

Measuring what really matters

Towards a coherent measurement system to support person-centred care

Dr Alf Collins

In this thought paper, Dr Alf Collins introduces 'Dorothy', a hypothetical patient with a number of long-term conditions, and puts forward ideas to help ensure that the system, and the measures used in the system, always take account of what matters to Dorothy.

The paper describes the principles of person-centred care and the activities that a person-centred system should undertake in different contexts. It then describes how to think about constructing measurement systems for use in each of these contexts. The paper also describes the core constituents of person-centredness to demonstrate the steps that could be followed in order to develop a coherent measurement system.

The Health Foundation wants a more person-centred health care system. 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 our behalf.

We want health care services to deliver care 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. We are working with patients, professionals, and health care providers so that people have a better health care experience and better health.

We hope that this paper will stimulate ideas, reflection and discussion.

Thought paper
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In 2013, he was awarded an honorary Fellowship of the Royal College of Physicians for his work in person-centred care.

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1. Introduction

Dorothy is 72 and was recently widowed; she now lives alone and life is a struggle. Her knees are playing up – she is seeing a surgeon next month to discuss an operation and she is worried about that. Her diabetes hasn't been good for a year or two and her doctor has recently told her that her smoker's cough is more serious and is something called 'COPD'. All in all, she is feeling quite low; maybe she should talk to someone? Maybe she should even think about moving home – even the stairs are a struggle now.

What are the problems that this paper is attempting to address?

Dorothy may well have a dozen or so appointments with health or social care professionals over the next year – more if she becomes unwell with her diabetes or COPD.

The problem is, how can we make sure that the professionals she sees do a good job from Dorothy's perspective? How can we make sure that they take account of 'what matters to Dorothy'?* These questions go to the heart of what it is to practise person-centred care.

Part of the solution to this problem is measurement, because if we can measure the degree to which the system takes account of what matters to Dorothy, we can begin to construct a more person-centred system.

The measures currently in use suggest that the present system is not as person-centred as it could be¹ or at least we don't think it is – we don't use enough person-centred measures for us to be sure. We have numerous ways of measuring the quality of health and social services, but few of those measures come from the perspective of patients.

Critically, we value and often prioritise objective measures of performance such as cost or surrogate measures of cost like length of stay, not just because they are important (which of course they are) but because we **can** measure them.

The second problem is, organisations and individuals orientate themselves in order to deliver on what is measured.² So if we tend to collect objective system data, we will organise our delivery system accordingly and in doing so we run the risk of losing track of what matters to individuals like Dorothy.

This paper puts forward a number of ideas to help ensure that our system and the measures we use in our system always take account of what matters to Dorothy. It describes the principles of person-centred care and the activities that a person-centred system should undertake in different contexts. It then describes how to think about constructing measurement systems for use in each of these contexts. Specific measures are not described in detail, though the Health Foundation's recent evidence review, *Helping measure person-centred care*, provides details of the most commonly researched measures and measurement tools.³

You may not agree with some of the thoughts in this paper, but I hope you find it a stimulating read.

What is person-centred care?

There isn't an agreed core definition of person-centred care, nor is there agreement on the constituents of person-centred care.³ Terminology changes over time and over successive central administrations, so the evidence base is confused and confusing. Terms are often used interchangeably and **principles** (such as personalisation) are generally not distinguished from **activities** (such as collaborative care and support planning). This is important when it comes to measurement: you can't measure a principle, but you can measure an activity.

A detailed review of the relationships between all of the philosophies, principles and activities in the field of person-centred care is beyond the scope of this paper. However, the paper does describe the core constituents of person-centredness in order to demonstrate the steps that could be followed in order to develop a coherent measurement system.

The next section outlines a series of statements or principles; the *Oxford English Dictionary* defines a principle as 'a fundamental truth or proposition that serves as the foundation for a system of belief or behaviour or for a chain of reasoning'. This seems like a reasonable starting place.

* This paper continually refers back to Dorothy, but in doing so it uses her forename as shorthand for 'Dorothy and her day-to-day support network' – be they friends, relatives or carers.

2. Principles underpinning person-centred care

Principle 1. Being person-centred means affording people *dignity, respect and compassion*

Whenever Dorothy interacts with public services, she should **always** be treated with dignity, respect and compassion. These ‘experience standards’ are basic human rights that are enshrined in the NHS Constitution.⁴

Principle 2. Being person-centred means offering *coordinated care, support or treatment*

It’s not just individual encounters that matter. From the perspective of Dorothy and her family and carers, services should appear seamless – they should offer coordinated care, support or treatment across multiple episodes and over time. Someone should be responsible for coordinating her care, support or treatment – whether Dorothy is at home or in a bed in a care home or hospital.⁵

Care coordination is of critical importance at the time of **transitions** between services. Though this is classically thought of in terms of quite major transitions (eg from child services to adolescent services), transitions occur in public services all the time – a referral from a GP to a specialist service is a transition. At this time, patients should be supported to make informed decisions about opting into (or out of) seeing specialists rather than being ‘referred’.

What is also important at times of transition is that there is clarity between providers regarding who is responsible for care coordination; if care is being transferred, is the responsibility for care coordination also being transferred?

Compassion and coordination are not enough

If Dorothy were to experience an unheralded, immediately life-threatening event (and assuming she hasn’t expressed in advance her wishes **not** to be treated), she should receive safe, effective treatment. She should also be afforded dignity, respect and compassion and services should coordinate their activities, but we would expect the teams caring for Dorothy to be primarily ‘task-oriented’.

Assuming she survives, staff should begin to support her recovery. Dorothy should experience compassionate and coordinated care, but the term ‘experience’ is an insufficient descriptor of a person-centred system. ‘Experience’ is variously defined as ‘to encounter/to undergo’ (*v*), or as ‘contact with, and observation of events’ (*n*). The connotation is that the person experiencing a service is a passive recipient and not an active participant. And in order to recover, Dorothy needs to become an active participant, so the system should also afford her *personalised* and *enabling* care, support or treatment.

Principle 3. Being person-centred means offering *personalised care, support or treatment*

Being person-centred means treating Dorothy primarily as a person, not primarily as a bundle of diagnoses or symptoms.

