NHS
England

Person-centred outcomes
Understanding what really matters

Person-centred Outcomes: understanding what really matters

A summary of learning

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Contents

1 Foreword

This is a very exciting and timely project and I am privileged to be associated with it. This report has implications for how all of us think and feel about health and social care – its potential to help transform our care and wider public services.

What we are talking about here is essentially what really matters to patients and service users – putting them, their families and carers at the centre of decision-making, and understanding the goals and outcomes are most important to them. This enables a person (all of us) to receive the treatment and support that helps to meet personal goals and aspirations.

The importance of person-centredness has featured in health and social care policy documents for almost two decades. Since 2000 a raft of White Papers and commitments have sought to rebalance professional and public leadership in health and social care, and to make care more responsive to the patient and service user.

Not only is this the 'direction of travel' repeatedly exhorted by national policy, and reinforced by the NHS Constitution and values; but it is also supported by the concepts of ethics, addressing health inequalities, equity, fairness, balance, power-sharing between the service and the patient/user, treating 'the whole person', co-production and co-design.

Moreover we believe that it will help deliver more sustainable health and care services and a more efficient system overall. For example, through links to overall wellbeing and the preventative agenda, it is likely to be more cost-effective if solutions 'engage with the experiential wisdom' of the people who use services (Slay and Penny).

Since 2010 the NHS has had an outcomes framework in place, yet commissioners have continued to commission and pay for services along traditional lines based on activities, processes and targets. Where commissioning is carried out against service specifications, the measures appear dominantly clinically-based with some measures of patient experience. This report challenges commissioners and providers to think more about how they should personalise the outcomes that they measure and 'change the conversation'.

As this stage of the programme the focus must be on how best to sustain this crucial work and enable the patient and user voice to continue to challenge the health and care system to focus on what matters to all of us – our broader quality of life?

Linn Phipps
Person-centred mentor
February 2016

2 Executive Summary

This work examines the concept of Patient Centred Outcome Measures (PCOMs) from a number of perspectives. It considers the recent work of the Pathfinder sites commissioned by the Patients and Information Directorate of NHS England to investigate approaches to PCOMs for Children and Young People. In addition, as well as an Evidence Scan, extensive stakeholder engagement was undertaken to gather viewpoints from various groups and organisations.

This approach has enabled the collation of a widespread knowledge base, both implicit and explicit, and identifies a direction for future work in this area.

The first outcome of the work was to change the focus from Patient Centred Outcome Measures to look at *Person-centred Outcomes: understanding what really matters*. This may seem like semantics but is actually critical in defining future progress.

The current direction of Healthcare is laid out in the Triple Aim of the Five Year Forward View (5YFV). It is clear in that unless we support people to stay healthy and well in addition to supporting those who become ill to recover then the ever increasing demand on the NHS is not sustainable. Hence the change in focus from 'Patient' to 'Person'.

Having iterated this critical shift in focus, the second shift becomes almost self-evident. We need to determine 'what matters?' rather than 'what's the matter?' Unless we understand 'what matters' then it is too early to start applying measures. Hence the consistent feedback from the stakeholders is that current person-centred measures appear to be primarily driven from a clinical model rather than a 'person-centred' model.

With this shift to the person or individual and the many different perspectives this engenders it becomes clear that there is no 'silver bullet' or best measure that covers all aspects of person-centred care. What matters to the individual and the public at large is not always what matters to professionals. People themselves can play a critical role in their own health and care. To unlock this potential, formal services and the wider community sector need to interact in ways that tap into the 'renewable energy' of individuals, social networks and communities. This has potential to improve individuals' health and wellbeing, thereby reducing demand on health and care services and lead to a range of wider social outcomes. This in turn will support the efficiency drive identified in the 5YFV.In some ways this programme was set-up to explore a panacea solution – meeting personal outcomes from the perspective of the patient, carer, service user and understanding these as person-centred outcomes from a population perspective to inform commissioning intentions and service redesign. It is generally agreed that until there is a clear and shared sense of what outcomes should be measured, any attempt to design, develop or re-purpose measures would be premature. It is clear from the work of the Pathfinders that proposed models of Person Centred Outcome Measures have their place along with other measures such as PREMS and PROMs and that the different approaches all have both benefits and shortfalls. The fundamental requirement is that there is a consultation between individuals and their professionals that gets to the root of 'what

matters to me'. However, aggregating this information to a population level in order to inform commissioning is fraught with challenges.

Summary messages

- Designing interventions, treatment, approaches and goals to best meet PCOMs is about collaboration between the individual and their professionals.
- Data from rating or measurement of qualitative PCOMs is useful for service level improvement, but the subjective, even unique, nature of PCOMs mean that aggregation to support commissioning is not straight forward.
- Person-Centred Outcomes are seen to be fundamentally different to PROMs and different, but possibly linked to PREMs.
- At the more relational level there is particular value in person-centred outcomes retaining individual perspectives, while, for service level influence and commissioning decisions metrics are needed that can be meaningfully aggregated.

Drilling down through all the previous work of the stakeholders and the many content rich discussions that have taken place this report concludes that the development of a framework to guide the conversation between professionals and individuals is the most important step forward that can be taken. The proposed framework includes a core set of five themes that have sufficient commonality to cover the key components of quality of life and well-being and could be used to provide a consistent frame of reference to inform service design and delivery.

THEME 1: Improving health – feeling as well as possible (physical and emotional as sub domains)

THEME 2: Supporting relationships – family, friends, community

THEME 3: Enabling participation – everyday tasks, activities, leisure, learning and work (including. volunteering)

THEME 4: Enhancing security – safety, housing, finance, benefits

THEME 5: Facilitating independence, choice and control (including risk taking and information and advice)

Such a framework has the potential to guide the conversation with people about what support can be provided by the healthcare system as well as helping identify what alternative services may offer. In itself, such a shift in focus from a purely clinical perspective to one that provides signposting or navigation to other services may reduce pressure on both primary and secondary healthcare and enable people to

engage more support from the wider care system, along with assets across their local community.

The extensive stakeholder engagement that has been carried out identifies that there is a great deal of interest in such a shift in service provision and that many influential organisations are working to achieve this. We suggest this momentum is capitalised on and opportunities for engagement are harnessed in future workstreams across NHS England to support the Health and Wellbeing agenda of the 5YFV and to truly 'change the conversation'.

3   Understanding what really matters to people

'Personalised care will only happen when statutory services recognise that patients' own life goals are what really count'.

National Voices – Five Year Forward View (5YFV)

PCOMs were first documented in the Patient Participation Guide 2013 as part of three initiatives to help improve patients' engagement systemically and effectively in national and local commissioning. NHS England subsequently committed to developing PCOMs for people with 20 different rare and complex conditions in the response to the Mandate refresh 2013.

The NHS England 2014-16 business plan 'Putting Patients First', makes a commitment to focus on the needs of people in every decision by making it possible for patients to easily and regularly tell us how they feel about their treatment, and demonstrate how we are using this feedback to make improvements.

In December 2014 an invitation to tender was issued by NHS England for a project about PCOMs. Described as, 'a relatively new concept which involves putting patients at the heart of the development of measures rather than what has traditionally happened with clinicians agreeing on what are the most important outcomes for patients and then consulting with patients'.

Seven sites (increased to eight) were selected from 48 applications and each developed a project in line with their individual perspective of what they understood a PCOM to be. The projects have been interesting and exciting initiatives that have been useful in allowing some experimentation around the concept of PCOMs, which is still a turn of phrase very much in its infancy.

The Director of Insight at NHS England announced PCOMs as 'an opportunity break new ground …. which puts patients truly at the centre and gives them a voice.

'Patient Centred Outcome Measures (PCOMs) is a concept aimed at putting patients, their families and carers, at the heart of deciding which goals are most valuable for individuals, i.e. letting patients choose the outcomes that are important to them'.

NHS England

3.1   Background

In May 2015, NHSIQ (now the Sustainable Improvement team – S.I team) were approached by NHS England's Patients and Information Directorate to explore options for a piece of work around Patient Centred Outcome Measures (PCOMs), with the aspiration of creating a new national model for measurement that was truly

patient-centred.

Additionally, the S.I team were asked to provide support to a cohort of eight PCOM Pathfinder sites that had been directly commissioned by NHS England in December 2015. The Pathfinders' commission was to develop better understanding of PCOMs for Children and Young People. The S.I team was to share the learning and undertake a formal learning exercise to maximise the spread of learning and benefits of the work.

3.2 Purpose

This work is about achieving the optimum outcomes for individuals and the population at large for the best value across the system. This remit was developed further following reflection and consultation between the S.I team, NHS England and other key stakeholders.

It was not the intention of this work to focus on person-centred care of and for itself, but to consider whether individual person-centred outcomes can be generalised to provide population level data to inform strategy, infra-structure and commissioning. The original premise for this work was that person-centred outcomes have a value at the four levels described below. For the:

- Individual – enabling a person to receive support to meet their personalised goals and ambitions;
- Service provider – enabling the service (where appropriate) to be stylised for and or designed around the individual and their preferences;
- Commissioner – to understand how to stimulate and support services to meet personal goals and the needs of local communities;
- Wider system – to appreciate and understand the inter-dependencies of health and care, housing, education, employment and other factors that contribute to quality of life outcomes.

The findings from the work provide evidence that, whilst this premise appears logical and straight forward, the reality of aligning personal outcomes at a population or commissioning level is more complex in practice.

4 Methodology

4.1 Developing relationships with key stakeholders

The concept of Person Centred Outcomes is not new. The S.I team engaged extensively with a wide range of stakeholders to capture the learning to date, share ideas and thinking and tackle the complexities of person-centred outcomes and measurement in a joined-up and co-designed manner.

4.2 Learning exchange

The S.I team organised a Learning Exchange to bring together the eight Pathfinder sites, and other stakeholders to share their project findings and learning from their work. This format enabled an exchange of ideas, ways of working and opportunities for joined up thinking.

4.3 Learning exercise

In order to more fully capture and summarise the general learning, generic themes and messages that cut across the experience of the different sites as they worked on their individual projects a Pathfinder Learning exercise report is also available (see Appendix 1. The report looks beyond the individual project-based challenges and considers the learning more relevant to the development and implementation of PCOMs more generally.

4.4 Evidence scan

The Evidence Scan focused on:
1. A single key research question agreed with the NHS England commissioners, *'What examples can be found to demonstrate where person-centred information is used in a structured way to influence population-level commissioning decisions with the intention of improving population health and wellbeing?'*
2. An exploration of the wider context of approaches to and models for person-centred outcomes and measurement. (see Appendix 2)

4.5 Summit

The Health Foundation, with input from S.I team, convened a two-day event with a diverse group of stakeholders to explore, debate and examine the challenging subject of measuring personal outcomes. This approach ensured discussions were aligned with work that was going on nationally and that person-centred outcomes are central to thinking within the NHS and beyond.

This provided a snapshot of current thinking and focused on four key areas of discussion.

- What is different about measuring personal outcomes?
- How does measuring personal outcomes benefit individuals?
- What are the opportunities and challenges for the wider system of measuring personal outcomes?
- What are the roles of leadership, culture and organisational change in measuring personal outcomes?
(see Appendix 3)

4.6 Additional perspectives

Forty-five additional pieces of evidence – including papers, documents, briefings, tweet chats and meeting summaries from a range of sources were reviewed. Learning pertinent to the wider conversations and useful for informing this report have been distilled down and summarised into key messages. (see Appendix 4)

5   Summary of findings

This programme examined a number range of aspects around PCOMs and builds on considerations that were being looked at by a number of organisations and stakeholder groups. While the findings are presented below for each major activity, they are all inter-related. Therefore, the quotes – the majority of which come from the Summit event – show how connected all these themes are and provide corroboration across the different aspects of work.

5.1   Defining the scope of work

> *'It may well be five or 10 years before it is possible to proceed with significantly greater confidence than today.'*
>
> *The NHS Confederation*

Two key considerations emerged during the early deliberations. Firstly that the word Person should be used as a more appropriate term in place of Patient, reflecting a broader perspective than just healthcare, and also including carers, people not yet in the system and those for whom the notion of being a patient is not appropriate. The second consideration was that the focus should not immediately be concerned with Measures, but moreover begin to understand the key question ……. What are the outcomes we are really seeking to measure?

It was agreed the work would not lead to the development of a new "silver bullet" measure but should examine the opportunity to influence the way health care and other system-level services are aligned, commissioned and delivered. Any attempt to design, develop or re-purpose measures would be premature.

> *'Commissioning for outcomes takes both commissioners and providers out of their historic comfort zones with multiple meaningless performance indicators being replaced by a much small number of clinical and patient centred outcome measures. My advice is that this has to be seen as a long-term project, with early engagement of everyone concerned and a practical focus on agreeing how best to phase the process. Bite sized pieces that all parties can swallow are critical'.*
>
> *Dr Stephen Richards*

Consequently the evolution in programme title:

Person-Centred Outcomes: understanding what really matters

The phrase 'person-centred' is offered in place of 'patient-centred' for the purpose of this work to acknowledge the lifestyle and well-being of the whole person rather than simply their health and care related circumstance. It is broadly accepted that health and care is one of several contributory factors that support the delivery of person-centred outcomes. This also aligns within the thinking of the 5YFV, which talks about prevention and pre-emptive lifestyle choices. This reflects the work of Lindstrom and Eriksson (2011) who use the analogy of the 'river of life' as a potential vision for

personalized health systems. Downstream, healthcare systems offer disease management, which can be likened to trying to save people from drowning in the river. Upstream, healthcare is more closely aligned with people's values of health and wellness to achieve quality of life, and is designed to prevent or mitigate risk of disease which compromises health and wellness. In this vision, healthcare systems offer a balanced portfolio of services to populations, both supporting people so that they can experience a good life when they are well and healthy and providing support when disease or illness occurs so that individuals can be rehabilitated and returned, where possible, to good health.

At present, work around person/patient centred care and other interventions tends to focus on the downstream aspects. The vision for this work includes keeping individuals well which is critical to achieving the aims of the 5YFV in ensuring the future sustainability of the NHS by reducing demand on services.

5.2 Findings from the Learning Exchange

Six key themes emerged as priority areas:
- How do we ensure outcome measures are robust/academically verified?
- What does a PCOM look like?
- Use of Technology
- How do we get clinicians to buy into this work?
- How could PCOMs be used by commissioners?
- What is the relationship between PCOM, PROM[1], PREM[2], PDOM[3], PGOM[4]?

5.3 Findings from the Learning Exercise

Some of the early messages from the Pathfinders included:
- There are common themes for desired goals of treatment across a range of specialties.
- Progress towards goals can be measured.
- Changing culture and practice is the challenge.
- PCOMS can enhance the holistic care of families and children and empower them to have increased participation in their treatment.
- The focus on physical rather than psychological aspects of health and wellbeing was viewed as counterproductive to recovery.
- Peer relationships enable social functioning, which was reported to be a neglected aspect of inpatient care due to the focus on improvement of physical health.
- Mixed views about the use of technology to review / monitor outcomes.
- To properly embed person-centred outcomes into commissioning is likely to take two to three years.
- PCOMS can help to rebalance and recalibrate commissioner focus on non-medical (more than medicine) support.

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[1] Patient Reported Outcome Measure
[2] Patient Rated Experience Measure
[3] Patient Defined Outcome Measure
[4] Patient Generated Outcome Measure

The key perspective shared by all the Pathfinder sites is that PCOMs are about people defining what matters to them, allowing individual voices to be heard more freely and fully and to support assessment and evaluation of services from a user-based perspective.

'More than being included in decisions in my care, I want to be involved in planning my care and deciding what the outcomes I want are. I want to be seen as more than just a condition or test result. I want to actually be seen as a person who has dreams and hopes and aspirations'. (Summit)

The personalised approach retains rich qualitative data, which can guide personal encounters with health and care professionals and support service improvement. There are, however, significant practical and methodological challenges in aggregating progress towards individually defined goals.

'Measurement is the first step that leads to control and eventually to improvement. If you can't measure something, you can't understand it. If you can't understand it, you can't control it. If you can't control it, you can't improve it.'

James Harrington

Another mutually agreed consideration about how PCOMs differ from a Patient Reported Outcome Measure (PROM) is that for the latter the respondent is invited to respond but has no opportunity to define the area of response. PROMs are valued for their ability to help a clinician assess their progress against a specific goal, but the crucial point is that PROMs measures outcome areas selected by the clinician, not by the client. They also noted that the symptom-based nature of PROMs means that while they can measure identified problem areas they are limited in their ability to provide insight into the broader issues of an individual's life or goals.

'For me, the individual's outcome is the first priority. We haven't really sorted out how to aggregate that up for populations. But showing clinical outcomes, PROMs and PCOMs can give us some very rich data'. (Summit)

Pathfinders described the need to better shape the interface between clinician and service user, to overcome the tendency to 'chop people into parts' and to avoid people feeling that they are treated as a 'collection of conditions'. Instead, the aim is to allow clients to feel respected and listened to.

'If we're thinking about the things that people with long-term conditions want – some come from their peer support network, some from the GP, some from the consultant. There are also many non-clinical things, and they need support to

access those: healthy walkers groups, Citizens Advice Bureau, so you need to link into them too'. (Summit)

Pathfinders shared very similar views about the factors that would support implementation of their PCOM. Almost all mentioned the need for the tool to be seen as robust and to be validated, that it should be easy to use, and that there should be high levels of buy-in amongst those for whom it is intended. Alongside all these however, support at higher levels was seen as essential. Organisational support would be needed to maintain use of a new tool, by acknowledging its value, recognising time spent on using the tool, and building its application into normal practice.

'I feel quite strongly that any measurement tool has a measurement function secondarily to its function as a tool for the individual'. (Summit)

At all levels, recognition and support from NHS England was seen as important. Respondents hoped that, having demonstrated initial support for the Pathfinders' PCOMs by funding their early development, NHS England would acknowledge the value of the completed tools and recommend and support their implementation.

Both the Learning Exchange event and the Learning Exercise report recognise that the Pathfinders were and still are at different stages in the development of their PCOMs. All have worked with patients, service users and carers to develop domains or outcome areas, some are already using outcome measures while others have them planned, and all have given consideration to validation and the implications of different approaches to data collection.

The key messages that emerged from the Pathfinders is that PCOMs are first and foremost about the preferences, priorities and aspirations of the individual and should be self-determined – as such they are qualitative.

- Designing interventions, treatment, approaches and goals to best meet PCOMs is about collaboration between the individual and their professionals.
- Data from rating or measurement of qualitative PCOMs is useful for service level improvement, but the subjective, even unique, nature of PCOMs mean that aggregation to support commissioning is not straight forward.
- Person-Centred Outcomes are seen to be fundamentally different to PROMs and different, but possibly linked to PREMs.
- At the more relational level there is particular value in a PCOM retaining individual perspectives, while, for service level influence and commissioning decisions metrics are needed that can be meaningfully aggregated.

5.4 Evidence Scan

- The Evidence Scan: Examines and distinguishes between person-centred outcomes (self-directed) and health reported outcomes (resulting from a specific intervention) and acknowledges there is a valid place for both

  'There is a structure set up to meet the goals set by clinicians to put precedence on the biomedical goals and we don't have the chance to explore the personal goals of individuals. We've socialized patients into learned helplessness and clinical staff to set their own agenda'. (Summit)

- Discusses the use of both qualitative and quantitative data and intelligence and considers some of the opportunities and challenges around designing, developing and implementing approaches to Person Centred Outcomes Measures.

  'You shouldn't use purely statistical data for planning and commissioning. You could make very bad decisions. There has to be qualitative data too' (Summit)

- Raises some of the complexities of person centred outcomes and associated measurement, interpreting, understanding and issues of comparability in using this type of information at a population level.

  'Outcomes are emergent and can be shaped by interaction with others. So every healthcare interaction is an opportunity to find out about these outcomes'. (Summit)

- Identifies the need to consider balancing person-centred perspectives
- Explores a number of models that use and consider outcomes frameworks to shape and direct service options, along with characteristics and traits required to enable robust approaches to measurement.
- Acknowledges the difficulty that stems from the variety of contexts in which the term 'patient-centred outcome measures' is used.

  'It is not possible to define what makes a good measure until there is some clarity about what teams are trying to achieve. … Context and purpose need to be considered when designing and implementing measurement strategies.' (De Silva, 2014).

> An overriding message that emerges from the literature is that no single method or measurement can be recommended beyond all others: the value of a measure comes from its appropriateness to the situation, and triangulation of methods is important to strengthen evidence by drawing from different perspectives

5.5 Summit

The video produced to frame the summit discussions identified a number of themes from consultations with patients, carers and their families. These are:

'We want to make conversations about meaning and value explicit not implicit'.

'We also had to look at what you're bringing to this – not us fixing you – it's what matters to you and how will we work alongside what you bring to move you forward'.

Living a normal life

Feeling connected

Being part of the solution

Being recognised

Feeling well (as well as possible)

Long-term independence
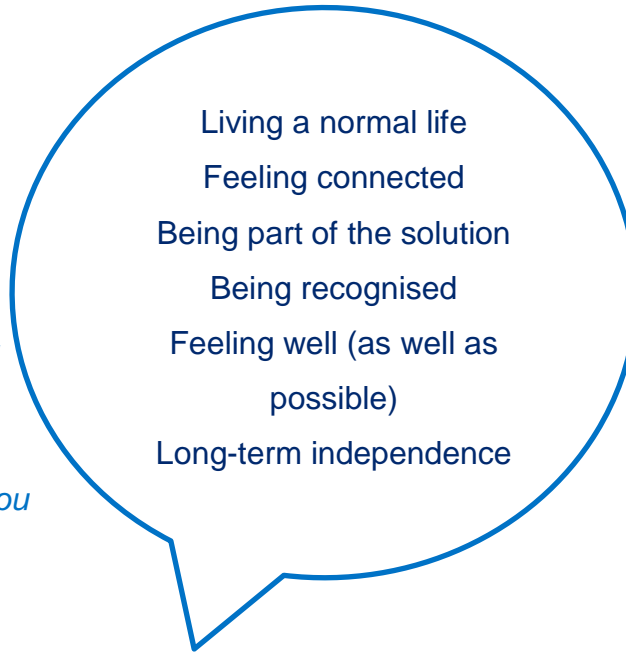
'If we start from the point of 'what's important to the patient?' then it may completely change the decisions that are taken about what interventions they receive and when'.

'If you go back to the 'purpose of support', it is to ensure that people have what they need to be able to live (and die) well on their own terms'.

The video is available at
https://vimeo.com/147586809

The learning from the Summit is captured in a thought piece and:

- Affirms that measuring personal outcomes is fraught with challenges, from identifying personal and population level outcome themes to designing and using appropriate tools to capture data and understanding the contribution an intervention makes to a person's life as a whole.

'If we really want to improve people's outcomes, no one care setting can do this alone. So personal outcomes measures become real measures of the system as a whole and whether it works for patients and service users'. (Summit)

- Emphasises that in the current health system the factors that are most important to people are often not measured at all – and therefore not commissioned – so they are not prioritised by the health system.

'I don't feel that healthcare professionals take my outcomes into mind very much. They often look at the clinical outcomes, the test results in front of them, whereas I would take into account how many days that week I'd been able to get dressed and go out of the house'. (Summit)

Key message 1: More than just health care

Personal outcomes tend to reflect an individual's whole life and focus on **quality of life and wellbeing**, not solely health outcomes. As such healthcare is one of many contributors within the wider system that enable, support and facilitate personal outcomes.

Quality of life, well-being and health outcomes are closely connected and as such it is imperative that healthcare proactively works alongside other public and community services in the interests of individuals and the local population

Key message 2: It's about the individual

Personal outcomes are the **priorities, preferences and aspirations of the individual** at a given point in time and in given circumstances. These will change as an individual's situation changes and the support system needs to be able to respond dynamically.

Key message 3: Require a change in conversation and approach across the system

Personal outcomes are often crucial to the quality of life of an individual, but very often they are not the focal point of an intervention. Enabling a focus on what really matters to the individual requires a **change in conversation**, with a view to co-producing personalised options and solutions.

Key message 4: Let's get on with it

Personal outcomes are individual, by definition, and as such cannot readily be aggregated to understand or measure at a population level. That is not to say it is impossible, but the priority must be to get it right for the individual first and foremost. Let's **prioritise personal outcomes** and work out the next stage as we go.

5.6 Additional perspectives

This highlighted commonalities that could inform follow-up work and the wider arena in which person-centred outcomes are positioned. Underpinning this are messages around mutual dependence and the need for genuine and different thinking, particularly around collaboration throughout the systems to achieve the aspirations for person centred care within the 5YFV and beyond.

- A shift is required from top-down control to collaborative decision-making.

  'We have lost the connection with the people we treat because the plans we make are not perceived by them to be for them.'

- Inherent within this is letting go of the traditional medical model of most health systems that assume responsibility and make decisions on behalf of the patients.

  'People judge the experience in healthcare by the way they are treated as a person, not by the way their disease is treated or by a provider's assessment of their clinical outcome.'

- This is not about the system; it is about individuals - solutions lie within people rather than processes.

  'To create health systems that are truly focused on achieving the goals as articulated by patients, everyone involved in health systems must change their perspective in every facet of healthcare to allow for the creation of innovative, personalized solutions and health experiences where it is not all about the system, but rather "all about me".'

- Person-centred or personal outcomes are not new, complex or a complicated concept. They could be a small set of outcomes that, at a personal level is led by the individual and may comprise a simple rating mechanism.

  'Getting the metrics right is essential. ... We need to focus on a small set of high value outcomes.'

- It is difficult to make generalised statements from a field that is so diverse and means different things to different people

  'Health systems must engage the population actively in determining these

important decisions to achieve benefit, and reduce harm.'

- Greater recognition that health and disease are a complex interaction of multiple social determinants.

'To date, medicine has not achieved the health outcomes that many, less expensive strategies have been able to achieve, such as environmental or social programmes'

- A change is needed to frame and document conversations around what matters to people as individuals, identifying personal health and wellness goals; thus shifting the entire dialogue to focus on the person, not their disease or illness.

'Imposing solutions on the public will be neither welcomed nor sustainable; and what matters to the public is not always what matters to experts'

- There is increasing evidence, and a growing movement around social and community networking offering the potential for alternative approaches to prevention that simultaneously build local capital and potentially create a sustainable positive impact on health.

'People themselves can play a critical role in their own health and care. To unlock this potential, formal services and the wider community sector need to interact in ways that tap into the 'renewable energy' of individuals, social networks and communities. This has demonstrable potential to improve individuals' health and wellbeing, reduce demand on health and care services and lead to a range of wider social outcomes.'

- Wellbeing incorporates all those aspects of life that we need to make us happy, including the physical, material and social. It is not merely the absence of negative aspects of life, such as illness or poverty, but takes account of the presence of all the things one needs to lead a good life, such as strong friendships and self-esteem.

- Measuring wellness can be used to galvanise appropriate activity across the whole system — aligning currently diverse strands including government, commissioners, and providers and reach across the healthcare, social services, and education sectors, into areas such employment, crime prevention, and policing. Connecting PCOMs and wellbeing offers an opportunity to inform all aspects of policy, through national and local platforms.

'Supra-sectoral wellness metrics will become the method of choice to assess performance of local health economies and commissioners as well as to allow local government the opportunity to critically appraise the connectivity of health systems with their populations'

6 Summary of findings

The findings from this programme of work have drawn together a common set of messages and learning around:
- Language, definition and shared understanding
- Focus and choice of outcomes (what really matters)
- Rating achievement, measuring outcomes and aggregation
- Outcomes modelling.

6.1 Language, definition and shared understanding

One of the early findings from this work was around the use of language and terminology and in particular the lack of clarity around definition and interpretation of outcomes. There is a plethora of acronyms and terms used to describe person-centred, outcomes, experience and measures. This can be unhelpful in trying to be consistent. The term PCOM has enthusiasts and dissenters in equal measure.

Whilst there is currently no clear definition of a person-centred outcome, the sense is that it is different to a PREM (Patient Reported Experience Measure) that considers 'how was it for you' and a PROM (Patient Reported Outcome Measure), which focuses on the patients view of a specific intervention, and even a PDOM (Patient Defined Outcome Measure), which seeks to elicit the preferred outcomes from a specific intervention. The language of PCOM has become used as something of a hybrid – for some it is about experience, others personal outcomes and others again it is a descriptor of a tool or resource.

It is clear that the taxonomy and language of outcomes is developing. To this end and for the purpose of providing clarity and consistency, the following definitions are proposed:

Outcomes refer to the impacts or end results of services on a person's life. Outcomes focused services are therefore those that aim to achieve the goals, aspirations or priorities of individual service users. (Glendinning et al 2007)

Clinical (health) outcomes are the anticipated or actual impact on an individual's health resulting from a health or social care intervention.

Personal outcomes are the most important health, wellbeing and life goals an individual aspires to at a given time and in given circumstances. These may or may not be documented as part of a support plan. In any event they should be the focal point of any conversation between a person and their service delivery professionals. They may or may not be one and the same as Clinical (Health) Outcomes.

PCOM (Person-centred outcomes measure) has become used as a generic descriptor for all endeavours to measure the success or otherwise of personal outcomes. It is considered that to provide a formal definition may have an adverse impact and not have the desired effect of providing consistency. At this stage it is considered best it remains a generic turn of phrase.

PCOF (Person or population centred outcomes framework) is proposed as an agreed

suite of outcome domains that enable focused conversations and engagement with and for individuals and communities about health, wellbeing and quality of life priorities. The framework provides an opportunity for public sector commissioners and service providers to design and create local service delivery models and options to meet locally defined preferences and priorities. There will be a clear onus on local populations to be engaged in the co-production of local priorities within a national framework.

6.2. Focus and choice of outcomes (what really matters)

In many ways focus and choice is the crux of the current outcomes agenda – who is responsible for choosing the outcomes and within what boundaries? For some the focus must always be on clinical / health outcomes, whilst for the large majority a broader quality of life and well-being focus is the more appropriate approach. This latter perspective poses some challenges for traditionalists within the NHS, although the fact that health, quality of life and well-being are so inextricably linked makes it an acceptable proposition.

> *'The NHS lacks a genuinely patient-centred approach in which services are designed around individual needs, lifestyles and aspirations. Too often, patients are expected to fit around services, rather than services around patients.'*
>
> *Equity and Excellence: Liberating the NHS*

A focus on personal outcomes must start from the perspective of the individual and their situation and circumstances, with the consideration that improving health and health care are contributory enablers within a broader system to support the person to simply 'get on with their life as best they possibly can'.

> *'Personalised care will only happen when statutory services recognise that patients' own life goals are what count; that services need to support families, carers and communities; that promoting wellbeing and independence need to be the key outcome of care; and that patients, their families and carers are often 'experts by experience'.*
>
> *National Voices*

Taking these considerations together, it might be fair to suggest that person-centred care re-thinks the relationship between people and the services that provide health and care, whereas personal outcomes begin to rethink the wider context of a person's life, within which healthcare will have a role.

> *'It makes sense to privilege well-being as the main goal of commissioning public services because it captures what really matters to people – feeling good and*

being able to flourish in society.' 'A lot of public money is misspent because problems are diagnosed and solutions proposed by professionals who, however intelligent and well-meaning, fail to engage with the experiential wisdom of the people who are intended to benefit from their services.'

Slay and Penny

6.3. Rating achievement, measuring outcomes and aggregation

There are many and varied approaches to understanding, scoring, rating and measuring the views and experiences of patients and carers. Hundreds of measures have been developed to consider patient-centredness, patient experience, patient health-related outcomes, patient satisfaction, patient needs and patient communication. Few, if any, get to the heart of what is truly important to the individual; the 'so what' of a healthcare intervention – the person-centred or personal outcome. Fewer still can be used to scale up the findings to a population level to inform commissioning, strategy development and service and system redesign.

