education, Medical, Continuing’ [MeSH]
Total number of records retrieved	1,924
Filter	Excluding studies that: <ul style="list-style-type: none"> - did not include interventions employing formerly homeless persons - did not involve ‘care navigator’ support for staff and patients.
Number of records included in review	8

Intervention 7: Shared decision-making in child/adolescent mental healthcare

Specific inclusion criteria	Focus on: <ul style="list-style-type: none"> - dissemination of information to patients regarding mental health conditions and treatment options - facilitating shared decision making between young people and care staff - shared decision making for groups other than adolescents with mental health conditions.
Search terms	<ul style="list-style-type: none"> - (‘Decision Making’ [MeSH] OR ‘Patient Participation’ [MeSH] OR ‘Information Dissemination’ [MeSH]) AND (‘Adolescent’ [MeSH] AND ‘Mental Health Services’ [MeSH]) - ‘shared decision-making’ AND ‘Adolescent’ [Mesh]
Total number of records retrieved	364
Filter	Not applied.
Number of records included in review	6

The Health Foundation is an independent charity working to continuously 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.

Working at every level of the system, we aim to develop the technical skills, leadership, capacity and knowledge, and build the will for change, to secure lasting improvements to healthcare.

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