Unifying and universalising Personalised Care? An analysis of a national curriculum with implications for policy <u>and education</u> relating to person-centred care

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Highlights

- A national *Curriculum* on Personalised Care aims to unify different approaches
- It locates the unity in a core set of professional capabilities and values
- The *Curriculum* **neglects key aspects of person-centred care and important** challenges
- More attention to value tensions and ethics could support professional practice
- Ambitions to tackle inequalities must focus on structures and systemic prejudice

Abstract

England's National Health Service continues to signal a commitment to person-centred practice. It recently established a Personalised Care Institute which published a national *Curriculum* for all healthcare practitioners.

The *Curriculum* describes an educational framework which aspires to unify approaches and universalise provision of Personalised Care. It presents 8 models and approaches and 6 components within Personalised Care as a whole, locating their unity in an underlying common core repertoire of professional capabilities and an anchoring belief in people's strengths, resourcefulness and ability to develop their own solutions with appropriate support. The *Curriculum* indicates some complexity in the provision of Personalised Care but leaves unanswered questions about the theoretical coherence of the concept. It neglects several practical-ethical implementation challenges. The practical potential of the *Curriculum* could be strengthened by revisions to support professional engagement with the normative complexities of person-centred practice. We advocate explicit attention to: the value-laden judgements involved in deploying the Personalised Care repertoire; the problems that entrenched social inequalities and systemic prejudices pose for universal provision of Personalised Care; and neglected aspects of person-centredness (including values beyond empowerment and choice). We also suggest a need for broader discussion about competing views and the tensions involved in person-centred practice.

1. Introduction

Many healthcare systems internationally aspire to improve service provision by making healthcare more 'person-centred'. Exactly what this means and how it can be achieved remains open to debate – as does the question of whether any of several near-synonyms for person-centredness should be preferred. While there is ready agreement that person-centred approaches are not disease-centred, technology-centred or organised primarily for service providers' convenience, positive characterisations of person-centredness (and similar terms) draw on and variously emphasise several different ideas[1-4]. These include the importance of biopsychosocial assessment and more holistic engagement with patients (as a corrective to narrowly biomedical approaches) and various other forms of humanising, individualising or personalising healthcare, for example by tailoring treatments, and respecting and empowering patients as active agents[5-8]. Numerous practice-concepts and practical tools have been developed in association with person-centredness and variously linked to ideas about evidence-based healthcare. Some, including shared decision-making and self-management support, are now internationally established norms of good practice, although they too are variously interpreted[9].

The growth of ideas and interventions may be a positive reflection of the value of person-centredness, but questions need to be asked about how well they contribute to securing person-centredness for diverse people in diverse healthcare situations, about their coherence and compatibility, and their implications for the pursuit of other values in healthcare[10,11].

In this paper we examine a national-level effort to unite and promote multiple ideas and initiatives relating to person-centred healthcare and personalisation in social care. As part of a series of consolidating initiatives[12,13] the Personalised Care Institute (PCI) was established by the National Health Service (NHS) in England in 2020 to serve as a training centre of excellence. Its flagship *Curriculum*[14] is intended to provide an "educational framework" to ensure that all healthcare practitioners learn "the essential elements" of personalised care(page 4). The *Curriculum* aspires to "unify the different ways of approaching Personalised Care" for all NHS staff with its specification of constituent elements, learning outcomes, and a framework for accreditation and governance(p.4). An overview of the 80-page *Curriculum* is provided in Box 1.

Our analysis is intended constructively to inform future versions of the *Curriculum* and to invite a broader discussion (with international relevance) about policy conceptions and educational aspirations relating to person-centred practice.

After outlining our approach in Section 2, we present our critical analysis in four subsequent sections (Presentations of Unity; Recognition of Complexity; Pursuit of Personalised Care for all; and Relating Personalised Care to Person-Centred Approaches) before discussing recommendations to strengthen the *Curriculum* specifically and educational policy for person-centred approaches more generally.