The current range of national measures does not adequately focus on person centred outcomes. Some are focused on experience and many are focused on process and activity. Measures should be designed for a specific purpose and within a given context.

The first challenge for measurement is to know what is to be measured. Until there is clarity around what outcomes are appropriate, suitable and agreed, measurement is technically not possible.

The findings indicate that measuring personally selected outcomes, whilst possible and straight forward from an individual's perspective, is anything but straight forward in the context of aggregating data for meaningful use at a population level. This may be compounded by the complexity of understanding and allocating the contribution towards an outcome from potentially multiple interventions and other factors.

Personal outcomes can be rated by the individual using a Likert scale or outcome star approach or similar – this would only be valid for the individual and the data would not be suitable for aggregation.

Qualitative views may be best used at population-level as an additional data source for triangulation, rather than attempting to convert them into a measure.

'It is not possible to define what makes a good measure until there is some clarity about what teams are trying to achieve. … Context and purpose need to be considered when designing and implementing measurement strategies.'

De Silva, 2014.

Whilst it was envisaged that person-centred data could be used in an aggregated form to provide a population perspective, the current datasets available within the health and care system are not designed for this purpose. This provides for three options:

- Accept that the current datasets are insufficient and use the PCOF to inform rich and personalised conversations to deliver improved personal outcomes.
- Identify and adopt a suite of proxy measures that can provide a perspective for Person-centred outcomes, but recognise that any such proxies were not designed for this purpose and there will therefore be limitations as to the usage and value of such a dataset.
- Once an outcomes framework is defined and agreed, design and develop a new suite of measures.

6.4. Outcomes modelling

It is becoming more common place to hear the phrase what matters to you? rather than just what is the matter, but without a framework for such a discussion it can be quite a challenge both for professionals and patients, service users, carers, people to focus on what really matters.

A focus on personal outcomes is fundamentally about changing the conversation. The S.I team advocate that in order to really make such a conversation personalised and meaningful it is crucial to have a frame of reference to guide that conversation.

The findings from this programme suggest that a suite of domains, themes or simply a framework of outcome areas could be helpful to support the 'change in conversation'. Introducing a model in this way could also allow a population perspective and enable further exploration of measures that could be used at a generalizable level.

Apps et al, 2013 suggest, 'outcomes in health and social care – whether measured as personal outcomes or through pre-defined categories or domains – can be categorised into a relatively small number of reasonably universal or 'archetypal' goals upon which there is a good deal of agreement from service users, as well as practitioners and serviced providers'.

A number of outcomes frameworks have been developed and used in a variety of settings as referred within the evidence scan and summit findings. The S.I team advocate that a framework be agreed as the focal point for all health and care conversations, both at an individual and population level. In so doing services can be co-designed around personal outcomes and in line with a framework of person / population centred outcomes for a community.

7 Conclusion – changing the conversation

The ***Person-centred outcomes: understanding what really matters*** programme of work represented an exciting opportunity to 'dissolve the traditional boundaries' around health and care and to focus on a broader context of personalisation to better understand population-level health and well-being, with the opportunity to truly co-create meaningful service and system level solutions.

In order to begin to properly focus on personal outcomes there needs to be a change in the conversation. The things that matter most to patients, carers and citizens are not always health outcomes.

> *'It's about reframing the conversation from "what is the matter?" to "what matters to you?"'.*
> *Maureen Bisognano from the Institute for Healthcare Improvement*

To enable productive conversations and dialogue it is imperative that there is consistent understanding and application of personal outcomes; the most important health, wellbeing and life goals an individual aspires to at a given time and in given circumstances. Biomedical outcomes should not be the starting point for the conversation.

The extensive stakeholder engagement has enabled the identification of a core set of five themes that have sufficient commonality to cover the key components of quality of life and well-being and could be used to provide a consistent framework to inform service design and delivery.
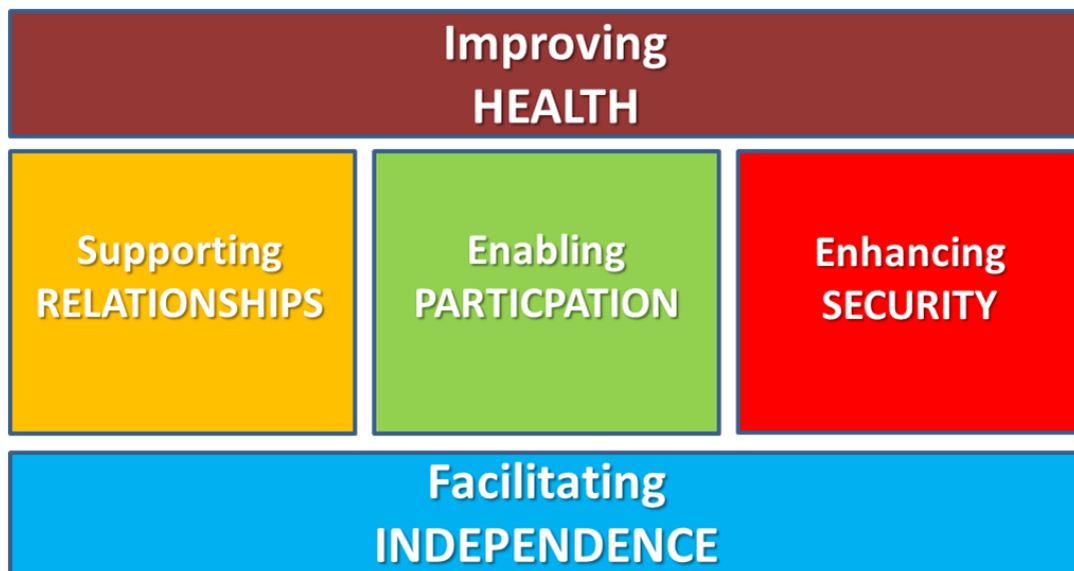
Out of these arose a number of other components, which are highlighted below:

Such an approach provides an opportunity to change the conversation within the whole system, providing a useful guide for commissioners and service providers, whilst truly focusing on what really matters to patients, carers and citizens.

The thinking behind the design of such a framework is:

- Personal / Population-Centred Outcomes are an approach to 'changing the conversation' to focus on what really matters. This is an opportunity for meaningful dialogue about the things that matter most and is fundamentally relational.
- Personal / Population-Centred Outcomes start from the perspective of the health, wellbeing and quality of life goals of the individual / community.
- Personal outcomes are unique and as such cannot simply be aggregated.
- Population-Centred Outcomes are likely to be more generalist and therefore can be more readily aggregated.
- Personal / Population-Centred Outcomes can only be described and defined by / with the respective person / population. (Choice, control, agency)
- Service models and options should be locally co-designed and co-produced to be responsive to Personal / Population-Centred Outcomes.
- For Personal / Population-Centred Outcomes to be satisfied local commissioners and providers must operate in a joined-up / integrated manner across the wider public service system.
- Personal / Population-Centred Outcomes are likely to focus on Quality of Life not just clinical (health) results. Recognising the role healthcare contributes to wider Quality of Life is imperative.
- Personal / Population-Centred Outcomes cannot be delivered with a silo mentality.

In some ways this programme was set-up to explore a panacea solution – meeting personal outcomes from the perspective of the patient, carer, service user and understanding these as person-centred outcomes from a population perspective to inform commissioning intentions and service redesign. In truth the panacea does not currently exist – that is not to say that it could not, but the complexities and competing drivers mean that it is imperative to put in place the right foundations.

'There is no 'silver bullet' or best measure that covers all aspects of person-centred care.'

We consider an outcomes framework as the first crucial step. Such a framework would create a real opportunity to bring the health and care system together, along with other public sector services to focus on designing and delivering services that really matter to people and communities.

Given the focus of the 5YFV and the broad range of work currently underway that links together person-centredness and the development of whole system thinking, the S.I team believe this may be an opportune time to adopt an outcomes framework. To champion such a behavioural change requires a clear system-wide focus, leadership, narrative and engagement. To this end the S.I team recommend that the learning from this work and the passion and energy across the system be used as a catalyst to support this change. This could be achieved by the development of a manifesto for a call to action to develop the necessary 'levers and nudges' to take this agenda forward.

It is clear from the enthusiasm from the many stakeholders involved in this work that there is a real appetite for further action.

'We need a balance between perfect and not used and imperfect but usable. Don't wait till the model is perfect to start rolling out and testing – otherwise it'll never happen!' (Summit)

Appendix 1 – Pathfinders Learning Exercise

Executive summary

Introduction

This report summarises learning about the development of Person Centred Outcome Measures (PCOMs) based on the experience of six sites selected by NHS England as 'Pathfinders'. The role of Pathfinders was to develop PCOMs for children and young people and to report on their findings. Detailed accounts of each Pathfinder's work have been submitted to NHS England; this report cuts across all six projects to reflect on the learning that relates to PCOMs more generally. Nevertheless, each Pathfinder's PCOM has been developed for a specific context and purpose, and differences in the PCOMs reflect the purpose for which they were developed. The material for this report was derived from face to face interviews with Pathfinder representatives from each site.

What is the nature of a Person Centred Outcome Measure (PCOM)?

Although responses to this question initially seemed self-evident, there was less clarity about the more detailed aspects of PCOMs. Pathfinders all believed that PCOMs are about 'people defining what matters to them'. Across the six sites PCOMs were being developed to influence service provision at three levels: individual encounters with a clinician; service level; and commissioning, yet every PCOM built on the concept of the individual's view as central. Two sites also stressed that all aspects of a PCOM's development should involve active engagement of service users. Patient Reported Outcome Measures (PROMs) were seen to differ from PCOMs in that for PROMs, the respondent is unable to influence the area of response. Views differed about whether or not experience of care could be included in a PCOM. There were also no clear views on how, over time, tools developed as a PCOM would be seen as different to a PROM.

Why develop PCOMs: what problems do they address and what do they aim to achieve

While most Pathfinders envisaged their PCOM influencing more than one level in the health system, most identified one specific level as their key focus. For some this was the individual encounter between client and clinician. For these the aim was to support clinicians to allow clients' voices to be heard more freely and fully. Another key aim was to support assessment and evaluation of services from a user-based perspective. For this, it is necessary to truly hear what it is that service users want, and then develop a metric to assess, from the perspective of the service user, how close the service comes to delivering that. The third aim was to influence commissioning, again, from understanding what individuals want, assessing how effective services are in supporting them to achieve that, and developing metrics that commissioners can use to guide service provision and, potentially, funding. Some Pathfinders also envisaged their PCOM providing useful information for research. The purpose of each PCOM influenced its shape and characteristics. Those that focus on the relational interaction between client and clinician focus more heavily on the qualitative individual details, while those that require collated scores focus on collecting data that can be more readily aggregated. The time period over which data is being collected and the condition of the client may also influence the nature of the PCOM.

Developing PCOMs

In keeping with the concept that PCOMs are about people defining what matters to them, each Pathfinder's PCOM operates with outcome areas identified by service users. A key difference is whether each new respondent to the PCOM defines their own priority outcome areas and, within those, their own goal; or whether outcome areas and issues of importance within those areas are pre-defined by representative service users, with new respondents scoring the selected issues against a rating scale. Two Pathfinders are working with PCOMs that allow each individual to define their own priorities and goals, and then score themselves against those self-defined goals. The others, to varying degrees, are building on literature, input and feedback from relevant service users in an iterative way to establish the priority domains or outcome areas that will shape the tool. One PCOM then invites individuals to design their own individual goals within the agreed priority areas; others have or plan to develop questions or issues within the agreed domains to which individuals can respond. The degree of freedom for response influences the ease or otherwise of collating individual scores; it also influences the richness or otherwise of the data from a qualitative perspective. All Pathfinders have considered validation of their tools, though most are not at a stage to have completed this. Data collection is either paper-based or electronic. Electronic data collection has the advantage of avoiding personal bias, and of speedy analysis and access to findings. It is not, however, without its own bias. Concerns about data security may constrain responses.

Implementation

Reflecting on what would be needed to support implementation of the tools they had developed, Pathfinders shared the opinion that while evidence of validity, ease of use and local clinician buy-in were important, organisational support would also be essential to maintain use of a new tool. Some emphasised the ongoing role NHS England could play by recognising the value of the validated PCOMs and supporting their wider roll-out. Pathfinders were strongly aware of the barriers to implementation. An issue for some PCOMs is the invisibility of a preventative approach, making it difficult for busy clinicians to dedicate time to work that will not be seen or acknowledged. Another is the anxiety felt by many clinicians of inviting service users to express their own views or needs, fearing, for a range of reasons, that they will be unable to respond adequately. Finally, there is a challenge for PCOMs that retain a relatively high degree of individual variation and detail when the PCOM is intended to influence higher level decisions. Standardised responses that can be easily aggregated tend to be more readily valued than qualitative data that relies on skilled analysis and that offers insight rather than answers. In response to the question of whether their PCOM could be used in a wider setting, some Pathfinders had designed their tool to be context-specific while others hoped for widespread use, but all could see a way that the approach they had taken could be replicated.

1 Introduction

1.1 Background

In December 2014 NHS England invited organisations working with children to submit bids for grants of up to £50K to support the development of Patient Centred Outcome Measures (PCOMs) for children and young people. The criteria stipulated that 'PCOMs should have patients at the heart of the development of measures - thereby creating measures that are most important to patients with the condition/symptom[4]'. Eight sites were awarded 'Pathfinder' status and asked to work on their individual projects with an initial request to submit final reports by early April 2015, though this deadline was later extended. The short time frame shaped the nature of the projects that were submitted.

Pathfinders have already reported on the details of their individual projects to NHS England. The purpose of this report is to summarise general learning, drawing on generic themes that cut across the experience of the different sites as they worked on their individual PCOMs[5].

Many of the sites shared similar experiences in the conduct of their work, such as the challenge of recruiting adequate numbers of participants and other limitations influenced by the short time frame, but the aim of this report is to look beyond the project-based challenges and to consider the learning that may have relevance to the development and implementation of PCOMs more generally.

To set the scene, of the six sites whose views are reported here, each worked towards developing their own version of a PCOM to support positive changes in the setting in which they work. The nature of each PCOM reflects the context in which it was developed.

Pathfinders began their work at different stages: for some the Pathfinder funding provided the opportunity to begin work on a PCOM, while it enabled others to further develop work they had already begun.

Five of the Pathfinders work in direct contact with the children and young people for whom their PCOM was developed. Two sites worked on PCOMs that aim to improve children's stay in hospital: one is designed for young in-patients (five to ten years of age) at a specific children's hospital; the other focuses on the short stay that children with eating disorders or self-harm injuries spend in an acute general paediatric hospital before moving to the next stage of their care. Three Pathfinders are developing PCOMs that aim to improve individual contact between the client (the children and young people and/or their parent or carer) and the clinician. Of these, one is introducing a goal-based approach for psychological interventions in a specialist children's hospital; one is developing use of an online tool that that allows individuals to identify then monitor outcomes that are meaningful to them; and the other is developing a PCOM for families addressing childhood feeding disorders.

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[4] NHSE (2014) Bid Template: Children and Young People Patient Centred Outcome Measures Pathfinder
[5] Over time the term PCOM has also been interpreted to mean Person (rather than Patient) Centred Outcome Measure.

Finally, the sixth is developing a PCOM for children living with asthma that aims to support commissioners to improve approaches to contracting.

From their work, grounded in experience, the views of each of the Pathfinders throw light on the different ways in which PCOMs can be conceptualised and used. The variety of contexts and perceptions broadens any notion of a single approach. This report draws on the Pathfinders' descriptions of the purposes for which PCOMs were designed, the ways they were developed, how they might be implemented and the challenges to be addressed.

1.2 Methods

Each of the eight sites was contacted and invited to take part in a face to face semi-structured interview with a researcher, loosely based on a list of open ended questions that were sent to the interviewee prior to the interview. Interviews were approximately 90 minutes long and were recorded and transcribed. Interviewees from two of the sites were not available to be interviewed.

The researcher worked with the transcripts to identify common themes then, from each, developed a short report with summaries of the interviewee's comments supported by excerpts from the transcribed interview[6]. Each interviewee was sent their own short report and invited to approve or correct it. The report that follows is drawn from the six approved short reports.

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[6] Where interview excerpts have been edited for comprehension and brevity words added by the researcher are indicated in square brackets.

2 What is the nature of a Person Centred Outcome Measure (PCOM)?

2.1 What is a PCOM?

When inviting sites to submit their bids for Pathfinder status NHS England described PCOMs as 'new outcome measures which are based on the views of patients[7]', but provided no detailed definition of the term, part of the purpose of Pathfinders being to develop the concept further.

Each site had clear views of their own about the nature of a PCOM, though few had framed a specific definition. The purposes for which the PCOMs were developed are discussed in more detail in the following section of this report, but in order to understand the different perceptions of a PCOM it is generally important to understand the context in which they were developed, as views differed with the purpose for which the measures were designed.

Service users are central: they define what matters to them
The primary essential component of a PCOM, for all sites, was that a PCOM is about people defining what matters to them.

> Interview 6: *[PCOMs] are solely generated by patients themselves and reflect their individual concerns rather than those of clinicians.*

> Interview 1: *It's things that people define, things that matter to them …*

As described in the following section, across the six Pathfinders PCOMs were designed to influence three different levels of the health system. They aimed to:
- shape interactions between individual service users and clinicians
- evaluate and improve ways that specific services are delivered
- influence the way that services are commissioned.

At each level service users were seen as central. The Pathfinder that designed a PCOM to influence commissioning still emphasised the need for outcomes to be defined solely by the individual.

> Interview 3: *A Person Centred Outcome Measure, the outcome is defined by the person. Nobody else. And it starts at individual level and is then aggregated up to a whole population level when you're working with it as a commissioning tool.*

Service user-involvement in design of the PCOM
In addition to the shared understanding that service users should identify outcomes for PCOMs, two Pathfinders emphasised the centrality of a person centred approach in the design of the PCOM, stressing that people representative of those who will

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[7] https://www.england.nhs.uk/2015/02/pcoms-cyp/

respond to the tool must be genuinely and actively involved in development of the tool.

> Interview 5: *… obviously involving patients in the development … that those involved in developing it feel absolutely that they're empowered to share their ideas so that [development is] not done as a tick box. It's done in a way that is meaningful for people, that it is accessible, so even when you are developing [the tool] insuring that [there is] a range and representative sample [involved in the development] … saying what is important to them and what they would like to be asked and what it would mean to them.*

> Interview 4: *… it isn't just that the outcome measure needs to be person centred or defined by the population which it's developed for … but actually it's around who reports it and the acceptability of implementation. That needs to be person centred and also around how it's been developed, that needs to be person centred …*

When asked for additional criteria that are essential for a PCOM several respondents mentioned appropriateness for the client and ease of use of the tool for both client and clinician.

> Interview 1: *It has to be simple, sensitive, relevant and meaningful to the users, both patients and professionals, to make it worth their while to change their previous habits and patterns of communication.*

One respondent supplied a list of essential criteria for a PCOM. The list is below.

Interview 3:

- *It's built on high quality evidence, international, national and local*
- *It combines qualitative and quantitative approaches to measure improvement*
- *It benchmarks improvement and tracks changing expectations*
- *Visually engaging; easy to use for young and old; feels like a game*
- *Uses people and family's words*
- *It's flexible to reflect local difference*
- *Commissioners, individuals, families, communities and providers can personalise it without compromising national and local benchmarking*
- *It supports continuous improvement and a sense of 'journeying towards perfection' as it opposed to away from where we are today*
- *It provides learning and reflection at three levels: individual person, operational NHS (or other) front-line team and strategic whole system leadership – both commissioner and provider*
- *It provides actionable real time feedback for clinical teams at ward, clinic and practice level if you want it to*
- *It has a locally designed operating system that fits in with existing model of care and meets the care system where it is in its journey towards person-centred planning.*

2.2 What is the difference between a PCOM and a Patient Reported Outcome Measure (PROM)?

PROMs measure areas identified by the clinician not the client
Respondents were united in their view that the central way in which a PCOM differs from a Patient Reported Outcome Measure (PROM) is that for the latter the respondent is invited to respond but has no opportunity to define the area of response.

> Interview 2*: So a Patient Reported Outcome Measure is something that the patient reports but as a recipient of a questionnaire or measure that may have very little to do with them individually … the only requirement for a Patient Reported Outcome Measure is that they are truly allowed to report an outcome. But … the patient didn't necessarily have the opportunity to contribute to the content of what they are being asked about.*

> Interview 4*: … my interpretation of a PROM … it could be a clinician-driven outcome but is reported by somebody who's accessing the service.*

PROMs are valued for their ability to help a clinician assess their progress against a specific goal, but the crucial point is that PROMs measures outcome areas selected by the clinician, not by the client.

> Interview 6: *…Well I see them as very different things … as a clinician I do want to know, in terms of a specific outcome measure that might pick up on things that map onto a diagnostic profile or something [similar],I want to see if the child has shifted on that, but that might not be the family's priority …*

Respondents pointed out that PROMs are not necessarily developed from the lived experience of people with the relevant condition. They also noted that the symptom-based nature of PROMs means that while they can measure identified problem areas they are limited in their ability to provide insight into the broader issues of an individual's life or goals.

> Interview 2: *What we've been using in the past were published standardised questionnaires which are very good PROMS. But these have been quite symptom-based so [they] assess children's anxiety, their depression, their low mood, their self-confidence and a number of quality of life issues that are impacted by health. They haven't addressed positive aspects of functioning so well and in the main they are devised by clinicians and they have limited forced responses: 'always - sometimes - never' … and may or may not reflect well the desired changes that are central to a patient. So you can administer quite a long and detailed questionnaire and from that you can see whether a child's report of depression is in the clinical range. But that is only one aspect of a child's functioning and may or may not reflect that child's life as a whole. What I was trying to get away from was the imposition of a pre-existing set of clinical descriptors, which are usually pathologising … orienting us to a much more holistic point of view, but also being very overt about what children and families want….*

2.3 What is the difference between a PCOM and a Patient Reported Experience Measure (PREM)?

PREMs can only be retrospective
There was common recognition that Patient Reported Experience Measures (PREMs) differ from PCOMs in that they are retrospective, while PCOMs can be either prospective or retrospective. Experience can, obviously, only be measured after the event.

Differing views on role of experience in PCOMs
Pathfinders held different views about the extent to which experience and outcome overlap.

For one site that believed all aspects of a PCOM's development should be driven by the service user, when it became evident that service users made no distinction between experience and outcomes this was accepted as a valid perspective, which was then built into the design of the PCOM.

> Interview 4:*… experience and outcome are inextricably linked for this patient group and certainly when you're talking about non-physical health conditions … from the literature review as well as the stakeholder engagement that sort of redefined how we … conceptualized a Patient Centered Outcome measure …- it wasn't just an outcome it was about experience and their engagement with care and health professionals.*

The respondent for this site emphasised that if a PCOM was to be person-centred the service users should shape the understanding of an outcome.

> Interview 4: *… if it's truly person-centred then let the children and young people decide … let their voices be heard and let them define, because ultimately they're in receipt of the services that we're delivering and that should be the driver as opposed to us imposing our preconceived ideas or expectations upon them … we don't understand what is it that we need to do to make it better for them. And that's why we were very keen on inductively letting them develop and dictate to us what they perceived to be an outcome, whether that's integrated with experience, then so be it!*

The same respondent acknowledged that the emphasis on experience for this PCOM may have been influenced by its focus: the PCOM addresses the relatively short period when children are in acute general paediatric inpatient care. The measure aims to better shape this short phase in the children and young people's care pathway. But the respondent also pointed out that when considering mental rather than physical health, experience is especially closely bound to future outcomes, and questioned the necessity of strictly separating experience and outcome.

> Interview 4: *…we defined and contained them to a discreet part of their care pathway … we impose this sort of discreetness because that's the bit that we have control over … But I wonder, because this was relating to mental health, where we have outcomes relating to things that were intangible, these are a bit more abstract and therefore they sort of transcend experience. Do we need*

> *to define them into discreet categories or could they relate to both aspects of it?*

By contrast, another respondent acknowledged the importance of experience but believed firmly that measures of experience should not be substituted for outcome measures.

> Interview 3: *… we've done six years of working with qualitative life and service experience data and we know that experience of care is really important and not the final destination or outcome. What matters to most people is how that experience impacts on their life and whether or not it helps them to heal or keep well. Having a great relationship with your GP is brilliant, but how does that change your ability to keep well? It's not just about experience measures, it's about the 'so what?'*

> Interview 3: *People often confuse measuring experience of care and PCOMs, and think that one can be substituted for the other. If people have a good experience of care it may aid recovery. But the outcome is that they recover and are able to go back to work or play with their grandchildren again. Because the health system has …. directed people towards a focus on experience of care in recent years and system leaders see that as being 'person centred', they may find it hard to grasp the difference between experience of care and PCOMs, and believe one can be substituted for the other.*

2.4 Summary and discussion

While apparently agreeing on the basics of what defines a PCOM and how it differs from a PROM and PREM, more in depth exploration uncovered less clarity about the distinctions.

All Pathfinders shared the view that a distinctive feature of PCOMs is that the respondent defines the outcome areas that will be measured. Some also believe that service users representative of those for whom the tool is intended should develop and shape all aspects of the measure.

PROMs were seen to differ from PCOMs in that, for PROMs, the items against which service users respond may be selected purely by clinicians, are often symptom-specific, but most important, they are pre-defined so the respondent does not have the opportunity to select the outcome areas.

PREMs differ from PCOMs in that they are inevitably retrospective, while PCOMs can be prospective or retrospective. Views differed about the role of experience in outcome measures. One Pathfinder expressed strong views that experience of care, while important, should be recognised as a process measure, and as such be kept distinct from outcomes and not included in PCOMs.

The two Pathfinders that were emphatic about involving service users in developing their PCOM both included experience of care in the outcome areas for their measure, because these were topics identified by the service users during the design of the

tool, and one made the additional case that for mental health, experience was particularly important. This respondent acknowledged that if a measure that included experience might not fit the strict definition of a PCOM, because of its person-centred nature it also did not fit the perceived definition of a PROM or a PREM.

> Interview 4: *I think [what we have developed] isn't a PROM. I don't know whether it is a PCOM. But it isn't a PROM and it isn't a PREM. It's a sort of hybrid of the two and so we can call it person-centred because it is centred on the individual; they report it, they've identified what is important to them in relation to their experience and outcome and the quality of their care so that's what it encompasses.*

Another way in which the definition of a PCOM emerged as less clear-cut than it initially appears is in the extent to which a PCOM retains its person-centred quality, when it has become a ready-made tool.

Even Pathfinders who were developing PCOMs for use in individual encounters recognised the potential to thematise responses and develop a tool with pre-identified domains. But at the same time, some recognised the tension between the benefits of this approach, and the risk of losing the personal quality of an individual approach.

> Interview 2: *How do you retain the purity and the richness of the individual goals and not lose that when you try to generalise, but it certainly looks as if within groups of related specialties you could ask relevant questions … You would be unlikely to come up with anything totally unexpected …*

With the emphasis on individuals selecting their own outcomes as a defining feature of PCOMs, once development of a tool has been completed and the questions set, to what extent does this continue to be seen as a PCOM?

Some Pathfinders envisaged that when their tool was finally developed, although it might suggest or identify domain areas, respondents would still define their own goals within the proposed domains. Others, however, were working towards a tool with pre-set questions or outcome areas, which would support aggregation. Pathfinders with whom this was discussed were unclear about how, over time, a PCOM developed in this way would be distinguished from a PROM.

3 Why develop PCOMS – what problems do they address and what do they aim to achieve?

As noted earlier, across the range of Pathfinders PCOMs were developed to address issues at individual, service and commissioning levels. Some sites identified one level as their key focus, but most recognised the potential for their PCOM to have influence at other levels too.

3.1 Address perceived over-medicalisation of the client-clincian encounter: support clinicians to hear the client and their carers' priorities

Allow service users' priorities to be heard

All sites had at the centre of their PCOM the intention of allowing the patient or client's voice to be heard, but for the three Pathfinders that were developing a PCOM for use in the interaction between client and clinician the challenges to be addressed were particularly clear.

Respondents spoke of the need to better shape the interface between clinician and service user, to overcome the tendency to 'chop people into parts' and to avoid people feeling that they are treated as a 'collection of conditions'. Instead, the aim is to allow clients to feel respected and listened to.

> Interview 6: *I'm very conscious, having met with lots and lots of families, that professionals don't always focus their time and attention on what matters most to families … and that can actually exacerbate the problem …because the things that matter to families are not being attended to.*

> Interview 1: *I think we have two issues: one is that people tend to be chopped up into specialties so if you're a person, and you've got a number of things wrong with you, different people will deal with different parts of that illness or that condition… so [the children] have a lot of different people involved, each one of whom has a particular view through which they look at the child, from either the point of view of their seizures, their musculoskeletal control, or their appetite, etc, all those. That makes it hard to deliver holistic care, and the patient or family as a whole gets lost in the process.*

> Interview 1: *And I think on a philosophical sense it is also about bringing in concepts of respect for patients and their carers. What we always say is that parents are experts in their children's care, but it was difficult to harness that expertise, information and experience in a clinical setting*

Support clinicians to move beyond the prism of their own specialty

In their aim to support patient and carers' voices to be heard, these three Pathfinders each worked to develop a PCOM that would support healthcare professionals to temporarily set aside their own perspective. Respondents observed that healthcare professionals tend to define a situation and focus on their view of a problem with a

symptom-based approach, not acknowledging, noticing or asking what the priorities are from the child or family's position. In this way the family's issues risk remaining unaddressed. The tool would support the clinician to hear the family's perspective.

> Interview 6: *So as a clinician it doesn't matter what I'm working with. I might be working with renal failure or whatever, I need to go into that encounter and think okay of course I'm interested in this child's kidneys … but also I need to take account of what's the day-to-day impact on (him/her) in terms of being able to attend school … and social life … and that becomes part of my clinical practice because we know from these person centred ways of doing things that actually that's what matters*

> Interview 1: *… one of the quotes we got from asking a clinician about they how they'd found using the [PCOM], was that it was surprising to them that the things they thought were important, the things that they thought they were going to be talking about in the consultation, were quite different from the priorities the family chose, and they suddenly realised that their expectation was completely out of kilter. They were being thorough, they were well-meaning. There was no sort of failure on their part to engage with the family. They just hadn't seen it from their point of view.*

Potential to generalise and identify key concerns
All three Pathfinders had suspected that when individuals and families expressed their own goals and concerns the issues raised would group around similar themes. As they progressed with development of their PCOM two sites found this to be the case, supporting them in their belief that a standardised tool could be developed, identifying typical areas of concern. Clinicians could use a PCOM of this nature to invite clients to identify the concerns of relevance to them, and by doing so, help the clinician to recognise and maintain a broader, more person-centred focus.

> Interview 2: *… I chose deliberately to try and get as many specialties as I could involve [in the Pathfinder project]. I wanted as broad a range as possible because I wanted to test out and establish whether in fact there were these commonalities.*

> Interview 2: *What are the goals in this hospital for children of a variety of ages with a variety of conditions? What are their goals? … clinicians can become can become overly focused in their own "silo" in a particular medical specialty … and I deliberately wanted to say that if we do throw this back to the patient, are there commonalities about the problems children present to us? And there were. There were groupings,*

> Interview 2: *And what I hoped would happen was if we do see enough patients we might identify some common themes, which is what we did. So it is administered at an individual level but we discovered it was generalizable.*

> Interview 6: *… it seems very compelling to try and … derive something that might capture what are common areas of concern because then you can flip it into saying … if you see a child and a family where this is an issue, these are the sorts of things we know that you should attend to.*

A standardised tool that invited service users to indicate their own priorities and issues of concern would be particularly useful in maintaining a united focus when multiple healthcare professionals are working with a family in the absence of a multi-disciplinary team.

