

# Embedding PROMs and PREMs into Dudley's MCP contract

## Findings of a rapid review

*A project delivered by ICF International, in association with the Strategy Unit, for Dudley Clinical Commissioning Group*



MIDLANDS AND LANCASHIRE  
COMMISSIONING SUPPORT UNIT

Strategy Unit

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**This project was delivered by ICF International as part of a broader programme of work led by the Strategy Unit to support Dudley CCG's new models of care programme.**

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# Background to the project

## There were three main aims for this project

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### Our brief was to:

1. Gather learning from analogous examples of outcomes-based commissioning about how to define and measure person-centred outcomes and experiences, and any issues and challenges associated with this.
2. Define the 'outcomes' and 'experiences' that are most relevant to the MCP and most valued by service users and the public.
3. Review tools and approaches for capturing person-centred outcomes and experiences, mapping these against the findings from 2. above, to produce recommendations for the MCP contract.

The CCG has identified improving access as one of the three key outcomes for the MCP. A separate project, being undertaken by the Strategy Unit, is scoping access measures to recommend for the contract, so we have excluded 'access' from the scope of our work to avoid duplication.

# We used a mixed-methods approach, bringing together published evidence and insights from key informants

- Targeted reviews of the literature – eg. on patient-reported outcome measures, measuring patients' experiences.
- Conversations with experts in the field, including areas that are developing or using outcomes-based contracts (see right for a list of who we spoke to).
- Reviewing the outcomes of the CCG's public consultation activities and attending key consultation events.
- Scoping relevant measurement tools, including reviewing key publications (eg. Da Silva 2013, 2014; Hunter and Leeder 2013) and resources (eg. the Compendium of Measures for Person Centred Coordinated Care).

## Who we interviewed:

- Rachel Lissauer, Acting Director of Commissioning, Haringey CCG
- Alan Nye, GP and Executive Director, Pennine MSK Partnership
- Charlie Wood, Director of Contracting and Performance, Bedfordshire CCG
- Elaine Moss, Chief Nurse and Director of Quality and Governance, Mansfield and Ashfield CCG and Newark and Sherwood CCG
- Nick Hicks, Chief Executive, COBIC
- Chris Graham, Director of Research, The Picker Institute
- Helen Crump, Fellow in Health Policy, Nuffield Trust
- Michele Peters, Nuffield Department of Population Health, University of Oxford University
- Tim Williams, CEO, My Clinical Outcomes
- Tim Benson, Chairman R-Outcomes
- Emma Stanton, CEO, Beacon UK

*We are happy to put you in touch with people we spoke to.*

# There are hundreds of PROMs and PREMs, but many are not suitable for the MCP contract

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There are hundreds of patient-reported tools available; we reviewed well over 100 in depth. Most tools can be immediately discounted though, either because they focus on a particular condition (eg. diabetes, stroke) or because they were designed for use in hospital settings. **You asked us to focus on generic tools** that can be used with a wide range of groups and in different settings, and we have made recommendations on that basis.

Recent commentaries have made a distinction between patient-reported and person-centred (or patient-defined) outcomes. The latter are outcomes that are valued by people, not just outcomes that they are asked to report on. **We have prioritised tools that capture person-centred outcomes**, using insights from the CCG's public consultations and wider literature to shape our understanding of what matters most to people who use services and the general public.

The MCP will cover all out of hospital services, so the CCG needs outcome and experience measures which are suitable across health and social care. **We found few tools that could be used across health and social care**, and only a handful that capture the aspects of service integration that people value. Some tailoring of tools and approaches may be necessary.

The use of PROMs and PREMs – especially in outcomes-based commissioning – is in its infancy. We have brought together the best available evidence about how to implement and use these tools, but there are major gaps in knowledge. **We would encourage the CCG to take an iterative approach to implementation**, learning as you go and being willing to change and adapt where necessary.

# Considerations for selecting PROMs and PREMs



# The literature and our interviews point to four key guiding principles for choosing PROMs and PREMs

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**Link measurement to the delivery and improvement of care, don't measure just for the sake of it**

**Measure what is meaningful, accepting that some things will have to be measured imperfectly**

**Work with stakeholders at every stage, especially in defining what should be measured and how**

**Keep it as simple as possible, and see measurement as an ongoing process, not a one-off activity**

# 1. Link measurement to the delivery and improvement of care

## There are two main functions of PROMs:

- **Individual level:** supporting the delivery of care, eg. by supporting routine patient assessment and management (eg. of long term conditions), improving communication between people and practitioners, enhancing patient involvement and the personalisation of care.
- **Aggregate level:** eg. providing evidence on the performance and quality of services, supporting the measurement and benchmarking of services, informing service redesign.

Sources: Hunter et al 2014; Devlin and Appleby 2010

- Many of the people we spoke to emphasised the importance of Dudley developing an approach to measurement that underpins and drives the transformation and improvement of care.
- Outcomes-based commissioning is a key vehicle for driving transformation, incentivising providers to change behaviours and ways of working; if measurement doesn't support this goal then it's not doing a good job. Pennine MSK found that measurement can itself trigger behaviour change, by harnessing healthy competition between providers and providing markers of improvement.
- PROMs have two main functions (see left), and we would encourage Dudley to select and use tools in a way that fulfils both of these.
- A recent study explored perspectives on how PROMs for long term conditions should be used, involving qualitative research with a range of stakeholders including clinicians, service providers, health and social care managers and patient-focused voluntary organisations. A clear view emerged among those interviewed that the priority was for PROMs to be effective at the individual level (Hunter et al 2014).