2. Our approach

We developed our analysis primarily via critical readings of, and reflective discussions about, the *Curriculum*. To check our interpretations, we used keyword searches to systematically investigate the occurrence and usage of terms relevant to the conceptualisation and enactment of personalised and person-centred care (See Supplementary Material). The *Curriculum* convenor contributed to the development of this paper with a view to informing an update of the *Curriculum*.

We approached the *Curriculum* with a working view of person-centredness as a concept rooted in the broad ideas of treating patients holistically and relating to people appropriately as humans or persons. We recognised that these are plural or multi-faceted ambitions and inevitably expressed in diverse ways[4,15]. We brought an interest in the ethics of person-centred approaches, including concerns that some aspects of person-centredness may tend to pull away from others and detract from other important healthcare quality considerations[5,10,11,15-17], and awareness that some efforts to promote person-centredness can perpetuate social disadvantage in healthcare[18-20].

[Box 1]

3. Presentations of Unity

As noted above, the *Curriculum* aspires "to unify the different ways of approaching Personalised Care". Personalised Care is presented as having six components that can be delivered via eight "models and approaches"(p.15) (Table 1). The *Curriculum* introduces and provides learning outcomes for each of these elements. Although the elements are "separated for conceptual reasons, they should be considered as part of an integrated whole"; the sections about them form "an educational series"(p.15).

3.1 Unity in repertoire

The *Curriculum* locates the unity of Personalised Care in the repertoire of values and skills it delineates. Healthcare professionals require a set of "common core capabilities"(p.15) to deliver the various models, approaches and components that make up the whole of Personalised Care. The core capabilities are arranged in three broad groups: Generic professional capabilities; Values in Personalised Care; and Capabilities in Personalised Care (Table 1).

[Table 1]

3.2 An anchoring belief and the core values of Personalised Care

Beyond stipulating that a cluster of models, approaches and components together constitute a whole underpinned by common core capabilities, the *Curriculum* suggests some theoretical unity in its account of Values in Personalised Care. It describes these values as "anchored in the belief that people, their circles of support, and communities have their own expertise and strengths, are resourceful, and have the capacity to develop their own solutions with the appropriate support" (p.18). It also characterises Personalised Care as placing "significant importance on working in ways that enable people to reach their potential of being capable, resourceful and empowered"(p.18).

The Values in Personalised Care are presented first as a series of shifts away from what, implicitly, is *not* Personalised Care. The language of "shifts to" and presentation of apparently binary alternatives could generate problems if interpreted literally. Table 2 reproduces the shifts as worded in the *Curriculum* and provides our analytic commentary on the implications of word choices. We suggest edits to help avoid losing what is valuable in what is shifted from and unduly narrowing the gains in what is shifted to.

[Table 2]

The *Curriculum* then lists a broader set of Values in Personalised Care, adopted from a previous *Person-Centred Approaches* document[13]. We comment on this adoption in section 6.

4. Recognition of complexity

The *Curriculum* acknowledges that "Practising in health and social care is a complex combination of many behaviours, decisions and interactions"(p.6). Here, we highlight how the *Curriculum* indicates, but does not make explicit, that Personalised Care involves complex value judgements (by which we mean judgements about what matters) and practical and ethical challenges.

4.1 Deploying the repertoire: value judgements in selecting and combining approaches?

The first of eight "models and approaches" in the *Curriculum,* situated at a meta level, is "Using a range of consultation models". It is introduced with recognition that "many" of "the numerous consultation models used in healthcare… incorporate aspects of Personalised Care", and that "It is unlikely that strictly following one model will be sufficient to engender Personalised Care in most settings"(p.27). The account suggests practitioners need to "incorporate aspects of [various models and approaches] into an approach that is appropriate to the person, setting, and their unique experience and skills as a practitioner"(p.27). It notes a requirement for "flexibility" in the "application" of models "to support person-centred consultations"(p.27).

The section "Using a range of consultation models" recognises that healthcare professionals need to work responsively across diverse situations and that the appropriateness of their approach depends on the particularities of the people and situations involved. There is, however, little discussion of the kinds of judgements involved in selecting between models and approaches with different emphases. The *Curriculum*'s reasonable approach of specifying learning outcomes in relation to particular models, approaches and components has perhaps led to some neglect of the skills and value judgements required to interpret and enact Personalised Care as a whole.