> Interview 6: *… one of the problems with this area is that, quite rightly, there are a number of different professionals [involved] … and there can be multiple pathways … and they'll [each] get one bit but that's only a small part of … what the issues are for the families … We're fortunate [in this hospital] in that we have a multi-disciplinary team, but you don't get that at every level, and so the people who are most likely to meet families, they all need to be aware of what the key issues are.*

The same respondent spoke of the liberating effect a standardised tool could have for service users if a clinician could invite a patient or carer to identify, from a standardised list of patient-derived concerns, those of relevance to them.

> Interview 6: *… it is a very powerful kind of giving permission to be able to say, these are the sorts of things that actually matter to people, this is what people have told us matters, because actually if you come and see a clinician, many of these things, people might not think it is appropriate to raise them, and yet we know they matter.*

The third Pathfinder had anticipated finding common themes amongst the priorities identified by those using their PCOM but, to date, the accessible data showed no obvious groupings of priorities. Developers of this tool considered it a possibility that within segmented groupings priorities may later become evident.

> Interview 1: *We had wondered whether you would get a clear, sort of obvious top three [priorities] … but we haven't found that.*

3.2 Address gaps in evaluation: develop user-based measures against which services can be assessed

Each of the Pathfinders identified an evaluative component to their PCOM. They aimed to create the capacity to assess the service, in some way, against the outcomes identified by service users.

Prospective approach

A respondent from one Pathfinder described the perceived challenges that had, until now, left psychologists assessing their work using clinically-based PROMs and by measuring users' satisfaction with their experience of the service. Until now they had no measure against which to assess whether they had met the outcomes prioritised by service users.

> Interview 2: *Medical and surgical outcomes are well established … but psychology has lagged behind … [psychologists] say, we do preventative work, as an effective psychologist you anticipate and identify the precursors to problems and try and help families <u>before</u> a problem arises and how do you*

measure that? And what would be a true outcome?' So psychologists find it very much easier to use a satisfaction with experience measure which … to my mind actually isn't necessarily synonymous with outcome.

Interview 2: *[previously] we had a list of behaviours which were in the clinical range, we had a list of symptoms which were not in the clinical range … and didn't really start with an individual evaluation of what children really wanted out of it.*

The same respondent acknowledged that not all services provided by hospital psychologists could be meaningfully assessed by a PCOM, but for situations of extended contact between a clinician and client, individual outcomes could be developed at the outset and progress assessed during and at the end of the intervention.

Interview 2*: In a child and adolescent mental health service in the community it's much easier. The team gets a referral, the child comes to the clinic, and you have a series of appointments. There's a clear beginning, middle and end and it's delivered in, more or less, one context*

Interview 2: *So [the new PCOM] is a metric which allows you to get a before and after measure. … … say you do it … at the beginning, and one in the middle, and one at the end and say you have eight to twelve sessions which is common for that sort of intervention. It would be very useful if you are confident that your metric is based on what patients have said they'd like outcomes to be. Then you can use it and incorporate it with the medical outcomes…. So you're evaluating your bit of the service*

Retrospective approach

For two sites, the key reason to develop a measure was to give their client group a voice of their own, unconstrained and not influenced by the voice of parents, carers or clinicians, and by doing so they aimed to improve specific in-patient hospital services.

Interview 5: *The initial idea came from the fact we wanted younger children to have a voice. For them to give feedback … There isn't much for younger children, there's a lot for teenagers … for the younger children there's very little. It's all based on parents' views of what they think that their child thought.*

Interview 5: *The purpose of the tool is to give quick feedback to ward staff of the children's experience, and to allow staff in different wards to learn from each other.*

Interview 4: *… we know through anecdotal feedback … that potentially our care doesn't really meet their specific requirements … what we wanted to do through developing some sort of outcome measure that was centered around these children and young people with these specific conditions was to assess what they thought of their care … metrics are really familiar to us within acute care settings because we have bench marks that we're measured against. It's*

about trying to develop some sort of indicator that then can inform practice and services.

Interview 4: *These children's stories or narratives are very powerful and I think they make you sit up and listen … it's made us reflect on who cares for these children and young people and what is the quality of that care and of that experience? … if we don't have a metric to really demonstrate that then maybe they're left unheard. What else is evident out there for these children and young people? The friends and family test - there's fairly scant information you can elicit from that …*

Factors that shape the PCOM

Both sites developed their PCOM specifically for the time during which they have contact with their service users, in order to shape the service to better meet the patients' needs. Both saw a role for quantitative measures to support service improvement, and both felt strongly that if the PCOM was to be genuinely patient centred the questions and the way the tool was designed must be driven by the service users themselves. Having designed the tool it would be used by future in-patients to assess the services they had received.

The nature of the time period - the discreet period of a hospital stay - shaped the nature of the outcomes that could be identified. So too, did the emphasis on patient-centred design. Both Pathfinders reported that for the children themselves, thoughts of outcomes beyond their hospital stay seemed irrelevant: they were focused on their time in hospital.

Interview 5: *I think for them what was really important was their stay at the hospital. When we then went on [to look further into the future]… that was too challenging, too difficult, and it didn't feel meaningful.*

Interview 4: *The children and young people were focusing on their experience of in-patient care, where the parents and carers were reporting their dissatisfaction or issues surrounding what happened before, and what happened after. So I think they [the parents] did see this macro picture which is very useful and needs to be considered, but does that relate to this discreet aspect of care that we are interested in? So I think there is scope to include [the parents' views] but potentially it could be a separate measure.*

3.3 Address commissioners' need for a metric against which to assess services: provide aggregated information on service users' needs and priorities

Potential for aggregated personal priorities to influence commissioning

Several Pathfinders commented that their PCOM, by identifying the most common priorities for service users, could provide a useful guide for commissioners, indicating areas of need that should be met.

> Interview 4: … *it could be used as a quality assessment tool. It could be used as a commissioning tool to see whether services are appropriate for the patient group. It could be used as something around ensuring the design configuration of services and the workforce who are delivering them are appropriate, have that fit …*

> Interview 6: *… as a commissioner I'd be saying in terms of my service specification, I want to be reassured that you have the provision for doing [the things that were identified by the study as the areas most important to families] … I'd be wanting as a commissioner to say to the providers … can you demonstrate to me how you are going to meet these basic criteria?*

Developing a PCOM for commissioners to use as a monitoring metric

As another respondent who had developed a PCOM for use in interactions between client and clinician said, if the tool was used as a means of measuring the extent to which service users felt that their self-defined goals were being met, commissioners might find the results useful, alongside other more clinical measures, as a means of demonstrating whether the service is providing what users want.

> Interview 2: *… what commissioners would want to know, I think - is that the service is meeting the expressed needs of the patients in that service, and this would be a way …that they would see a measure. … They do need something that is honed down enough and that's where you have to be careful not to lose the individual content but if you have established something that has enough commonalities, it theoretically is a good measure for that service of what enough patients in it need-… It's a way of summarising, of commissioners knowing that they haven't travelled too far from what they think the service is delivering.*

One Pathfinder identified commissioners as the key audience for their PCOM. The respondent for this site emphasised that even when commissioners have a strong sense of the nature of the services that service users want, still they need a metric against which they can measure performance.

> Interview 3*: The problem is that the current system metrics do not focus the system on what matters to people … you can have the best possible insights, great co-design, but when it comes to the commissioning system actually behaving differently, they tell us and believe they need a metric to drive change. They need something that they can put into a contract and say we're going to monitor this.*

Interview 3:… *what we need to do is redesign the commissioning process so there is a way of making this [ie what people want] visible within the commissioning process and getting NHS system leaders, providers and clinical commissioners' attention focused on it.*

3.4 Provide useful data for research

Two of the PCOMs where the primary intention was to support a more person-centred focus at the individual level identified the potential, over time, to use their findings for research purposes.

Research opportunities from aggregated data

For the PCOM where data is entered electronically by the service user, the site offers the person providing the data the option of giving permission, at the time of entry, for the anonymised data to be accessed and grouped by condition.

Interview 1: ….*[the person/carer who enters the data] can choose to keep their information entirely private; they can choose to share it with the designated professionals who can't control the information but they can see that information; and then we've put in another layer … which is that on a website you can see anonymised data from a selected group so that, again, [the person whose data it is] would have to say yes, I will agree to be part of this cohort, this study or whatever.*

Although, across the broad group of people who have used the tool to date, the accessible data shows no obvious groupings of priorities, it is anticipated that within segmented groupings priorities may become evident. This information could be useful for commissioners and for research.

Interview 1: *As an example I am going to meet a group of families who have all got a rare metabolic condition … because it's such a rare condition there is no way to pull together what the priorities would be for research in the future ... So if they sign up … to all tick the patient-centred outcome measures trial box … that should give information, for admittedly a very small group, about what their priorities are, the things they're really challenged by at home and the consultants and specialist nurses and so on can then use that information to channel their requests for research funding and development in the future.*

Potential, and risk, of generalisation

In another of the sites where the PCOMs is currently being used to support a more person-centred approach, the respondent could see that as responses consistently appeared to cluster into thematic groups it would, theoretically, be possible to develop a standardised questionnaire. The questionnaire could then be used with specific, identifiable groups of respondents to provide data that could be useful for research purposes. As the interviewee acknowledged, however, the risk of such a development is that the personal aspects of the current individual approach would be lost.

Interview 2: *So if I have discovered themes that would apply to quite a large cohort of patients all of whom have an illness or condition which gives them,*

for example, a visible difference … It is very practical to have one [standardised] set of questions because then one can do all sorts of things with it. It allows one to establish norms … And that of course is attractive because then it becomes not just something for a particular patient but it becomes potentially a research measure and it's convenient and it's score-able and it gets generalizable, but you have to be cautious about that.

3.5 Summary and discussion

Pathfinders developed PCOMs to support more person-centred communication between clients and clinicians; to develop person-centred measures against which services could be assessed and improved; and to provide commissioners with a metric which they can use to monitor and improve service provision. Pathfinders also noted the potential for PCOMs to provide data that might be useful for research.

As noted earlier, the nature of the different PCOMs varied with the context for which each was designed. While currently at various stages of development, the intended end stage for some PCOMs was that respondents should define their own outcomes, while others Pathfinders intended the final PCOM to invite the respondent to rate specific, defined issues against a rating scale. Some PCOMs were designed to be used retrospectively and some prospectively too. Some focus purely on outcome and some include experience. Each of these qualities, as well as being influenced by the setting, also shapes the way in which the measure, produced by the PCOM, can be used.

Considering variables that may influence the shape of a PCOM, an obvious starting point is whether the PCOM is intended primarily to influence relational outcomes at an individual level, to provide evaluative potential at service level, or contracting guidance at commissioning level. At the more relational level there is particular value in a PCOM retaining individual perspectives, while, for service level influence and commissioning decisions metrics are needed that can be meaningfully aggregated. Likewise, for relational purposes a PCOM is valuable when used prospectively, while evaluative and monitoring purposes require retrospective use, ideally in conjunction with prospective data.

Another variable, referred to in Section 3.2 above, is the time period which the PCOM is intended to influence. Both PCOMs that were designed to address a relatively short inpatient stay focus largely on the experience of that stay, because, as the respondent quoted below stated, a short stay could not reasonably be expected to produce significant outcomes.

Interview 4: *But we knew that they weren't going to be recovered by their three day inpatient stay with us. This was the beginning of potentially a long journey with other mental health services, and [we wanted to know] what was it that was important to those children and young people whilst they were in that discreet phase of their care pathway.*

A third variable of potential relevance is the condition of the respondents, or the stage in their care that the PCOM is intended for. The same respondent emphasised that although it would be valuable to hear, from the children and young people

referred to above, the outcomes that seemed most important to them, it would be inappropriate to ask such questions at that stage in their care. Retrospective questions about their experience of care were more relevant, as the service users themselves identified.

Interview 4: *… it's about going back to the condition of these children and young people and whether they are able to, because of their condition and their mental health status when they are in crisis, to make that choice as to what they want and what is important to them at that point in their care pathway. Whether it is possible and acceptable and ethical to expose them to that, when potentially there's other pressing things that they need to consider.*

4 Developing PCOMs

4.1 Selecting the domains or outcome areas

The process for selecting domains was influenced by the nature of the PCOM that was being developed.

Open-ended selection of outcome areas for the respondent
For two of the PCOMs the essence of the tool is that the client selects their own outcome areas, initially at least, in an undirected way. For one tool, designed for use in interaction between an individual client and clinician, up to three outcomes are defined by the service user during the first meeting.

> Interview 2: *… we would see a family … we'd see them for the first time and we've had a referral letter and I might myself … say, I've heard that this might be an issue for you, is there a problem?' And as we get into an area … where people acknowledge there's a difficulty then I can introduce the goals and say you know, thinking about what you'd like to be different, what it is you'd like to change the most, what might that be? And get an understanding of that and get the words right for the child and say where are you now? [towards that goal].*

This respondent emphasised the collaborative nature of a PCOM: the individual defines their own priorities, outcome areas and goals, then the clinician works with the client to agree realistic goals for their work together.

> Interview 2: *[A PCOM] should be defined by the patient and then taken forward in collaboration with the clinician … possibly reshaped then worked on. There could be goals that the clinician is unable to influence… It would be wrong to embark on an intervention for an outcome you would have no possibility to influence or have control over.*

As the same respondent explained, the nature of a PCOM determined in this way is different to a 'pure' person centred outcome defined entirely by service users. The purpose of the collaboratively developed goals is to shape the treatment and the clinician must feel confident that the agreed goals are relevant and realistic for the situation.

> Interview 2: *… so what we're trying to do, in using goal-based measures, is to come to a collaboration between the patient and the psychologist, as what should be worked on…. In terms of the therapy in that session, in terms of the intervention … so I might have a referral which talks about generalised low mood or anxiety in a sort of symptom way and the child says, you know, I would like to know how to feel less angry about having this illness or this condition. I would like to know how to make friends. I would like to feel more self-confident. They may not come out with that as directly. You may have to help them arrive at something. But what you're trying to arrive at is something which you both define and can work on together   It has to be doable. … it's not as pure a measure as one derived from a group of patients sitting together in a focus group saying this is what I would choose an outcome. It's in the*

context of treatment….To me this seemed much more patient-centred than what we were doing before.

Another Pathfinder's PCOM is designed for service users (children or their parent or carer) to self-complete electronically. Following an introductory conversation where the individual's issues are discussed, the individual identifies their own outcome areas or 'priorities' by selecting, from the tool's website, either the heading of 'physical symptom' or 'social and emotional impact', then, from the dropdown menu beneath each heading, either selects one of the listed priorities, or takes the 'make my own' option, to describe for themselves their priorities.

> Interview 1: *… the first thing we do is we sit down with a cup of tea and we talk to people, we don't sit in front of the screen because it's all about the relationship. However, once they've identified what they want, it might be a physical symptom of which we've got a list, it's not an exclusive list, it might be something with emotional or social impact, there's another list there, but for both these [lists] the top thing on the list is 'make my own' and that allows free text.*

Defined domains with varying degrees of open choice within them

Each of the other four Pathfinders is working towards defined domains or outcome areas for their PCOM and each has worked in similar ways, collecting information from different sources for comparison and confirmation. Two started their work with literature searches; one built on work previously completed by others; and one worked entirely with service users.

The PCOM that was developed with and for very young children (5-10 years old) recognised the need, when working with children so young, to provide options of outcome areas, rather than offer free choice.

> Interview 5: *… with such young children we had to be quite specific and quite concrete from the beginning … we had specific categories we thought would be important and then gave them the options. Just simple choices that they could make.*

Acknowledging the limited time for the project, and the fact that others had already worked on similar issues, the Pathfinder selected the list of categories that they offered to the children who designed the tool from work completed by the Picker Institute.

> Interview 5: *… so we thought instead of starting completely from scratch … using Picker who are already experts in doing outcome measures … based on user involvement ... they've got a massive pool of questions so finding the most relevant ones for the younger children and then involving children to … look at the categories and what areas they thought were most important to them, so we're using what's already there …*

The other project that emphasised the centrality of involvement of service users in the design began the project with an evidence scan then involved wider groups of stakeholders, though their primary focus was children and young people.

Interview 4: *It was about using the literature as a platform to then explore and get people to rate or establish what was good and not so good about their experiences and aspects of care … using the literature we used this nominal group technique. It was about gaining some sort of consensus around aspects of care and their experiences and outcomes, and rating what was important and what wasn't important to them.*

Another Pathfinder used a five stage process for defining outcome areas. They began by reviewing published literature and other national data to identify ten central themes or 'touchpoints' relevant to the selected topic that affect people's lives. They then worked with a group of ten 'expert families', recruited by GPs for their experience of living with the condition. The families discussed the ten touchpoints and selected the six most important. Children with the condition selected the four most important. Information about the ten touchpoints was then discussed with a wider group (approximately 30 families), recruited locally. Having compared findings from all three sources (national data, the expert group, and the wider group), findings were taken back to the original ten expert families to invite reflection, comment or change for any areas where views differed.

Interview 3: *So we then went back to the [expert] families and we said, this is what we found out. This is what you told us mattered to you, but actually this didn't come up. You didn't pick this one. But it's coming up a lot locally with a wider group of families … So we worked with them and we positively challenged their decision with commissioners in the room as well. So we could help them to think about whether their personal preferences were representative of the bigger community. And also of the national data.*

The six touchpoints selected and shaped by the expert group at this fifth stage became the domain areas for the tool. Within each defined domain area respondents select their own individual goals.

Lastly, one Pathfinder selected domains by a four stage process with service users. First, all people attending their clinic over a specified time were invited to respond in a free-form way to four open questions exploring what, in relation to their condition and the treatment, mattered to them. The issues that emerged were discussed in focus groups, and the emerging themes were developed into a questionnaire that invited clinic attendees to rate the importance of each of the identified themes and to suggest additional items. Finally, the themes were discussed and further consolidated in eleven in-depth telephone interviews.

Interview 6: *… we had different phases. The first phase was just very open ended … in terms of those four questions … we asked everybody who came [into the clinic] over a three week period to fill it in. [Someone] was on hand to help them if they had language issues or couldn't write … so it was completely not guided or led in any way. And then we did a focus group … just to make sure we understood things, we'd unpack them a bit more. And then we took those and we turned it into a paper format saying these are the areas, can you rate for salience and can you add any others? …. And then the interviews at*

> *the very end … in-depth exploring of the stuff that came out, so that was 11 hour-long interviews.*

Respondents for this Pathfinder acknowledge that their tool is not yet complete. They plan to use it with a broader range of service users before confirming the final outcome areas.

> Interview 6:*... So it needs a larger scale repeat of this really, that you look at stratified ages, and different types of presentation in different settings.*

> Interview 6: *Then I can give it to you [as the parent or carer] or I give this to the young person and this is a standardised instrument. These are the sorts of things that we know can be important. Could you rate where you are on those; are they important to you? And you'd have a blank bit in terms of any qualitative additional things.*

4.2 Selecting and using measures

Not all Pathfinders have developed their PCOM to a stage where they are ready to identify measures for their selected domains. Of those that have, each provides the respondent with a rating scale against which to gauge progress towards the goal, but the extent to which they are measuring individual or common goals differs.

As noted earlier, Pathfinders who are developing tools to support individual encounters with clinicians recognise the benefits of identifying common themes so that individual responses could be aggregated, but this is not their primary focus. By contrast, for Pathfinders who are developing PCOMs primarily to improve service delivery or commissioning, aggregation is crucial.

Scoring against self-defined goals in self-selected domains
The PCOM that invites service users to identify their priorities online provides them with a rating scale of 1-10, allowing individuals to rate themselves in terms of how close or far they feel from their self-defined goal. They can score themselves as often as they wish, and can also add their own qualitative comments to indicate the meaning of points along the scale.

> Interview 1: *And once they've [identified their priorities] they set up what they'd like in terms of a 0-10 and at the moment we've just got a Likert Scale, but you can put personal free text so you can say what that means for you. So if I felt my anxiety, if it's up to 10 and I wasn't getting any sleep at night, then I could put that in there and then … you can personalise it. On a day to day basis you can check in.*

In this way, the goals are individual and so is the approach to rating. All who use the PCOM rate themselves on a scale of 1 to 10 but the meaning of each score is personally defined.

Another PCOM designed to focus interaction between a client and clinician also invites the individual to define their own goal, and to score themselves on a scale of one to ten against the self-defined goal. The interviewee commented that a

numbered scale of one to ten seemed a more valid approach than a non-numeric line on which, from her experience, individual responses seemed unpredictable.

> Interview 2:… *you have to make it developmentally appropriate so I think 1-10 works well because children understand marks out of ten.*

> Interview 2 *What I've always found with adults or older kids (is) if you just give them a line … whether its 0-10 or 0-100 and get them to make a slash, that is the purest thing because they are supposed to make a slash across the line and you're supposed to measure it. But the trouble is, what people mean by 7 out of 10 and where they mark it can be extremely different. … I've done a lot of that and said OK, where you've marked that looks to me like a 7 or 8 out of ten [and they say] 'Oh no I didn't mean that!' So I find it better to delineate boxes.*

Fixed scoring for pre-defined questions

The tool designed by and for young inpatients offers a three-point rating scale, depicted as a ramp on the animated tool. As with the questions for this PCOM, the Pathfinder built on work previously conducted that was demonstrated to be effective with young children.

> Interview 5: *We had the benefit of working with Health Tracker … they've done a lot of research … in terms of how best to depict questions and answers and animated versions … and they have already devised a ramp which is a nice visual depiction starting from always to sometimes to never … And those three categories fits in with the Picker answers so we are using evidence that is already there …*

For the tool described above, respondents rate themselves in one of three categories against a fixed issue (for instance, whether they felt their care was delivered in a way that gave them enough privacy) that has already been selected during the design process.

Non-numeric scoring against self-defined goal within pre-defined domains

Finally, the PCOM designed primarily to inform commissioners also scores goals on a ten-point rating scale. The PCOM consists of six pre-set 'touchpoints' or domains, but the specific goal within each of the six touchpoints is defined by the individual service user. Having set the goal, each individual decides their current position (their distance from their self-defined goal), on a graphic 'journey' with 10 (unnumbered) steps. The steps are deliberately left unnumbered: the respondent reported that the literature review indicated that respondents feel judged by numerical scales.

> Interview 3: *So in our PCOMS graphics, there are no numbers and there are blanks to describe what 'good' looks like. And then we ask people, if that's what good looks like, where are you right now compared to that definition of good?*
> Interview 3: *There are steps related to 'how far are you away?'.... You don't have to have numbers to have a scale do you? We describe them as little kind of journeys and people chose the graphics for [each touchpoint]….*

Interview 3: *One of the reasons we didn't include numbers is because our review of outcome measurement tools told us that when there are number scales, they feel judged. We did a research review of 30 different outcome tools and their evaluation and that was one of the findings.*

This PCOM is designed to be used by commissioners each year, with the aim of providing qualitative data and two quantitative measures. As the quantitative measures are comparative, they become available on the second and subsequent uses of the PCOM.

Analysis of the annual data will provide aggregated information about movement, on an annual basis, along the pathway towards or away from the goals set in each domain. This data will be contextualised by analysis of the changing nature of people's goals, including whether goals are becoming more or less ambitious.

As the interview excerpt below explains, the first measure is the total number of people who report having stayed the same or moved further from their goal, subtracted from the number who report having moved closer to their goal. The second measure is the average distance from the goal, across the whole sample.

The respondent noted that over time, as the PCOM data set is tested and developed, additional quantitative measures may be added.

Interview 3: *And we have a mixture of qualitative and quantitative [data] that describes where people are right now and you know, actually where they want to get to as THEY define it. Not how it's defined by anyone else.*

Interview 3: *There's only two things at the moment that we're planning to have quantitative measures on. How many people say they're closer to their goal and ... how many are farther away from their goal? So those two are quantitative measures … This is what you would know: are people's lives improving more than not improving for a given domain? … And how does that compare with last year? That is then tempered by how are residents' goals changing.*

Interview 3: *We also then qualify that quantitative data with a description about how people's goals are changing …. it's not good enough to just record the goal, we also have to be able to look for the trends to see whether people's goals are getting more ambitious as well. So are their expectations about what is possible in their lives rising?*

Of the four approaches to measurement described above, only the third, with fixed questions and a fixed (three-point) rating score is consistent across respondents. For the other three, if an individual's goals remain the same, repeated use of the tool allows measurement of progress for each individual towards or away from their goal, but the creation of individual goals creates challenges for aggregating individual scores. On the other hand, the nature of the individual goals provides rich qualitative data.

4.3 Validating the measures

In different ways each Pathfinder had considered validation of their PCOM.

Initial validation of themes
One respondent described the iterative process by which the Pathfinder work had identified then confirmed the themes for their PCOM as a process of ongoing validation.

> Interview 6: *… it was an iterative process and they were validating … what other parents had said … with the interviews and focus groups*

The same respondent acknowledged that further validation of the themes would be needed by using the PCOM with a broader range of clients, then statistical testing of measures.

> Interview 6: *… we need to trial this in different settings … when we draw up something we'd need to do an acceptability and feasibility pilot in different settings as a next step. And a better psychometric work-up of what the thing will look like … I think that would require some quite careful [work] about what would be appropriate statistical techniques*

A respondent from another Pathfinder made similar observations about the next steps for their PCOM, were they to develop it as a standardised tool, acknowledging the skilled work that would be needed.

> Interview 2: *So I'd take the themes, theoretically, and we'd write questions and test them out, and you do it in a variety of ways, for example using focus groups … and then you do the required analyses and test retest reliability … and then you end up with a questionnaire*

Validation of measures
The Pathfinder that built on work conducted by others (Picker Institute and Health Tracker) had the advantage of using questions and a rating scale that had already been validated by the companies that designed them. In addition, before finalising the tool the response process was assessed for validity by trialing the questions with children of mixed abilities to assess whether their responses matched their views, and to check any difficulties or bias in recording responses.

> Interview 5: *Picker have got validated questions and we used the basic structure of some of their questions and the Health Tracker company … they've done a lot of cognitive testing …*

> Interview 5: *We've done cognitive testing, Picker came round and … we went to the wards and we got children to say what they would answer before they answered it and why would they answer that. And then selecting it, and asking them if there were any things that didn't make sense, and that was when we still had time to change it.*

Interview 5: *I think there were 12 children of different ages and we had girls and boys and we had a couple with learning disabilities and we went through it with them, just asking their feedback about every question about what question and why would you answer that, did you understand it. So we checked all of that.*

Selecting adequate sample size

For the PCOM that is designed primarily for commissioners, if data is being collected from a sample of the population that the PCOM aims to represent, the sample size is calculated based on the number of responses that must be collected to produce PCOM data with a 95% confidence ratio.

Questionable role of validation when aggregating qualitative data

As the respondent from this Pathfinder emphasised, validation of qualitative data is a challenging concept.

Interview 3: *The validation of qualitative measures is a very different science to the validation of quantitative measures. We've thought about this a lot and we've looked at sample sizes ... there's an equation, a statistical equation that sits behind PCOM sample sizes. It gives a 95% confidence ratio for the data that this PCOM generates.*

Interview 3: *… but you have to be careful not to get too hung up on the validation thing because this is a management tool … We look for tools that create insight when we are doing improvement work. …you know, there are validated measures out there like clinical outcomes (that would sit alongside a PCOM). This PCOM is coming from a completely different mind-set.*

Interviewer: You can be confident you've got the right sample size, but don't you need to know, as you aggregate those individuals in your sample, that each response is meaningful and meaningful against each other?

Interview 3: *Well internally it is. This isn't a questionnaire. The outcome is self defined. If I say to you, 'Tell me what a good school life is?' and you say, 'The teacher understands my asthma and lets me have my inhaler with me at all times', of course, that's valid for you as an individual because you determined that. It's not like a survey where you need to know that the same person would give the same answer to the question each time they did the survey … and when you're aggregating data from a qualitative perspective, it's a completely different process to aggregating survey results.*

4.4 Collecting the data – how is it collected and by whom

Pathfinders either collected their data in paper-based format or electronically. While some saw an electronic approach as inevitably better, and considered financial cost the key barrier, others identified challenges that accompanied use of the internet.

Perceived advantages of electronic approach

Two Pathfinders that developed their PCOM using pen and paper believed that, were it financially viable, an electronic approach would be more effective.

> Interview 2: *I had to use paper and pencil and it would be better if responses were made on an iPad or tablet because children prefer that … it's perfectly doable in the context of what you're trying to do with the child.*

> Interview 6: *… ideally if we developed it into a tool you want to have it on a tablet so that the responses get exported straight into … a file that you can then analyse the data and send off your returns or it maps onto any other [related work].*

The animated tool designed for use with very young children in hospital was conceived of as an electronic tool from the outset. From the users' perspective the benefits are that a tablet-based approach is familiar and popular with children, and from the service perspective it allows instant access to data along with simple analysis and presentation of findings.

> Interview 5: *The benefit of it being an on-line system is that the data analysis can be taken just off the back end really easily and it can come out straight away in graphs and in whatever format you want it so that's brilliant, it's not going to mean trawling through data.*

Challenges and disadvantages of electronic approach

As the same Pathfinder experienced however, producing an animated electronic tool is costly and challenging, particularly when working with different partners. Development of the tool relied on input from the designers of the questions, software developers, and the clinical team. Combining views and standards and recognising what was changeable at which stage was a demanding process, particularly in a short time-frame.

> Interview 5: *But there's a lot of challenges that come with that. Obviously it's expensive … When you've got only a specific amount of time, you are working with software developers, you are working with designers, artists, and they all have very different ideas and very different views and different backgrounds and areas of expertise. So trying to bring something together can be quite a lengthy, challenging process and that's why communication's absolutely key.*

The other Pathfinder that is developing a PCOM for use with hospital inpatients warned against the assumption that young people necessarily prefer an electronic approach. When working with service users to assess their preferred way of responding, while one group was happy to give feedback electronically, others

wanted contact with an individual some time after the event. Further exploration will be needed to assess the representativeness of these views.

> Interview 4 *… for the children admitted with self-harm ... they were happy to do it via an electronic device, to assess their outcome during that change in who was delivering the care.*

> Interview 4 *I suppose we have this preconception that we're in the technology age and everybody's got an iPhone or an iPad and wants to use a devise … And also, in data collection, its relatively easy if it's in an electronic format but for the children with eating disorders that wasn't acceptable … they wanted to report their outcome to a person, whether that be via telephone or face-to-face, some months after they had been admitted, to provide that measure.*

The Pathfinder that operates by individuals entering their own data electronically initially offered an alternative paper-based option but this quickly proved unpopular.

> Interview 1: *When I first developed this we did have a paper version because we thought people might not trust an electronic data collection system. One family used [the paper one] and they gave up very quickly.*

The respondents observed that all service users invited to use the tool were familiar with internet use, though they acknowledged that, as a younger population (young people and their parents and carers), the users of their PCOM were not entirely representative of the wider population.

> Interview 1: *… the social demographics of our users have tended to be parents of children … so we're looking at an age range who are quite computer literate anyway and its second nature to them … but I don't think that necessarily applies to the whole population.*

The Pathfinder has, however, found wide variations in the extent to which users of their PCOM feel comfortable with recording personal details online, and the extent to which users trust the site's security.

> Interview 1: *… when you ask people to put in details that might matter a lot to them personally … the range of what people will share and what they'll decide, no they couldn't possibly put on, that is very wide.*

> Interview 1: *So there are limitations inherent in using an electronic system that I think do go right back to people's fears about what's accessible … we just have to reassure them of the security of the information ... I think the difference is that stuff that's electronic can be spread so quickly, whereas if you put something on paper, even if someone was determined to leak it, there's a slower pace of that happening. I think that does frighten people.*

Possibly influenced by security concerns, but also, as noted in the interview excerpt below, because of service users' perceptions of what an electronic tool with a rateable scale requires, respondents from the same Pathfinder observed a qualitative

difference between the topics that people discuss with them verbally in clinical settings, and the issues they record online. Online recording appears to prompt more symptom-based medically-oriented issues whereas, when face to face, people seem more ready to discuss personal concerns.