## 2. Measure what is meaningful

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- There are three differing ways in which measuring what is meaningful can be understood, all of which are important:
  1. Focusing on the experiences and outcomes that are most valued by service users, carers and the wider community
  2. Choosing measures which providers see as relevant and useful, and which relate to things that providers can effect change on
  3. Measuring in a way that produces informative and actionable data.
- Traditionally PROMs have focused narrowly on dimensions such as physical functioning and pain, often failing to address issues such as empowerment, social participation and control of daily life. Standard quality of life measures have been criticised for this (eg. Carr and Higginson 2001). Not all measures have been designed with service user and/or carer involvement.
- There are many things that people value for which standard measures and tools don't exist. But, as one interviewee commented, *"It is better to measure something that matters to people imperfectly than not to measure it at all"* (see Haringey case study for more information).
- Another interviewee commented, *"How do you get people to buy into PROMs and use them over a long period of time? They have to see the value of what they are gathering, they have to get something out of it personally. They will disengage if they think it is just gathering data for the sake of it."*

## 2. Measure what is meaningful (continued)

- There are two main types of PROM (see box on right). The key advantage of generic PROMs is that they enable comparisons to be made between different groups and services, and can be used for population level measurement. Specific PROMs are more likely to capture things that are meaningful and are more sensitive to change.
- We are now starting to see a third category of PROM emerge, which has the potential to combine the benefits of the two existing types – measures which are designed for use across multiple groups which have similar needs and/or priorities for care. For example, PROMs for long term conditions; we have recommended one of these for the MCP contact (see slide 43).
- Experiences shared by our interviewees suggests that Dudley should consider segmenting its population into broad groups (eg. older people, people with long term conditions, people with mental health conditions) rather than measuring at a population level. Focusing on groups of people with broadly similar needs or priorities will produce more meaningful and useful data.

### There are two main types of PROM:

- **Generic:** can be used across different groups or conditions and/or across different settings. The broadest instruments can be used at a population level and include health-related quality of life measures such as EQ-5D and SF-36.
- **Specific:** are designed for use with specific groups, for example people with a particular long term condition (eg. diabetes, Parkinson's Disease).

### 3. Work with stakeholders at every stage

#### Work with stakeholders at every stage

- Ownership of what is being measured is vital. The key challenge is winning hearts and minds, not least because measurement places a burden on services and practitioners so they have to understand why they are being asked to gather data. As one interviewee explained, *“Providers have to see the value in it, it has to be something they want to do”*.
- The best way to create ownership is to ensure that stakeholders are meaningfully engaged in defining outcomes and deciding how these are measured.
- Engagement can also have a positive impact on the data gathered and how it is used. Tools that have been developed in collaboration with patients and/or carers are likely to be seen as more relevant and user-friendly and this may increase response rates. Evidence shows that providers have a more positive attitude towards PROMs when they have been engaged in the planning stage (Boyce et al 2014).

### 4. Keep it as simple as possible

#### Keep it as simple as possible

- Avoid “death by measures” – it is better to focus on a few things and measure them well, than to measure everything.
- The measures chosen at the beginning of a contract don’t have to endure for its lifetime; this is especially true of a contract which will last for several years. If measurement is used to incentivise different ways of working and drive improvement, there is a strong rationale for changing what is measured periodically. Change programmes are dynamic, and so measurement should be.
- People generally prefer questionnaires that are short, clear and simple; the range of themes covered by a questionnaire will have to be traded off against the likely response rate.

## There are several factors that should be borne in mind when selecting tools; trade offs may have to be made between different criteria

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<b>Selection criteria</b>	<b>What does this mean/include?</b>
<b>Usefulness</b>	Supports the design, delivery and/or improvement of care; easily integrated into practice settings.
<b>Meaningfulness</b>	Captures things that are valued by people; ideally developed in collaboration with service users, carers and the public.
<b>User-friendliness</b>	Is an acceptable tool for people to complete, including language that is simple and easy to understand; length of the tool / time needed to complete.
<b>Feasibility</b>	The extent of effort, burden and disruption to care arising from use of an instrument; ease of analysis and interpretation.
<b>Responsiveness</b>	The ability of a tool to measure important change over time, where change has occurred.
<b>Cost</b>	Some tools are copyrighted and there may be a cost to use them and/or they require training to use.

## There are several factors that should be borne in mind when selecting tools; trade offs may have to be made between different criteria

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Criteria	What does this mean/include?
<b>Validity</b>	Whether a tool measures what it intends to measure in the different settings in which it may be used.
<b>Reliability</b>	Whether a tool produces stable and consistent results over time.
<b>Widespread usage</b>	Widely used tools provide data that can be used for benchmarking; there is more likely to be learning about how to implement these tools effectively.

We encourage you to give priority to tools which support the delivery and improvement of care, and which assess outcomes that are meaningful to the people who will be completing them.