This means paying attention to ‘what matters to Dorothy’ and her family and carers in each of her/their interactions with public services.

‘What matters’ will depend on the context of Dorothy’s interaction with public services and a number of parameters will define that context – Box 1 explores this in more detail. Note for now that other than at the time of very highest dependency such as when Dorothy is unconscious (and in such circumstances, Dorothy’s advocates should be supported to speak on her behalf), Dorothy should always be offered personalised care, support or treatment.

Principle 4. Being person-centred means being *enabling*

Enablement is an ill-defined term but it is generally agreed that it describes the degree to which people feel supported to develop their own unique range of capabilities.⁶

There is clearly overlap with other commonly used (and often poorly defined) terms such as activation, health literacy, involvement and participation.

Public services that offer personalised, coordinated care and support could restrict themselves to providing clinical services alone. The added dimension of enablement means that systems and services should orientate themselves towards supporting patients to recognise and build upon their own strengths and/or to recover from setbacks or episodes of ill health so that they can live an independent and fulfilling life.

Box 1: Further thoughts about personalisation or ‘what matters to Dorothy’

Personalisation is about ‘what matters to Dorothy’. But how Dorothy speaks about what matters to her will depend on the context within which she interacts with public services.

If Dorothy sees an orthopaedic surgeon about her knee, she is likely to want to ‘help the doctor out’ by articulating what matters to her in a way that fits with what she believes doctors want to know.⁷ She is more likely to focus on her impairments and less likely to focus on what she **can** do – unless she is invited to do so.

If the surgeon invites her to take part in a shared decision making conversation about an operation, she may be asked about how she would like the operation to support her in achieving her life goals. However, she is more likely to be asked about her preferences in terms of her attitudes to risk and what is known about specified outcomes from the operation from a clinical perspective. So, the way in which Dorothy talks about what matters to her will critically depend on the surgeon’s skills in shared decision making.⁸

On the other hand, if Dorothy works with a support partner in a collaborative care and support planning appointment, she is likely to be asked about her life goals, how she plans to work towards them and what support she needs to help her get there. If she meets a highly skilled support partner, she might be supported to think about SMART goals that are **meaningful** and **adaptive** (rather than **measurable** and **attainable**) because goal setting is not really about attaining goals at all – it is about ‘enjoying the journey’ and learning and adapting along the way.⁹ This is important because what matters to Dorothy may not actually be attainable and it is the system’s job to support her to adapt to changing life circumstances.¹⁰

There are important considerations here:

- The way that Dorothy articulates ‘what matters to me’ depends on the context of her engagement with the health service and is highly dependent on the mindset and skills of the practitioner.
- ‘What matters’ may be straightforward (‘treat me with dignity’) or it may not be attainable (for instance, ‘what matters is walking along the beach for miles and miles like I used to with my husband’). Skilled support over time can help Dorothy adapt, should it be the case that what she wants in her life turns out to be beyond her grasp.

The philosophy of co-production provides the theoretical underpinning for the principle of enablement. Co-production sees patients as assets not burdens and seeks to support them to recognise, engage with and develop their own sense of resourcefulness, and to build on their own unique range of capabilities.¹¹

The relationship between the four principles

These four **generic principles** should provide an operating framework for public services (see Figure 1 on page 7).

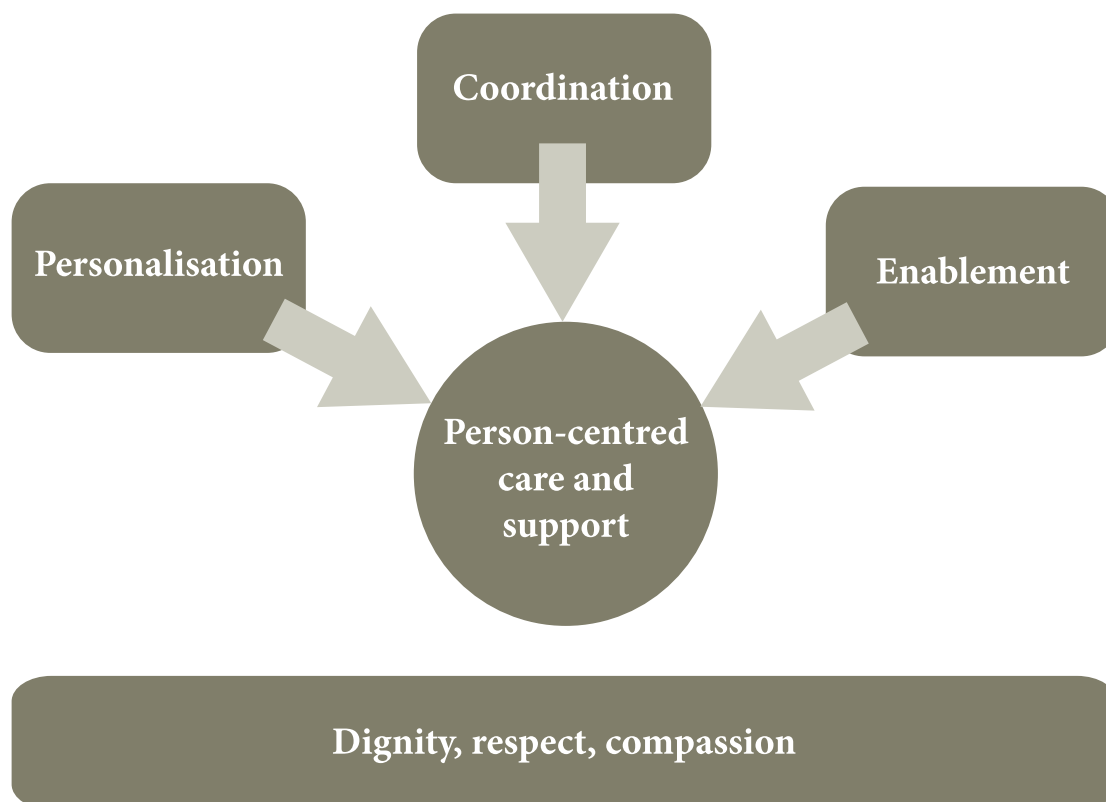
The principles clearly overlap and all the principles won’t necessarily be enacted in every encounter between Dorothy and public services. For instance, as discussed earlier, where Dorothy is highly dependent, she should

be offered dignity, compassion and respect and services should coordinate to provide her with the highest possible standard of care. She should also, insofar as possible, be offered personalised care according to the wishes of her advocates.