> Interview 1: *[when looking for the most commonly mentioned priorities] we had seizures first, constipation as the second and we had sleep problems and pain as equal third but … I think that's only valid on a simple level because when I think about my clinical experience with families, the things that they talked to me about were not necessarily the same as the things they were putting on the computer …it may have been things like marital difficulties, the impact on their finances or the fact they couldn't get their other children to school on time or the whole range of bits and pieces that are much more of that how-do-I-get on-with-my-life bit, rather than the medical bit … [The PCOM is] seen as a technical tool and they'll make a conscious selection of what they feel would be measurable … which is why you're getting the technical medico stuff.*

Addressing risk of personal bias

Moving to consider who should administer the PCOM in situations where it is not self-completed, a respondent who had developed a PCOM for use with individual clients recognised the potential for bias, with the risk that, when assessing movement towards or away from goals following an intervention, the service user, and parents in particular, may be reluctant to acknowledge anything other than positive outcomes, particularly if speaking to a medical doctor.

> Interview 2: *….   parents in particular are very eager to please clinicians they may feel they depend on. So I think that is a major theoretical difficulty.*

In the interest of validity it could be helpful for someone other than the clinician to collect information from the client, yet part of the therapeutic value of introducing a PCOM is the enforced opportunity it creates for a clinician to work with the service user to hear their goals. An ideal compromise could be for the clinician to work with the service user to establish the initial goal and their current rating in relation to it, but for someone other than the clinician to ask the service user for their subsequent ratings in relation to the goal, in an attempt to convey anonymity and reduce potential bias.

> Interview 2: *I think the answer is yes and no and think that lots of people will say no, it does need to be an outsider.[But] if you want to inform the clinician about what's important to you, it's essential they get to know what these goals are. … it's part of the therapy.*

> Interview 2: *… once you had established the goals, you could then take it away from the clinician if you like and they will continue doing what they do with the young person … and then an assistant, someone outside the system [could collect the data and] could feed back anonymously to the clinician…*

Another Pathfinder suggested a similar approach.

Interview 4: …*without doubt the person who is asking the questions certainly, if it's a face to face contact there may be some sort of bias in relation to the responses and how one sees them responded to … we sort of perceive [the PCOM] as standalone but actually this could be integrated as part of their care pathway … Whether there's a logical conclusion to their care in which somebody … could implement the measure that could potentially be a bit more impartial than the person who's delivering the care.*

Varied options for data collection for commissioning PCOM

The means by which data is collected for the PCOM that has been developed primarily for use with commissioners depends on the care model in the area where the PCOM is being used. Having opted to use the PCOM for a specific condition, if the Clinical Commissioning Group (CCG) has adopted an approach whereby each person with that same condition has a personal care plan, data collection for the PCOM can become part of the care-planning process.

If this is not the case, a CCG can collect the data in other ways. Possible options, to be explored with the relevant CCG, would be through personal contact between the individual and a representative of the care system (for example care navigators, care coaches; trained research volunteers, or other staff who are in contact with the service users). In the future, electronic approaches may be possible. If the interview-based approach is used it is unlikely that the whole population will be surveyed and a sample will be selected.

Interview 3: *And it depends on their readiness for person-centred care planning. So if ... there is a person centred care plan in place, the PCOM will become part of that conversation.*

Interview 3: *If you're not … . we can find another way of operationalising it for you. So that might be through an app or it might be through PCOM researcher volunteers going out and talking to patients. It might be using care navigators. It might be using care coaches. It might be using care home staff - if it was residents in a care home. So we don't specify the 'how' it is operationalised, we co-design that with commissioners and providers who we're working with.*

Interview 3: *It is a very bespoke design that fits with the service they want to evaluate, what needs to be measured, and at what level commissioners want to measure impact and change.*

4.5 Summary and discussion

Pathfinders are at different stages in the development of their PCOMs. All have worked with service users to develop domains or outcome areas, some are already using outcome measures while others have them planned, and all have given consideration to validation and the implications of different approaches to data collection.

The key purpose of each PCOM influences the relative balance between an emphasis on, on the one hand, individually defined outcome areas, personal goals

and scores along personalised journeys, and, on the other, pre-defined (by representative service users) outcome areas or questions that invite responses along standardised rating scales.

The personalised approach retains rich qualitative data. As well as providing material to guide personal encounters with health and care professionals, qualitative data can support service improvement and commissioning. There are, however, significant practical and methodological challenges in aggregating progress towards individually defined goals.

Pathfinders that developed PCOMs to evaluate and influence service delivery, having identified the issues of key importance to service users, aimed to develop a tool that focused not on individually identified issues, but on collecting data that could be meaningfully aggregated.

> Interview 4:*… it wasn't going to be an individualised tool, it was going to be [how] we could collate all this information and use it to inform how we develop and deliver services, how we configure care, how do we train our staff … this is about developing some sort of metric that can inform… a huge amount of investment ...*

It is only when respondents score themselves against the same goal, issue or question that responses can be meaningfully collated.

The challenge of aggregating personal scores towards or away from individually defined goals is discussed in Apps et al[8] As they point out, outcome goals vary significantly in their relative importance and difficulty and if the performance of health or social care services is to be meaningfully assessed by progress towards individually defined goals, it would be necessary to account for how inherently easy or hard it would be for the different personal goals to be met.

Thus, while individually defined goals provide valid and valuable data in their own right, there are significant challenges in using them to produce aggregated scores.

Pathfinders' experience of approaches to data collection throws interesting light on the assumption that electronic methods are inevitably preferable. While most service users find electronic surveys easy to use and service providers benefit from ready access to findings, it is a helpful reminder to hear that some young people may prefer face to face contact; that concerns about privacy may limit the nature of people's responses; and that the broad understanding of the type of data an electronic tool might collect may influence the subject areas raised by respondents in open-ended questions.

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[8]Apps J., Crowther, T. and Forder, J. (2013) *Personal outcome measures and postal surveys of social care. Quality Outcomes and Research Unit* http://www.pssru.ac.uk/archive/pdf/4619.pdf See pages 28-30 for a discussion of the challenge of aggregating personal outcomes..

5 Implementation

5.1 What will be needed to support implementation

Evidence of validity and robust development, local knowledge and buy-in

Factors acknowledged by several Pathfinders as important for achieving implementation of a PCOM included evidence that the tool was valid and had been properly evaluated, ease of use for clinicians, that staff are fully aware of the tool and that someone can take responsibility to maintain awareness.

> Interview 4: *So I suppose it's about having that buy-in from local organisations and people need to be convinced that it's useful, (that) it's going to measure what it said it measures, and having that robust approach to developing a tool, that's fundamental. Having that academic buy-in, you know, rigorously do some psychometric testing or do a multisite study and having that disseminated in published journals is useful, but also people saying this is a useful tool, it's been developed by children and young people for children and young people. So I think it is a multi-level approach*

Ease of use

For one Pathfinder, ease of use had been supported by using some of the project funding to make the tool accessible across a range of settings, including tablets and mobile phones.

> Interview 1: *The other challenge for us was that … you couldn't do it on a mobile device … and one of the lovely things about this PCOM project was that there was sufficient funding for us to make it user-friendly … So that's one block that been removed.*

Organisational support is essential

Reflecting on their experience to date with encouraging use of the tools they had developed, Pathfinders recognised the effort needed to maintain new practices. Even amongst clinicians who had used the new PCOM and found it effective, that experience alone would not be sufficient to keep the tool in use.

> Interviewer: Do you feel like if you stopped prompting them now, do you think they'd keep going?

> Interview 2: *Not in this format no. But that would be like most things. You know, people like to work their own way at their own time and I think as a profession we have been less corporate in our approach.*

As another Pathfinder reflected, however enthusiastic the champions of a new tool, they need organisational support, both practically and personally, to help them play their role effectively. Ideally a new PCOM would be seen as part of standard practice.

> Interview 1: *We've learned that it's vital to have buy-in from the health-care team and that the champions need to have support from the organisation they are working in. Although the individual [champions of the tool] are absolutely strong advocates for it and energetic and enthusiastic, if they're not given*

practical time, support and feedback and some sort of approval from the organisation, it tends to wither. So that's another key factor. Making it part of normal practice

Interview 1:   *there could be organisational support for it, saying, we are expecting you to engage with this … if they could say, count the number of times that they logged into a patient's [PCOM] site and count that as clinical time spent reviewing the patient then it would be counted and recognised and therefore valued.*

For the Pathfinder that developed a PCOM for commissioners a key learning was the importance, not just of getting early buy-in from commissioners in general for introduction of the PCOM, but of getting buy-in from the commissioning manager.

Interview 3: *… one of our learnings would be that the commissioners have to be involved from the start but actually there's a really important caveat on that … the end user of the PCOM has to be involved. … the person who has to own the PCOM is the commissioning manager, because if they don't own it they won't use it.*

The respondent for the commissioning PCOM emphasised that, for appropriate and full implementation, it was crucially important that CCGs recognise and value the tool for the commissioning insights it could provide.

Interview 3: *We don't just leave them with the data analysis. We interpret it for them. We say, what are the actionable implications for providers and commissioners? … What insight have we got about what's working well? What insight have we got about how we need to improve quality? And what are the actionable implications for providers and commissioners that fall out of this data? Our job is to help them to interpret this PCOM data so they use it as a management insight tool to improve people's lives.*

Interview 3: *This isn't engagement work. This is metrics. This is commissioning insights. …you need your engagement team to help you do that co-design work at the beginning. …But it's about evaluation and contract monitoring. So you're going to be holding people to account for improving these different things*

Active recognition and promotion by NHS England
Finally, one Pathfinder pointed out the central role NHS England could play to support implementation. Having funded the Pathfinders this respondent saw an ongoing role for NHS England by acknowledging the value of the tools that have been developed and promoting their uptake. This could also be achieved by CCGs adopting the metrics and making them part of funding agreements for relevant services.

Interview 4: *… this is what we hope for in having NHS England fund a project is that they would have buy in from the outset to say this is a tool that we've invested in to be developed and this is something that we would like to roll out across England and paediatric in-patient care, trusts or for commissioners to*

say this is a quality metric that we want you to deliver on, this is something that is part of a package or portfolio of metrics that will then have money attached to it …

5.2 Barriers to implementation in service provision

Some respondents had clear thoughts about the challenges to be addressed when promoting use of a new tool.

Inadequate recognition of value of preventive work
A major issue is the invisibility of a preventative approach. The PCOM that enables service users to enter their own ratings against self-defined goals has, as one of its key benefits, the capacity to highlight issues that may be emerging as problematic, allowing clinicians to observe, then pre-empt their development. Prevention or pre-emptive work is not, however, readily recognised or valued. Staff struggle to allocate time to check patient-recorded information in order to avert a crisis, partly because the effectiveness of the approach is unacknowledged.

> Interview 1: *The incentive isn't there either financially or in terms of activity monitoring for people to be able to practice preventive health care. It's not counted and it's not rewarded. Whereas if you're busy. Great!*

> Interview 1: *At the moment [use of the PCOM is] all extra. It might save them time but they don't know. They may go on [to the PCOM] and check and the seizures are fine, the appetite's good and pain's not an issue and the parents' comments say everything's tickety boo at the moment and they've got nowhere to write that. Or no one can say well done, you've pre-empted something there, gold star! There's no recognition of that preventive work.*

Busy staff have limited scope for new approaches
For staff under pressure it seems easier to continue with familiar approaches rather than risk trialling a new tool. The more busy staff feel, the higher the risk of trialling something new that may not prove worth the input. Again, this emphasises that however effective a new tool, particularly in a busy environment, there are significant staff concerns to be addressed before people are willing to adopt a new approach.

> Interview 1: *… as well as thinking, yes that's a great idea, you have to get past the resistance to change. So you have to be able to persuade people that it's going to work for them … when you've got a habit of working in a set way and you're overwhelmed you don't risk changing it. So things about saving time, saving money, more efficient use of resources are one thing but it's also protecting them from their fears about I'm going to be overloaded or this is a whole new structure and it might not work and where does that leave me. You have to address some of those fears as well … So although they like the concept I don't think we've gone far enough in terms of proof and then salesmanship to clinicians*

Fear of opening the floodgates and being overwhelmed
Along with the fear of a tool proving ineffective an additional concern is that it may increase the workload of already overburdened staff. An example of this concern was

described, illustrating the perceived risk attached to an invitation that allows patients to voice their own perspective.

> Interview 1: *… there was a senior nurse … who said [about this tool], I can see what it can do but what is the additional psychological support that you have in place for families who are using this? And I said, we don't have additional psychological support because this is a supportive technique to improve communication, and your staff are already providing the psycho-social support for these families … It was exactly that sentiment … we need extra resources or we can't do it. … don't ask [the client] because there's an ethical and moral obligation to provide services when the need is recognised. It's safer not to ask. ... And yet from the family's perspective they already have that unmet need and they're dealing with it on their own …*

Respondents from the same Pathfinder further discussed the concerns that limit clinicians' readiness to adopt a person-centred approach. Recognition of these very genuine concerns will be essential for identifying ways of addressing them: unless addressed, clinicians are likely to resist implementation of PCOMs that invite a truly person-centred perspective.

Clinicians can be afraid of removing barriers between them and the patients or families they work with, fearing that if patients and families feel genuinely free to voice needs or questions the clinician may be overwhelmed by hopes or expectations they are unable to meet and, likewise, be faced with demands and needs that will be too time-consuming to manage. It often feels safer for healthcare professionals to maintain a power imbalance between them and the patients or families to keep the questions at bay.

> Interview 1: *So there is an element there … an ingrained power imbalance between service provider and service user. There are pockets where this has been evened out but I think that's down to the individual … the degree of comfort they have with giving away some of the professional power which comes as a package with your role and the bravery to admit that you may not have all the answers to the questions that a person brings to you … which moves away from the old premise that you go [to a health professional] to be fixed and you go for answers and to be told what's best for you. So it's unravelling all of that. It's quite a lot to expect.*

> Interview 1: *… it is very uncomfortable – managing expectations becomes a very important part of that role and in a one to one encounter with a family and any health care professional … there will be these sort of unspoken hopes and expectations about what you can offer, and for somebody to say that that might actually not be possible, it is very difficult as a fellow human to disappoint somebody and not to keep that curative [approach].*

> Interview 1: *… from a professional's point of view, I think that's part of the resistance, because recognising the family's priorities in care and recognising that maybe there are things you haven't got the skills and resources to deal with does make that uncomfortable. The phrase 'can of worms' has been used. It's like encouraging disclosure in the GP's practice. And people were*

resistant to that because of the fear of how do you handle it? Similarly there are parallels with this, if you let people choose what they want to talk about … then it's opening this can of worms and [clinicians feel], I fear I don't know how I would handle that.

5.3 Barriers to implementation in commissioning

Limited recognition of value of qualitative data and reluctance to pay for it

The respondent who developed the PCOM for commissioners observed that a key barrier to implementation of PCOMs for CCGs is their tendency to focus on quantitative rather than qualitative data. The respondent emphasised that much of the value of PCOMs is their qualitative component, capturing the aspects of what really matters to people: by not valuing the qualitative data CCGs lose the opportunity to benefit from the improvement-focused insights that PCOMs offer.

> Interview 3: *We know by the very nature of PCOMs and the first principle of starting with what matters to the individual that if we are going to make sense of PCOM data at system or population level, qualitative analysis will have to be part of the process.*

The same person reflected that when discussing potential implementation of PCOMs with CCGS or other care systems, the aspect of cost that they are most challenged by is the qualitative analysis.

> Interview 3: *Changing NHS system leaders' mind set around the value of investing in qualitative data analysis is likely to be a critical success factor in the widespread adoption of PCOMs.*

Priorities are driven by the wider system

This respondent made the point that care systems measure what is demanded of them, and unless CCGs are required to report on PCOMs they are unlikely to implement them.

> Interview 3: *Care systems only measure what their masters demand they submit returns on. This means they measure what matters to NHS England – not what matters to the people they serve. The uptake of PCOMs will be determined by the importance they are given within mainstream system metrics, such as the CCG outcomes framework. If they are not mainstreamed through core management systems like this, they will remain a minority sport*

The same point was made by another Pathfinder, who expressed some concern that, after being supported as a Pathfinder to initiate development of a PCOM, if the site pursues development and validation of the tool, could they feel confident that NHS England will give it full recognition and promote its use.

> Interview 4: *… if we do any development of a validated tool, would that be adopted and would we have that sort of senior NHS England signup to it, and I suppose that potentially will be a concern or a sticking point when we get to that point.*

5.4 Spread: could PCOMs be used more widely

A final consideration is the extent to which the PCOMs developed by the Pathfinders could be used more broadly, in other locations. Views varied with the nature of the tool.

The Pathfinders who were developing PCOMs for use in interactions between clients and clinicians were actively encouraging or trialling their tool in a wide range of settings, as a means of validation and promotion. PCOMs with open ended questions have potential to be relevant in a wide range of settings.

The Pathfinder that was developing a PCOM to improve the short stay that children with specific disorders spend in hospital intended that the PCOM should be used across all similar settings. The respondent recognised that support from NHS England would be needed to achieve this, but voiced a strong view that this would be important.

> Interview 4: *… what you don't want is disparity betwee, this commissioning group's doing this and this is doing that …*

Other Pathfinders that developed a PCOM following close consultation with the service user group or the intended user of the data (CCG) had developed tools that they saw as context-specific and thus, while keen to encourage adaption in other areas, respondents from these sites did not see their PCOM as ready for instant adoption elsewhere.

For the Pathfinder that designed a PCOM for very young children in one hospital, the aim was that the tool should reflect the experience of being a patient in that specific hospital. As the respondent commented, it would be ideal if the tool prompted other hospitals to design a similar tool, but each hospital's questions should reflect the experience relevant to their own particular hospital.

> Interview 5: *As much as I'd like to say [the PCOM] could go to [another hospital] that wouldn't be true to what it's trying to represent. It's trying to represent as much as possible … the experience of this hospital and what they thought was important to them based on their experience here. So what I'm saying is the criteria need to reflect the population where it's been developed.*

> Interview 5: *… we've tried to represent as much as possible the variety of children we see here. We tried to get different specialties of different ages within the 5-11 [age range] and based on their experience and their views of this hospital, this setting.*

> Interview 5: *I would love other people might take this but then … to change the questions to reflect their population … you've got to reflect those that you involved in the development of the measure itself.*

Similarly, the PCOM designed specifically for commissioners, being seen as a local improvement tool as well as an outcome metric, would ideally be co-designed afresh

in each local setting. In this way the selected domains, though unlikely to be totally different in each area, would reflect the local context, and this would enable the local baseline for improvement to be established.

> Interview 3: *Well if you were going to do it in a robust way … you'd have to repeat the process that we've done, but not just to design the PCOM to find out what your baseline is but to identify the improvement challenges. So you can't see this as just a metric. It's actually a quality improvement process that involves a metric that you can measure. So the metric is generated from the quality improvement work but this kind of approach could be built into service redesign process ... the commissioners do service reviews every three years of most big services so it would become part of one of those service reviews.*

> Interview 3: *… how this gets embedded will be different in every area … it's not about a one size fits all process to operationalise this. It's about being clear about what the intention is for the metric and what it will deliver in terms of insights and management capability to the organisation who are using it.*

The respondent commented that, should PCOMs become a national metric, some of the domains or 'touch points' will be common to all services and people, with a smaller number specific to particular services, geographies, providers or patient groups. This flexibility was seen as important for the improvement aspect of the tool.

> Interview 3*: If you want to have something that can be nationally benchmarked you have to take the leap of faith of knowing that if you allow people to co-design this they will inevitably pick some of the same touchpoints or domains, and you will be able to compare those at scale, but local issues and local investment decisions will also mean that there will have to be some variability in those touchpoints too … It has to be grounded in local decisions and investment choices which then translate into a change in people's lives. So you know, if you're looking for a quick fix, a set of I-statements that you can churn out in a survey, that's not a PCOM.*

5.5 Summary and discussion

Pathfinders shared very similar views about the factors that would support implementation of their PCOM. Almost all mentioned the need for the tool to be seen as robust and to be validated, that it should be easy to use, and that there should be high levels of buy-in amongst those intended to use it. Alongside all these however, support at higher levels was seen as essential. Organisational support would be needed to maintain use of a new tool, by acknowledging its value, recognising time spent on using the tool, and building its application into normal practice. For a new tool to continue to influence commissioning decisions ideally funding of related contracts should be linked to achievement of the metrics that the tool assesses. At all levels, recognition and support from NHS England was seen as important. Respondents hoped that, having demonstrated initial support for the Pathfinders' PCOMs by funding their early development, NHS England would acknowledge the value of the completed tools and recommend and support their implementation.

Respondents spoke with much insight about barriers that limit the implementation of PCOMs. For tools and approaches that have the potential to avert worsening physical or mental health, the challenge for staff is how to justify the time spent applying them, when there is no evidence or recognition of successful preventive work. It is only if application of such a tool becomes compulsory, or at least if the time spent using it is built into common practice, that a preventive approach can be seen to be valued as effective.

Another concern is the fear that staff will be overwhelmed by unmanageable demands and expectations if they 'open the floodgates' by inviting service users to freely voice their questions or their needs. Respondents spoke of the professional barrier that many clinicians feel is necessary to keep questions at bay. Unless and until these genuine concerns are acknowledged and addressed it is unlikely that a person-centred approach can truly be adopted.

A related issue is the tendency to value quantitative value far more highly than qualitative data. While all of the Pathfinders are working to develop metrics to support their aims, some retain individual, rather than standardised responses, and for these the qualitative data provides a rich source of information that can inform service provision and commissioning. Analysis of qualitative data is less readily seen as affordable, and yet personal views are essential to set the context for quantitative data and to open the possibility for new perspectives on the familiar.

Finally, to what extent can the PCOMs that have been developed be used in a wider context? That depends entirely on the way in which they were developed. Some Pathfinders viewed their PCOM as a tool that would address a particular issue in any setting; others developed a tool that would be responsive to the particular situation in which they shaped it. Even those in the latter category, however, saw the approach they had taken as replicable, and all are enthused to pursue development and implementation of their PCOM.

Many thanks to all the Pathfinders who spoke with such openness, insight and enthusiasm about their work.

Appendix 2 - Evidence Scan

Introduction

This report summarises the findings of an evidence scan that asked the question: what examples can be found to demonstrate where person-centred information is used in a structured way to influence population-level commissioning decisions with the intention of improving population health and wellbeing? The aim was to learn, from measures others have used, issues to consider when selecting, designing and using person-centred outcome measures to influence commissioning decisions.

Methods

A search of published and grey literature for examples that met the agreed criteria found little that directly addressed the research question. In the absence of directly replicable models the study was broadened out to consider the wider context, and considerations that could influence the way that person-centred outcomes and measures might be used to help shape commissioning decisions.

Background, context, audience and purpose

Much has been written about the meaning of patient or person-centredness, about ways to measure the experience of person-centredness, and about the processes that might support it. Until recently far less attention has been focused on ways of measuring person-centred outcomes, particularly at population level. A major challenge in interpretting the literature is the range of contexts in which the terms 'patient-centred' or 'person-centred' are used, and likewise, the variety of contexts for which person-centred measures can be designed. A central recurring theme throughout this study is the fact that a good measure cannot be designed in abstract: context and purpose are essential starting points when selecting a measure.

Since 2000, health and social care policy documents have increasingly emphasised the importance of a person-centred approach and, over time and in different settings, the ethos supporting person-centredness and the way it has been interpreted has varied considerably. For example, commitment to person-centredness has supported the personalisation agenda, personal budgets, personal care plans, co-production, Patient Reported Outcome Measures (PROMs), consumer choice, integration and outcome-based and value-based commissioning.

In this complex environment, when considering the value and nature of person-centred outcome measures it is critical to retain clarity about the purpose for which outcomes are being measured so that measures are selected that can address the right questions, but also that consideration is given to who determines the nature of the outcomes that should be measured.

Several writers make the point that person-centred processes are frequently assessed against outcomes that are defined by service providers, commissioners or policy-makers, but not against outcomes determined by service users themselves.

When considering approaches to identifying and measuring person-centred outcomes from health and social care it can be helpful to see them from two contrasting directions. One starts from the perspective of the individual service user and, aiming to maximise responsiveness to service users individually and

collectively, sees person-centred outcomes as indicators of what individuals hope to achieve. From this standpoint outcomes should be recorded in a way that can capture personal priorities and definitions.

The alternative standpoint aims to maximise value and effectiveness of service provision and sees person-centred outcome measures as a way of assessing, evaluating and steering services to better achieve these goals. From this perspective it is important that measures are robust, that they can be aggregated in a meaningful way, and that they can be used for comparison across areas and over time.

When attempts are made to combine data from different perspectives it is important to remain aware of the purpose for which the data was collected, the population it was drawn from, and the means by which it was collected to avoid misusing data out of context.

Commissioning – what role might person-centred outcome measures play?

The majority of health services[9] are commissioned by Clinical Commissioning Groups (CCGs) and social services and public health by local authorities. The three Outcomes Frameworks for the NHS, Adult Social Care and Public Health guide commissioning, with the intention that services should increasingly be commissioned on the basis of outcomes rather than processes.

CCGs are assessed against an Indicator Set which makes limited reference to patient centred outcomes, some reference to experience of care, and focuses chiefly on process and clinical outcomes.

Indicators in the Adult Social Care Outcomes Framework are more heavily focused on a person-centred approach than those in the NHS Outcomes Framework. This emphasis is born out in other supporting documents for local authorities.

Arguments have been made for a single national outcome framework across the NHS, public health and adult social care. Closer alignment could support a more integrated emphasis on person-centred outcomes but cultural and practical differences that shape different understandings of the nature and use of person-centred outcomes in some areas of health, compared with social care, mean that achieving a unified perspective across the whole system would be unavoidably challenging.

The increasing focus on outcome-based commissioning highlights the complexities and considerations involved in designing and implementing such an approach and included in the considerations is the question of which outcomes will become part of the contracts, how they will be measured, and who will make these decisions. The point has been made that outcome-focused approaches are not inevitably person-centred approaches: they will only become so if service users are genuinely and actively involved in selection and development of outcomes and their indicators.

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[9] CCGs commission for emergency care, elective hospital care, maternity services, and community and mental health services while NHS England commissions for primary care, specialised services, armed forces, prison health and specialised dental services.

Qualitative approaches for using person-centred outcomes to influence commissioning

As noted already, approaches for collecting and using person-centred outcomes can be polarised into those that start from the perspective of the individual, with a focus on 'subjective', or 'soft' data, and those that start from the perspective of the service, with a focus on 'objective' or 'hard' data. Four approaches are described that use qualitative data and collate it to inform commissioning.

Two of the approaches, both focused chiefly on social care, make use of initial assessments conducted with individual service users to identify their goals, and also of service user reviews that check whether progress has been made towards those goals. Both approaches require that service providers conduct their dealings with service users in an outcome-focused way, and both acknowledge that the prime reason for collecting the outcome-based information is to guide interaction with the service user, but this same information can also be used to inform service delivery and commissioning at population level. One of the approaches developed a workshop process in which service users, providers and commissioners work together to collate and analyse the information collected from individuals to consider the implications for commissioning. The other approach indicates the potential for quantifying the collected qualitative data, but simultaneously acknowledges the challenges in doing so, and recommends the workshop process described in the other approach for combining and considering data from different sources in order to strengthen evidence.

A third approach holds a series of workshops in participating CCGs with varied stakeholders including patients, service providers and commissioners relevant to a selected population group or condition, to discuss feelings and views about the current approach to service provision and changes they would like. Information collected at the workshop is combined with data collected from a national archive, and with existing commissioning data sets to inform future commissioning.

The fourth approach is designed for local authorities and is founded on the principle of co-production. People who will use local services work with providers to identify priority social economic and environmental outcomes and these outcomes form the basis of tenders for commissioning, and of ongoing monitoring and evaluation.

Together, these four qualitative approaches demonstrate ways that person-centred outcomes can be used to inform commissioning by mapping out the priorities and wishes of service users in a relatively undefined way, allowing individuals the freedom to shape their own responses. By doing so they can be seen to provide a perspective that is genuinely user-based, but the very richness of the data limits the potential for aggregation

Quantitative approaches for using person-centred outcomes to guide commissioning

Moving to look at approaches designed to produce quantitative measures that can be readily scaled up, three approaches for producing specific measures are described, then two examples of practical ways that measures are being sought to assess the achievement of selected outcomes for segmented populations. As with all measures, the extent to which those described in this section can be considered good examples

of person-centred outcome measures depends on the context in which they will be used and the purpose for which they are intended.

Patient Reported Outcome Measures (PROMs) are designed to measure respondents' perception of their general health (generic PROMs) or of their health in relation to specific diseases or conditions (condition-specific PROMs). They are created as standardised questionnaires that ask respondents to respond to specific pre-defined categories. Ideally all PROMs are validated but given the vast number of PROMs and the age of many, evidence of validity should always be reassessed before use. Another significant variation between PROMs is the basis from which question topics and response categories are derived. Some are designed entirely by clinicians, some by building on findings from relevant patients or service users, and many with mixed input. In this way no overarching statement can be made about the validity of PROMs, nor the extent to which they can be considered to truly measure person-centred outcomes. Critics of PROMs point to the lack of opportunity for respondents to identify their own priorities. Although, when introduced into the NHS for routine use before and after four specific clinical procedures, it was envisaged that routine use of PROMs would soon spread more widely this has not been the case and there is little evidence of data from the four routinely used PROMs being used to inform commissioning. If, however, PROMs are well designed to ask questions and offer responses based on information collected from relevant service users, they can provide a useful measure that contributes to an understanding of person-centred outcomes.

The International Consortium for Health Outcomes Measurement (ICHOM) aims to develop robust health outcome measures that focus on the outcomes that matter most to patients, and that can be used internationally for comparison and improvement. ICHOM has already developed 12 Standard Sets of Outcome Measures for various conditions and is working to produce more. Each Standard Set has been developed by working with leading international clinicians, registry leaders and patient representatives. From a long list of potential outcomes patient representatives prioritise the outcomes of most importance to them, and the international team then works across disciplines to identify feasible, valid and reliable outcome measures. Each Standard Sets of Outcome Measures is made up of a number of domains, each with a PROM for measurement, and a reference guide indicates time points for data collection and associated risk factors. One CCG in England has incorporated the ICHOM Standard Set of Outcome Measures for Low back Pain as a small part (currently less than 1%) of its new outcome-based approach to commissioning for musculoskeletal care.

As part of the work to identify outcomes and experiences that matter most to users of care and support, National Voices worked with service users to develop a set of 38 'I-Statements' that outline key issues of importance, grouped under six headings: goals/outcomes, communication, information, decision making, care planning and transition. While some of the statements relate to overall goals or quality of life, more relate to aspects of care that are essential for preventing deterioration and to experience of care. As such, they prompt reassessment of the meaning and categories of person-centred outcomes. The term is often used to refer to the outcomes individuals want from their lives, while the 'I-statements' report on what people want from their contact with support services. Equally, a distinction is usually

drawn between measures of experience of care, and measures of outcomes (whether from care or more generally) while the 'I-Statements' cover both experience and outcomes. It is important, therefore, to remain aware of what exactly the 'I-Statements' include, and to consider whether ratings of experience of care and outcomes from service use match the intended requirement for person-centred outcome measures. A key advantage of the 'I-Statements' is the further work done by the Picker Institute to develop a set of 18 validated questions closely related to the original 38 statements that can be inserted into surveys to allow quantification of the extent to which the 'I-Statements' are being met.