**What outcomes and experiences matter to people**



**What outcomes and experiences matter to people**

**Dudley's public engagement**

# Access

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One priority to emerge from consultations to date is ease of access. Some Dudley residents have expressed concern at the difficulty of arranging GP appointments at convenient times, and have stressed the importance of appointment booking and accessing of information being simple, centralised and user-friendly.

## Initial point of contact

- People like the principle of having a 'single point of access', either online or by telephone, if it makes it quicker and simpler to get in touch with the right person.

## Accessibility of GPs

- The primary concern people have expressed about current provision is the difficulty of arranging a GP appointment for a convenient time, in the near future.

## Transfer to secondary care

- Some people have reported that the time it takes to arrange follow-up appointments at hospital can be excessive.

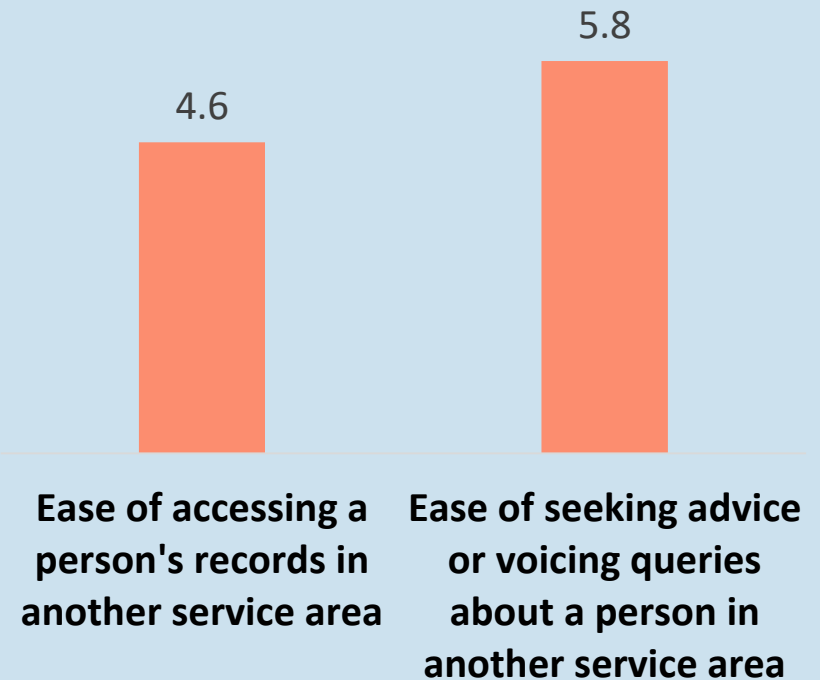
# Continuity

Another key theme in public feedback has been the importance of continuity. This primarily concerns issues with information not being passed between practitioners effectively, and the impact of this on service delivery.

## Continuity in service delivery

- Patients report practitioners asking them for information that they have already provided to another practitioner. They want this information to be shared effectively among practitioners, so that they don't have to repeat themselves.
- People want continuity in terms of the person they are seeing, especially their GP. Patients in Dudley are more likely than the national average to have a preferred GP they wish to see at each primary care interaction.

Average rating (out of 10) given to two different aspects of joint working by practitioners directly involved in patient care:



Source: Explain, 2016. *Dudley CCG – Vanguard Research Report*.

# Communication

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Communication has been another key concern expressed by members of the public during engagement. Some people feel that there are issues with communication, whether between different practitioners or between practitioner and patient, which affect the speed and quality of service provision.

## Communication between practitioners

- Slow transfers between different services, with some appointments taking too long to arrange or being made only after chasing by patient
- Lack of communication between primary care doctors and specialists affecting diagnostic and referral processes
- Carers being omitted from decisions about a patient's care due to practitioners not being made aware the patient has a carer who needs to be involved.

## Communication with patient and/or carer

- Some people reported a lack of feedback following GP consultations
- Carers can feel excluded from important decisions about the person that they care for.

## Priorities looking forward

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As well as being asked for their views on service delivery at present, patients and the public have also been asked for their views on what is most important to them in terms of the development of the MCP. Discussions have included:

- Risks to avoid
- Opportunities for improvement
- Any concerns they have about service areas which might be affected.

Recent consultations have asked patients and practitioners how they would measure the MCP's success. Early responses to this question are included on this slide.

### What outcomes matter to you? What does success look like?

- Assessment of outcomes needs to be holistic – taking into account social indicators, and the interplay between social indicators, and, health and wellbeing.
- Do staff know a patient's information prior to their appointment?
- Are staff knowledgeable about patients' options for referral or treatment?
- People need tracking through different stages of treatment. Successful outcomes at all different stages matter.
- Patients feeling empowered and involved in decisions that affect them.
- Reduced A&E admissions, and better wrap around care for repeat A&E admissions.

**What outcomes and experiences matter to people**

**Insights from the literature**

# We focused our review of what outcomes matter most to people on two key groups: older people and people with long term conditions

There has been extensive work exploring the things that older people value most, in their lives and in relation to health and care services. We have identified eight key themes:

## Autonomy and independence

- Support to remain as independent as possible for as long as possible, staying in their own homes if able and/or desired.
- Choice, involvement and control over the delivery and planning of their care – eg. timing, personnel, decisions – with advice if wanted.