4.2 Plurality of outcomes and perspectives: value tensions when priorities conflict?

The *Curriculum* recognises that the outcomes prioritised in Personalised Care are not the only relevant outcomes, and that outcomes can be assessed from different perspectives:

> "I measure and value personalised outcomes as well as clinical, systematic and financial outcomes". [Values in Personalised Care, p.19]

> "Evaluate efficacy of virtual interactions using range of outcome measures (from clinical, service and user perspectives)". [Learning outcome, Personalised Care in the remote and virtual environment, p.53]

The document does not, however, explain that the plurality of outcome areas and perspectives can give rise to value tensions (tensions between different things that matter) and thereby require ethical judgement about which or whose priorities should prevail. The challenges of responsiveness to patients are under-examined. The notion that healthcare professionals should not be judgemental about patients recurs, but little is said about handling conflicts between the priorities of patients, healthcare professionals and institutions. For example, a requirement to "Work constructively with resistance in a non-judgemental way"(p.49) leaves the nature or direction of 'constructive' work unspecified, and there is no mention of the need for, or appropriateness of, compromise as part of an ability to "Reach a shared agreement when managing highly complex situations, and those that involve significant risk"(p.61).

There is some recognition that efforts to achieve one good thing may tend to undermine another, and that healthcare professionals need to exercise judgement in enacting Personalised Care. For

example, learning outcomes for Health literacy include "Understand… The need to balance simplicity with accuracy when developing or communicating health information"(p.35), and for Patient Activation include "Be able to… Share the results of a PAM [questionnaire]… using appropriate sensitive language"(p.39).

There is also some recognition that working with a patient's priorities may come into tension with norms embedded in established care pathways, practice guidelines or systems:

> "Understand… The difference between executive and performance coaching and the tension this creates when balancing changes of importance to the person and changes of importance to the workforce or system" [learning outcome, Health coaching, p.49].

> "The practitioner: recognises and shows understanding of the limits of a single pathway of care in providing the holistic care of the patient" [capabilities in enabling choice, p.71]

However, there is no mention of how competing values or system pressures can or should be handled.

The *Curriculum* does not explicitly mention the need for healthcare professionals to use ethical judgement, for example when the choice, control and empowerment advocated within Personalised Care conflict with biomedical priorities, 'evidence-based' guidelines, organisational protocols, or with other aspects of person-centred approaches. The words 'ethic*' and 'moral*' feature only among reasons in favour of shared decision-making and in the citation of a code of professional ethics.

4.3 Practical challenges: professional difficulties?

The *Curriculum* reflects a view that all healthcare professionals can learn the values and skills required for Personalised Care, and that appropriate training can enhance those skills. Consistent with the downplaying of value tensions and ethical challenges, however, there is little recognition that practitioners may experience uncertainty or difficulty in adopting Personalised Care. The three instances of "uncertainty" in the *Curriculum* all refer to managing the uncertainty of healthcare outcomes or how health conditions progress, not uncertainty about what to do as a matter of Personalised Care. Similarly, "difficulties" feature mostly as things that patients contend with and not as things that healthcare professionals experience. Only one of four "stories from practice" gives any hint of professional difficulty, and that is a temporary worry, quickly shown to be unfounded (p.24).

5. Pursuit of Personalised Care for all

The ambition apparent in the *Curriculum* is that all health and social care should be Personalised.

5.1 Personalised Care for people in unequal social circumstances

A page dedicated to "Equality, diversity, and inclusion" affirms that these "are at the heart of the values of the Personalised Care Institute". It claims that "Truly Personalised Care is inclusive, values people for who and what they are and seeks to understand their cultural context" and "Personalised Care is for everyone"(p.24). The page is subtitled "(tackling health inequalities)" and suggests that "some of the models and approaches described in this curriculum may have a particularly positive impact on groups who are most impacted by health inequalities"(p.24). The reasoning is that "people from lower socioeconomic backgrounds are disproportionately impacted by multiple long-

term conditions and tend to have lower levels of knowledge, skills and confidence required to manage them" so support to develop these "can result in better health outcomes, improved experiences of care and fewer unplanned admissions"(p.24).