Five CCGs in North Central London are working to develop a value-based approach to commissioning. With segmentation as the starting point they identified three populations with which to work: frail elderly people, people with diabetes, and people with mental health problems. Stakeholders from each population segment worked with their advocates and healthcare professionals in interactive workshops to identify themes that mattered to patients, then potential outcomes were generated from the themes. These were further refined with commissioners and providers, resulting in outcome frameworks against which services could be designed. The next step is to develop measures for the agreed outcomes. Laborious work is being undertaken to identify measures that can act as indicators for each of the selected outcomes. The process begins with consideration of whether any existing dataset can provide a direct or proxy indication of the specific outcome. If this looks possible further questions are asked to assess the relevance and feasibility of using that dataset. If no appropriate datasets are available consideration is given to using existing PROMs, and if the outcomes defined by the local population cannot be measured with existing measures, it may be necessary to develop measures locally. The consultant working with the North Central London CCGs to develop this approach observes that outcomes are very consistent across similar groups of people in different localities, noting about 80% similarity across different regions. From this observation it is reasonable to surmise that the focus will, over time, shift from creating new outcome sets for specific populations to reviewing and adapting standard outcomes to match specific needs of local people. In the same way if valid outcome measures have been defined for specific outcomes, that aspect of the work will also become less onerous.

North West London Whole Systems Integrated Care (WSIC) programme is also working to identify measures that match outcomes identified for a segmented population group in order to drive outcome-based commissioning. Having selected the section of the population aged 65 and over, ten Early Adopter sites each worked with patient representatives and providers to identify outcomes and develop re-worked 'I-Statements' that could be locally owned. The outcomes were then collated by the WSIC central team and grouped into five domains, each with an 'I-Statement.' The central team went on to develop a core set of 16 metrics aligned to the five domains. As with the North Central London measures, most of the metrics draw on data that is already collected, allowing comparison across sites and over time, and benefitting from previous validation of data collection processes.

In both practical examples, while all proposed measures can be linked back to outcomes identified with clear input from service users, many of the selected

indicators are drawn from standard data collected primarily to measure inputs, processes and outputs rather than outcomes.

Measures, considerations and challenges

An overriding message that emerges from the literature is that no single method or measurement can be recommended beyond all others: the value of a measure comes from its appropriateness to the situation, and triangulation of methods is important to strengthen evidence by drawing from different perspectives.

Clarity of purpose is the starting point, and alongside this question, agreement about whose views influence the decisions about which outcomes are measured, and the extent to which service users have genuine influence in these decisions.

When selecting or developing measures the first step is to identify the relevant population. Generic measures across the whole population allow comparison across different patient groups and different services, but have limited exploratory value. Segmentation of the population by condition or demography allows identification of more homogenous outcome domains, leading to more specific measures.

The process of selecting measures is best addressed by determining the most pertinent criteria the measure should address given the context, the audience, and the purpose for measuring the outcome. Many lists of potential criteria are available and the relevance of each criterion varies with the purpose.

As noted above, it is pragmatic to begin by considering whether existing datasets can match the selected criteria and provide adequate indication of the chosen outcomes. If not, a PROM may be selected that can provide a relevant measure. If a new data collection process is to be established there are many considerations to address, even if using a well-validated tool. If no existing datasets or tools appear adequate to measure a chosen outcome a new tool may be designed. Development, testing and validating a tool is a lengthy process, and once developed, the establishment process is still ahead.

Attempts have been made to quantify qualitative data but there are major methodological challenges to doing so. Qualitative data are best seen for the value they offer in their own right.

Conclusion

A key message repeated throughout this report is that the value of any person-centred outcome measure depends on its appropriateness to the purpose for which it is intended, the audience and the context. Alongside this it is crucial to be clear about who will select the outcomes that will be measured.

Approaches for reporting person-centred outcomes described in this report include qualitative methods that most closely capture the essence of personal outcomes but are not readily scaled up and quantitative approaches that, to varying degrees, meet criteria of validity and reliability and can be aggregated, analysed and compared, but that limit or remove opportunities for identification of what matters to service users outside of pre-defined options and leave little opportunity for prioritisation. If domains of interest to service users have been comprehensively identified and represented in a quantitative tool it may offer adequate representation of service user views.

The growing interest in outcome-based commissioning prompts additional attention to outcome measures, but unless service users genuinely influence decisions about outcomes, there is no reason to assume that the measures can be considered person-centred. If service users are genuinely involved in selecting the outcomes, and work continues to identify existing data sets that act as direct or proxy indicators for most of the selected outcomes; if PROMs are used to measure outcomes not addressed by standard datasets; and if a small proportion of data is collected specifically to measure locally defined outcomes, to what extent does this match the expectations of person-centred outcome measures?

Again, the answer depends on the purpose for using person-centred outcome measures. The approach described above holds potential promise for hearing from local populations the clinical and health-related quality of life components they want from their services, and data collection can support measurement of the extent to which their wishes are being met.

Others, however, have different hopes for person-centred outcome measures and see them as a way of changing the system to one that is more responsive to broader concerns. There is no evidence of a measure in use, or in development, for commissioning that can achieve this. Qualitative data provides the best source of rich data that outlines individual priorities. Data of this nature can be collated but not readily quantified.

Appendix 2 - Evidence Scan

1 Introduction

This report summarises the findings of an evidence scan that set out to address the research question: what examples can be found to demonstrate where person-centred information is used in a structured way to influence population-level commissioning decisions with the intention of improving population health and wellbeing?

The research question, commissioned by NHS England, aimed to identify examples where person-centred outcome measurements had been devised, collected and used to inform population-level decisions about health-related services. The purpose was to learn from the experience of others the issues, benefits and challenges of specific decisions about what aspects of patient-centredness to measure, what indicators to select, data to collect, by what means, how to aggregate the data and how it could be used to guide population-level decisions about service provision. It was agreed that the scan would include published and grey literature in the English language.

The literature scan was part of a broader programme of work investigating ways that person-centred outcome measures could be understood, and used to inform commissioning intentions and resource allocation.

2 Methods

Initial scans of published literature by two people individually (a researcher and a librarian), using combinations of search terms including person or patient-centred/ness, measures, outcomes, PCOM, data, population, commissioning, planning, monitoring, decision-making and others, yielded thousands of papers but from scanning topics and reading abstracts and whole texts of 50 of the potentially more promising documents it was evident that none of the papers addressed the question and that skilled and painstaking effort would be required to identify articles that did.

An experienced librarian from Health Education England conducted a search of published and grey literature. The search strategy used is attached (Appendix 1). Again, the search yielded thousands of papers and the librarian identified 80 of the most promising. All the identified abstracts and most of the full papers were then read for relevance.

In addition to searches by the librarian, potentially relevant papers from websites and reference lists were read and conversations held with other researchers and practitioners in an attempt to uncover unreported examples or work in progress.

In brief, disappointingly little emerged that directly addressed the research question. The report that follows describes approaches that aim to address the challenge of aggregating person-centred outcomes to influence commissioning decisions and, in the absence of many replicable models, discusses some of the broader considerations and challenges.

A limitation of this study is the lack of direct input from commissioners. Ideally, as a report that focuses on the role of person-centred outcomes in commissioning the perspective of commissioners should be an important component. Time did not allow commissioners' views to be sought.

3 Background: context, audience and purpose

What are person-centred outcome measures?

A key challenge in the quest to make practical use of person-centred outcome measures is the lack of a shared understanding about the meaning of the term. The concept of patient-centredness is complex and as De Silva, in her extensive review of the empirical literature on person-centred measures notes, 'the complexity of the concept contributes to the challenge of articulating its shared meaning and describing how it can be applied in practice' (De Silva, 2014, p.8).

While much has been written on ways of measuring person-centred processes, activities, and the experience of patient or person-centredness, far less has been written on ways of measuring person-centred outcomes (De Silva, 2014, p.11). Where empirical work has been done, until recently it has focused mainly on assessing the impact of person-centred interventions on individuals in order to tailor care more effectively, rather than, as intended for this study, looking at person-centred outcomes at a population level to influence the way resources are allocated. The challenge is not only finding how to measure the outcomes, but determining what outcomes to measure.

Much of the difficulty stems from the variety of contexts in which the term 'patient-centred outcome measures' is used. As De Silva emphasises, 'it is not possible to define what makes a good measure until there is some clarity about what teams are trying to achieve. … Context and purpose need to be considered when designing and implementing measurement strategies.' (De Silva, 2014, p.24).

Before considering the potential value of using person-centred outcome measures in the specific context of commissioning, some of the current settings in which the term is used are described below, in order to untangle the relevant meanings for this study.

Varied policy contexts

The importance of a person-centred approach has been increasingly and explicitly acknowledged in health policy documents since 2000, and particularly since Lord Darzi's *Next Stage Review* (Department of Health, 2008) with its drive towards quality, individual choice and empowerment. Alongside this, the direction set in the 2006 White Paper *Our health, our care, our say* (Department of Health, 2006) and the personalisation agenda of *Putting People First* (Department of Health, 2008) supported increasing emphasis on co-production, personal care plans, personal budgets, integrated care, and other practical applications of a person-centred approach.

In 2010 the White Paper *Equity and Excellence: Liberating the NHS* (Department of Health, 2010) further emphasised quality and patient involvement in decision making, and committed to increase the use of Patient Reported Outcome Measures (PROMs) as a means of providing information about 'how patients feel about their own health, and the impact of the treatment or care they receive' (ibid. p.54).

Momentum towards person-centred care also developed through the integration agenda, set out in the document *Integrated Care and Support: Our Shared*

Commitment (Department of Health, 2013) which built on the work of National Voices with their 'I-Statements' (National Voices, 2013). The 'I-Statements' were further developed by the Picker Institute into a set of questions which could be used in existing surveys to measure people's experiences of integrated care in health and social care (Picker Institute, 2013). Work undertaken through the Better Care Fund, the Integrated Health and Social Care Pioneers and the later Vanguard sites all includes a person-centred focus as the programmes work to deliver services that operate across sectors.

Alongside the move towards integrated care the increasing focus on outcome-based commissioning also recognises the need to view services from the perspective of the people who use them, rather than from the position of the organisation that provides them. 'Outcome-based commissioning aims to achieve better outcomes through more integrated, person-centred services and ultimately provide better value for every pound spent on health and care' (NHS Confederation, 2014, p.3)

Each of these threads of policy and practice build on the concept of person-centredness; each needs to achieve and measure outcomes; but they do so in different contexts, from different viewpoints and for different purposes.

Which outcomes and who defines them

In a guide to measuring impacts and outcomes from the Better Care Fund a diagram usefully represents the range of different levels at which outcomes can be understood and (theoretically, at least) measured (NHS England, 2015, p.6).

Starting with the individual level, the diagram lists outcomes measured by people's experience of health, care and support. At the next level are outcomes for individual provider organisations. At the local level there are outcomes for commissioners. Finally, at the local whole system level, there are outcomes for the Better Care Fund. Other programmes will have different top level outcomes to work towards, but essentially**,** clarity is needed about the level at which outcomes are being measured, and, importantly, who determines which outcomes should be measured at that level.

De Silva, in her review, notes that even where processes are person-centred, the outcomes from those processes are often defined by others: 'throughout the empirical literature, the outcomes of person-centred care tended to be measured using data about satisfaction, quality of life, functional status or health service use. In other words, person-centred care was sometimes seen as a mechanism by which

other outcomes may be achieved and those outcomes were measured using other sources, not person-centred care tools' (De Silva, 2014).

Collins (2014) makes the case that organisations orientate themselves to deliver on what they measure, and few of the measures in use come from the perspective of patients. Thus, providers and commissioners tend to value person-centred care only in terms of its impact on pre-defined system outcomes. '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 processes.' As a result, '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' (ibid. p.12).

SCIE, in their review of outcomes-focused services for older people, provide a description of what a person-centred service, and outcomes might mean.

> *'Outcomes' refer to the impacts or end results of services on a person's life. Outcomes-focused services are therefore those that aim to achieve the goals, aspirations or priorities of individual service users. They can be contrasted with services whose content and/or form of delivery are standardised, regardless of the circumstances of users; and with services whose goals, content and mode of delivery are primarily determined by those who commission or deliver them rather than those who use them'.* (Glendinning et al. 2007).

Two different starting points: the individual or the organisation
In its work on person-centred outcomes, the Health and Social Care Alliance highlights two different (and admittedly polarised) directions from which the motivation and approach to measuring outcomes can be seen (Health and Social Care Alliance, 2013).

One approach, essentially service driven, starts from the perspective of the individuals who use the services. From this perspective the central motivation for recording outcomes is to maximise responsiveness to those who use the services, both individually and collectively. The individuals' personal definitions of what matter to them and what they hope to achieve are the outcomes to measure.

The alternative approach is driven primarily by accountability, evaluation and improvement with the key motivation for measuring outcomes being to maximise value and improve effectiveness at population level. From this perspective the validity of responses and the ability to aggregate them is central.

Miller (2012) further characterises this as a split between a relationship-focused ethos aimed towards outcomes for the individual versus a consumerism-focused one that emphasises choice and cost-containment.

This polarised view captures the tension between the personal and macro approaches to measuring outcomes. Any attempt to merge the two approaches faces the challenge of retaining the quality of individual perspectives while supporting the aggregation needed for population-level influence. As the Health and Social Care

Alliance (2013, p.3) notes, 'context, purpose and principles are key considerations. In practice settings, quality of engagement can be compromised by evaluative undercurrents. Using outcome 'measures' at decision-making levels other than those for which they were intended is problematic …'.

Summary

In both policy and practice there is a keen focus on person-centredness. The meanings, methods and motivations for a person-centred approach vary. Despite the considerable literature on person-centred measures there is far less focus on measuring outcomes from a person-centred perspective, particularly beyond the level of the individual. A central question which has potential to shape or re-shape services and systems is the one of which outcomes should be measured, and, who makes this decision. There follows the practical question of how the outcomes, once determined, should be measured. A separate but crucially related question is who will use the measures and for what purpose.

1 Commissioning – what role might Person Centred Outcome Measures play?

Current commissioning focus on outcomes

The current approach to commissioning was set out in the White Paper *Equity and Excellence: Liberating the NHS* (Department of Health, 2010) which outlined the intention to move commissioning away from a focus on process targets and towards outcomes. As part of this move the White Paper established three Outcomes Frameworks: the NHS Outcomes Framework (Department of Health, 2014b), the Adult Social Care Outcomes Framework (Department of Health, 2014a), and the Public Health Outcomes Framework (Department of Health, 2013b).

Clinical Commissioning Groups (CCGs, also established in the same White Paper) and local authorities commission for services against priorities set in the Outcomes Frameworks, which are reviewed annually. Since 2010, the increasing emphasis on integration has led to growing numbers of shared indicators across the Frameworks.

Current CCG reporting arrangements – limited focus on person-centred outcomes

The performance of CCGs is assessed against a CCG Outcomes Indicators Set (COIS) (which reflects the NHS Outcomes Framework), the CCG Assurance Framework, and a complex web of other indicators. The CCG Assurance Framework identifies five domains against which the performance of CCGs is assessed. Under the domain headed 'Well led organisation', there is a requirement to 'Involve and engage patients and the public actively' (Department of Health, 2015a).

Ham et al. (2015) reviewed current and alternative reporting arrangements for CCGs and emphasised the value of the COIS, recommending that it, along with the three Outcomes Frameworks (which they suggest be merged into one) should form the basis of future approaches for reporting on health system performance. Indicators in the COIS are developed by the National Institute for Clinical and Health Excellence (NICE) to ensure that they are evidence-based and cost-effective, and the Health and Social Care Information Centre (HSCIC) undertakes technical feasibility assessments of the indicators. The vast majority of these indicators measure process or clinical outcomes, some measure experience of care and a small number could be seen to measure patient centred outcomes: ('People with long-term conditions feel supported to manage their condition'; 'Health Related Quality of Life for carers'; and 'Health Related Quality of Life for people with a long term mental health condition') (Department of Health, 2015b). It is hard, under the current arrangements, to see where else in the COIS a focus on person-centred outcomes is stipulated.

Social care commissioning – stronger focus on person-centred outcomes

Local authorities commission against the Adult Social Care Outcomes Framework and the Public Health Outcomes Framework.

The Adult Social Care Outcomes Framework has three domains which, arguably, require reporting against a more person-centred approach than does the NHS Outcomes Framework. The first three indicators, under the domain of 'enhancing quality of life for people with care and support needs' are: 'proportion of people who use services who have control over their daily lives'; 'proportion of people using

social care who receive self-directed support, and those receiving direct payments'; and 'carer reported quality of life' (Department of Health, 2015b).

In 2015 the Local Government Association published a document titled *Commissioning for better outcomes: a route map* (Local Government Association, 2015) which set a framework of nine standards to support local authorities with self-assessment and continuous improvement of their commissioning practices. The nine standards are grouped under three domains, two of which are potentially relevant to the development and use of person-centred outcome measures.

Standard 1: Person-centred and focused on outcomes – 'Good commissioning is person-centred and focuses on the outcomes that people say matter most to them. It empowers people to have choice and control in their lives and over their care and support.'

Standard 4: Co-produced with people, their carers and their communities – 'Good commissioning starts from an understanding that people using services, and their carers and communities, are experts in their own lives and are therefore essential partners in the design and development of services. Good commissioning creates meaningful opportunities for the leadership and engagement of people, including carers and the wider community, in decisions that impact on the use of resources and the shape of local services.' (Local Government Association, 2015 p.5).

The document suggests ways that each standard might be enacted, and lists potential evidence to demonstrate progress. Suggested evidence includes routine and consistent collection of quantitative and qualitative information against outcomes, including feedback from people who use social care, their carers and advocates, but no specific outcomes or measures are suggested.

Some local authorities also commission against the *Making It Real statements* from Think Local Act Personal (TLAP). The latter is a framework of six themes, substantiated by 'I-Statements' developed nationally by service users and carers, that offers a means by which organisations can measure their progress towards personalisation. (Think Local Act Personal, 2012). Organisations that sign up to *Making It* Real are expected to select three priorities from the framework to work towards, and to self-report each six months on their progress. Reporting requires the organisation to grade itself on a four level rating system against the relevant 'I-Statements', each of which, at the end of the document, are supported by qualitative examples of ways that the 'I-Statements' might be met.

Closer integration between health and social care commissioning
As noted above, the review by Ham et al. (2015) recommends that the three Outcome Frameworks be merged into one. The Local Government Association and NHS Clinical Commissioners also put the case for a single national outcomes framework across NHS, adult social care and public health to support the development of common objectives and a system-wide approach to self-assessment for and by commissioning bodies. (LGA and NHS Clinical Commissioners, 2015).

The Alliance, reporting on the work on person-centred outcome measures in Scotland, also suggests that a comprehensive set of outcome measures should

underpin integration of adult health and social care, and notes the potential of a person-centred approach to support integration. The report, *We've Got To Talk About Outcomes* (Health and Social Care Alliance, 2013), notes that while a person-centred outcomes approach has been widely adopted in adult social care in Scotland, adoption in healthcare settings has been far more limited.

The authors suggest that integration of health and social care can support increasing cross-fertilisation of ideas and approaches, but, as the extended extract from their document below describes, there are very significant cultural and practical barriers to be overcome. These differences are not specific to Scotland.

> *The concept of 'personal outcomes' is virtually unheard of in more mainstream and bio-medically oriented NHS services, where clinical outcomes measures and PROMs are more familiar. The limited uptake in healthcare settings was recognised in the 2012 Review of the Talking Points Personal Outcomes Approach. It was attributed, in part, to the somewhat different interpretation of outcomes that is prevalent in health. However, the review also recognised that a future of health and social integration means that such disparities must be reconciled. … Facilitating personal outcomes requires more than a different understanding however. A Personal Outcomes Approach demands a significant shift in the way that data are managed, analysed and understood. It also necessitates a departure from consistency, standardisation and compliance to embrace flexibility and responsiveness using case by case judgement and authentic motivation. That will be challenging within NHS settings where managerialist approaches to service delivery, clinical governance and evidence-based practice are the cornerstones of quality, and it may be premature or even inappropriate in some settings. A focus on personal outcomes is consistent with the shift from narrow professionally-led agendas towards shared agendas that accommodate individual values and aspirations. The possibility that healthcare professionals might be required to support the achievement of outcomes in other domains presents a number of new challenges, not least the issue of how far the focus should be on supporting broader and more personalised quality of life concerns.* (Health and Social Care Alliance, 2013, p.29.)

Move towards outcome-based commissioning
As already noted, the White Paper *Equity and Excellence: Liberating the NHS* (Department of Health, 2010) established frameworks for outcomes that set priorities against which CCGs and local authorities should commission. Nevertheless, payment for agreed services has continued along traditional lines, where providers are commissioned for and paid by activities, processes and targets, such as the number of contacts with patients, number of admissions, number of operations, hours of services, waiting times.

Increasingly, interest is growing in outcome-based commissioning whereby, instead of being paid for processes, providers are paid for outcomes that matter to the people who receive them. Part of the appeal of this approach is its potential to incentivise providers to innovate, and to work collaboratively to find better solutions for their populations and to reduce duplication and waste (The Health Foundation , 2015). If the concept of 'outcomes' is applied in its fullest sense it is unlikely that any single

provider will be able to deliver a given outcome in isolation from other providers, so joint accountability is needed for outcomes and costs (Outcomes Based Healthcare & Capsticks 2014).

While the appeal of this approach is evident, the practical considerations involved in enacting it are challenging and require extensive prior investment and long lead times. Decisions and agreements are needed about the contracting mechanism to use, the nature of the contract, and the incentive mechanisms. Outcomes can be commissioned on the basis of population, conditions, or a pathway. Contracts can be agreed with a prime provider, an alliance or a joint venture. Decisions and agreements are needed about payment systems, about how risk or benefits will be shared, and the transition to a new approach must be carefully handled. Much work is underway to explore the opportunities and approaches for outcome-based commissioning and value based commissioning, but most pertinent to the question of person-centred outcome measures is the question of how outcomes, for outcome-based commissioning, will be chosen. And then, how they will be measured.

A paper written in 2010 warned that while the move towards outcomes-focused commissioning was a positive development it was not necessarily synonymous with a person-centred approach:

> *Outcomes-focused approaches are not, however, the same as person-centred approaches. They can complement each other, but the difference depends on who sets the outcomes and on the power relationships between the commissioner, the provider and the person requiring support. An organisation using an outcomes-focused approach can retain full professional control over the commissioning process and therefore marginalise the role of people using services, and their families*. (Department of Health, 2010b).

More recently, a briefing from the NHS Confederation on outcome-based commissioning made a similar point (NHS Confederation, 2014). The paper emphasised the need for careful consideration of which problems offer enough scope to add value to people's outcomes to justify the investment of time and skill needed to develop outcome-based commissioning. 'Providers and commissioners together need to think through the specific problem to which outcome-based commissioning is to be applied, the improvements to care sought, and how financial and quality risk around service change will be managed'. As they go on to say, the nature of the outcomes sought are a crucial consideration, and to add real value, they must be 'patient-centred, based on local needs and priorities and address prevention.' 'Contracting for patient-centred outcomes will rest on effective user engagement throughout the process of developing the outcome-based contract, as well as during its delivery.' (NHS Confederation, 2014, p.9).

Value based commissioning, where value is seen as health outcomes for patients divided by the cost of delivering these outcomes, follows the same principle, with the requirement to identify outcomes for patients across a whole care pathway or condition.

While not inevitable, outcome-based commissioning holds potential to drive forward the development of person-centred outcome measures, with the requirement for robust person-centred outcomes, and hence measures, to commission against.

Progress, however is slow. The NHS Confederation document suggests 'it may well be five or 10 years before it is possible to proceed with significantly greater confidence than today' (ibid. p.17).

Summary
Since 2010 commissioning in health and social care has been guided by outcomes, and there is growing interest in services being commissioned for, and paid by, outcomes. As ever, a key question is which outcomes, and who defines and determines them. Current commissioning reporting frameworks for CCGs make limited explicit demands for a person-centred approach to setting outcomes. By contrast, commissioning in social care, with its agenda of co-production and personalisation, has a more explicit focus on the role of person-centred outcomes in its operating principles. The growing interest in outcome-based commissioning, and the move towards a more integrated approach to health and social care provision may drive the need for a stronger focus on person-centred outcome measures.

2 Qualitative approaches for using Person Centred Outcomes to influence commissioning

Focus on 'subjective' or 'soft' outcomes

The move towards personalisation encapsulated in the *Putting People First* programme (Department of Health, 2008) led to an early focus on using person-centred information to influence commissioning in social care. A paper published in 2009 states: 'The transformation agenda means that many previous measures are becoming less useful and councils are having to develop new ways of understanding outcomes.' The paper distinguishes between '"objective outcomes" (such as improved health or lower residential care admissions)', and '"subjective outcomes" which concern what is important to individual people', acknowledging both as important (Department of Health, 2009 p. 10). In other documents the same distinction is made between 'hard' and 'soft' data, where personal outcomes ae seen as 'soft' outcomes in contrast with 'hard' measures of service performance, throughput and clinical outcomes (Apps *et al.* 2013).

In the four qualitative approaches described below, 'subjective' person-centred outcomes are collected and collated in a qualitative, initially non-numeric way, to inform commissioning with local authorities or CCGs.

5.1 Working Together for Change

In 2009 two documents were published that, together, set out an approach designed to collate individually defined personal outcomes in a way that could guide commissioning decisions. One document: *Outcome-focused reviews: a practical guide* (Bennet *et al.* 2009) presents a process, developed with people receiving social support, to conduct initial assessments with individual service users to identify the goals they want to achieve and develop a support plan that records their intended outcomes. The same process is used to conduct outcome-focused reviews by going back to the same individuals to look again at the outcomes they selected, asking what is and is not working, and checking how much progress has been made.

The second document, *Working Together for Change* (Department of Health, 2009) describes a six-stage workshop process in which commissioners, providers and local service users collaborate to analyse the information from outcome-focused reviews or support plans on what is and is not working locally, and together consider how best to use this information to inform planning and commissioning.

The outcome-focused review process, though open to local change, proposes a set of outcome domains as general headings under which outcomes might be organised. The stated benefits of these pre-defined domains are that they allow the person conducting the support plan to check that the full range of needs is covered; they enable commissioners to understand how individual goals relate to local and national policy aims; and they make the information more useful for performance management and commissioning. The seven domains are:

    1) Community life: leisure, learning and work
    2) Managing money

3) Family and relationships
4) Choices and changes
5) Living safely and taking risks
 6) Health and wellbeing
7) Everyday tasks

During the assessment and review process service users select their top three goals. As well as supporting service providers in their contact with the individual, prioritisation of goals can provide useful information for commissioners, indicating the domains of most significance to those who use the services.

There are several accounts online, dated between 2009-2012, of councils who applied this approach (Bennet at al.2009; Early et al. 2014; Shared Lives Plus, 2013).

5.2 Talking Points

The Joint Improvement Team in Scotland has conducted extensive work to develop a framework that aims to use information from individual outcomes to influence organisational decisions. The name for the approach is Talking Points. It aims to develop a 'personal outcomes focused approach' that achieves 'coherence and connectedness' between the two different levels of outcomes: first, the perspective that starts with the individual and sees personal outcomes as what matters to the person using the service; and second, the evaluation-focused concept of outcomes that assesses the impact of an activity or of a service.

The originators of the approach stress that their primary emphasis is on the first of the above two levels. 'In a personal outcomes focussed organisation, it is the outcomes for individuals that should primarily drive activity. Over time, organisations can use outcomes information gathered through support planning and review to verify whether they are achieving the outcomes they intended and unintended outcomes too. They may then wish to review their organisation outcomes over time' (Cook and Miller, 2012, p.16 Italics in original).

The Joint Improvement Team recruited several local partnerships in Scotland to work with them to develop and test their approach. Many organisations in Scotland have since gone on to use it.

The approach requires service providers to 'engage with individuals in outcomes focused ways' and to record information in outcomes-focused support plans. Outcomes are seen to fall into three main categories: quality of life or maintenance outcomes (the aspects of a person's whole life that they are working to achieve or maintain); process outcomes (those that relate to the experience of seeking, obtaining and using the support services, and which may influence the extent to which other outcomes are achieved); change outcomes (those that relate to the improvements in physical, mental or emotional functioning that individuals seek from a particular service intervention or support) (Cook and Miller, 2012, p.11).

The outcomes, though recorded primarily to guide the service's contact with the individual, 'can be used to support an element of outcome 'scoring' during (assessment and) review, enabling progress in achieving individual outcomes to be

measured using numeric scales or Likert-style importance and/or improvement scales. In this way scoring can indicate which types of outcomes are and are not being met for people.' (Health and Social Care Alliance, 2013, p.20).

As this report goes on to say:

> *This approach can therefore inform service redesign and improvement, contribute to outcomes focussed planning and commissioning and has the potential to inform national thinking.*
>
> *While the Talking Points outcomes framework offer strong **potential** to enable personal outcomes data to be collected, realising this potential is less straightforward. The most significant issue is deciding how to record personal outcomes data, notably the emphasis placed on capturing qualitative data or relying upon quantitative scoring mechanisms in a way that supports aggregation for reporting purposes.* (ibid. pp.20-21. Emphasis in original).

On the same theme the authors of the Talking Points guide note that 'further work is needed to determine the best ways of categorising responses and of indicating reliability.' They also note that 'The rich and detailed nature of the information gathered means it is particularly valuable for improvement purposes. However, the subjective nature of the information (as with all information based on personal experience) does limit the extent to which generalisations can be made from aggregated data, which is a limitation when using information for performance reporting' (Cook & Miller, 2012, p.30).

They note the importance of triangulating data before any robust conclusion can be reached. The authors recommend the Working Together for Change process as a practical approach that can bring together data from a range of sources to inform commissioning.

5.3 Experience Led Commissioning

Experience Led Commissioning (ELC) is described as 'a new approach to planning and buying healthcare services. It is built around the idea that if we listen to and deeply understand people's experiences, we will design better, more person-centred services that deliver better care for people in [the local area]' (Experience Led Commissioning, 2014). Unlike the other approaches described in this section, ELC works chiefly with CCGs, rather than with local authorities.

When engaged to work in a specific area, the standard ELC approach is to hold five or six 'co-design events' where patients, carers, service providers, front line medical staff, GPs and commissioners meet, in workshop settings, to discuss how they feel about the current approach to service provision, changes they would like, and how those changes could happen. Workshops are generally preceded by a viewing of DVDs showing patients (from the relevant population group or with the relevant condition) talking about their experiences of care, helping participants to engage with the lived experience. As well as collecting local views the workshop events are intended to create a sense of ownership, commitment and momentum for change.

ELC uses information from these local person-centred planning processes in conjunction with patient perspectives drawn from secondary analysis of 'a national data archive of health experience that has been systematically collected and analysed by the University of Oxford's Health Experience Research Group' (Cheshire & Ridge, 2012).

The analysis of this national data, along with existing commissioning data sets, is combined with local views to inform future commissioning. There are accounts online of CCGs using the ELC approach(Experience Led Commissioning, 2014; Cheshire & Ridge, 2012).

5.4 New Economics Foundation: Commissioning for outcomes and co-production

The New Economics Foundation has also designed a qualitative approach that aims to use outcomes to influence commissioning. It starts from the premise that well-being plays a central role in people's lives, and has designed a process that aims to make well-being the explicit overarching goal of commissioning public services in local government. 'In practice this means using well-being as a framework for organising support for people and as a measurement tool against which progress can be evaluated. It makes sense to privilege well-being as the main goal of commissioning public services because it captures what really matters to people – feeling good and being able to flourish in society' (Slay and Penny 2014, p.23).

In the paper titled *Commissioning for outcomes and co-production: a practical guide for local authorities* (Slay and Penny, 2014)*,* the authors presents a structured approach for developing an outcomes framework which sets out the priority outcomes (social, economic and environmental) for the local area. Co-production is at the heart of the approach: the framework is co-produced with providers and with the people who will use the services. The outcomes selected as a result of applying the NEF approach form the basis of tenders during the procurement phase of commissioning, and are the basis of ongoing monitoring and evaluation throughout delivery of the services.