At all other times, Dorothy should always be afforded dignity and respect and also personalised, coordinated, enabling care or support.

The principles are the essential ingredients of a person-centred system. They will be mixed together in different proportions according to the context (see section 4 on page 9). The mechanism they are delivered by will be a set of **activities**.

Figure 1: The four principles of person-centred care



3. Implementing the principles

Each of the person-centred principles discussed above can be put in place by carrying out person-centred activities (see Figure 2 on page 8).

Person-centred activities

Collaborative care and support planning, self-management support and shared decision making are activities which can ensure that services reliably deliver the person-centred care and support principles.¹²

- **Self-management support** (SMS) is perhaps more accurately described as a construct – an umbrella term for a range of activities. It encompasses (at least) peer-to-peer support, group education programmes (generic or condition specific, lay-led or professionally led, including mental health recovery programmes), re-ablement and rehabilitation strategies, health coaching and behaviour change or lifestyle counselling. What distinguishes these activities is that they all aim to support people to develop the knowledge, skills and confidence to manage their own health and/or to recover from an episode of ill health. In other words, their **purpose** is

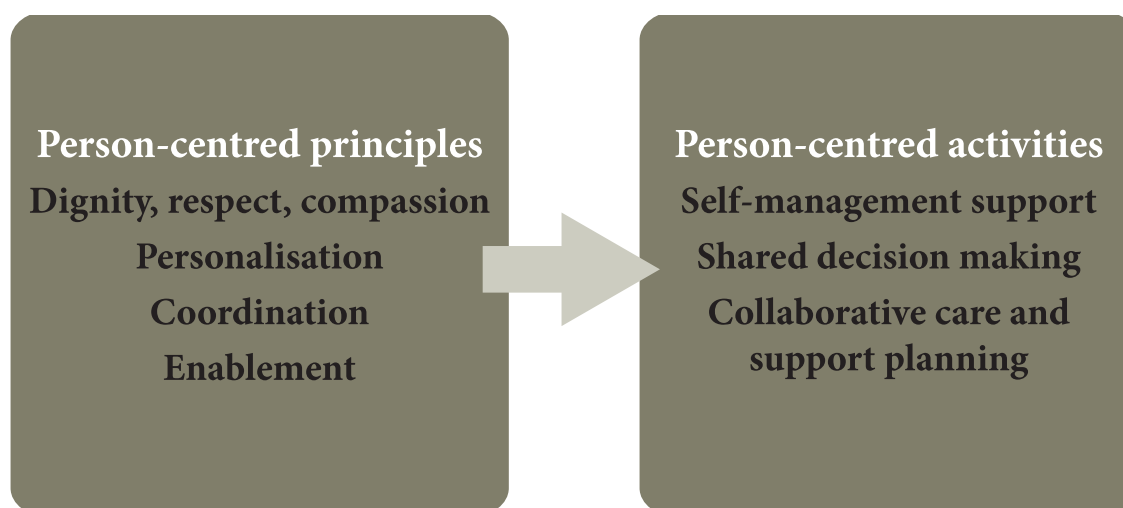
to support people to recognise and to develop their own sense of resourcefulness, to build on their own capabilities and to become everyday problem solvers.

- **Shared decision making** (SDM) has a slightly different purpose. It is an activity that supports patients to make a **specific** decision such as whether or not to take a course of medication, to undertake a mental health recovery programme or to invite others to act on their behalf (for example when undergoing an operation).

SDM is an activity that supports patients to confidently make a single informed decision about their health or health care, whereas SMS is an activity that supports patients to confidently make daily informed decisions and take actions about their health or health care. There is clearly a great overlap between the two disciplines.

- **Collaborative care and support planning** draws on the thinking behind both SDM and SMS in that it helps people become knowledgeable, confident self-managers by supporting them to make informed decisions about the care or support packages they need in order to do so.

Figure 2: The relationship between person-centred principles and activities



The relationship between the principles and the activities is complex and is one of the significant barriers to the reliable implementation of person-centred care. The following is an attempt to codify the person-centred activities according to the emphasis that each places on the person-centred principles.

- **Dignity, respect and compassion:** all of the person-centred care activities afford Dorothy dignity, respect and compassion.
- **Personalisation:** all of the person-centred activities place an emphasis on personalisation ('what matters to Dorothy').
- **Coordination:** only collaborative care and support planning is designed to support care coordination.
- **Enablement:** self-management support is primarily enabling. Collaborative care and support planning is enabling and can also be thought of as a gateway to other enabling services. Shared decision making enables patients to confidently make a specific health-related decision, though SDM is not specifically designed to support patients to take specific health-related actions.

We now have a series of principles and activities that bear a complex relationship to each other. Before we can begin to make sense of all of this there is, unfortunately, another layer of complexity to add.

The relationship between shared decision making and self-management support

One of the other significant barriers to the reliable implementation of person-centred care is the fact that most successful person-centred encounters require health or social care professionals to flex between using SDM and SMS skill sets. Given this, it's worth considering the relationship between SDM and SMS in more detail.