## Relationships

- Maintaining as many good relationships with family, friends, neighbours and the wider community as they want to.
- Companionship.
- Being in touch with people like them (similar interests, cultural and/or religious background or health conditions).

## Appearance

- (Support to) keep a clean and presentable appearance.
- Able to keep their home and garden clean and looking good, either by themselves or with support from staff.
- Adaptations and/or equipment provided to support self-care where possible.

## Activities

- Able to do activities, solo and in a group, that are important to them.
- Able to try new things.
- Getting out and about, from own home or care home.
- If desired, able to have a daily routine.

## Older people also value.....

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### Health and wellbeing

- Feeling as healthy and active as they can be (physically and mentally).
- Support to regain and maintain better health and ability to do daily activities after illness.
- Avoiding unplanned or unexpected care.
- Supported to manage long-term conditions.

### Safety and Security

- Feeling safe or protected from harm at home.
- Confidence that help is available when/if needed.
- Financial security – access to all necessary benefits, and enough money to maintain chosen life.

### Individuality

- Care that suits their needs and choices, and recognises what they can do rather than what they can't.
- They are recognised and listened to as people and treated with dignity and respect by all services they come into contact with.
- There is equitable access to care, regardless of social, economic or cultural circumstances.

### A good death

- They are able to plan and be involved in decisions around end of life care and what happens after they die:
  - Pain issues.
  - Location.
  - Support for their carers after their death.

Sources: Bamford & Bruce 2000; Gabriel & Bowling 2004; Glendinning et al 2006; Murray et al 2009; NHS Listening Event 2013; NHS Croydon CCG; Qureshi & Henwood 2000; Redding et al 2014.



## Peters and colleagues (2015) reviewed literature to identify outcomes that are most important to people with long term conditions

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Dimension	Sub-theme
Ability to achieve personal goals	<ul style="list-style-type: none"><li>▪ Disruption to life</li><li>▪ Hope/staying positive</li><li>▪ Activity</li><li>▪ Plans and goals/purpose in life</li></ul>
Being involved and in control in relation to health decisions	<ul style="list-style-type: none"><li>▪ Care planning</li><li>▪ Empowerment</li><li>▪ Patient involvement</li><li>▪ Choice</li><li>▪ Patient preference or priorities</li><li>▪ Control</li><li>▪ Mastery</li></ul>
Social aspects	<ul style="list-style-type: none"><li>▪ Social participation</li><li>▪ Social support</li></ul>

# Peters and colleagues (2015) reviewed literature to identify outcomes that are most important to people with long term conditions

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Dimension	Sub-theme
Coping well or badly with long term conditions	<ul style="list-style-type: none"><li>▪ (Process of) adjustment to long term conditions</li><li>▪ Distress</li><li>▪ In(dependence)</li><li>▪ Psychological wellbeing</li><li>▪ Coping</li><li>▪ Autonomy</li></ul>
Feeling informed in the way you want	<ul style="list-style-type: none"><li>▪ Health literacy</li><li>▪ Health education</li><li>▪ Empowerment/information</li></ul>
Safety	<ul style="list-style-type: none"><li>▪ Feeling safe</li><li>▪ Accommodation and housing</li></ul>
Stigma	<ul style="list-style-type: none"><li>▪ Internalised stigma</li><li>▪ External stigma</li></ul>
Burden	<ul style="list-style-type: none"><li>▪ Burden of treatment</li><li>▪ Burden of care/services received</li></ul>

# There are seven dimensions of experience valued by people who use health and care services and their families

Dimensions of experience



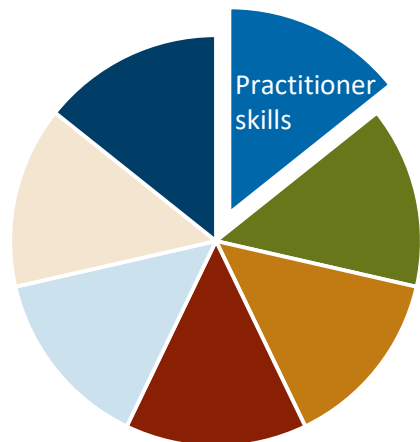
- Literature shows that service users value seven dimensions of experience; priorities may differ from person to person – it's not one size fits all (McIver and Ellins 2008).
- The seven dimensions are framed within person centred care – high quality care should address all these dimensions within an approach which treats patients as whole people, respecting their values, opinions and preferences.
- There is some overlap across the dimensions – this is to be expected in joined up care.

Patient experience is an important indicator for quality of care.

## Practitioner skills

People want their treatment and care to be effectively delivered by trusted practitioners, within an ethical approach.

- The Picker Institute has identified aspects of care that are most important to patients as including: fast access to reliable health advice, and effective treatment delivered by trusted practitioners (Richards and Coulter 2007).



- Research on the quality of general practice in England has shown that many patients want to see a GP that they know and trust (Freeman and Hughes 2010); this may be especially important to more frequent users of general practice services including older people and those with long term conditions.
- One of 4 areas that really matters to patients is to “*get the basics right*”, which includes ensuring that staff are competent and don’t lose patient notes (Department of Health 2007).