The approach works towards three aims: prevention, well-being and value for money. It is built on three components: coproduction; partnership; reflection and evaluation. The three components are seen as essential aspects of each of the three structured commissioning phases, which NEF names as 'insight, planning and delivery'. They are discrete, sequenced phases that involve specific activities, including needs and assets assessments, service design and procurement (ibid. p.17).

> *With NEF's approach, commissioners develop an outcomes framework, and ask providers to work with people they support to design the activities that will achieve those outcomes. Specifying broad outcomes over specific outputs and services gives providers the space to be innovative and flexible in shaping services. It affords providers the freedom to work closely with the people they support to co-produce services around their personal and collective needs, strengths and wishes. It also enables providers and commissioners to generate public value across the triple bottom line and beyond the service itself.* (ibid. p.19).

With its emphasis on co-production NEF believes it can improve the effectiveness of commissioning decisions and the reach and capacity of services. As their report says 'A lot of public money is misspent because problems are diagnosed and solutions proposed by professionals who, however intelligent and well-meaning, fail to engage with the experiential wisdom of the people who are intended to benefit from their services' (ibid. p.32).

The report includes several examples of local authorities that have applied the approach that it recommends.

Summary
A number of mapping approaches have been developed that work with individual service users or members of local populations to identify desired outcomes and then extrapolate from those to determine the implications for commissioning. Four approaches are described here. Two of the approaches build on outcomes initially collected from individuals as part of service assessment and review by aggregating individual responses: one using a qualitative thematic approach and the other through a process of quantification. The other two approaches start at the population level, working with individuals as representatives of the wider population to identify the outcomes they want services to achieve. Three of the approaches described here work mainly with local authorities and one predominantly with CCGs. What all four have in common is that they illustrate *processes* for working from outcomes to commissioning, not quantitative measures for doing so. By collecting a range of subjective outcomes each of the processes offers insight into the wishes and priorities of service users relatively unconstrained by pre-defined choices or categories and in this way they can be seen to provide views on person-centred outcomes that are genuinely user-based. While it is possible to collate subjective views into categories, it is methodologically challenging to quantify them, hence the difficulty of meaningfully aggregating outcomes from qualitative processes.

3 Quantitative approaching for using Person Centred Outcomes to guide commissioning

In contrast to the qualitative processes in the previous section, the approaches described below have been designed specifically to produce quantitative measures to guide service delivery and, potentially at least, commissioning. The first three describe actual measures, the fourth and fifth outline practical approaches for identifying measures to assess selected outcomes for segmented populations.

6.1 Person Reported Outcome Measures (PROMs)

Patient Reported Outcome Measures are standardised, validated questionnaires that are completed by patients to measure their own perceptions of their functional status and wellbeing. They are designed to measure respondents' perceptions of their general health or their perception of their health in relation to specific diseases or conditions, or both (Dawson et al. 2010). Patients rate their health by responding to closed questions, which can then be scored. Originally designed for clinical trials, PROMs operate on a comparative basis, with analysis focusing on the difference between the ratings before and after an intervention.

As Appleby and Devlin (2010) note, there are literally thousands of different PROM questionnaires or instruments. Not only do they differ in the wording, nature and number of questions asked, and ways in which their answers are scored or summed up, they also vary considerable in their reliability and validity.

A main distinction among PROMs is whether they aim to describe or measure health in a way that is generic, so that the same instrument can be used to compare health and changes in health across different patient and population groups, or whether they are condition-specific. Generic measures
focus on the impact that a person's state of health has on his or her overall life, and are generally referred to as measures of health-related quality of life (HR-QoL) or Quality of Life (QoL). Commonly used examples are the SF-36 and EQ-5D. Condition specific instruments focus on limitations or problems that people may experience as a result of a specific problem or condition (for example, the Oxford Knee Score; or the VF-14 that measures visual functioning).

The White Paper *Equity and Excellence: Liberating the NHS* (Department of Health, 2010), which called for wider routine use of PROMs, saw them as a means of addressing a perceived lack of responsiveness in the NHS which, in the words of the paper: 'lacks a genuinely patient-centred approach in which services are designed around individual needs, lifestyles and aspirations. Too often, patients are expected to fit around services, rather than services around patients.' (ibid. p.8). PROMs were seen as a way to 'assess the quality of care delivered to NHS patients from the patient's perspective' (Health and Social Care Information Centre website).

To what extent are PROMs 'person-centred'?
Many papers can be found, nationally and internationally, that describe PROMs as a means of collecting person-centred information. Conversely, others argue that PROMs are not patient-centred, or at least, not necessarily so. As the Health and

Social Care Alliance observes, 'the extent to which the 'patient voice', either collective or individual, is included in the development of PROMs varies enormously, as does the emphasis on biomedical or more holistic concerns' (Health and Social Care Alliance ,2013, p.11). There is no standard way of developing PROMs: in some cases some or all of the questions are developed 'from the ground up', based on issues raised by relevant patients or service users. Some PROMs are designed entirely by clinicians, and some are designed by clinicians with input from or following consultation with patients.

However they were developed, PROMs ask standardised questions to measure the impact of a condition or an intervention on pre-defined aspects of the respondents' health, or health-related quality of life. What they do not capture is the importance that respondents attach to these aspects. The Health and Social Care Alliance points to this limitation, emphasising that services must be driven not only by evidence of what works, but also by what matters to individuals who use the services. 'Giving people the opportunity to comment on the impact of interventions on their quality of life in predefined terms is welcome but insufficient' (ibid. p.3) The Health and Social Care Alliance contrast the externally predefined categories of PROMs with tools that allow respondents to first nominate the areas of life that are most important to them, and then to rate their level of functioning or satisfaction with each of those areas.

Feasibility of widespread use of PROMs
When, in 2009, the routine use of PROMs was introduced into the NHS for four clinical procedures (hip replacements, knee replacements, groin hernia and varicose veins), it was anticipated that wider use would soon follow. Devlin & Appleby, in 2010, noted that 'work is now underway to explore the plausibility of and case for extending routine measurement to a range of chronic conditions including diabetes, asthma, stroke, chronic obstructive pulmonary disease (COPD) and others.' (Devlin & Appleby, 2010 p.3)

Peters et al. (2013) reported on a pilot study to explore the feasibility and usefulness of developing and using PROMs to assess services for long term conditions in primary care. Researchers tested use of a generic and a disease specific PROM.

They found that PROMs scores for long term conditions could not be readily traced back to inputs of services in the same way as they can for elective surgical procedures. The range and diversity of services to people with long term conditions makes it challenging to use evidence from PROMs in a diagnostic way to highlight specific aspects of services that require improvement. The researchers concluded that the form and content of PROMs should be considered in the light of the use for which they are required. They recommended that, for those with multiple long term conditions 'neither the very broad-brush aspects of health of generic measures nor the very specialized disease specific measures' (ibid. p.102) will be useful, but perhaps PROMs that focus on sense of control and confidence in self-management may be more relevant, and more responsive to change over time.

Essentially, this work emphasises the central importance of clarity about what exactly should be measured and the feasibility of those measurements providing information that can support decision-making by specific audiences, whether those be service-users, service providers, or commissioners.

Use of PROMs data to inform commissioning

Devlin & Appleby (2019, pp.36-38), writing soon after the introduction of PROMs, listed ways in which commissioning (at that time conducted by Primary Care Trusts) could be supported by PROMs as a basis for deciding what to commission, who to commission from, and how best to commission services.

No work has been found, as part of this evidence scan, that explores reasons for the apparent lack of evidence of commissioners making use of PROMs findings. Arguably, a familiar lesson emerges: outcome measures intended for specific audiences should be co-produced with the intended audience to maximise the likelihood of uptake. Nevertheless, where PROMs have been well designed to measure outcomes relevant to service users, there is no reason they cannot be seen to contribute to information about person-centred outcomes, with the usual proviso of acknowledging who information was collected from and in what context it will be used.

6.2 International Consortium for Health Outcomes Measurement (ICHOM)

The International Consortium for Health Outcomes Measurement (ICHOM) was founded in 2012 to define a common language for measuring outcomes. It aims to develop Standard Sets of globally consistent outcomes that matter to patients, for many medical conditions

The following three statements are found on the 'About' page of the ICHOM website (http://www.ichom.org/why-we-do-it/)

> *Doctors think about prostate cancer in terms of PSA levels. The average patient doesn't. That's why we need to change how we evaluate and talk to patients about their health. At ICHOM, we're developing a new paradigm focused on health outcomes – the results that matter most to patients. The end result? A world where patients ask their doctors about meaningful outcomes, and doctors can respond with data-driven answers. To us, it's more than improving the doctor-patient relationship. We're creating a new definition of success that transforms health care in several important ways.*

> *ICHOM's mission is to unlock the potential of value-based health care by defining global Standard Sets of outcome measures that really matter to patients for the most relevant medical conditions and by driving adoption and reporting of these measures worldwide.*

> *What is a health outcome? Outcomes are the results people care about most when seeking treatment, including functional improvement and the ability to live normal, productive lives.*

ICHOM aims to develop robust health outcome measures that have validity and relevance internationally, for the purpose of improvement and comparison. The ICHOM website is emphatic that outcomes are only relevant if seen from the perspective of what matters to patients. Their process is best defined in their own words:

> *ICHOM takes a unique approach to defining health outcomes. First, we involve patients directly in the process. After all, they're the ones who experience health outcomes first-hand. All of our patient representatives have been treated for the condition they are evaluating. Then we bring together leading physicians from across the globe who specialize in treating this condition. These physicians hold diverse perspectives and are pioneers in their respective countries. Finally, the ICHOM team facilitates as physicians and patients discuss – and agree upon – the outcomes that matter most to them.*
> (http://www.ichom.org/how-we-work/)

Having identified a condition for which to develop a measure, ICHOM facilitates a process whereby it works with leading international clinicians, registry leaders and patient representatives to identify a comprehensive set of potential outcome measures, then, from the long list of potential outcomes, patient representatives prioritise which outcomes matter most. The team then works across disciplines with experts to consider and identify measures for the prioritised outcomes that are feasible, valid and reliable.

To date (December 2016) ICHOM has completed 12 Standard Sets of Outcome Measures for a range of conditions including coronary artery disease, cardiovascular and circulatory disease, localised prostate cancer, low back pain, and eight others.

Each Standard Set of Outcome Measures comprises a number of domains grouped under different categories: most of the Standard Sets include a category labelled 'patient reported measures'. For example, the measures for coronary artery disease include measures under the categories of patient reported health status (domains include health-related quality of life, functional status, depression, dyspnea and angina); cardiovascular disease progression (domains include reinfarction, stroke, heart failure); survival; and acute complications.
(http://www.ichom.org/medical-conditions/coronary-artery-disease/)

Each of the 12 Standard Sets is accompanied by its own reference guide that defines each measure, indicates PROM instruments for measuring the identified outcomes, time points for collection, and associated risk factors.

Some of the Standard Sets are accompanied by an article that describes the process by which the measures were selected. The complexity of the considerations involved is illuminating and a salutary reminder of the challenges when designing a robust and feasible measure in one single country, let alone an international measure. Some of the considerations are listed in the following section of this report.

Use of ICHOM for commissioning
In the UK, Bedfordshire CCG is using the ICHOM Standard Set of Outcome Measures for Low Back Pain as part of a new outcome-based approach to commissioning for musculoskeletal (MSK) care (Van Tuykom & Stoefs, 2014). In April 2014, the CCG signed a five-year contract with Circle Partnership that established Circle as the preferred provider of MSK care. Under the new contract payment is comprised of two parts: a fixed part (bundled payment) which is currently

97.5% of the payment; and a variable part (outcome-based payment) which is 2.5%. Over time the CCG aims to increase the variable part to 20%.

The outcome-based payment is based on five quality criteria and aims to incentivise quality. The five criteria, with their respective weightings (ie of the 2.5%) are:

- Innovative use of technology – 20%
- Truly integrated care – 20%
- Improved patient outcomes - 30%
- Quality of patient experience – 20%
- Production of an annual report – 10%

A baseline will be measured in the first year and then each quarter, Circle will report its performance against these criteria. Patient outcomes for low back pain are measured against the ICHOM Standard Set for Low Back Pain. Outcomes for conditions other than low back pain included in the contract will be measured using indicators from the National Rheumatoid Arthritis Society and generic measures of patient outcomes, such as the EQ-5D.

6.3 'I-Statements' as outcome measures

A document from The Health Foundation, reporting on that fact that outcome-based commissioning requires commissioners to work constructively with their local populations to determine the health outcomes that matter most to them, notes that 'a number of areas, such as North Somerset, have used and built on the 'I' Statements developed by National Voices'. (The Health Foundation, 2015 p.11)

The series of 38 'I-Statements' were developed by National Voices (National Voices, 2013) through a series of national workshops with people who use services and 'system leaders' to identify the outcomes and experiences that are most important to users of care and support. Statements from the *Making it Real* initiative (Think Local Act Personal, 2012), developed directly with social care service users, were also incorporated.

The 'I-Statements' are grouped under the following six headings:
- My goals/outcomes
- Communication
- Information
- Decision making, including budgets
- Care planning
- Transition.

Statements under the goals/outcomes heading are:
- All my needs as a person are assessed and taken into account
- My carer/family have their needs recognised and are given support to care for me
- I am supported to understand my choices and to set and achieve my goals
- Taken together, my care and support help me live the life I want to the best of my ability.

Under the communication heading statements include:
- I tell my story once
- I am listened to about what works for me, in my life.

And under the information heading the statements include:
- I have the information and support to use it, that I need to make decisions and choices about my care and support
- I have information and support to use it, that helps me manage my condition(s)

It is evident that while some of the statements relate to overall goals and quality of life, more relate to aspects of care that are essential for maintaining quality of life or avoiding deterioration and to the experience of care for the service user and their carer/s.

These statements prompt re-assessment of the meaning and categories of 'person-centred outcomes'. While, often, the term refers to the outcomes individuals want from their lives, the 'I-Statements' relate mostly to what people want from their contact with support services. A distinction is generally drawn between measures that relate to experience of service use and measures that relate to outcomes from service use, but, as noted in the work by Cook & Miller (2012), in some cases the experience of seeking and using support services may influence the extent to which other outcomes are achieved. Also, in chronic situations where people's lives are closely bound to the services they use, the experience of service use and the outcomes from it may be almost inseparable.

The 'I-Statements' may provide information to inform commissioning, but as always, it is important to be clear what is being measured: experiences of care are not the same as outcomes from care and clarity is required about the types of person-centred outcomes that are being measured and for who, before extrapolating more widely from them.

The 'I-Statements' have the advantage of subsequent work by the Picker Institute which developed a set of 18 questions based on the 'I-Statements' (Picker Institute, 2013).

The questions closely relate to the 'I-Statements', offering a choice of responses, for example:

   1. *All of my needs have been assessed*
   2. *Some of my needs have been assessed*
   3. *None of my needs have been assessed*

4. Don't know/ can't remember

The Picker questions have been cognitively tested with people from a range of backgrounds including people with experience of using various health and social care services. The questions have been prepared, ready to insert in surveys to help commissioners assess and plan services. In this way responses to the questions allow for quantification of the extent to which the relevant 'I-Statements' are being met.

6.4 Practical approaches to developing outcome measures for commissioning: North Central London

The Outcomes Based Healthcare (OBH) group is working with five CCGs across North Central London to develop a value based approach to commissioning for three distinct populations: frail elderly people; people with diabetes; and people with mental health problems.

Segmentation as starting point
In common with other approaches to outcome-based commissioning OBH emphasises segmentation as the key starting point. In traditional approaches to commissioning people are categorised according to the services they use at any point in time. By contrast, segmentation identifies groups of people who share characteristics which influence the way they interact with health services. By categorising people into groups with similar healthcare needs and priorities, care can be more effectively tailored as it becomes more feasible to define meaningful and measureable outcomes for the distinct groups.

As OBH say: 'To get the best health outcomes and minimise health care costs, the healthcare system should respond to the needs of different population groups in different ways. Often the best place to start is with conditions and demographics – getting your segmentation right is key.' (Outcomes Based Healthcare, 2015).

OBH identify the following criteria for effective segmentation:

- homogeneity: each segment shares common health prospects and priorities that can be addressed through careful system planning;
- distinctiveness: each segment has unique health and health service delivery needs;
- completeness: the set of population segments must include every person, acknowledging that individuals will move between segments as their health needs change.

In its work with North Central London OBH worked with expert reference groups to develop entry criteria for each of the three nominated population groups and then identified data resources that could help indicate which members of the population met the criteria.

Identifying outcomes for each segment

Having identified a limited number of segments, outcomes can be defined for each, and, according to OBH, outcomes are very consistent across similar groups of people in different localities. They report that, from their experience, 'something like 80% of the work on outcomes for a specific population segment can be applied to that same segment within a geographically different population' (ibid.). It is on this basis that standard outcome sets, such as those developed by ICHOM, are useful. OBH suggests that over time the focus will shift from the creation of new outcome sets towards reviewing and adapting standard outcomes to match the specific needs of local people.

In order to identify outcomes in their work with North Central London, OBH then worked with stakeholders from each of the three segments. They worked with 'people with a relevant condition, their advocates and professionals' (ibid.) in interactive workshops to generate a range of common themes that matter to patients, and from these they generated potential outcomes. They also collected views of outcomes through surveys. The initial lists of raw outcomes that emerged were later categorised and prioritised, then refined and agreed with representatives from local commissioners and providers (including consultants, GPs, specialist nurses and social care providers) and patients. The resulting outcome frameworks were then ready to be used as the basis for designing services.

OBH lists the outcomes identified for people with diabetes in North Central London in the second appendix to its paper *Contracting for outcomes: a value-based approach* (Outcomes Based Healthcare & Capsticks, 2014). As an example, identified outcomes are listed below under four domains, 'patient-identified outcomes' being one of them. The Appendix lists outcomes under a total of eight domains, the remaining four not listed here being 'Outcomes related to clinical outcomes/complications'; 'Amount of time out of normal routine'; 'Experience of care/treatment process'; and 'Clinical outcomes/ complications over time – ie delayed onset.'

People with Diabetes Outcomes (from Outcomes Based Healthcare & Capsticks, 2014)

1.Mortality
1a. A measure of mortality rate
1b. A measure of premature mortality rate: years of life lost

Health related Quality of Life
A measure of quality of life

3.Outcomes related to Symptom Control (eg hypoglycaemia, lethargy)
3a. Symptom-free – a measure of symptom control
3b. Symptom recognition- a measure of the recognition of high/low blood sugar

Patient-identified Outcomes:
4a Control – a measure of feeling in control of diabetes
4b. Confidence – a measure of feeling confident in managing diabetes

4c. Support – a measure of feeling supported in health

4d. Fear/anxiety – a measure of feeling free from fear/anxiety

4e Happiness/mood – a measure of mood

4f. Self-management, monitoring –a measure of being able to monitor diabetes

4g. Self-management – a measure of being able to understand how to manage diabetes

4h. Self-management, managing – a measure of how to feel more able to self-manage diabetic care

Identifying measures for each outcome

The OBH group distinguish between outcomes and the other quantifiers against which commissioning might be measured: 'Outcomes are distinct from people's experiences of healthcare and whether they feel satisfied with those experiences. They are also distinct from the 'process' of healthcare – an outcome does not tell us whether x or y happened, it simply focuses on the result. Experience, satisfaction and process measures are key to measuring quality, but they are not the same as the results that matter most to an individual.' (Outcomes Based Healthcare, 2015). Nevertheless, they point out that while much of the data collected in the NHS is designed to help measure inputs, processes and outputs, 'with care, it can often be used to measure outcomes' (ibid.). OBH claims that for a typical patient segment 'data exists which allows 50% - 60% of outcomes to be measured – and this may be a good enough start. The rest may require additional data collection, often asking people to report back on their outcomes' (ibid.).

OBH identifies three categories of outcome measurements. The first, which it calls Clinical and Social Outcome Measures (CSOMs), refers to data that are already collected and available, measuring health and quality of life from a clinical perspective (physical or psychological aspects of disease, symptom control, complications, the avoidance of adverse effects and the speed of recovery) and from a social perspective, measuring factors that relate to someone's life situation (such as housing, education and employment), which may interact with their health condition. Examples of CSOMs include Quality Outcomes Frameworks, the Adult Social Care Outcomes Framework and Hospital Episode Statistics.

The second category is Patient Reported Outcome Measures (PROMs) which, as noted above, are structured, standardised, validated tools that capture people's own reports on pre-defined outcomes. These are either generic or condition-specific.

OBH identifies a third category of 'Patient Defined Outcome Measures' (PDOMs): the outcomes that are not pre-defined but that emerge from exploring what matters with the relevant population group and the professionals associated with their care. Most of the outcomes identified as important by local stakeholders will be included in outcomes measured by CSOMs and PROMs. OBH uses the term 'PDOMs' for any locally identified outcomes for which neither clinical data nor existing PROMs are available. It is then necessary to consider whether or how to collect data to measure these outcomes. Some of the considerations are addressed in the following section of this report. A key point however, is that it is always important to first assess what data is needed to measure each outcome, and then to determine whether that data already exists.

OBH has developed a series of questions in pursuit of the appropriate 'data architecture' for each of the identified outcomes. The questions are below.

- *What data would be needed to measure this outcome?*
- *Is that data available – or is there a good enough proxy? If so, which dataset and who holds it?*
- *What exactly does that dataset cover? Who and what is included and excluded?*
- *How often is the data collected and what is the delay before it becomes available?*
- *What permissions are required for access?*
- *Are there any other constraints or issues with the dataset?*
- *What is the detailed technical measure we need? What numerator and denominator is appropriate?*
- *What is the most appropriate baseline position to use so that progress over time can be measured?* (ibid.)

If the outcomes are better suited to being collected as a PROM, a slide set from OBH provides the following examples of matching outcomes identified by patients to questions in existing PROM tools.

PROMs recommendations – Serious Mental Illness example (from Outcome-based Healthcare slides)

Patient centred outcomes	Subjective statements	PROMs selected	Corresponding questions in current questionnaire	Total no. of questions
Patient identified outcomes related to Quality of Life				
Quality of Life: a measure of Quality of Life	Extent to which I feel I have a good quality of life	DIALOG (Q1-11)	A.Q1-Q11	11
Activities: a measure of ability to undertake routine daily activities	Extent to which I feel I am able to undertake routine daily activities without my illness getting in the way	BASIS-32 (Q1-2)	A.Q12, Q12	2
Self-management and self-knowledge				
Symptom control: a measure of feeling in control of symptoms (eg hallucinations, delusions	Extent to which I feel I am in control of my symptoms	BASIS-32 (Q21-24)	A.Q14-Q17	4
Self-management: a measure of ability to manage care/medication	Extent to which I feel I can manage my own care/medication confidently	PAM-MH (Q4,Q5,Q7,Q8, Q12)	A.Q18-Q2	5
Control: a measure of feeling in control of one's life	Extent to which I feel in control of my life	MHI-38 (Q14)	A.Q23	1

Where no existing data is available to provide a reasonable outcome measure it may be necessary to develop locally defined outcome measures. When developing a new outcome measure it can be productive to collaborate with other commissioning groups that share similar characteristics, enabling mutual benchmarking comparisons.

OBH acknowledge the process of matching outcomes to measures as a slow painstaking process, but emphasise it as essential for measuring whether the care provided makes a positive difference to people's lives. This work is ongoing in North Central London.

6.5 Practical approaches to developing outcome measures for commissioning: North West London Whole Systems Integrated Care

North West London Whole Systems Integrated Care (WSIC) programme began in 2013 when it became one of the Department of Health's integrated care Pioneers. The area covers eight CCGs and eight local authorities. Co-production and personalisation are key components of the WSIC programme, with its vision of being person-centred and transformational. A comprehensive evaluation of the programme gives more detail about its inception and development, as it works towards adopting an Accountable Care Partnership model (Wistow et al. 2015).

The approach used to develop outcomes and metrics, described below, illustrate work that aims to maintain a person-centred model while developing outcomes and metrics that can be used at population-level, eventually, as the basis of commissioning contracts for shared accountability across providers operating with a capitated budget. (The following account of work in progress is based on personal communication with a member of the WSIC central programme team).

Segmentation as the starting point
The WSIC approach is being led by ten Early Adopter sites, with the WSIC programme aiming to achieve a balance between local ownership at site level and standardisation and consistency driven by the central programme team. At the start, in 2014, commissioners and providers worked together at local level to develop their visions for integrated care. As with North Central London, segmentation was recognised as the key starting point. The population group for the central team's work on outcomes focussed on people aged 65+, with the acknowledgement that this will later need to be widened: many of the conditions in the defined population group are common to people outside it.

Identifying outcomes for the segment
Each site then worked with lay partners[10], patient focus groups and providers to identify outcomes for the selected population group. Part of this work involved re-working the National Voices 'I-Statements' to establish a revised set of 'I-Statements' that local stakeholders could own for themselves. The WSIC central programme team collated the outcomes and grouped them into the following five domains, each with an accompanying I-statement.

1. People have a high quality of life – *taken together my care and support gives me the opportunity to contribute and help me live the life I want to the best of my ability.*
2. Care is safe, effective and people have a good experience - *I feel safe, in control and well informed. I am respected for my own experience and knowledge. I know people are there when and where I need them.*
3. Professionals experience an effective, integrated environment – *the professionals involved with my care talk to each other. We all work as a team.*
4. Care is financially sustainable – *the care I receive is part of a service built on long-term sustainability*

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[10] North West London WSIC has established a group of 130 lay members who make up the 'users forum', on which they can draw for focus groups.

5. Care delivery is efficient – *I am supported by people who respect my time and I am not being admitted into hospital unnecessarily.*

Identifying measures for each outcome

The team has developed a core set of 16 metrics aligned to the five outcome domains against which to support the sharing of data on the effects of integrated care across the Early Adopters, providing a catalyst for sharing and learning of best practice. Most of the core metrics draw on existing data sets, benefitting from the fact that they have already been validated, they have been collected over time and allow for longitudinal comparison, and they are common across sites so allow for cross-boundary comparison. The core metrics will support Early Adopters in the development of their localised outcomes and metrics, with the final decision on specific outcomes and metrics in regards to the commissioning of local integrated services remaining with the CCGs and Local Authorities.

Development of the core metrics began by drawing on the Early Adopter sites' business plans, aligning them with the NWL 'I-Statements', further aligning them with the Better Care Fund and Seven Day Standards programmes, matching them against the PIRU guidelines for useful metrics (Raleigh et al. 2014), then discussing them with service user focus groups, carers and care home residents. The central team are finally going back to the Early Adopter sites to ask for their endorsement and adoption.

Examples of the selected metrics for the first two domains, aligned with the relevant I-statement are shown below.

North West London WSIC Outcomes and Metrics for Over 65

Outcome domain	Outcome patient description	Core metrics	Measurement	Data source
People have a high quality of life	Taken together my care and support gives me the opportunity to contribute and help me live the life I want to the best of my ability	GP Patient Survey: How confident are you that you can manage your own health.	% responding very confident/fairly confident	NHSOF
		Social care –related quality of life	Aggregated score across 8 survey questions	ASCOF
		Number of days in hospital	Average days for population	Hospital Episode Statistics
		GP Patient Survey: Did you help put your written care plan together	% responding yes	National GP Patient Survey Ipsos MORI
Care is safe, effective and people have a good experience	I feel safe, in control and well informed. I am respected for my own experience and knowledge. I know people are there when and where I need them.	GP Patient Survey: In the last 6 months, have you had enough support from local services, or organisations to help you manage your long term condition	% responding yes	National GP Patient Survey: Ipsos MORI
		Patients with all the following: care plan/goals set/crisis plan within previous 12 months	% with all 3	EMIS SystmOne
		A&E activity for ambulatory sensitive conditions	Per 100,000 population	HES

Early in the development of the WSIC individuals and organisations worked together to co-produce an extensive online toolkit (http://integration.healthiernorthwestlondon.nhs.uk/).

In the section of the toolkit that addresses outcomes, the tension between measuring population-wide outcomes on the one hand, and personal outcomes on the other, is acknowledged. The toolkit emphasises that personal outcomes must be addressed in one-to-one encounters with health professionals, and, where relevant, in care plans. The following excerpts from the toolkit illustrate this approach.

> *Part of creating a successful integrated care model is to ensure that we personalise our approach as much as possible. This extends to personalising the outcomes that we measure for different people. Both commissioners and providers will need to think about how to personalise the outcomes that they measure. This will ensure that individual needs are addressed, rather than being lost in a system that only measures outcomes on a population level.*

> *The Population and Outcomes working group had a long discussion of how to personalise outcomes. They discussed the importance of highlighting the fact that different people will think of success in their care in different ways. In order to truly capture whether people are achieving the outcomes and goals that they want to, clinicians and care professionals must engage individually with the people for whom they care and discuss with them their personal aspirations.*

> *The working group decided that it was necessary for care professionals who are coordinating care, whether this be a care coordinator, a GP or someone else, to have in-depth individual conversations with their patients about what constitutes personal success for them and their family*

> *Personalising outcomes means focusing on the individual goals of people, rather than simply on their clinical outcomes. A vital part of doing this is using a personalised, individual care plan that lays out the clinical needs of an individual next to the goals and aspirations of that person regarding his or her care.*

It is not evident that any way has been found to aggregate, from the personalised plans, up to population-wide data that could be used to influence commissioning.

Summary

While the qualitative approaches described in the last section of this report focused mainly on mapping and grouping person-centred outcomes, approaches in this section pursue approaches for quantifying and measuring outcomes in ways that allow them to be aggregated.

Patient reported outcome measures (PROMs) record patients' responses to pre-defined questions. Views differ about whether PROMs can rightly be said to collect person-centred information but, other than from an absolute standpoint, it is difficult to generalise about the vast range of PROMs because they differ so widely in the way questions have been generated, some using topics and responses derived entirely from patient views, some designed entirely by clinicians, and many involving some combination. PROMs also vary in the way responses are collected and collated and in their overall validity.

Inevitably, if responses from individuals are to be aggregated some form of standardisation is essential and the opportunity for individual personalisation of responses is diminished. Each of the approaches described in this section (with the exception of some PROMs) starts with input from members of the relevant population to derive, or at least influence development of what is referred to as person/patient centred outcomes. Each of the approaches then works with the standard considerations of validity, reliability and feasibility to develop measures. As well as adopting a different methodology for dealing with data, approaches described in this section tend to address a somewhat different question to some of the approaches in the previous section, no longer asking what outcomes people want from their lives but focusing more on what outcomes people want from the services they use.

The International Consortium for Health Outcomes Measurement (ICHOM) aims to build on patient and clinician input and works with the challenges of global data sources to develop Standard Sets of outcome measures for specific conditions that are intended for international use and comparison.

'I-Statements' were developed from direct work with service-users, building on their views of what they wanted from the services they use and subsequent work by the Picker Institute aligned the statements with validated standardised questions that can be used in questionnaires. As well as measuring outcomes from services 'I-Statements' also focus on experience of using services, prompting a reminder that it is important to be clear about what is being measured and whether any given measure addresses a specific question of interest.

Practical approaches to identifying the outcomes peoples want from the services they use inevitably need to divide the broader population into workable groups. More recent approaches to segmentation recognise that when people are grouped around conditions or demographics needs and priorities become more predictable and manageable for planning. Based on this recognition, work is continuing not only to identify the outcomes required by people within segmented populations, but also to identify measures for them. When working to select measures for patient-defined outcomes not all measures are necessarily generated directly from the original outcomes identified by the patients, in the way that the Picker questions have been generated from the 'I-Statements'. In the interests of feasibility, validity and comparability it is pragmatic to first consider whether clinical or social data sets that already exist might provide an indicator for the identified outcomes, or, if not, if a PROM exists that could be used to collect data. In the absence of either, a new tool may be necessary. As work continues to identify outcomes and measures for segmented populations, increasingly it should be possible to adopt or adapt measures used by others, rather than undertake the work involved in developing new approaches. It can be challenging to match this increasingly standardised approach with the emphasis on personalised outcomes at the heart of social and integrated care, other than seeing a personalised approach as located almost exclusively at service delivery level.