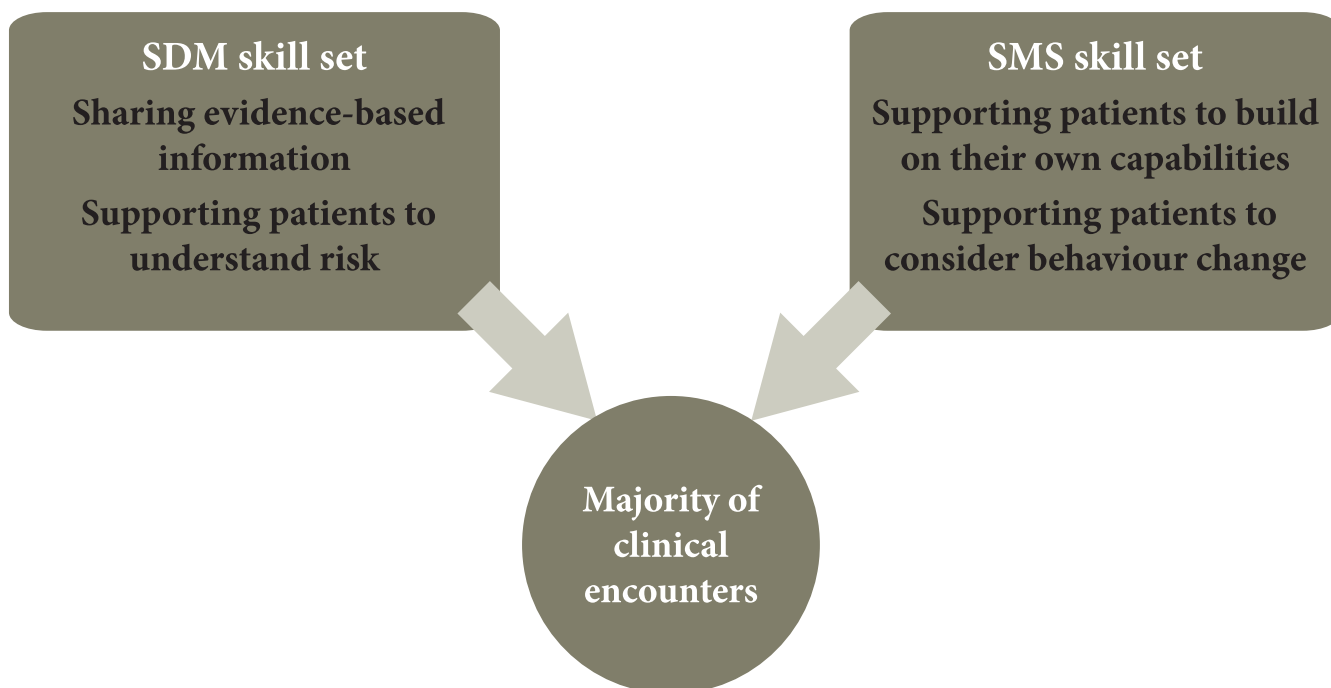
Both SDM and SMS are characterised by:

- health or social care professionals who value the role played by people in making decisions and/or taking actions to manage their health
- health or social care professionals who work in partnership with people and enact the person-centred principles as outlined above.

One distinguishing factor between SDM and SMS is that they each place slightly different emphases on the role of information in supporting people to either make decisions and/or take actions to do with their health.

SDM places an emphasis on supporting patients to understand evidence-based information about treatment probabilities and risk with regard to a specific decision. SMS places an emphasis on supporting people to incorporate evidence-based health information into their everyday lives in order to become knowledgeable, confident, everyday problem solvers.

Figure 3: Shared decision making and self-management support skill sets



Another key aspect of SMS is that it draws heavily on behaviour change theory, so it is an activity (or perhaps, as mentioned previously, a construct) that supports people to adapt to changing life circumstances and/or to take actions to bring about change in their lives.

Figure 3 illustrates the subtle differences between SDM and SMS, while also demonstrating the fact that most clinical encounters mix the skill sets.

We now have a series of principles and activities that overlap, bear a complex relationship to each other and that skilled practitioners use flexibly in clinical encounters. We need to look at those clinical encounters in more detail so that we can ground all of this complexity (and potential confusion) in the real world.

4. Matching person-centred activities to the clinical context

Delivering high quality person-centred care depends on matching the person-centred activities to the appropriate *clinical context*.

Dorothy could experience a number of health events over a year. Each of these health **events** will lead to an **episode** of treatment, care or support. Note that an event = what happens to Dorothy and an episode = an encounter (or a series of encounters) between Dorothy and public services. Broadly, there are four clinical contexts within which Dorothy could interact with public services.

The contexts

Dorothy may well experience a number of health events in the next year. These events will either be unheralded or anticipated and will lead to a number of contexts within which she will receive care, support or treatment from public services.

Unheralded

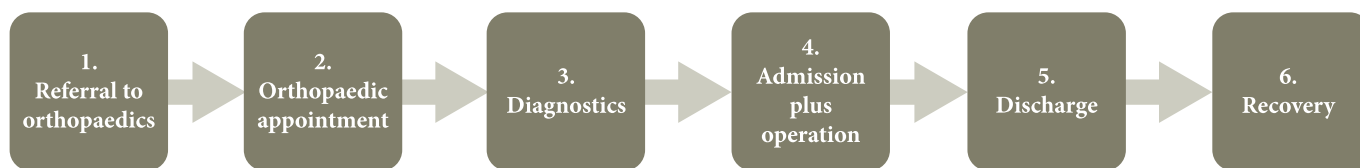
- **Context A:** Life-threatening new symptom/change in symptom/health status (eg Dorothy experiences a heart attack).
- **Context B:** Non life-threatening new symptom/change in symptom/health status (eg Dorothy sprains an ankle).

Anticipated

- **Context C:** Life-threatening change in symptoms/health status (eg Dorothy experiences a severe exacerbation of her COPD).
- **Context D:** Non life-threatening change in symptoms/health status (eg Dorothy experiences a mild exacerbation of her COPD, or worsening pain from her arthritic knee).

Each of these episodes could encompass a single encounter (eg a single attendance at a GP surgery with a sprained ankle) or could encompass entry onto a care pathway (eg a referral to an orthopaedic surgeon to discuss options for managing pain from an arthritic knee).

Figure 4: The system perspective of Dorothy and her knee pain



All of the instances describe ‘episodes of care’ in response to ‘health events.’ Contexts C and D are interesting though, because they describe changes in symptoms or health status that are **anticipated**. And we can support people to anticipate future events by transforming the system so that it becomes proactive, rather than reactive. A proactive system would be enabling – it would support patients to develop the knowledge, skills and confidence to manage their own health. In other words, it would support them to live a valued and meaningful life.

Such a system would also begin to integrate its activities across time – so that individual episodes of care would begin to feel (from the perspectives of Dorothy and her relatives or carers) more like a seamless process.