# Interpersonal

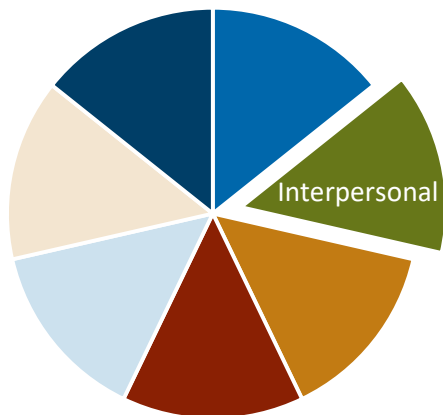
People want their practitioners to be ‘human’, with the interpersonal skills that enable relationships to be built and maintained.

- Research with NHS patients has shown that relational aspects of care hold central importance for patients (regardless of health conditions or care setting). In primary care, being treated with dignity and respect and being involved in care has been most strongly correlated with overall experience (Roberts et al 2011).

## Interpersonal aspects valued by patients include:

- ✓ Being treated as a person, not a number
- ✓ Being listened to and taken seriously
- ✓ Being given time
- ✓ Having rapport with practitioners
- ✓ Being treated with respect and dignity
- ✓ Practitioner empathy
- ✓ Having equality within the helping relationship

Sources: Department of Health (2007); Levine et al (2012); McIver and Ellins (2008); Richards and Coulter (2007); Roberts et al (2011).



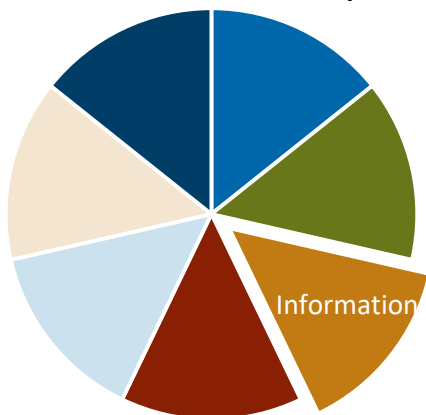
# Information

People want clear, comprehensive information – whether this is verbal or written – about their diagnosis, treatment and care.

- Research with NHS patients (50 narrative-based interviews) has shown that being informed and given options was amongst the six most common themes of what was important to patients (Roberts 2011).
- A Scottish study (1040 interviews with representative sample of population) exploring patient experience of GP practice found that when being prescribed medication the following information was important:

- What the medicine was for
- How and when to take the medication
- Being told about side effects.

(McKissock et al 2008).

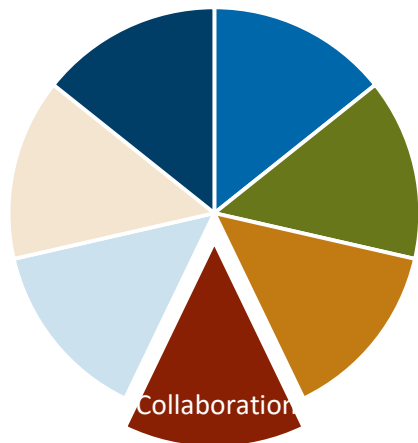


# Collaboration

People want to be regarded as partners in their own care; they want to be involved in decisions, to have care plans and regular reviews, and to be supported in self-care and self-management.

- Shared decision making, self-management support and care and support planning are three key elements of a collaborative approach. All three are reliant upon practitioners working in partnership with people, in an approach that is enabling rather than directive (Ahmad et al 2014; King et al 2013).

**Collaboration is especially important for people living with long term conditions.**



- Successive NHS patient surveys have shown that many people would like more involvement in decisions about their care than they currently have; this gap in expectations and experience is reported across all care settings (Roberts et al 2011). Studies have also challenged the view held by some that older people are less interested in being involved in their care and prefer a more paternalistic approach (Bastiaens et al 2007).

## Person-centred coordination

People want joined-up care, with seamless transitions between services. They want practitioners to work as a team and keep them informed. They want a single point of contact and do not want to repeat their 'story'.

- This dimension captures the body of work looking at integrated care. Patients are less concerned with how services are configured, they care more about how their needs are assessed and met overall (Cameron et al, 2012).

- Because this dimension is more valuable to certain types of patients (eg. older people and those with long term conditions), profiling respondents when measuring may be beneficial (see table).

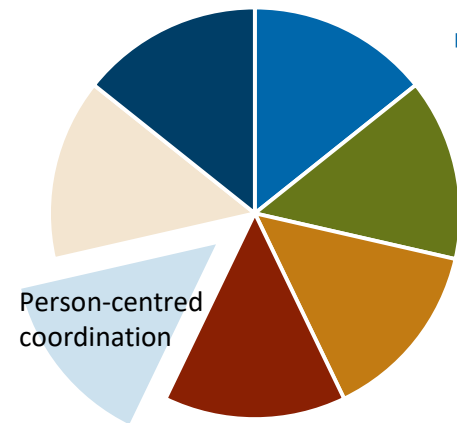
### Recommended targeting (Graham et al 2013)

#### Demography based:

- Older people;
- Families and children with complex needs.

#### Condition based:

- People with long term conditions (including mental health);
- People with disabilities (including learning disabilities);
- People with dementia;
- People who are at the end of their life.



It is important to avoid focussing on measuring single services, but to measure across transitions – this is a current data gap (Graham et al 2013).