This may hold true to some extent but seems over-optimistic. The *Curriculum* does not acknowledge the structural hierarchies and significant social inequalities that limit many people's capabilities to access and benefit from health services and to manage their health more broadly[20,21]. There is no acknowledgement of culturally ingrained and institutionalised social prejudices, or how these might be manifest *within* enactments of components of Personalised Care, for example in microaggressions[22]. There is no discussion of how discriminatory attitudes and deep-rooted experience of these may mean there is insufficient respect and trust within interpersonal interactions to ensure people who are racially or otherwise minoritized experience anything like equal benefits of Personalised Care[23].

5.2 Personalised Care across diverse health care needs and situations

Several components of Personalised Care focus on supporting people with long-term conditions. The emphasis on patient empowerment within the Personalised Care repertoire perhaps renders it less appropriate for acute, emergency or high dependency settings, or at the very end of life when people's needs for care from others exceed their capacity for self-care. In these contexts, an emphasis on dignified, respectful and compassionate treatment may be more appropriate.

Some *Curriculum* learning outcomes, including "Be able to give people time, listen, build trusting relationships and value what matters most to people"(p.65), seem insufficiently actionable, for example, in busy clinics.

6. Relating Personalised Care to person-centred approaches

The *Curriculum* suggests a close relationship between Personalised Care and person-centred approaches but leaves the form of that relationship somewhat unclear. When person-centred approaches are mentioned explicitly, there is some ambiguity about whether they are a subset of or synonymous with Personalised Care. For example, Personalised Care is said to combine the "healthcare oriented principles of person-centred care" with the "more social care oriented principles of personalization"(p.2); statements about values in Personalised Care are attributed to a document about Person Centred Approaches (p.19); and learning outcomes for the "Using a range of consultation models" element of Personalised Care include being able to comment on the "effectiveness" of consultation models "in encouraging person-centred care"(p.27). But in some respects, Personalised Care as characterised in the *Curriculum* accommodates a *narrower* range of values, and perhaps of applications, than person-centred care.

The "anchoring belief" of Personalised Care (see section 3.2) is strongly resonant with what Bettine Pluut identified as the "Empowering patients" discourse of patient-centredness[5]. Two further discourses of patient-centredness identified by Pluut are much less evident in the *Curriculum*. "Being responsive" to diverse people and needs features primarily in connection with choice and inequalities. "Caring for patients", which Pluut characterised particularly in terms of respectful and effective care of vulnerable people, hardly features at all. The term "respect*" occurs 8 times in the *Curriculum*, but only three relate to respect for people or their dignity more broadly than respect for autonomy or specific concerns. The stem "vulnerab*" only occurs twice, as a label for particular groups. There is no consideration of how healthcare systems or poor selection or execution of components of Personalised Care could themselves render people vulnerable, or disrespect or disempower them – for example by undermining confidence, trust, or experiences of being heard

and cared for. The *Curriculum* also says little about caring, compassion or kindness. There are 251 instances of the word "care", but 124 occur within "Personalised Care" and most others label an activity or institution (e.g. care pathway, care home) that could be instantiated with more or less care for the people served. "Compassion" features only once and "kind*" features only in the sense of type of.

Further, little is said about attention to patients' biographical identities, narratives or stories despite their significance and place in some theoretical accounts and practical enactments of person-centred care[2,24,25]. The *Curriculum* conveys little sense of the idea of practitioners and patients meeting as two persons or as equals in an encounter.

Although the emphasis on empowerment (building on people's strengths) and personal choice and control helps foster a sense of unity across the approaches and components of Personalised Care, it also raises concerns (in addition to limiting applicability as mentioned in 5.2). A focus on empowering patients without critical attention to the different forms of power in play – including those constraining what is 'acceptable' - risks perversely disempowering people in important respects and perhaps shifting undue responsibility to individuals[16,26]. A strong focus on individual choice can also detract from attention to broader concerns about relational dimensions of healthcare experience that many see as important for person-centred care[2,7,16,27].