Collaborative care and support planning

In order to move the system **from** providing episodic, fragmented, reactive care, support or treatment **to** providing ongoing, coordinated, proactive care, support or treatment, we need to put in place collaborative care and support planning.

Collaborative care and support planning is a discrete and specific activity that changes the context of the relationship between Dorothy and public services. It puts in place a proactive system that can support Dorothy to develop the knowledge, skills and confidence to manage her own health and to anticipate future health events – and indeed may delay the onset of such events.

Putting a measurement system in place for the different contexts and activities

Before we can construct a person-centred system and associated measurement system, we need to look at the performance of the system from Dorothy’s perspective.

Let’s look at how the system performs when it comes to helping Dorothy with her knee pain.

Example: Dorothy’s knee pain

Dorothy’s knee is getting worse. She sees her GP who is concerned about her and refers her to an orthopaedic surgeon. The orthopaedic surgeon takes an X-ray that confirms arthritis and she is offered an operation.

She has the operation six weeks later and after a short stay in hospital she returns home to convalesce. At the orthopaedic review, Dorothy is asked to fill in a PROM (patient reported outcome measure), where she found that, compared to a lot of people like her, the outcome from the operation had been good.

Figure 4 shows the steps in the process of treating Dorothy’s knee from the system perspective. Now let’s compare this with Dorothy’s perspective on the process.

Steps 1, 2 and 3: referral to secondary care, orthopaedic appointment and diagnostics

System perspective

These steps were highly efficient. Dorothy was seen by her choice of consultant and listed for an operation within a very short time.

Dorothy’s perspective

Dorothy’s GP gave her some simple painkillers a few months back, but she was worried they might upset her so she didn’t take them. When she went back to see her GP, he assumed her knee pain was getting worse despite painkillers, so he thought it best that she saw a surgeon. The GP didn’t tell Dorothy about treatment options, and he didn’t ask her what her point of view was.

The surgeon was very nice. He ordered an X-ray and told Dorothy that in his expert opinion she needed a new knee. He seemed to know what he was talking about, but Dorothy couldn’t get a word in edgewise.

Steps 4 and 5: admission and operation, discharge

System perspective

Dorothy received exemplary treatment. She was admitted very quickly, operated on by one of the best surgeons in the trust and discharged according to the trust protocol. The system worked well.

Dorothy's perspective

It felt like a bit of a whirlwind, but the operation itself seemed to go well. She had quite a lot of pain the first night and was finally given painkillers when the nurses had finished with the other patients.

A physiotherapist came the next day and gave her some sheets of paper telling her what to do after the operation. Dorothy wondered if they were the right exercises for her, but she didn't complain and she started some of the exercises right away. Three days after surgery the pain had settled well, but Dorothy was surprised that she was sent home at seven o'clock at night. She didn't feel terribly confident about managing at home.

Step 6: recovery

System perspective

Dorothy was seen by the consultant a month after her operation. Her knee had healed well and she was walking relatively pain-free. She was discharged.

Dorothy's perspective

Dorothy recovered at home and although it was a struggle for a few weeks, she managed – somehow. A few weeks after her operation it seemed worthwhile. It was just a lot more of a struggle than she expected.

The perspective problem

What seems to be happening in the example of treating Dorothy's knee is that the system is measuring its activities (processes) in a way that doesn't always take account of what matters to Dorothy – and it is certainly not putting in place the person-centred care principles. In the final analysis, the system thought it was performing well, while Dorothy just put up with a system that (from our perspective) was clearly underperforming and that might well have undertaken an unnecessary operation.

It seems that we are measuring our processes from the wrong perspective and focusing too much on (non-person-centred) processes and outcomes.

5. Outcome-based commissioning and person-centred care

Much has been written about 'outcome-based commissioning' or 'value-based commissioning' where value = outcome/cost.¹³ A number of authorities have written engagingly and persuasively about the concept of outcomes and value, though most authors do not clearly define what constitutes an outcome, nor how an outcome measure differs from a process measure. This lack of definition can create confusion, especially for commissioners who want to commission outcome-oriented services.

The problem is, other than for highly defined conditions, we know very little about person-centred outcome measurement;¹⁴ most of what is known about person-centred care focuses on person-centred processes or activities. This mismatch in understanding has led to most researchers asking:

- **'Does person-centred care lead to improvements in what we currently measure (ie biomedical or system defined outcomes)?'**

This has led to a situation where we tend to **value** (in the case of providers, value = practise; in the case of commissioners, value = pay for) person-centred care only in terms of its impact on pre-defined system outcomes. And although there are many instances where practicing person-centred care does lead to improvements in predefined system outcomes, there are other instances where research has either shown either small improvements or no benefit at all. There are numerous reasons for this, including the following.

- **The correlation between person-centred care activities and the outcome in question is positive but only weakly so.** For instance, implementing high quality self-management support tends to be associated with a reduction in unscheduled admissions, but other processes also need to be put in place in order to reliably reduce admissions.
- **The person-centred care activity is not correlated to the outcome in question at all.** For instance, in the example of treating Dorothy's knee, Dorothy had a good patient reported outcome from her operation in the end, but neither the surgeon nor

the GP implemented shared decision making. If Dorothy had understood all of her options, she might not have chosen surgery ('wrong process/wrong outcome').

In these examples, person-centred processes don't **reliably** deliver on outcomes; in other words there is little or no **coherence** between processes and outcomes. This does not mean that practising person-centred care is wrong. It means that the relationship between person-centred processes and outcomes has not been logically structured.

This has led to the current situation where, by valuing outcomes (as we currently measure them), we often prioritise outcomes over patients in the way we construct services and carry out our processes. This 'outcome first/patient second' mentality appears hard-wired into the way that policy and guidelines are constructed and means that our services are rarely, by definition, person-centred, other than when person-centred measures are used to construct the system, processes in the system and outcomes from the system.

How can we change this state of affairs?