4 Measures: considerations and challenges

Many of the documents already mentioned in this report comment on issues to consider when selecting, using or designing a measure. There is general agreement that there is rarely one single method or measure that can be recommended beyond others: triangulation of measures is the best way to capture different perspectives, by drawing on different methodological approaches (De Silva 2014, p.25. 39; Cook & Miller, 2012). De Silva cites examples that illustrate the impact different data collection methods may have on response rates, but also on findings.

> *… a team in the US examined whether the mechanism for distributing surveys influenced the results. Over a 17-month period, all families of babies discharged from the neonatal intensive care unit at one hospital were surveyed after discharge with two parallel surveys, one posted and one by telephone. The response rate was 94% by telephone and 29% by post. Three out of the five questions yielded significantly different answers in posted and telephone responses.* (Cheldelin et al. 2013, cited in De Silva, 2014, p.24).

Ham et al. (2015), list the following issues to consider when selecting a measure

- Clarity about the aims of measurement
- The domains and population groups to be measured
- The unit of measurement
- The approach to measurement
- Data and technical issues that need consideration

Purpose for measure, and population group
Essential first steps involve clarifying the purpose for measuring person-centred outcomes and the aspects of person-centred outcomes that should be measured and, alongside this, the over-riding consideration of whose voices should be heard when reaching these decisions: will the person-centred outcomes that are measured reflect outcomes seen as important by the people who use the services, or outcomes considered important by those who design, deliver, commission or evaluate them. These issues being agreed, the next decision is whether generic measures are sought for the whole population, or whether the population is to be segmented. Generic measures allow aggregation and comparison across different patient groups or health services, but, with no specific conditions to consider, population-level data can only explore generic issues such as experience of care (for example, using the Picker questions) or broad aspects of quality of life or activation (using tools such as SF-36, EQ-5D or the Patient Activation Measure). Once the population is segmented, if segments and segmentation processes have been carefully chosen outcome domains within the segment are more homogenous and measures can be more specific.

Selecting measures: selecting appropriate indicators
When outcome domains have been identified the next question is what exactly should be measured as an indicator of the selected outcome/s.

Many research groups provide lists of criteria against which potential indicators can be checked. Of course no indicator meets all criteria, but the lists prompt assessment. As Ham et al. (2015, p.42) emphasise: '(d)etailed assessment of indicators, including data, specification and production issues, is a lengthy technical process, but one that is essential for ensuring the end products are reliable and credible'.

Again, the purpose for measurement is crucial. If, for example, the intention is to identify areas for improvement, areas of change, or to ascribe change to specific aspects of service provision, each of these purposes will influence the range of useful indicators, with amenability to change within a reasonable timeframe and attributability to the services of interest being criteria of particular relevance.

Ellison et al. (2014) propose the development of a 'wellness' metric: they suggest six desirable criteria or characteristics for their metric.

- Simple, easy to understand
- Broadly accepted as a valid measure supported by a strong evidence base
- Proven to be amenable to change following intervention
- Applicable across all public services, not confined to health and social care
- Applicable to all population levels (national, regional, local, individual)
- Cost effective to measure, can be implemented quickly.

The Policy Research Unit in Policy Innovation Research (PIRU) (Raleigh et al. 2014, p.6) provided guidance to the Integrated Care and Support Pioneers on selection of indicators for measuring the quality of integrated care. They list eight standard criteria against which all indicators should be assessed: importance and relevance, validity, accuracy, reliability, feasibility, meaningfulness, implications for action, avoidance of perverse incentives. PIRU then point to some wider considerations particularly pertinent to the context of their report. Although the PIRU brief was to identify indicators that were available from existing data sources, many of the same considerations are relevant when selecting indicators for person-centred outcomes more generally. The PIRU list is below.

- Size of the population covered [by the indicator]
- Representation of important aspects of the care system
- (Wholly or partly) within the control of care services i.e. attributability
- Change detectable within suitable time frames
- Unambiguous interpretation
- Likelihood of being meaningful to users, carers and the public
- Likelihood of being meaningful to care professionals, managers and commissioners
- Reflecting the user perspective and/or value for money perspective
- Timeliness [of access to the recent data]
- Ability to assess the impact on inequalities between user groups and areas in terms of access and outcomes of care
- Measurable from routinely collected data.

Can existing data provide one or more indicators?

Considerations listed in Section 6.4 of this report outline an assessment of the availability, relevance, feasibility and validity of existing data sets to provide indicators that address the identified outcomes. As Outcomes Based Healthcare (2014) say, 'Choices have to be made on whether available data is 'good enough for now', or whether additional data collection is warranted'.

Is there a well validated tool for collecting the data?

If a decision is reached that no suitable data is available, ideally a well validated tool is used to collect data. As noted earlier, there are numerous PROMs surveys available; their validity varies greatly. The International Society for Quality of Life Research (ISOQOL) identified minimum recommended standards for PROMs, which include: documentation of the conceptual and measurement model; evidence for reliability, validity (content validity, construct validity, responsiveness) and interpretability of scores; and acceptable patient and investigator burden (Reeve et al. 2013).

The working group that developed the ICHOM Standard Set of Outcome Measures for Patients with Coronary Artery Disease (McNamara et al. 2015) selected PROMs based on the following four criteria:

- The domain coverage
- The psychometric properties
- The feasibility to implement
- The clinical interpretability

Once a tool is selected each of the following decisions must be made:

- How will people with the relevant condition be accessed?
- Will the whole population be surveyed, or will a representative sample of the population be selected?
- When and how often should people be surveyed? What is the baseline and what is the rationale for the follow-up data collection points (will data be collected, for example, at regular intervals, eg, monthly or quarterly; or at specific points of interaction with the health service, eg post-operative)?
- What medium should be used for data collection (eg paper survey; online form; electronic app)?
- How will the data be stored?
- How will the data be validated, and analysed?

The chosen tool must be piloted and, even if validated previously, it is important to assess comprehension and response rates in the relevant population. There are many benefits to keeping the data collection process as uncomplicated as possible. What initially seems manageable can become burdensome over time, and where metrics are onerous to collect completion rates and data accuracy both suffer.

Designing a new tool

If no existing data or tools are adequate to act as an indicator for a specific outcome, careful consideration is needed before inventing something new. Each of the decisions noted above must also be made for a new tool, but first, decisions must be reached about the way that data is to be collected, the nature of the questions and

potential responses, and the validation process. If a new tool is developed there is an extended time lag before data is available for comparative purposes.

Aggregating qualitative responses in a quantitative way

As described in Section 4 of this report, qualitative accounts of person-centred outcomes are valuable in their own right, but they also offer apparent potential to be aggregated quantitatively, to inform population-level decisions. There are, however, considerable methodological challenges.

Apps et al. (2013) explored the feasibility of including, in the Adult Social Care Survey, an open-ended question about the person-centred (user-defined) outcomes that individuals want from the services they use. The aim would be to later review the same individuals to report the percentage of outcomes per area or local authority (or other grouping) that were 'met'. Apps et al. describe some of the challenges:

> *A key issue is how to ensure that outcomes cited (big and small) are comparable across areas and services. In particular, there would be a need to establish the relative importance of some outcome goals compared to others. In other words, some people might state aspirations that would be very difficult for social care to achieve compared to others. In assessing the performance of social care, it would be important to account for how inherently hard it would be for these goals to be satisfied. One option to address this issue is to include additional questions that measure the importance of outcomes and perceived impact of services on these, although this would add to length and complexity. Another option, one that has been used by [local authorities] to date, would be to use a pre-determined framework to code, weight and map responses. Of course, questions would remain about which framework should be used, who should complete the mapping, and what measures should be taken to ensure bias and 'subversion of service user voice' are avoided.* (Apps et al. 2013, p.5)

The authors conclude, from their review of the literature, that when person-centred user-defined outcomes are grouped into categories, either as a mapping process or as domains to use in 'pre-defined' questionnaires, many of the frameworks created are very similar to the measures already used in the Adult Social Care Survey. From this they draw the following conclusion:

> *What this similarity seems to suggest is that outcomes in health and social care – whether measured as personal outcomes or through 'predefined' categories or domains – can be categorised into a relatively small number of reasonably universal or 'archetypal' goals upon which there is a good deal of agreement from service users, as well as practitioners and service providers.* (Apps et al. 2013, p.32).

Summary

Clarity about the purpose for a measure is the essential starting point and with this, a reassessment of whose views should influence the choice of what is measured. It is invaluable to use more than one approach to measurement: each method brings a different perspective. When outcome domains have been identified the next decision

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is by what indicator or indicators they should be measured. There is a trade-off between metrics that capture the issues in a way that most closely represent their person-centred nature, and metrics that are readily aggregated. Qualitative statements offer insight into experience and individual views, but demand much skill, time and judgement if they are to be aggregated. They are often best seen as valuable in their own right. Questionnaires or other approaches developed specifically to measure outcomes in new ways may hold promise of coming closer to the lived experience than existing approaches, but creating and validating new data collection tools requires significant time and skills. Many existing tools (PROMs) are available for collecting data from service users; the literature recommends careful consideration of their relevance, validity, feasibility to implement, and interpretability. Having selected a tool, there are many further steps before data becomes available to use. Indicators drawn from existing data sources generally offer a less onerous approach and can provide comparison over time. Lists of criteria against which potential indicators should be assessed can help guide decisions about whether available data can be relevant and adequate.

5 Conclusion

There is widespread interest in the concept of person-centred outcomes in health and social care literature and policy documents (De Silva, 2014). The meaning, application and intention attached to the concept vary with setting and ethos (Miller, 2012; Health and Social Care Alliance, 2013).

Critiques of some current 'so-called' person-centred outcome measures point out that the outcomes and measures that are valued have usually been pre-defined by providers and commissioners, and are not necessarily those that would be selected by people who use the services (Health and Social Care Alliance, 2013; Collins, 2014).

Any attempt to design or select measures for person-centred outcomes requires clarity about the context and purpose for the measure. If a measure is to be useful it is essential to be clear about the type of decision that it will be used to influence, the reasons for introducing a new measure, and, crucially, who should determine which outcomes should be measured (De Silva, 2014, Ham et al., 2015).

The focus for this report is decision-making for commissioning purposes at population level. When deciding what data should be used to influence decisions, one rich source of person-centred outcomes is data that does, or could already exist in the form of service users' personal definitions of what matters to them and what they want to achieve. If services operate in an outcome-focused way these statements are collected from individuals in qualitative format and can be grouped or, theoretically at least, even quantified to guide commissioning decisions. If services do not collect this information as part of service delivery they can gather it by holding occasional events when views are heard (Experience Led Commissioning, 2014, Slay & Penny, 2014). There are significant methodological challenges involved in attempting to quantify individual qualitative statements (Apps et al. 2013; Cook & Miller, 2012) but as qualitative data, individual views flesh out and make sense of quantitative data and provide an invaluable component for triangulation.

While qualitative data provide insights, quantitative measures support aggregation and comparison. There is no single best approach to measurement of person-centred outcomes: the value of a measure can only be judged by its appropriateness to the particular audience and specific task. Selection of the measure will always involve consideration of its merits against identified criteria: the criteria will vary with purpose.

Working with outcomes at population level commissioners and providers need to feel confident that the measures they select are robust and can be aggregated in a meaningful way, so criteria of validity and reliability are central. Other key considerations will be the feasibility and affordability of accessing data for the chosen measure, and, crucially, the extent to which the measure can (along with other measures) convey useful and relevant information about appropriate sections of the population. Another criterion to weigh against the others is the extent to which the measure can be seen to be truly 'person-centred' and the extent to which the measure allows service-users' priorities to be heard.

The recent interest in outcome-based commissioning has brought added attention to the potential for using outcome measures to influence population-level decisions. Outcome-based commissioning does not inevitably lead to a focus on person-centred outcomes, but there are reminders that it should do so (Department of Health, 2010; NHS Confederation, 2014). Again, the question of who decides what is measured and the purpose for measurement is crucial in selecting the outcomes to focus on and the indicators for measuring them.

Some work has been done to segment populations by disease groups, conditions or demographics, then to include members of those populations in identifying outcomes that matter to them (Outcomes Based Health care, 2015; Van Tuykom et al., 2014, Cheshire & Ridge,2012). The next step is to identify indicators for those outcomes that can be manageably collected, aggregated and compared over time.

In some cases already collected data sources are available that can act as indicators for the identified outcomes. If no suitable data sources are available validated tools may be found to collect fresh data to indicate whether or not the outcome is being achieved. In the last resort, a new approach to data collection may be needed (Outcomes Based Healthcare & Capsticks, 2014).

As population segmentation and identification of outcomes for the segments becomes more common it is reported that the outcomes that service users identify become more predictable, with only small variation from area to area. It has been predicted that over time, rather than creating new outcome sets for each area, local areas will review and adapt standard outcomes to match their specific needs (Outcomes Based Healthcare, 2015). If this approach is pursued, already-identified outcomes will correspondingly be matched with already-identified indicators, either drawn from existing data sources or using identified survey tools.

Will measures defined in this way meet the intended purpose for commissioning? Essentially, it depends on how the purpose is perceived. If person-centred outcome measures are required to identify what, from a clinical and quality of life perspective, people want from their service and, subsequently, the extent to which their wishes are met, perhaps the current developments will match expectations.

For those who see person-centred outcomes from a wider perspective, as a way of being responsive to what matters to people, collectively and individually, and as a way of accommodating broader quality of life concerns, the approach described above may focus too heavily on pre-defined options and allow too little emphasis on priorities, outcomes and indicators selected and defined by service users. If the purpose for using person-centred measures in commissioning is to prompt a change in culture towards agendas that are less professionally-led, there is no evidence of a measure to achieve this, and it is likely that a change in the way data is managed and perceived would be needed before this could be the case, with a less standardised approach and a stronger focus on qualitative data (Health and Social Care Alliance, 2013). In the meanwhile qualitative views may be best used at population-level as an additional data source for triangulation, to support selected quantitative measures.

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1. Appendix 1: Literature searches by librarian

1.1   DATABASE SEARCHES

	Source	Criteria	Results
1.	AMED, EMBASE, HMIC, BNI, Medline, PsycInfo, CINAHL, HEALTH BUSINESS ELITE	(("patient centred" OR "person-centred" OR "patient centered" OR "person centered") ADJ3 (outcome* OR measur*)).ti,ab	4665 results.
2.	AMED, EMBASE, HMIC, BNI, Medline, PsycInfo, CINAHL, HEALTH BUSINESS ELITE	("patient centred information" OR "patient centered information").ti,ab	167 results.
3.	AMED, EMBASE, HMIC, BNI, Medline, PsycInfo, CINAHL, HEALTH BUSINESS ELITE	"values based".ti,ab	5199 results.
4.	AMED, EMBASE, HMIC, BNI, Medline, PsycInfo, CINAHL, HEALTH BUSINESS ELITE	1 OR 2 OR 3	10028 results.
5.	AMED, EMBASE, HMIC, BNI, Medline, PsycInfo, CINAHL, HEALTH BUSINESS ELITE	(commission* OR contract*).ti,ab	769553 results.
6.	AMED, EMBASE, HMIC, BNI, Medline, PsycInfo, CINAHL, HEALTH BUSINESS ELITE	((service* OR policy) ADJ3 (design* OR redesign* OR develop* OR reform* OR reconfigure*)).ti,ab	106668 results.
7.	AMED, EMBASE, HMIC, BNI, Medline, PsycInfo, CINAHL, HEALTH BUSINESS ELITE	5 OR 6	870750 results.
8.	AMED, EMBASE, HMIC, BNI, Medline, PsycInfo, CINAHL, HEALTH BUSINESS ELITE	4 AND 7	280 results.
9.	AMED, EMBASE, HMIC, BNI, Medline, PsycInfo, CINAHL, HEALTH BUSINESS ELITE	"working together for change".ti,ab	34 results.
10.	AMED, EMBASE, HMIC, BNI, Medline, PsycInfo, CINAHL, HEALTH BUSINESS ELITE	8 OR 9	313 results.

Search History – GREY LITERATURE

	Source	Criteria	Results
1.	Health Foundation	(person-centred commissioning).af	
2.	King's Fund	(person-centred commissioning).af; filter 'commissioning'	326 results.
3.	King's Fund	(person-centred commissioning).af; filter 'patient experience'	189 results.
4.	Nuffield Trust	("person-centred" commissioning).af; filter 'commissioning'	300 results.
5.	Picker Europe	(commissioning).af	
6.	Picker Europe	browse Tools & Resources	
7.	Picker Europe	browse Research & Policy	
8.	SCIE Social Care Online	(("person-centred" OR "person centered") AND commissioning).ti,ab	270 results.
9.	OpenGrey	("person-centred" OR "person centered" OR "patient centered" OR "patient centred") AND commissioning).ti,ab	0 results.
10.	OpenGrey	("person-centred" OR "person centered" OR "patient centered" OR "patient centred").ti,ab	162 results.
11.	Google	("person-centred information" commissioning).af	top 70 results checked.
12.	Google	("person-centred" outcomes commissioning).af	top 70 results checked.

Appendix 3 – Additional perspectives

Section A

45 separate pieces of evidence – including papers, documents, briefing and meeting summaries from a range of sources were reviewed in the context of relevance to PCOMs. Detail relevant to the wider conversations that might inform the PCOM report were distilled down and are summarised below together with pertinent key messages.

1. **Contracting for outcomes. A Value Base Approach,** Outcomes based healthcare in association with Capsticks. 2014

Outlines the Value Based Commissioning programme (commenced Sept 2013) and discusses how re-designing care around people's needs is a radically different approach to improving health outcomes. Details progress with work in NCL. By engaging in systematic outcome measurement, this programme will have a significant impact on the lives of people within NCL, resulting in care which is genuinely organized around the outcomes which are important to them.

Key messages

- Getting the metrics right is essential. We have to stop playing around with process measures
- We need to focus on a small set of high value outcomes. Who choses?

2. **Insight roundtable: Commissioning for outcomes,** Summary report; June 2014. NHSE

Sets the context for commissioning in the NHS i.e. to improve outcomes for the local population and describes the role of commissioners. Emphasis is placed on aspects around creating collaborations across the health and care system, and leading the transformation of the system in order to achieve improved health and wellbeing. Having clearly established this as their purpose, commissioners will regard outcomes based contracts as one of the means by which they achieve their goals.

Key messages

- Outcomes based commissioning may have many different forms, and there is no single evidence-based model or a blueprint to follow
- Commissioners will need to experiment to find the best approach for any given situation
- Their job is to have the confidence to create that innovative and transformational change

3. How much do clinicians support patient activation? Nov 2015. NHSE

This report offers a snapshot of current clinician attitudes and behaviours towards patient activation and identifies a range of perceived barriers and support needs.

Key messages

The comments made by clinicians in the survey show that:

- Many believe it is important to address elements across three key areas in the healthcare system to enable the delivery of person-centred care - better support for clinicians, targeted support for system change and support for individuals to engage in their health and care
- Clinicians were more likely to support statements that relate to people managing their behaviours and lifestyle, and following clinical advice and were less likely to support people making independent judgements and actions, and people functioning as a member of the care team

4. "It's All About Me": The Personalization of Health Systems, Snowden, Schnarr and Alessi. International Centre for Health Innovation and Western Health Sciences. Feb 2014.

This paper examines various aspects of personalisation, offers insight into "health personalization" from a people perspective and discusses what a personalised health system could look like and the necessary steps for health system to achieve this. "Value" should be defined in terms of quality of life, health and wellness, rather than by disease and illness, which health systems do not currently do. To achieve transformation, quality of life and wellness of the population need to be central tenants of all mission, vision, and values throughout health systems. A prerequisite for success is a better understanding and consideration of what people value and need from their healthcare systems, and how people want to engage in order to achieve this.   Currently, there are few opportunities for either of these, yet the most important feature of personalized health systems is that people can exercise self-determination and have input into defining the value health systems must deliver on, that is focused not on each individual citizen but on delivering value to the population it serves. If population health and wellness is core health systems "business", the system priorities and measures must be directly aligned to outcomes based on articulated value.   Personalization must reach beyond disease and risk management, and focus on quality of life, wellness, and the social determinants of health that achieve value.

Research communities need to shift from a dependence on typically disease specific clinical trials research, to a more values-based translational model that examines the impact of personalized health system approaches designed to fit with population values Translational research focused on value-based outcomes will need to bring a new perspective on evidence to guide and support policy structures for a personalized healthcare system. This will require a shift to a process of rational deliberation, where the best evidence and most reliable methods are used to shape

and inform public understanding and judgment, rather than self-interest of influential stakeholders in health systems.

To achieve a personalized health system, we need to define success by mapping health and wellness outcomes/goals onto the important work of clinical quality and performance outcomes throughout the health system, yet, despite well documented wellness measures in many global health systems, currently wellness is generally not linked to health system performance. Health systems at local and regional levels are not integrating measures of wellness in regional or community levels to inform and support personalization of health system services and outcomes. This is essential to enabling the direct comparison of health system performance relative to wellness of the population they are serving.

Key messages

- Personalized health systems must deliver value to the populations they serve within the context of the unique social, political, and philosophical perspectives underlying the culture of each population
- Health systems must engage the population actively in determining these important decisions to achieve benefit, and reduce harm
- Health systems must recognize that health and disease are determined by the interaction of any number of a broad range of socio-economic, ecological, historical, genetic, developmental, physiological, and cultural factors or determinants
- A shift from top-down control to collaborative decision-making requires that individuals, communities and populations collaborate on how health systems are structured to achieve value for the populations they serve.; requiring collective and individual clarification of role and responsibilities in personalizing strategies and services to achieve health, wellness and quality of life, rather than relying on the traditional medical model of most health systems that assume responsibility and make decisions on "behalf of the patients"
- A change is needed to documenting and framing conversation to those around what matters to people as individuals, identifying personal health and wellness goals; thus shifting the entire dialogue to focus on the person, not their disease or illness. In every subsequent conversation or transaction, the health and wellness goals are the focus of the conversation and the treatment plan is specifically designed in collaboration with the individual to achieve personal goals and outcomes
- Personalization must reach far beyond disease and risk management, and aspire to focus on quality of life, wellness, and the social determinants of health that achieve value

5. King's Fund - inequalities in life expectancy

It is useful to consider inequalities in the wider discussions around wellness, and outcomes. A more coherent approach to inequalities in health delivered through population health systems is needed reflecting the growing recognition that where we live, and who we live with, affects our health over and above our own individual

circumstances. Social relationships, norms and networks – and the absence of them – have an impact on the development of and recovery from health problems such as heart disease and also affect whether we take up and maintain unhealthy behaviours such as smoking. A recent systematic review suggests that there is some evidence that community development approaches that improve social inequalities also improve health behaviours, and by extension, inequalities in health. If we are to address inequalities in life expectancy and morbidity, there needs to be much wider integration with other public services and community assets. Other work shows that income itself may not be as important as those things that areas with higher incomes tend to have, such as better quality services, better lifestyles, or better housing and other wider determinants of health.

Key message

Our health is influenced and determined by more than our genetics or our access to health care. More important influences than either of these are our lifestyle behaviours and the wider determinants of our health – the physical, social and economic conditions in which we are born, raised and live.

6. **Making it better together: A call to action on the future of health and wellbeing boards,** June 2015. LGA

In this document the progress and opportunities around HWBB is discussed. It recognises that it is time to move on from relationship building to making an impact on delivery of services and, that there are still some cultural and behavioural challenges which must be overcome. Specifically, it identifies areas for local action around ensuring a focus on outcomes, developing, monitoring and reporting on progress towards a small set of agreed outcomes that will have the most impact. Uniquely the HWB has oversight of the entire local health and care system and the factors that impact locally on health and health inequalities such as education, housing, employment, transport, planning and the environment. For the benefit of residents, it is imperative that senior leaders come together to develop this oversight.

Key messages

- A focus on joint outcomes is needed; In addition, an emphasis on locally determined targets would bolster local leadership and action on key local priorities. HWBs provide the forum to do this
- They propose a single national outcomes framework for health, public health and social care with a limited number of key national outcomes for the whole system which will enable HWBs to determine their priorities locally

7. **Helping measure person-centred care. A review of evidence about commonly used approaches and tools used to help measure person-centred care,** March 2014. The Health Foundation

There is no universally agreed definition of person-centred care in the empirical literature, approaches to measuring person-centred care attempt to measure either

the holistic concept or specific subcomponents such as communication or shared decision making. Studies of person-centred care tend to focus on one of four main issues:

- How patients or professionals define the components of person-centred care
- The type of care that patients want or professionals' attitudes and values (preferences)
- The extent to which care feels person centred (experiences)
- What happens as a result of person centred care (outcomes.

Outcomes resulting from person-centred care were less commonly measured than processes, although more recently studies have begun to explore this? The movement towards patient-reported outcomes measures (PROMs) could be seen to be part of this; however this approach tends to use system-centric outcome measures, rather than those that may be of most importance to patients and families.

Key messages

- A large number of tools are available to measure person-centred care, but there is no agreement about which tools are most worthwhile
- There is no 'silver bullet' or best measure that covers all aspects of person-centred care
- These reviews suggest the potential for positive outcomes from person-centred care. However a recurring theme is an emphasis on the relatively low quality of the evidence base, and the equivocal nature of evidence relating to the benefits of person-centred care
- It is difficult to make generalisable statements from a field that is so diverse and means different things to different people. This reinforces the importance of robust and repeated measures of person-centred care, so that health services can better understand the benefits of this approach and the extent to which it is being implemented
- There is little research about measuring person-centred care focused on assessing the impact of interventions at a population level in order to allocate resources or gaining insight into the relationships between processes. Most studies focused on assessing the impact of interventions at an individual level in order to tailor care more appropriately

In other words, person-centred care is about co-production rather than consumerism.

An important finding is that patients have generally not been involved in defining what person-centred healthcare means

8. **Improving the public's health- A resource for local authorities,** The King's Fund 2013

This paper considers the significance of strong communities, wellbeing and resilience and the role of Local authorities in helping individuals and communities to develop social capital. There is growing recognition that although disadvantaged social groups and communities have a range of complex and inter-related needs, they also

have assets at the social and community level that can help improve health, and strengthen resilience to health problems. It includes evidence around the impact of a person's social networks on their health and survival. Social networks have been shown to be as powerful predictors of mortality as common lifestyle and clinical risks such as moderate smoking and obesity. Social support is particularly important in increasing resilience and promoting recovery from illness and strong social capital can also improve the chances of avoiding lifestyle risks such as smoking. However, in the most deprived communities, almost half of people report severe lack of support, making people who are at greater risk less resilient to the health effects of social and economic disadvantage. Lack of social networks and support, and chronic loneliness, produces long-term damage to physiological health and loneliness makes it harder to self-regulate behaviour and build willpower and resilience over time, leading to engagement in unhealthy behaviours.

Key messages

- Imposing solutions on the public will be neither welcomed nor sustainable; and what matters to the public is not always what matters to experts
- Good health impact assessments move beyond the purely technical assessment of impacts on outcomes, to include community views
- As a quick guide to which areas are likely to deliver in specific ways; taking action on helping people find good jobs, stay in work, active and safe travel, and public protection and regulatory services could deliver quick wins for improving health; whereas for reducing inequalities, the focus might best be on best start in life, healthy schools and pupils, helping people find jobs and stay in work and access to green spaces and leisure services – all supported by strong spatial planning
- Taking early years as an example, the evidence suggests that interventions can have significant impacts in improving public health and reducing inequalities; but they will require specific investment and may take time to deliver results. Such interventions could make an important contribution to reducing inequalities in health however; much of the benefit will come through longer-term impacts on health through improving people's access to education and employment

9. **Children and young people's health outcomes forum,** report of the Public Health and Prevent sub-group

Unlike other stakeholders in public health and the NHS, children and young people do not have a voice in the democratic process that defines how the public wishes to see its health provision delivered. Unlike adults, they are not routinely present in planning, commissioning and delivery processes. For this reason, the forum considered it imperative to hear the views of children and young people. They also directly engaged with over 350 young people about the relevance of the public health outcomes to their lives.

Key messages

- There is a real need for the health system and the culture within the system to take a positive attitude to health promotion
- This should be through an 'assets based approach' that nurtures the strengths and resources which children, young people and their families and communities have at their disposal rather than a negative 'deficit approach'
- Health promotion for children and young people has focused predominantly on reducing specific health-risk behaviours or sets of compartmentalised 'fixable faults' and this focus on separate behaviours has tended to preclude the inter-relationship between health-risk behaviours and the contextual factors
- Insufficient consideration has been given in public health policy to building health engagement, resilience, self-esteem and self-efficacy that might promote well-being in children and young people. Some progress has been made however, and there has been valuable learning in the last decade from the 'wrap around the child' approach of Every Child Matters, the multi-agency collaboration of the Teenage Pregnancy Strategy and the Positive for Youth policy statement

10. **Children and young people's health outcomes forum,** report of the long term conditions, disability and palliative care subgroup

The single largest challenge for this group has been the lack of accurate data in relation to the development of outcomes. This has been a long term challenge and has been repeatedly seen as 'too difficult' by those who have a contribution to make in meeting the needs of this group of children and young people. This has meant that for a group of children who test the interfaces of services and systems there is little currently that records their experiences or challenges and their often poor outcomes.

Key messages

- Healthcare outcomes for this group of children and young people need to focus not only on the condition and the broader determinants of health (including secondary prevention) but just as importantly on the child's, young person's and family's individual experience and their priorities for care. The single disease model, with its focus on diagnosis and guidelines for care, can mean that symptoms that are impairing and comorbidities that impact on multiple functions are overlooked. However, it is these that will have a major impact on a child or young person's quality of life and should drive the priorities of need and therefore for care
- Improved outcomes depend on comprehensive quality assessments, access to a range of interventions, well-coordinated over time and inclusive of the child's, young person's and family's priorities
- Outcome measures therefore need to combine life course outcomes (happiness, family functioning, educational achievement etc.) with health service outcomes so that measures reflect changes in the condition, impairment or disability and their impact on the child, young person and their family

11. At the heart of health: Realising the value of people and communities,
   Nesta. Feb 2016.

This report provides an overview of the existing evidence base with a particular focus on the potential benefits of adopting person- and community-centred approaches. Person- and community-centred approaches for health and wellbeing include a wide and diverse range of activities, interventions and approaches. These range from collaborative consultations with health and care professionals that focus on what is most important to people, to community dance classes in the local hall. They happen in formal health and care settings, people's own homes and in the wider community. Despite this diversity, these approaches are united by a common purpose: to genuinely put people and communities at the heart of what they do – focusing on what's important to people, what skills and attributes they have, the role of their family, friends and communities and, given all this, what they need to enable them to live as well as possible.

Key messages

- Person- and community-centred approaches for health and wellbeing have significant potential to improve outcomes for individuals, support the development of strong and resilient communities and, over time, help reduce demand on formal health and social care services
- There is evidence from both research and practice to demonstrate the benefits of person- and community-centred approaches, across mental and physical health and wellbeing – dimensions of value
- Person- and community-centred approaches have been shown to increase people's self-efficacy and confidence to manage their health and care, improve health outcomes and experience, to reduce social isolation and loneliness, and build community capacity and resilience, among other outcomes
- NHS sustainability ; These approaches can impact how people use health and care services and can lead to reduced demand on services, such as emergency admissions and A&E visits
- There are wider social outcomes; Person- and community-centred approaches can lead to a wide range of social outcomes, from improving employment prospects and school attendance to increasing volunteering. They also can potentially contribute to reducing health inequalities for individuals and communities

12. Growing healthy communities - The Health and Wellbeing Index

It has long been recognised that the health of a population is strongly linked to the circumstances in which people live. The health and wellbeing index clearly supports this assertion and highlights the extent to which economic, social and environmental determinants translate to good or bad health outcomes in their broadest sense. It also shows the scale and nature of inequality across the country and reiterates the need for a local, place-based approach to tackling health outcomes. A correlation assessment of the health determinants measured and the outcomes shows that the determinants that most influence health outcomes are tackling child poverty,

deprivation, unemployment, childhood education and social cohesion.