7. Recommendations for the *Curriculum* and broader policy implications

We have examined a first iteration of the *Curriculum*, working with leaders of the Personalised Care Institute who have welcomed constructively critical comment. We recommend that a revised *Curriculum*, or any similar initative, should more explicitly consider:

- value tensions and practical-ethical challenges that can arise in the pursuit of Personalised Care and the uncertainties and difficulties that practitioners may experience;
- structural/systemic aspects of health and social care provision that impede ambitions for the universal and inclusive provision of Personalised (or otherwise good) Care; and
- the relationship between Personalised Care and person-centred care and the implications of different value emphases within these.

We also suggest that claims of unity for the concepts of Personalised Care, Person-Centred Care and similar could usefully be de-emphasised. The policy initiative from which the *Curriculum* emerged promoted a particular selection of models, approaches and components. Although the impression of unity arguably bolsters its force, this impression is fostered in large part by focusing on just a subset of the values associated with person-centred care and that diminishes the universality of applicability.

The types of concern we have raised about the *Curriculum* recur internationally and we suggest they can also serve as starting points for wider discussion about the development of policy and professional education relating to person-centredness.

Claims about conceptual unity are not essential to the advancement of Personalised Care or person-centred care. Personalised and person-centred care *are* plural and complex, and not just because they can be represented in several different models of practice[4,15]. Putting less emphasis on conceptual unity and more on the plurality of values that can matter for person-centredness within health and social care could ensure broader applicability and encourage recognition of some

important value tensions and the skilful professional judgement involved in deploying combinations of values appropriate to diverse people and situations[4,5].

The question of whether and how a *Curriculum* or professional education should explicitly recognise and discuss value tensions and ethical challenges within Personalised Care needs to be taken seriously. If these are partly intended to encourage interest in Personalised Care, some might argue against introducing potentially off-putting complications. But several studies have shown that healthcare professionals who strive to adopt person-centred approaches must navigate various tensions between different goods and competing perspectives on priorities; these individuals can experience countervailing systemic pressures and risk being adversely judged against evidence-based guidelines and standardised indicators of good healthcare [9-11]. Obscuring these challenges arguably does practitioners a disservice and will potentially undermine the implementation of Personalised Care **or** person-centred approaches in the long run.

Value tensions are inevitable when people with multiple and different priorities and perspectives work together within health and social care systems that serve a complex mix of purposes. Rather than hiding this, we suggest efforts should be made to raise awareness and establish opportunities for health professionals (in training and subsequently) to engage in safe discussion of how value tensions are experienced and navigated. Educators and professional leaders can support acknowledgement that in many patient-specific healthcare situations a single 'best' course of action may not be readily identified or universally agreed upon, and sometimes the ambition should be to find a good compromise. Openness and encouragement of reflection and discussion about conflicting goals and priorities may help avoid dogmatic inflexibility and reflect a conception of Personalised Care that is meaningfully responsive to specific contexts and people.

We do not propose that professional curricula can themselves serve as detailed learning resources about value tensions and the practical-ethical aspects of Personalised Care. However, they could usefully indicate that and how challenges arise, suggest learning outcomes reflecting the capabilities needed to identify sources of value tension and navigate well through competing perspectives and priorities, and recommend that educational programmes support value-sensitive practice, including reflection on professional experience and challenges.

Similarly, while we strongly believe that education should seek to mitigate the risk of Personalised Care increasing health inequalities, we do not suggest that curricula can identify exactly what is needed to tackle systemic and structural barriers to Personalised Care. Of course, it is inappropriate to rely solely on education and individuals to tackle systemic and structural issues within and beyond health services. However, curricula might acknowledge these barriers and encourage educational programmes to support practitioners to develop strategies for working as well as they can to address them.

8. Conclusion

The Personalised Care Institute's *Curriculum* signals a welcome continuing national commitment to person-centred practice. It also suggests hope for some interlinked development of educational and broader improvement initiatives. But its characterisation of Personalised Care arguably over-stresses unity over diversity and emphasises some aspects of person-centredness to the detriment of others. The practical potential of the *Curriculum* is currently limited by lack of explicit attention to the value tensions and practical-ethical challenges that healthcare professionals must navigate. There is clear scope to address these issues in a revision and other curriculum initiatives. More generally, a wider discussion of the value tensions within and between different forms of person-centred practice could also support the development of professional practice.