6. Putting people first by putting person-centred measures first

As described above, some person-centred outcome measures have already been introduced into the health system. For example, PROMs are used routinely for patients who undergo hip or knee replacements, varicose vein operations and hernia surgery.¹⁵

This is to be applauded. However, as outlined above, there is often little logical connection between some person-centred processes and PROMs and there is little evidence that teams have used PROMs as a stimulus to improve their person-centred processes.¹⁶ Additionally, some PROMs have been developed without patient involvement – and of course PROMs are predefined outcome measures that might not necessarily take account of what matters to individuals like Dorothy.

So, we don't just need PROMs. We need a coherent person-centred measurement system where person-centred activities (processes) are:

- valued in their own right
- investigated and understood according to their relationships with each other and with person-centred outcomes.

Our system should always demonstrably and measurably put patients first in everything it does. In other words, our system should develop logic models that put person-centred activities (processes) and person-centred outcomes into coherent, theoretically principled sequences.

In order to put our coherent logic model and measurement system together, the question we should really be asking is:

- **What person-centred care processes do we need to put in place in order to reliably bring about improvements in person-centred outcomes?**

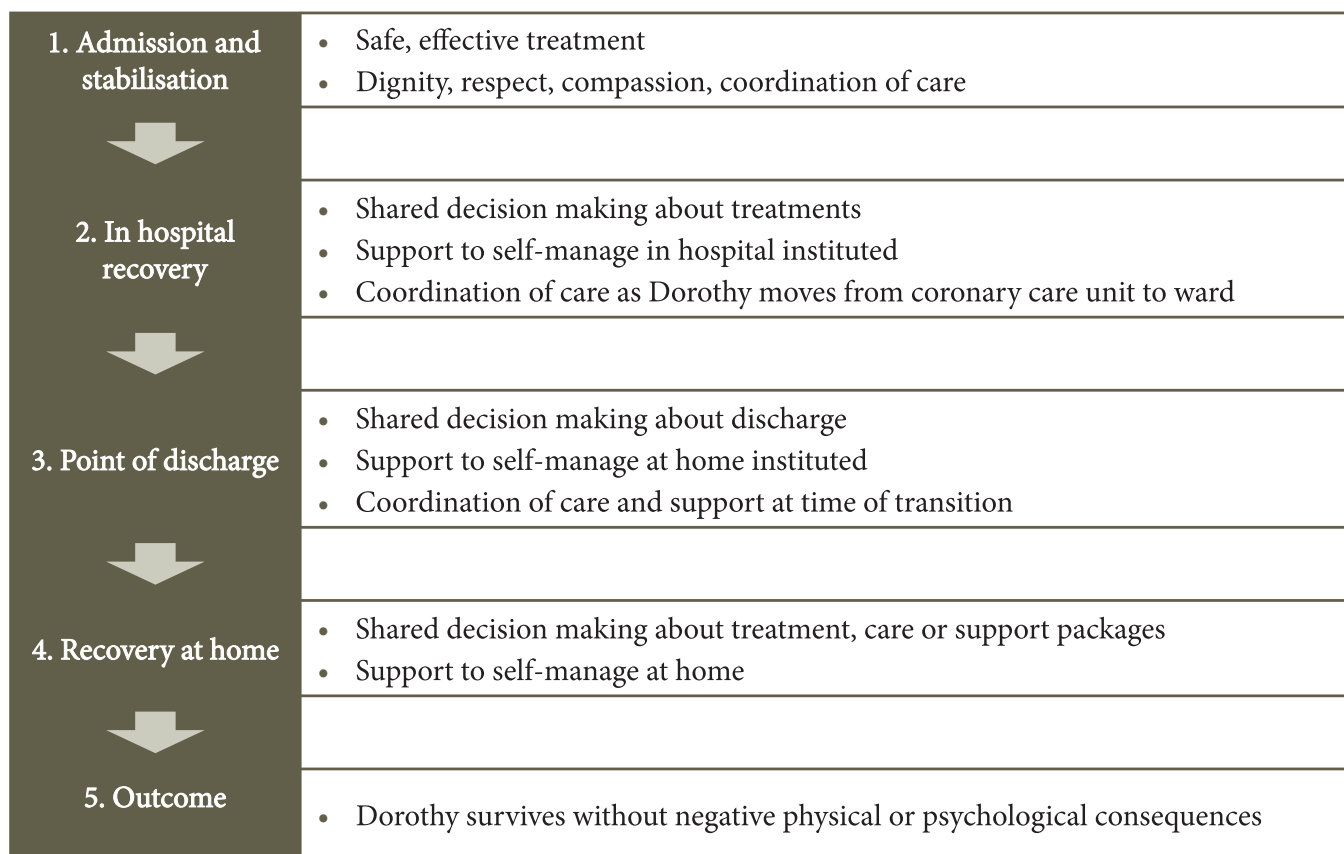
This more logical approach has only been adopted recently in the literature. Some authors have done this by investigating the relationship between patient reported experience measures (PREMs) and PROMs,¹⁷ while others have described a similar philosophy and used the term a 'personal outcomes approach'.¹⁸ In the US, others are beginning to investigate a similar way of thinking about combining person-centred process and outcome measurement and referring to it as a 'patient-centred outcome measurement' (PCOM) approach.¹⁹

Only when we develop a coherent, context-specific and logically coherent series of what could be described as person-centred process measures (PCPMs) and person-centred outcome measures (PCOMs) will we be able to describe public services as being truly person-centred. We are clearly a little way from this ideal at present, so let's look at how we might go about constructing such a system.

7. Person-centred process and outcome measures – PCPMs and PCOMs

In order to construct our person-centred system and our person-centred measurement system, we need to develop a logic model that always puts Dorothy first. Let's look at how to do this.

Figure 5: Person-centred logic model if Dorothy were to experience a heart attack



Dorothy experiences an unheralded, life-threatening event (a heart attack)

Figure 5 shows the person-centred logic model if Dorothy were to experience a heart attack.

A single indicator currently in use (eg ‘to what degree were you involved in decisions about your care?’) could be employed to understand whether Dorothy received person-centred care throughout this episode. The problem is that this indicator doesn’t reflect the diversity of person-centred activities that the logic model implies.

At the other extreme, the system could overwhelm Dorothy by using measures of shared decision making or self-management support at all relevant steps in the logic model.