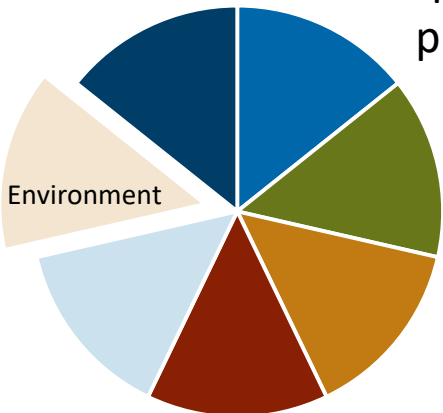


# Environment

People want the environment in which they receive care and support to be clean, comfortable, and safe. They also want receptionists to be warm and helpful.

- One of the areas that really matters to patients is to “*get the basics right*”, which includes making sure the setting is clean and safe (Department of Health, 2007).
- A large-scale UK study looked at patient survey, and interview and focus group data before and after a GP surgery moved to new premises. The “*calming influence*” of the new premises showed higher satisfaction scores following the move. Higher scores were attributed to informal seating, plants, decorative art, increased space/light, and a more modern appearance (Rice et al, 2008).

Research on patient experience of the physical environment is mainly focused on hospital settings. Patient experience of non-hospital settings is often mentioned as important but rarely explored in detail.

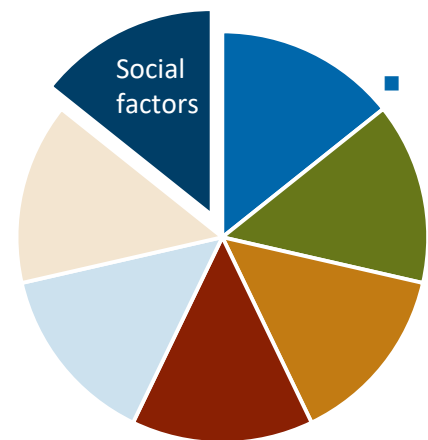


## Social factors

People want services to be aware of, and link with, the social context in which they live. They value support for social needs and want help to navigate and access community services that will improve their health.

- Treating people holistically requires recognition of the ways in which social context plays a role in illness, recovery and support needs. Social factors like housing, isolation and socioeconomic status influence health outcomes (Horne et al 2013).
- Patients value community resources (eg. peer support groups, coaching and buddying) and would like health services to tell them about community based services (NESTA 2013; Langford et al 2013; Infante et al 2014).

- Social needs can be addressed through health and care services being more connected with community based support – for example through approaches such as community navigators and social prescribing.



# Carers care about many of the same things that patients do, but they also have their own needs and preferences

## Outcomes

- Individual quality of life and wellbeing – physical and mental/emotional.
- Ability to maintain their own life – activities (eg. employment, education, leisure), relationships (family, friends, community) and time alone. Ability to maintain employment linked to concerns over financial burden of caring.
- Service-related outcomes:
  - Quality, quantity and flexibility of support; the right care, information and advice available at the right time for them and the person they care for, during and after the caring period has ended.
  - Ease of access to the right information to help them to be confident in their role as carer.

## Experiences

- **Practitioner skill:** being given the right information in the right way. Practitioners support the person they care for in the same way.
- **Interpersonal:** being treated with respect and dignity, and made to feel their role is important.
- **Collaboration:** recognition of their role as carer from practitioners; being treated as a partner.
- **Coordinated care:** services are connected so they do not have to repeat their story.
- **Environment:** their housing is suitable for the needs of the person they care for.
- **Social factors:** they are linked by practitioners to support groups or local services that can help.

Sources: Al-Janabi et al 2008; Carers UK 2016; Hain et al 2010; LE Wales 2010; RCGP 2013.

## Recommended measurement tools

### 1. Person-reported outcome measures

## If you want to measure....health-related quality of life

### Name of tool: EQ-5D

#### Description:

Contains 5 questions on a 3-point Likert scale, on the following areas of health-related quality of life (HRQOL):

- Mobility
- Self-care
- Usual activities
- Pain/discomfort
- Anxiety/depression.

Also includes a vertical visual analogue scale (EQ-VAS), where people are asked to indicate their health state (from best imaginable to worst imaginable).

#### Pros:

- Short, with easy to understand language.
- Data routinely gathered as part of GP Survey, so benchmarking is possible.
- Generic measure, so could be used to compare across groups and services.

#### Cons:

- Extensive evidence that EQ-5D has low responsiveness to change; studies show SF-36 performs better in this regard.
- Poorly suited to key groups eg. people with long term conditions.
- Narrow focus – ie. on physical functioning.
- There is a licensing fee – this will need to be discussed (alongside any desired alterations) with EuroQol after mandatory registration process.
- Data only routinely gathered for general practice, not other community-based services

# If you want to measure....social care-related quality of life

## Name of tool: Adult Social Care Outcomes Toolkit (ASCOT) SCT4

### Description:

Nine questions covering the following domains of social care-related quality of life (SCRQoL):

- Control over daily life
- Personal cleanliness and comfort
- Food and drink
- Personal safety
- Social participation and involvement
- Occupation
- Accommodation cleanliness and comfort
- Dignity

Available in both self-complete (SCT4) and interview schedule format (INT4). INT4 includes additional questions to enable practitioners to ask about expected SCRQoL and links with services.