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Competing interests:

The authors have no competing interests to declare

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Box 1 – Summary overview of Personalised Care Institute Curriculum (August 2020)

A Foreword by the Clinical Director of NHS England's Personalised Care group, Professor Alf Collins, introduces Personalised Care as "represent[ing] a new relationship between people, professionals and the system". Collins states that people want "to be treated as a whole person by professionals they trust; to be involved in decisions about their health and care; to be supported to manage their own health and wellbeing, through health coaching, access to self-management programmes and to peer support in the community; and their care to feel co-ordinated" then explains that "These are the core elements of Personalised Care that are now accepted internationally as good clinical practice" (p.2).

The Foreword also explains that "NHS England and NHS Improvement have brought together the healthcare-oriented principles of person-centred care with the more social care principles of personalisation in the Comprehensive Model for Personalised Care" (p.2). The Comprehensive Model (which is referred to in the remainder of the *Curriculum* as the Universal Model), has six components (see Table 1, column 4). The Foreword notes that the requisite skill sets for Personalised Care are not consistently taught (p.2)

The Introduction claims that the *Curriculum* "articulates the values, behaviours and capabilities required by a multiprofessional workforce to deliver Personalised Care". It presents its purpose as "to unify the different ways of approaching Personalised Care" and thereby to describe learning outcomes for individual practitioners, inform the educational aims and objectives of training courses, provide a framework for accreditation and governance, and describe the skill sets needed within healthcare teams (p.4). There is also an ambition that "This curriculum can be used to support an integrated approach across all systems and communities of practice in health and social care" **(**p.6**).**

The Introduction is followed by sections on the context and language of the curriculum, methods of learning, the PCI accreditation framework and notes about a programme of assessment. There is a section on "Equalities, diversity and inclusion (tackling health inequalities)" before the Structure of the Personalised Care Curriculum is outlined (see Table 1, column 4).

The next section introduces and lists the 'Core capabilities' (including values) of Personalised Care that are required by all practitioners. These were adapted from an earlier document on Person Centred Approaches[13]. Capabilities for Personalised Care are organised into three levels: 1. Capabilities to engage people; 2. Capabilities to enable and support people, and 3. Capabilities specific to delivering the six components of Personalised Care (p.20)

The remaining two thirds of the document comprise separate sections for each of 8 'models and approaches' and 6 'components of Personalised Care' (see Table 1). Each section provides a 'Definition and introduction', outlines 'Key elements' (for Models and approaches) or 'Descriptors of professional behaviours (for Components), lists 'Learning outcomes' at three different levels, and includes tabular summaries of 'How to learn this approach' (describing the potential contributions of different learning methods) and 'Standards for training' (with requirements for course design, course delivery, monitoring and evaluation, and sustainability).

Appendices provide a 'Glossary of Terms' and summary of 'The language of learning outcomes'.

Table 1: The structure of the Curriculum (copied from p14 with minor reformatting)

Curriculum	Core Capabilities	Models and Approaches	The 'Six Components' Level 3
Personalised Care	Generic professional capabilities	Range of consultation models	1. Shared decision making
		Health literacy skills	2. Personalised Care and Support Planning
		Motivational interviewing	
	Values in Personalised Care	Making Every Contact Count	3. Social prescribing and community-based support
		Knowledge, skills and confidence	4. Supported self-management
	Capabilities in Personalised Care • Core communication and relationship building skills • **Level 1** Capabilities to engage people • **Level 2** Capabilities to enable and support people	Health coaching	5. Enabling choice
		Supporting behaviour change	6. Personal health budgets and integrated personal budgets
		Personalised Care in remote and virtual environments	

Table 2: The *Curriculum's* presentation of value shifts involved in Personalised Care