A more sensible middle way might be for the system to:

- develop the context specific person-centred logic model
- ensure all staff understand the logic model
- employ practically useful indicators wherever possible (see below)

- employ readily available measures at specific points in the logic model, but only use them to stimulate rapid cycle improvement and not as a routine.

The indicators used at each step don’t need to be complex; what’s important is that they are *practically useful*. To take Step 3, point of discharge, as an example:

Dorothy at the point of discharge

- Dorothy is almost ready to go home
- A nurse asks, ‘Dorothy, on a scale of 1–10, how confident are you to go home?’
- Dorothy scores 5 and when the nurse asked her what the hospital could do to raise that number to 6 or 7, Dorothy told her that she felt she needed a walking stick
- Person-centred outcome: Dorothy is only discharged when she is confident to be discharged.

Dorothy undertakes a series of scheduled collaborative care and support planning encounters

PROMs are of use when applied to specific interventions for specific conditions – therefore many PROMs have been investigated to help us understand the outcomes from surgical procedures.

However, when it comes to the value of a review by a diabetologist of Dorothy’s management of her diabetes, how do we measure the impact of a single consultation? And how do we measure the impact of an integrated system that works to support Dorothy to manage her health across multiple episodes and over time?

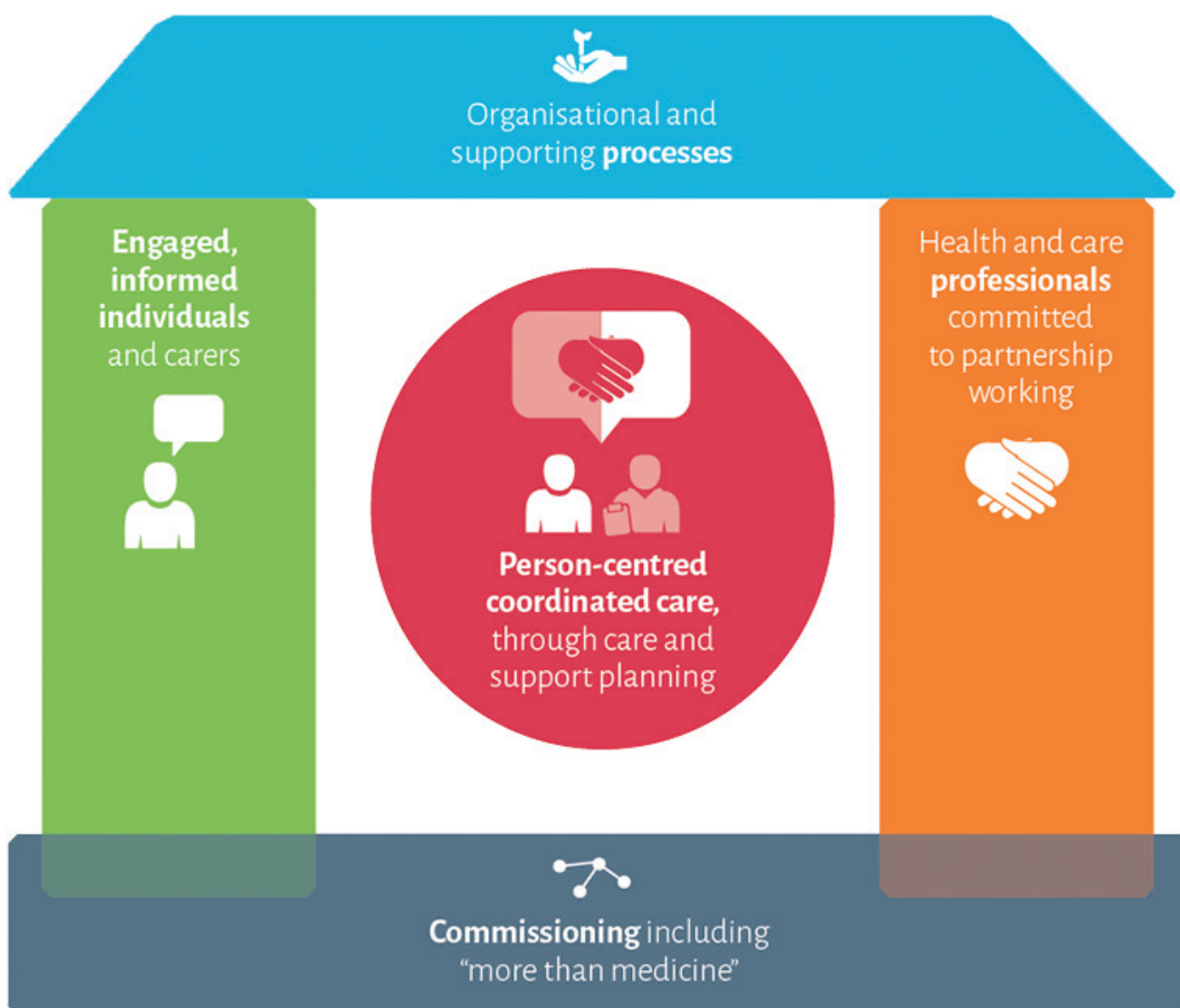
These questions are really asking, ‘when it comes to working with people who live with long-term conditions, what are public services setting themselves

up to achieve?’ Clearly, the system will have an overarching purpose over time and it will have a specific purpose for each episode of care. The measurement system will need to reflect this.

Before developing the logic model for this system, we need to think more about collaborative care and support planning. It is a process that helps Dorothy to clarify her goals and to identify treatment, care or support packages to help her to move towards her goals. It is a process that also ensures coordination of the activities of an integrated system around Dorothy and that shifts the system into anticipatory mode, such that it is more likely to be working in contexts C and D than in contexts A and B.

