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More specific concerns

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

- assumptions that lie behind these characterisations
- ambiguities that they leave unresolved
- implications of what they emphasise.

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

- Interactions and status differences between clinicians and patients
- Goal setting
- Patient activation.

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

Interactions and status differences between clinicians and patients

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

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

- knowledge or expertise
- contributions or influence and responsibility for condition management.

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

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

- knowledge or expertise
- contributions or influence and responsibility.

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

Differences in knowledge and expertise

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

- By recognising that patients can develop more of the scientific or biomedical kinds of knowledge about their condition than traditional models of care (and many clinicians) give them credit for, and enabling patients to do this.⁵²
- By recognising that patients have different kinds of knowledge to healthcare professionals, and regarding these different kinds of knowledge as somehow of equal value to the scientific/biomedical kinds. (Typically, patients are seen to have experiential knowledge of what it is like for them to live with their condition, and knowledge of themselves, their lives and what matters to them.)⁵³

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

- people with conditions that are and are not associated with impairments in cognitive functioning
- people who are more and less educated
- people who are more and less able to access various sources of informational, emotional and social support
- people who have had more and less time to come to terms with their diagnosis.

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

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

Differences in contributions or influence and responsibility

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

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

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

The Health Foundation's characterisation emphasises a shift from a traditional view in which patients believe that it is their clinicians' role to improve health to a view in which patients believe that they have an active role to play in changing their own behaviours to improve their

own health. The Health Foundation's characterisation also presents patients as potentially influential in deciding what information and skills they are taught.

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

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

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

Experience-based comments about equality in clinician–patient relationships

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

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

Participants highlighted the value of patients being able to access and develop what social scientists might call a secure trust⁵⁶ in healthcare professionals who listened, were aligned with patients as they struggled with their condition, who could hear patients sympathetically when they needed to say that they just wished the condition would go away, and who could help them maintain perspective, 'contain' the condition and cope. They also highlighted the importance of patients being able to work with healthcare professionals with whom they could be themselves, not have to worry about overcoming potential stereotype prejudices, and not have to work hard to present an acceptable face.

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

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

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

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

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

Goal setting

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

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

- health services should be responsive to diverse individual patients and their particular needs
- health services should encourage and enable people with long-term conditions to manage those conditions