The reality of achieving successful collaboration is not easy; there is a need to improve collaboration through a better understanding of the correlation between the economic, social and environmental health determinants and health outcomes within a locality. This includes enabling joint health and wellbeing strategies to be better targeted on actions that will make a difference. However, collaboration faces systemic challenges. Thinking across organisational boundaries has historically been difficult for the NHS and much of the public sector. Placing trust in your collaborative partner and allowing the free flow of information is critical to the success of any venture. Mutual understanding of the perspectives of the different organisations and open-mindedness about what can be achieved are vital

Determinants are those factors identified as having a key influence on an individual's prospects for good health. These fall under three broad areas: Economic; Unemployment, qualifications, childhood education, occupations and income Society; Deprivation, child poverty, fuel poverty, crime and social cohesion Environment; Household occupancy (overcrowding), natural environment, social housing, homelessness and living environment.

The indicators used to assess health outcomes sit within two broad categories: healthy lifestyles and health conditions. The lifestyles data indicates the propensity of healthy behaviours (differing from the determinants by involving personal choices about how one lives, as opposed to the wider economic/social/environmental context in which one is living). Health conditions group indicators reflect (what are often) the consequences of certain lifestyle choices. Healthy lifestyles ; Adult obesity, child obesity, sports participation, smoking, drug misuse, binge drinking, under-age pregnancy and low birth weight Healthy conditions; Life expectancy, infant mortality, cancer mortality, suicide mortality, circulatory mortality, alcohol mortality, excess winter deaths, hip fractures, diabetes, self-reported well-being. The health and wellbeing index indicates that positive improvements in an area's determinants performance can be expected to have a beneficial impact on health outcomes. It also highlights the regional diversity of determinants and outcomes, underlining the need for a local approach.

Key messages

- While determinants heavily influence outcomes, it is possible for determinants to be influenced and outcomes to be improved by partners working in effective collaboration
- Joined-up, place-based approaches can make a significant difference and this is further evidence for the case for radical decentralisation of powers to local areas to enable public services to collaborate across organisational boundaries
- Significant results could be achieved if Whitehall promoted place-based, outcome-focused approaches – with devolved responsibility for outcomes to local leaders, with no strings attached
- There is strong positive overall correlation between health determinants and outcomes scores; broadly reinforcing the view that the ability to influence

these determinants will have a strong impact on public health

Page 18 identifies 7 key questions are a useful prompt that, in order to be answered "yes" would require use of PCOMs approach/thinking.

13. Measure what you Treasure - Well-being and young people, how it can be measured and what the data tells us, NPC 2014

Wellbeing is Multidimensional: It incorporates all those aspects of life that we need to make us happy, including the physical, material and social. It is also a positive concept: it is not merely the absence of negative aspects of life, such as illness or poverty, but must also account   for the presence of all the things one needs to lead a good life, such as strong friendships and self-esteem.

While schools and charities typically measure objective outcomes like school grades or attendance to prove that they are having an impact, this is only part of the picture. Whether a child is enjoying school and getting the most out of it matters too. Although these 'soft' outcomes can be harder to quantify than 'hard' outcomes, feelings must be understood if we are to comprehend the effect an intervention has on a child's life. NPC developed its Well-being Measure to help address this need.

Key messages

- Research has shown that happiness is related to objective circumstances; for example, there is a close relationship between wealth and well-being up to a certain threshold
- Happiness is also dependent on subjective well-being—people's values, views and assessments of their life circumstances, including self-esteem and feeling connected to a community

14. Measuring wellness; equipping our leaders with the evidence they need to drive transformation in care delivery, measurably improving outcomes, Oliver Wyman. napc Sept 2014

Patient activation has been shown to be a better predictor of health outcomes than known socio-demographic factors such as ethnicity and age. More activated people are more likely to attend screenings, check-ups and adopt positive behaviours (e.g. diet and exercise), and have clinical indicators in the normal range. Studies of interventions to improve activation show that patients with the lowest activation scores tend to increase their scores the most, suggesting that effective interventions can help engage even the most disengaged. From this evidence base they have concluded that a wellness metric systematically and consistently measured across England would be a highly valuable tool to support system transformation.

Key messages

- Measuring wellness can be used to galvanise appropriate activity across the whole system — diverse actors can align for the wellness cause and be held

to account for improving wellness. These actors include government, commissioners, and providers and reach across the healthcare, social services, and education sectors, even into areas such employment, crime prevention, and policing. All of these areas affect people's sense of wellness.

- Without an agreed approach to measuring wellness we have no consistent and comparable means of measuring the effectiveness of pilot programmes and innovations aimed at better integrating care and designed services more effectively centred on patient needs.
- Health and well-being boards are the forum where key leaders from the health and care system work together with the aim of improving the health and wellness of their local population and reducing health inequality. There is a need to equip these system leaders with the evidence they need to ensure pooled resources are used more effectively.
- An agreed approach to measuring wellness will empower these leaders to measure the impact of their own innovations and to look for demonstrated examples of impactful interventions in other systems that they can adapt and apply locally to solve the challenges in their own area

15. Operationalising wellness; systemic approaches to drive transformation in care delivery, measurably improving outcomes, Oliver Wyman. napc Sept 2014

Measuring wellness can be used to galvanise appropriate and congruent activity across the whole health and social care system. Diverse actors can be incentivised to align around wellness and be held to account for its improvement. These could include all sectors within healthcare and social care and also potentially others from the broader care system, including education, justice, crime prevention and local government.

Health and care systems are complex adaptive systems and require the careful, specific and bespoke introduction of new metrics, often via a graduated methodology to diminish the likelihood of disengagement and unsustainability. Their introduction will likely be opposed if they affect existing activity based metrics and there needs to be a clear understanding of the roles of Payers and Providers of care and the behaviours they are likely to exhibit as a result. All these considerations need to be factored into the introduction process.

Key messages

A wellness metric can to support the shift from a reactive to a proactive health and care system. The principles that underpin the metric are largely independent of the parameters which govern the health and care system (e.g. unified government funder/ employer/ insurer). The metric should:

- Move away from a disease focus to a whole person focus – from "medicine by body part" to a person-focused system that unifies physical and mental health and incorporates non-biomedical and social parameters
- Shift from activity counting to more holistic assessments and outcomes – in essence, salutogenesis

- Move away from "sickness and repair" concepts to ones that encourage aspects of risk reduction and in some cases the prevention of ill health
- Address the years of lost or diminished life, not merely encourage longevity. The metric should seek to add life to years and reduce the years of misery associated with debility and multi-morbidity
- Have relevance to the individual. The recipient of care should be able to drive towards the outcomes they most value, rather than remain a passive recipient of activity prioritised by others. In this way, the metric should encourage and drive the four levels of patient activation
- Be constructed within a common thematic. Unified metrics will require different sectors (e.g. primary care, hospital care, social care, mental health care, education, etc.) to work together in order to achieve common goals.

Social isolation will also lessen as dependence on wellness metrics increases.

Wellness improvement schemes will be funded directly by healthcare providers in some healthcare systems, or by local government in others. Whatever the incumbent system, links between care and health will increase to the extent that the interface will become largely indistinguishable.

16. **How to summarise and report written qualitative data from patients: a method for use in cancer support care,** Marie J. Polley & Helen E. Seers & Helen J. Cooke &Caroline Hoffman & Charlotte Paterson

The goal of this study was to understand key themes to aid the analysis of qualitative data collected at three cancer support centres in England, using the Measure Yourself Concerns and Wellbeing (MYCaW) questionnaire. The simple questionnaire used predominantly Likert scale methodology. The results showed that clinical information from a cancer patient's perspective was collected that is not measured on standard quality-of-life questionnaires; furthermore, some themes acknowledge the multi-faceted aspects of complementary and alternative medicine provision, rather than information only relating to the therapeutic intervention. This enabled categories for qualitative MYCaW analysis to be established providing a tool for future research and/or service delivery improvement within cancer support centres

17. **Options for integrated commissioning Beyond Barker,** June 2015, The King's Fund.

The first paper in a series "Measuring Wellness" describes the evidence and rationale of moving from a reactive "sickness and repair" service within health systems to one which is proactive and based on the person, population health and a salutogenic approach. It describes the implementation of change at an individual level towards full activation, also identifying preferred metrics to measure that change. Patient activation is not only a better predictor of health outcomes than known socio-demographic factors such as ethnicity and age, but there is also a powerful economic case for driving improvements in patient activation. Aligning care provider teams and other stakeholders across health systems with an agreed

common measurement approach will facilitate collaboration around innovation in service delivery and achieve value for the populations they serve.

Effective, integration of services overcomes many of the negative consequences of a fragmented system from the user's perspective, such as the need for multiple assessments and visits to different providers. There is emerging evidence that the integration of health and care services can produce a range of benefits. This is particularly the case for local or regional populations and for older people, and there is also evidence that care coordination can benefit individual service users and carers, particularly around patient experience and higher levels of patient satisfaction. A recent review of international integrated health and care funding arrangements explored some of the challenges associated with the implementation of these arrangements and stressed the importance of their being underpinned by effective working relationships and leadership across the system The starting point should be to focus on the outcomes that well-designed integrated care should aim to achieve everywhere through a single, nationally agreed outcomes framework. A mandatory requirement should then be placed on all local authorities and CCGs to demonstrate how, by the end of the next parliament, those outcomes would be achieved locally through a single commissioning function for their local population.

Key messages

- There is clear evidence that when it comes to delivering benefits, the integration of clinical teams and services is far more important than the integration of organisations – and organisational integration in itself is no guarantee of improved outcomes
- Successful integration of services is dependent on having a shared purpose and a clear vision of what integrated care will achieve. It is important that attempts to integrate care move beyond high-level aspirations and involve the development of specific objectives
- Integration is not an end in itself but a means to better outcomes

18. Personal Well-being in the UK, 2014/15, ONS, Statistical bulletin. Sept 2015

Reported personal well-being has improved every year since financial year ending 2012 when data were first collected, suggesting that an increasing number of people in the UK are feeling positive about their lives. The greatest improvement has been for levels of anxiety. Personal well-being, people's thoughts and feelings about their own quality of life, is an important aspect of national well-being. It is part of a much wider initiative in the UK and internationally to look beyond Gross Domestic Product (GDP), and to measure what really matters to people.

The Annual Population Survey (APS) has included 4 questions which are used to monitor personal well-being in the UK: 1. Overall, how satisfied are you with your life nowadays? 2. Overall, to what extent do you feel the things you do in your life are worthwhile? 3. Overall, how happy did you feel yesterday? 4. Overall, how anxious did you feel yesterday? These questions allow people to make an assessment of their life overall, as well as providing an indication of their day-to-day emotions. Although "yesterday" may not be a typical day for an individual, the large sample

means that these differences "average out" and provide a reliable assessment of the self-reported anxiety and happiness of the adult population in the UK over the year.

Key messages

- The personal well-being statistics are used to inform decision making among policy-makers, individuals, communities, businesses and civil society. They complement other traditional measures of progress and quality of life, such as unemployment and household income. The personal well-being estimates are used as part of a wider programme to monitor and understand UK national wellbeing over time and in comparison to other countries
- One of the main benefits of collecting personal well-being data is that people are able to give their views about each aspect of their well-being. Without it, assumptions must be made about how objective conditions, such as people's health and income, might influence their individual wellbeing
- However, personal well-being measures are grounded in individuals' preferences and take account of what matters most to them by allowing them to decide what is important when providing an assessment of their own quality of life

19. Place-based systems of care - A way forward for the NHS in England, Nov 2015. The King's Fund

A system of care must decide on a single set of measures to underpin its shared objectives. This is likely to involve agreeing a small set of metrics to assess the overall performance of the system, as well as how these metrics will be collected and reported – including to the public. A larger set of metrics should also be collected to allow partners to understand how they are contributing to the overall goals of the system and identify areas for improvement.

As well as routinely collected performance data, this should include measures to test whether the system is behaving in a way that aligns with its agreed values and behaviours. For example, measures such as IntegRATE developed by researchers in the US can be used to measure how well teams are collaborating to deliver more integrated services to their patients), while tools such as CollaboRATE can be used to measure patient engagement and shared decision-making in routine practice

Key message

The experience of high-performing health care systems in other countries illustrates the value of a sustained commitment to quality improvement based on clarity of the system's goals and systematic measurement of progress towards them. This should be reinforced by an explicit quality improvement methodology that is consistently applied.

20. Powerful people reinforcing the power of citizens and communities in health and care, July 2015. Institute for Public Policy Research

In this paper the "key lever of change" - patient power - is explored in the context of "the current opportunity to make patients a key driver of change in the NHS". Inherent to success is, an unprecedented shift in the culture, attitudes and skillset in NHS institutions and workforces, to enable people to become active agents of change. While politicians have long declared that empowerment should be at the heart of the NHS, most decisions are still made by large bureaucracies and clinical professions, rather than people and communities. Attempts to empower patients so far have focused on making acute services like hospitals more responsive, but we now need to give people greater control over their own health in their homes and communities. A person is empowered over their health and care to the extent that they can manage and make decisions about their health, shape and choose the health and care services they use and influence the wider social conditions that affect them, whether individually or through their relationships with others, so that they can lead the lives they want to live. Empowerment in health and care has tended to focus on giving patients more rights, information and choices so that acute healthcare services are more responsive to them. There has been far less focus on empowerment around prevention and self-management; empowerment in health and care is not just about empowering people in relation to public services, but also about giving them the capability to exercise greater control over the wider social factors that affect their health. It is arguably as important from a heath point of view that a person has an influence over their housing and employment conditions as they do over the type of care they receive in hospital.

Personal budgets are perhaps the most radical of recent innovations to empower citizens in relation to public services. Described as radical because at their most extensive they hand public money to the citizen to directly purchase the care and support they want, these represent a radical break with the orthodox model of public service provision, in particular with direct payments, we are given direct control of the public money allocated for our needs and can decide ourselves how to spend it. Therefore patients and CCGs should move towards a form of payment by outcomes for most of the care they commission.

Changes to the way money flows around the system, such as by rolling out personal budgets for those with long-term conditions so the citizen becomes the commissioner, and by adopting payment by outcomes and capitated budgets are significant enablers. Equipping the healthcare workforce with the roles and skills required to provide these new models of care, as well as moving to a more coproductive culture and redesigning organisations so that they provide more autonomy to frontline professionals will support this - together with a more active role for citizens. Empowerment will be achieved through being more involved in and prepared for care planning; by actively seeking to achieve the goals agreed; by sharing their health data with professionals from different service organisations and by getting involved in the community and by helping others.

- Empowerment is a good thing in and of itself – people should have greater control over their own lives. Empowerment also produces better health outcomes, improved patient satisfaction and could save money in particular in reduced hospital admissions
- Reforms intended to empower patients have so far been inadequate. They have focused on the acute sector, seen people as individuals cut off from relationships and networks, empowered citizens in relation to individual services rather than treating them as whole people, and focused on people's needs not their capabilities
- This agenda requires a profound change in clinical and healthcare cultures and mind-sets. We need to move to a co-productive culture in which decision-making is genuinely shared between patients and healthcare professionals
- Research has shown that patient 'activation is strongly related to a broad range of health-related outcomes, which suggests improving activation has great potential'. This is because patients with chronic conditions live with their condition 24/7 and only spend a fraction of their time visiting clinical experts: the rest of the time they have to manage their condition themselves. Additionally patients who are engaged in their health and healthcare – through health literacy, shared clinical decision-making and self-management – are more likely to say that their healthcare is of high quality, and are less likely to report experience of medical errors
- Giving people the support and information they need to avoid getting ill, or when they have a chronic condition to self-manage it effectively, should save the NHS money by reducing demand on acute care. If people are not equipped and supported to self-manage, they are effectively left on their own and can end up with complications, health crises, preventable trips to the GP or A&E. Robust evaluations of empowerment programmes focused on peer support and redesigned consultations have been estimated to reduce acute care costs by 7 per cent. and save the NHS £4.4 billion a year across England (Nesta)

Requires a profound change in professional mindsets and cultures, particularly so that we ca shift from a paternalistic to a co-productive model of care ...shift from a medical mindset to one that gives much greater recognition to the social determinants of illness.

21. Wellness framework and indicators, British Columbia Atlas of Wellness 2nd Edition - Geography

Historically, health was focused on disease and illness, or negative attributes rather than positive factors however, more recently there has been a shift to view health from a more positive perspective. Health is also used interchangeably with well-being and wellness which are holistic in nature, encompassing more than just the physical aspects of an individual, but also the mental, spiritual, emotional, and social dimensions. In some cases, wellness includes a much broader range of dimensions. Current literature reveals additional terms corresponding and interrelating to the concept of wellness, such as wellbeing, life satisfaction, quality of life, human

development, flourishing, and happiness. High levels of wellness involve "progress toward a higher level of functioning, an optimistic view of the future and one's potential ; involving the "integration of the total individual – body, mind and spirit – in the functioning process "full-spectrum wellness is a multidimensional approach to health and well-being that extends from the individual to the collective and ultimately planet itself" It is about the connections between our state of wellbeing and our: Body, emotions, mind, and spirit; Earliest life experiences and our health over our entire lifespan; High-Level Wellness, family, friends, and community; Personal and work life; and, Environment – from our internal space, to our home, our neighbourhood, and the entire planet.

Another way to consider wellness is by using Antonovsky's salutogenic (or origins of health) model that focuses on factors that support and increase well-being rather than on factors that merely prevent disease. Two key factors promote salutogenesis. "Generalised Resistance Factors," which consist of such components as: social support, knowledge, experience, intelligence, financial resources, and tradition and a "Sense of Coherence," which is a positive way of viewing life and the ability to manage the stresses of living. Increasingly, salutogenesis is gaining acceptance as a useful model for promoting health and wellness and addressing health inequities. In a similar context, it looks at positive approaches to health, and views key influencers as wellness assets that enable people to stay well and lead happy, satisfying lives. Wellbeing can be seen as "a state of being with others in society where (a) people's basic needs are met, (b) they can act effectively and meaningfully in pursuit of their goals, and (c) they feel satisfied with their life."

Well-being has also been defined as "the presence of the highest possible quality of life in its full breadth of expression, focused on but not necessarily exclusive to: good living standards, robust health, a sustainable environment, vital communities, an educated populace, balanced time use, high levels of civic participation, and access to and participation in dynamic arts, culture and recreation"

Wellness and Well-being Framework Dimensions

Measuring wellness is an inexact and changing science made up of both objective and subjective indicators. In some cases, emphasis is placed entirely on subjective indicators, from both a personal (health, relationships, safety, standard of living, achieving, and community connectedness) and national perspective (the economy, the environment, social conditions, governance, business, and national security)

Key messages

- Most models of wellness include many dimensions In exploring wellness related frameworks from around the world, it is clear that there is no specific formula for measuring wellness, but there are many recurring dimensions that have been included in various frameworks
- While some frameworks have begun to use the terminology 'wellness' or 'well-being,' others have remained with an overall health perspective yet include many subjective wellness indicators

22. Realising the Value; scoping the review of the evidence document. Overview and methods. Feb 2016 Nesta

The Realising the Value programme seeks to identify a set of evidence based approaches to help the NHS to do more to support people with long-term conditions in managing their own health and care. The programme involves a consortium of collaborators; this report summarises the scoping review and shortlisting process and results. The purpose of this process was to identify "promising" approaches; the methods described provide a picture of the evidence available but might be subject to change in a full and comprehensive systematic review

Key messages

- There are a variety of person- and community-centred approaches for health and wellbeing that show promise across a range of outcomes
- The evidence is less clear for resource use changes and wider social impacts because these outcomes are less frequently reported than health and wellbeing, behavioural and biomedical outcomes
- The vast majority of the evidence regarding person- and community-centred approaches for health and wellbeing is currently disease-centred and lies within health care specialties and this may be due to the need to conduct RCTs where feasible to push the evidence base forward
- Person- and community-centred approaches are themselves difficult to define and measure
- Among the health and well-being outcomes reported, the most common were self-efficacy mental well-being outcomes, for example depression/anxiety global measures of health/quality of life disease specific measures, for example pain, functioning or symptom changes, knowledge outcomes and satisfaction. For wider social impacts, work/school absences were commonly reported, as were family impacts, teacher-related outcomes and social support outcomes
- Measuring person- and community-centred approaches for health and wellbeing - Embracing the benefits of taking a more person- and community-centred approach is now the goal for many health care systems but this is difficult to define and measure, and it is perhaps this uncertainty about how to measure the value of person- and community-centred approaches for health and wellbeing that may explain some of trends in the existing evidence base

23. Person Centred outcomes – what really matters? tweet chat

The tweet chat was the first for NHS Improving Quality's Person Centred Outcomes programme team, who wanted to explore a number of themes around Person Centred Outcomes including what are the outcomes that are really important to people (patients, carers and citizens), how health and care (and other sectors) contribute to these and how can we work best together to co-create a movement to prioritise Person Centred Outcomes and consider how this might be modelled to support commissioning and service delivery?

Taxonomy analysis ; 1278 tweets across 9/7 with a reach of over 3 million people including professionals, commissioners and individuals were posted for this tweet chat hosted by NHSIQ and @WeCommissioners. The common themes were around - conversations, starting with the person, goals, feeling, better, feeling well and my goals and a thread of recognising the need to change the balance between professionals and people in those conversations.

I would love it if every contact with a HCP started with the question "What do you want to get out of this meeting?"

Need to have a different mind-set to 'efficiency'.

"Asking what matters to you? Holistic assessment treating patients as people not conditions."

"Who is best placed to decide on what is a desired outcome? Why it is the individual patient of course "Am i feeling better"?

What matters to me is how my health affects my relationships with friends and family, how I can remain active etc.

Section B

This section contains summaries of the alignment of PCOM with policy and strategic drivers

1. The NHS Constitution.

Clearly states that the function of the NHS goes beyond health to include well-being, with a commitment to working jointly with other part of the public sector system. '*The NHS belongs to the people. It is there to improve our health and well-being…*'

Principle four
The NHS aspires to put patients at the heart of everything it does. It should support individuals to promote and manage their own health. NHS services must reflect, and should be co-ordinated around and tailored to, the needs and preferences of patients, their families and their carers. Patients, with their families and carers, where appropriate, will be involved in and consulted on all decisions about their care and treatment. The NHS will actively encourage feedback from the public, patients and staff, welcome it and use it to improve services.

Principle five
The NHS works across organisational boundaries and in partnership with other organisations in the interest of patients, local communities and the wider population. The NHS is an integrated system of organisations and services bound together by the principles and values reflected in the Constitution. The NHS is committed to working jointly with other local authority services, other public sector organisations and a wide range of private and voluntary sector organisations to provide and deliver improvements in health and well-being.

NHS values

- ### Working together for patients

  Patients come first in everything we do. We fully involve patients, staff, families, carers, communities, and professionals inside and outside the NHS. We put the needs of patients and communities before organisational boundaries.

- ### Respect and dignity

  We value every person – whether patient, their family or carers, or staff – as an individual, respect their aspirations and commitments in life, and seek to understand their priorities, needs, abilities and limits.

- ### Improving lives

  We strive to improve health and well-being and people's experiences of the NHS. We cherish excellence and professionalism wherever we find it – in the everyday things that make people's lives better as much as in clinical practice, service improvements and innovation. We recognise all have a part to play in making ourselves, patients and our communities healthier.

- ### Everyone counts

  We maximise our resources for the benefit for the whole community, and make sure nobody is excluded, discriminated against or left behind. We accept that some people need more help, that difficult decisions have to be taken – and that when we waste resources we waste opportunities for others.

'The involvement of patients, carers and the public in shaping and improving the way in which services are designed, delivered and improved is crucial.

'Foster a common culture shared by all in the service of putting the patient first' and '… patients must be the first priority in all of what the NHS does.'

Robert Francis QC

2. The 5YFV and PCOM

Sets out how the health service needs to change, arguing for a more engaged relationship with patients, carers and citizens so that we can promote wellbeing and prevent ill-health. As Atul Gawande says, 'Better is possible. It does not take genius. It takes diligence. It takes moral clarity. It takes ingenuity. An above all, it takes a willingness to try'. The 5YFV states, 'There are viable options for sustaining and improving the NHS over the next five years.' We believe a focus on Person-Centred Outcomes is one of the options that can make a long-term impact for both individuals and the system.

It suggests that the NHS can be prone to having:

- A factory model of care and repair
- Limited engagement with the wider community

- A short-sighted approach to partnership
- An under-developed plan of action for the broader influence of health and well-being.

And as a result, 'does not fully harness the renewable energy represented by patients, communities, employers and local government.'

Designing, developing and implementing a programme of work that focuses on person-centred outcomes is an opportunity to harness this energy, better understand priorities and preferences and use these to leverage real system-level change that can deliver personalisation for individuals, whilst maximising effectiveness and efficiency for the population. This is the challenge of turning individual transactional relations into generalizable population-level data-sets to flip the system.
One of the strengths of the NHS is often commented as being, '*the NHS is of the people, by the people and for the people.*' This statement is no truer than within the context of Person-Centred Outcomes.

Benefits from alignment of PCOM with 5YFV

1. A more engaged relationship with patients, carers and citizens, including new ways of working.
2. Increased numbers of patients say they are as involved as they wish to be in decisions about their care and treatment.
3. An increase in the number of health care ambassadors active across England.
4. People with Long Term Conditions are more actively involved in supporting culture change across the health and social care economy.
5. People with LD / MH are more actively involved in supporting culture change across the health and social care economy.
6. The NHS will have new and better partnerships with local communities, local government, the voluntary sector and employers are established / created / in place.
7. Shared budgets are actively being considered or in place.
8. Support and stimulate new ways of working to shape the NHS of the future. New care models are trialled at test sites and evaluated for adoption (adaption) and spread.
9. Driving down variation to close the care and quality gap.
10. Supporting the NHS to become an activist agent in health related social change.
11. Increase opportunities for health-related volunteering.
12. Better able to reach under-served populations.
13. A strengthened clinical triage and advice service that links the system together and helps patients successfully navigate it
14. Improved quality and responsiveness of care: 'right care, at the right time, in the right setting, from the right caregiver'.
15. Patients and carers are empowered to take much more control over their own care and treatment.
16. The system begins to reflect a results-led design, based on doing the right thing to meet the needs of people rather than simply by activity.

3. NHS Change Model

> 'If we preserve the NHS in aspic, it will die.'
> Rob Webster, CEO - Confed

'Person and community-centred approaches for health and wellbeing have significant potential to improve outcomes for individuals, support the development of strong and resilient communities and, over time, help reduce demand on formal health and social care services.'

At the heart of health: realising the value of people and communities

Our shared purpose

To create health systems that are truly focused on achieving the goals as articulated by patients, everyone involved in health systems must change their perspective in every facet of healthcare to allow for the creation of innovative, personalized solutions and health experiences where it is not all about the system, but rather "all about me". It's All About Me": The Personalization of Health Systems. Feb 2014. Snowden, Schnarr and Alessi. International Centre for Health Innovation and Western Health Sciences

Improvement tools

What is required to accomplish this shift is a process of rational deliberation, where the best evidence and most reliable methods are used to shape and inform public understanding and judgment, rather than self-interest of influential stakeholders in health systems. It's All About Me": The Personalization of Health Systems. Feb 2014. Snowden, Schnarr and Alessi. International Centre for Health Innovation and Western Health Sciences

Leadership by all

Only the HWB has oversight of the entire local health and care system and the factors that impact locally on health and health inequalities such as education, housing, employment, transport, planning and the environment. For the benefit of residents, it is imperative that senior leaders come together to develop this oversight: HWBs provide the forum to do so. Making it better together. A call to action on the future of health and wellbeing boards. June 2015. LGA

Influencing Factors

This is a significant realignment in thinking for citizens in most populations, and a very significant change in how health system decisions are designed and implemented to achieve value.   The most important feature of personalized health systems is that citizens can exercise self-determination and have input into defining the value health systems must deliver on, that is focused not on each individual

citizen (which is untenable), but on delivering value to the population it serves. To achieve this, personalization must reach far beyond disease and risk management, and aspire to focus on quality of life, wellness, and the social determinants of health that achieve value. It's All About Me": The Personalization of Health Systems. Feb 2014. Snowden, Schnarr and Alessi. International Centre for Health Innovation and Western Health Sciences

Measurement

If population health and wellness is at the core of what health systems are mandated to address, then system priorities and measures of performance must be directly aligned to measuring outcomes based on articulated value. Supportive infrastructure such as technology, payment systems and contractual levers will be required to effect this transformation and increase patient engagement. It's All about Me": The Personalization of Health Systems. Feb 2014. Snowden, Schnarr and Alessi. International Centre for Health Innovation and Western Health Sciences

Motivate and mobilise

The public needs to engage in a transparent and impartial dialogue to better understand the ethical and economic challenges of delivering healthcare services that create value within limited fiscal resources.

It is only through this public dialogue that communities and countries will be able to accelerate the transformational shift required to move from the traditional, top-down healthcare model, to one that introduces personalization in a rational and considered way that protects ethical boundaries, treats populations fairly, and delivers individual and population goals.

The key strategy for health systems is to engage the population actively in debating and determining these important decisions to achieve benefit, and reduce harm. The shift from top-down control to collaborative decision-making requires that individuals, communities and populations collaborate on how health systems are structured so that they are meaningful and achieve value for the populations they serve. This collaborative model will require consumers, communities, and populations to define their role and responsibilities in personalizing strategies and services to achieve health, wellness and quality of life, rather than relying on the traditional medical model of most health systems that assume responsibility and make decisions on their behalf. This is a significant realignment in thinking for citizens in most populations, and a very significant change in how health system decisions are designed and implemented to achieve value. It's All about Me": The Personalization of Health Systems. Feb 2014. Snowden, Schnarr and Alessi. International Centre for Health Innovation and Western Health Sciences

Project and performance management

Measuring wellness can be used to galvanise appropriate activity across the whole system — government, commissioners, and providers and reach across the healthcare, social services, and education sectors, even into areas such employment, crime prevention, and policing. All of these areas affect people's sense of wellness. Without an agreed approach to measuring wellness we have no consistent and comparable means of measuring the effectiveness of pilot programmes and innovations aimed at better integrating care and designed services

more effectively centred on patient needs.

The Health and Social Care Act 2012 established health and well-being boards as a forum where key leaders from the health and care system work together with the aim of improving the health and wellness of their local population and reducing health inequality. There is a need to equip these system leaders with the evidence they need to ensure pooled resources are used more effectively. An agreed approach to measuring wellness will empower these leaders to measure the impact of their own innovations and to look for demonstrated examples of impactful interventions in other systems that they can adapt and apply locally to solve the challenges in their own area. Measuring wellness; equipping our leaders with the evidence they need to drive transformation in care delivery, measurably improving outcomes. Oliver Wyman napc Sept 2014

Spread and adoption
In order to achieve a personalized health system, we need to define success by mapping health and wellness outcomes/goals onto the important work of clinical quality and performance outcomes throughout the health system. It's All About Me": The Personalization of Health Systems. Feb 2014. Snowden, Schnarr and Alessi. International Centre for Health Innovation and Western Health Sciences

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The empowered consumer

1. Drive to learn and better understand health and wellness
2. Drive to engage and connect to other consumers
3. Drive to "Take Control"
4. Drive to "Self-Manage" health information
5. Drive to ensure accuracy
6. Drive to collaborate with health providers, not be simply recipients of care
7. Drive towards consumer engagement