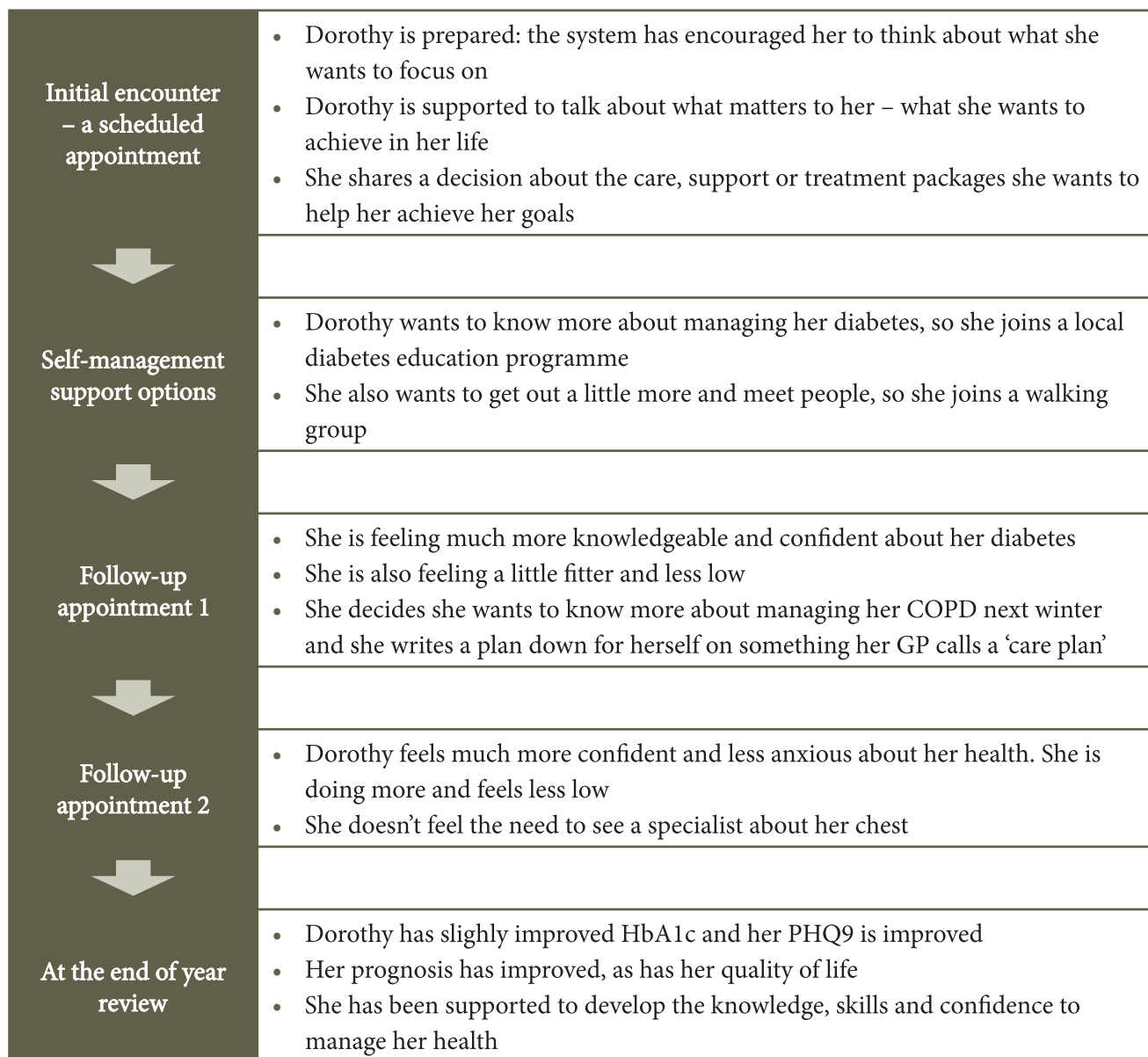
High quality, reliable collaborative care and support planning can be put in place by building ‘the House of Care’ (Figure 6).²⁰

Figure 6: The House of Care



Source: The coalition for collaborative care: <http://coalitionforcollaborativecare.org.uk/house-of-care>

Figure 7: A logic model to support high quality collaborative care and support



Health economies committed to building the House will want to develop a logic model and measure a number of processes that help them understand whether they are indeed building a high quality system.

Figure 7 shows what a logic model supporting such an approach would look like.

This model emphasises that a biomedical outcome is from Dorothy’s perspective actually a process measure. She has chosen to manage her HbA1c because she feels more confident of living a fruitful and longer life as a result – this is the outcome that she wants.

Through collaborative care and support planning, Dorothy will also have been supported to develop a plan to manage her COPD should it worsen. Two of the other contexts within which she might interact with public services will have been anticipated as a result.

This paper is not going to develop logic models for those contexts, as we hope that the two models above can serve as exemplars of how to go about developing a coherent measurement system across all of the contexts where Dorothy might interact with public services.

8. Conclusion

Measures don't just tell us about the performance of a system – they can drive the performance of the system. The right measure in the right place can be transformative; the wrong measure in the wrong place can be equally transformative. If we want to put patients first, we need to put person-centred measures first, but we need to get the right measures in the right place by thinking about context and about coherence. In other words, we need to be rigorous and methodical in our approach.

This paper has rigorously separated processes (activities) from outcomes to encourage policy makers, commissioners and providers to be equally rigorous when developing their person-centred systems and associated measurement systems.

The paper has also argued that commissioners who want to encourage providers to develop person-centred systems should be commissioning for high quality person-centred processes as well as high quality person-centred outcomes. Given this, there is an argument for us to redefine value as being not outcomes/cost, but quality/cost.

However, the core argument in this paper is that public services are not person-centred. Only when person-centred logic models are used to help patients, clinicians, managers and commissioners co-design services **together** will we actually begin to understand what person-centred services can and should look like.

Once we have designed those services, we can put in place person-centred activities and then continually improve by using person-centred process and outcome measures that are **coherent**, ie person-centred process measures (PCPMs) **drive** person-centred outcome measures (PCOMs). In other words, changes in PCOMs will be seen to be directly attributable to changes in PCPMs. We will also begin to understand the relationship between PCOMs and other measures such as biomedical indicators.

This development of such a coherent measurement system that starts with what patients want remains a little way away. Before we get there, we hope that this paper has stimulated you to think about how to construct such a system. If you haven't already done so, we recommend that you now read the Health Foundation evidence review *Helping measure person-centred care*³ for details of specific measurement tools that could be used to populate a person-centred, logically constructed measurement system for use in your own health and social care economy.

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