Shifts presented in the *Curriculum* under the heading 'Values in Personalised Care'		Researchers' analytic reflections and suggestions for *Curriculum* revision
[From]	**Shifts to…**	The current language of "shifts to" suggests a binary view**.** This is problematic, not least because it detracts from the idea of flexibility in responses to patients. A revision could instead use words such as "rebalancing" and "emphasis" to help avoid this.
Being seen only as a **patient with symptoms**[1] or separate conditions that need treating.	Being seen as a **whole person** with skills. Strengths and attributes as well as needs to be met.	Punctuation errors need to be corrected. It would perhaps be useful to acknowledge (as many accounts of person-centred practice do) that a person has feelings, emotions and concerns, a personal biography and usually a sense of identity, as well as symptoms, skills and strengths. A person's needs will sometimes include attention to their psycho-social wellbeing. Healthcare professionals should be ready to recognise and attend to these when appropriate and be careful not to cause harm in these domains. Sometimes a person needs and wants focused attention to their symptoms and will not benefit from a detailed probing of their "whole". The word "only" in the description to be shifted from helpfully reminds us that people should not be reduced to their symptoms or conditions, nor passified as patients rather than agents. Explicit attention to "respect" and "responsiveness" to each person's situationally specific needs could help preserve the aspirations behind this proposed shift while making the need for flexibility more evident.
Not having the information and support you need to make informed health and wellbeing choices and decisions	Having the information and support you need to make **informed choices and decisions**	This seems appropriate. In addition, it might be useful to recognise that people may need information to help understand and make sense of their situation even when not obviously making choices or facing decisions.
Having to tell your story **again and again**	Only needing to tell your story **once**	The scope and purpose of personal story telling can vary. This wording reflects the frustration people can experience if they are not listened to and if crucial information is not shared within a healthcare team. It also allows for the possibility that in some care settings, it may be important for people to tell

		aspects of their story more than once. There are sometimes aspects of stories that it is not appropriate to document in healthcare records. Also, a story may be variably expressed and heard differently by staff members who might be more and less able to help. Appreciation of different aspects of patients' narratives may be important for various aspects of person-centred care. Telling a story again might help someone to be known by and build relationships with more than one staff member.
Health and care professionals believing **they have all the knowledge**, expertise and responsibility for your health and well-being.	You and your health care professional **sharing knowledge** expertise and responsibility for your health and wellbeing	This shift depends on healthcare professionals relating to patients as credible knowers. It depends in practice on epistemic justice, which may be impeded by identity-based discriminatory attitudes and by the significant epistemic privileging of biomedical knowledge within healthcare systems.
A '**One-size-fits-all'** approach to meeting your health and well-being needs.	Having more **choice and control** so your health and well-being needs are met effectively in a way that makes sense to you.	This current wording hints at some potential tensions between different perspectives on what counts as effective, but there is an ambiguity about whose determination of needs will be prioritised. It is not clear that the criteria for assessing effectiveness as well as the means of achieving it should make sense to patients (which leaves scope for biomedical goals to be imposed as trumping individual patients' outcome priorities). Also, depending on the assumed baseline, not all people will want or benefit from [still] more choice and control. These issues perhaps warrant more explicit attention in the *Curriculum.*
Being asked "what's **the matter** with you?"	Being asked "what **matters** to you?"	This current wording implies ditching the question of what is wrong with someone, but in practice the question may continue to be important. People often need and want to be able to describe their symptoms, seek a correct diagnosis etc. An edit that supports "as well" rather than "instead of" might be useful here.
Being **told** what is wrong with you and how your health needs will be met.	Being valued as an **active partner** in conversations and decisions about your health and wellbeing	People may still need, and value being given, information about their diagnosis and how their health needs can be met. This may be a necessary part of, rather than an unwanted alternative to, being valued as an active partner.

| Feeling **powerless** against a complex health and care system. | Working in partnership with health and care professionals and **sharing power.** | Sometimes health and care professionals themselves feel somewhat powerless within a complex system. Working in partnership with them at an interpersonal level may be welcome but not suffice to overcome a patient's sense of powerlessness.

Questions also need to be asked about the kinds and limits of power involved. |

1. Bold emphasis in first two columns is in original.