### Pros:

- Data are routinely gathered as ASCOT questions are included in annual Personal Social Services Adult Social Care Survey (ASCS) but you may wish to use this toolkit with wider population.
- Tested to ensure it captures aspects of SCRQoL valued by service users.
- Usable across different groups of people in different settings.
- Potential for use in practice as well as outcome measurement.

### Cons:

- Calculation of SCRQoL scores requires adherence to weighting scores described in guidance documentation.
- Any alterations to the tool required can only be done with permission from ASCOT team.
- ASCOT team will need to be consulted to discuss whether a licence is needed.

## If you want to measure....social wellbeing (1)

### Name of tool: Warwick and Edinburgh Mental Wellbeing Scale (WEMWBS)

#### Description:

Contains 14 items on a five-point Likert scale, covering both feeling and functioning aspects of mental wellbeing. Developed to measure mental wellbeing of general population.

It has been produced in both paper and online completion formats.

A shorter seven item is also available (SWEMWBS) which relates more to functioning than feeling. Resulting scores need transforming using a conversion table.

#### Pros:

- Free to use (you just need to register with WEMWBS team).
- Widely used so there may be potential for benchmarking data.
- Can be used to support practice, in assessment and review and is responsive to change.

#### Cons:

- 14 items may be too long for many people.
- Shorter version requires more complex scoring calculations.

## If you want to measure....social wellbeing (2)

### Name of tool: ICEpop CAPability measure for Adults (ICECAP-A)

#### Description:

A 5-item self-completion measure of broader wellbeing. Covers the following dimensions:

- Feeling settled and secure
- Love, friendship and support
- Being independent
- Achievement and progress
- Enjoyment and pleasure

Designed for use in economic evaluations, and is part of a suite of capability-based questionnaires that also includes Carer Experience Scale (CES) – see slide 56.

#### Pros:

- User-friendly – short, with easy to understand language.
- Free to use (you just need to register with the team at University of Birmingham).
- No training required to administer.
- Generic so could be used across different groups (a specific version for older adults is also available).

#### Cons:

- Designed as a research instrument, suitability for practice settings is unclear.



## If you want to measure....empowerment

### Name of tool: Patient Activation Measure (PAM)

#### Description:

A measure of engagement in one's own healthcare, available in a short (13 items) and long (22 items) form.

Measures knowledge, skill and confidence for self-management. Captures patient beliefs about their ability to self-manage, and also the likelihood that they will act on these beliefs.

#### Pros:

- The measure identifies patients at one of 4 different 'activation stages'. This allows for population stratification, tailoring of care and measuring change.
- Widely used in the UK, including by other vanguards.
- Can help evaluate economic impact of the MCP; it has an evidence base on the cost of care (those with lower PAM scores tend to be higher utilisers of care).

#### Cons:

- Difficult language - not very user friendly.
- Narrow focus on behavioural dimensions of self-management.
- License fee.
- Fairly long, with short form still at 13 items.

## If you want to measure....outcomes for older people

### Name of tool: Older People's Quality of Life Questionnaire (OPQOL)

#### Description:

Designed in consultation with older people, available as either a long (35-item) or short (13-item) version.

Includes a global QoL rating and specific QoL items, with response options on a 5 point Likert scale.

The short version was developed by asking older people to prioritise the items which were most important to them. It covers: health, social relationships, independence, control over life, home and neighbourhood, psychological and emotional wellbeing, leisure and social activities, freedom and financial circumstances.

#### Pros:

- Both versions measure what has been found to be meaningful for people, rather than being based on pre-existing QoL measures.
- Free to use.
- Easy to understand language.

#### Cons:

- Even shorter version may be too long, at 13 items.
- Designed as a research instrument so suitability for use in practice is unclear.

## If you want to measure....outcomes for people with LTCs

### Name of tool: Long Term Conditions Questionnaire (LTCQ)

#### Description:

An 18-item tool designed for use by people with any long term condition (including mental health), and across health and social care. It covers domains found to matter to people with long term conditions (but not health status) – including questions related to physical, social, and emotional aspects, coping, and safety.

Still being piloted, and further development – including a translatability assessment into 6 most common second languages in the UK – is currently underway.

#### Pros:

- Was informed by a literature review of what matters to people with long term conditions, and qualitative research with people with long term conditions– making it far more person-centred than many other measures.
- Generic – can be used across different conditions and across health and social care.
- Free to use – but a licensing agreement will still need to be signed.

#### Cons:

- Long – but the developers would be happy for Dudley to select specific items if necessary (in consultation with them)
- As it is still in development there is not much information about how it can be used, or how useful it is.

## If you want to measure....personalised outcomes

### Name of tool: Older People's STAR / Wellbeing STAR™

#### Description:

These use a number of 10-point scales (arranged in a star format) where people are asked to plot where they feel they are at in particular areas of their life.

The Older People's Star covers seven areas of physical, emotional, social and financial wellbeing, and is designed to be used with a keyworker as part of an assessment and review process (a shorter quiz-style format is available for use in resource or day centres where there is less one-on-one time).

The Well-being Star, for people with long-term conditions, covers eight areas of physical, emotional, social and financial wellbeing and is designed for either self-completion or in conjunction with a practitioner.

#### Pros:

- User-friendly – language and layout easy to understand
- Covers things that matter to people
- Can be used in practice – eg. to support assessment and better care.

#### Cons:

- Only available under paid licence; training for all staff using the tool is compulsory
- Designed to be completed as part of key work and assessment rather than purely for measurement – therefore potentially labour intensive.

## The table below maps the shortlisted tools against our selection criteria

	Usefulness	Meaningfulness	User Friendliness	Feasibility	Responsiveness	Validity	Reliability	Widespread Usage	Low cost
EQ-5D	1	1	2	1	1	2	2	2	0
ASCOT SCT4	2	2	1	1	1	2	2	2	1
WEMWBS	2	2	1	2	2	2	2	2	2
ICECAP-A	1	2	2	?	?	2	2	?	2
PAM	2	1	1	1	1	2	2	2	0
OPQOL	1	2	1	1	?	2	2	?	2
LTCQ	1	2	1	1	?	?	?	0	2
Older People's / Wellbeing STARS	2	2	1	1	2	2	2	?	0

0 = Criterion not met  
1 = Criterion partially met

2 = Criterion strongly met  
? = Unknown

Some tools are still in development. Some criteria are therefore difficult to assess at this time.

## Recommended measurement tools

### 2. Person-reported experience measures

## Our shortlisted tools match onto the seven dimensions of experience summarised in the previous section

	CARE	IntegRATE	CollaboRATE	P3CEQ	GP Survey
Practitioner skills					
Interpersonal					
Information					
Collaboration					
Person-centred coordination					
Environment					
Community					

See slides 27-34 for description of dimensions of experience

# The CARE Measure

## Name of tool: The Consultation and Relational Empathy Measure (also known as the Patient Satisfaction Questionnaire or PSQ)

### Description:

10 items on a five-point Likert scale. It is described as measuring “*empathy in the context of the therapeutic relationship during a one-on-one consultation between a clinician and a patient.*” It asks respondents to rate their practitioner on key aspects of communication, collaboration and interpersonal care. It was originally developed and tested for use by GPs, but is now being used by other groups of staff including nurses and AHPs.

Developed by the Royal College of GPs for validation process of trainee GPs.

### Pros:

- Developed for use in a UK primary care context
- User friendly/plain language
- Available as a five-item visual version
- Freely available
- No training required to use.

### Cons:

- Measures experience of a single interaction, rather than a relationship over time.



# IntegRATE

## Name of tool: IntegRATE

### Description:

Four-item tool, developed to offer a quick and user-friendly way of assessing integration of healthcare delivery. Pilot studies shows it takes less than a minute to complete. The tool maps onto four domains of integrated care:

1. Information sharing
2. Consistent advice
3. Mutual respect
4. Role clarity

### Pros:

- Measures integrated care from the patient perspective
- Generic use (not condition or service specific)
- User friendly – short and wording of each item developed with patients through extensive qualitative research
- Freely available
- No training required.

### Cons:

- Not available in multiple formats.
- Developed in the USA, and not widely used in NHS...yet (still new).

Goals such as integration will take time to achieve, potentially several years. They will need to be measured long-term and different sources of evidence will have to be used to assess whether progress is being made.

# CollaboRATE

Name of tool: CollaboRATE	
<b>Description:</b>  Three-item tool (using a 10-point Likert scale) measuring patients' experiences of shared decision making in clinical encounters (Barr et al 2014). The tool was developed and piloted with end users.	<b>Pros:</b> <ul style="list-style-type: none"><li>▪ Generic measure</li><li>▪ Very user friendly – short, with simple language</li><li>▪ Has been used in several areas of the UK, although mostly in hospital settings</li><li>▪ Freely available</li><li>▪ Available in multiple formats</li><li>▪ No training required.</li></ul>
	<b>Cons:</b> <ul style="list-style-type: none"><li>▪ Asks patients to rate a single interaction, therefore does not capture the relationship elements of shared decision-making.</li><li>▪ Very health focused, would need revising for use in social care settings.</li></ul>

## Name of tool: The Person-Centred Coordinated Care Experiences Questionnaire

### Description:

11 item tool measuring the following domains of person-centred coordinated care:

1. Goal setting
2. Enablement
3. Self-management
4. Carer involvement
5. Care planning
6. Decision making
7. Information and communication
8. Knowledge of patient.

### Pros:

- Broad coverage of person-centred coordinated care dimensions
- Covers key domains of the National Voices 'I Statements'\*
- Freely available
- No training required.

### Cons:

- Appears longer than other measures: 11 items plus three open ended questions, plus reporting of demographic information over seven pages
- Open ended elements may mean it takes longer to complete
- Not available in multiple formats
- Is a relatively new tool evidence and so learning to support implementation is sparse.

\*Six generic 'I' statements for patient-centred coordinated care were developed by National Voices in consultation with the health and care system. These statements capture what matters most to patients and service users (See: <http://www.nationalvoices.org.uk/publications/our-publications/narrative-person-centred-coordinated-care>).

## The GP Survey

### Name of tool: GP Patient Survey

#### Description:

Annual national survey run by Ipsos MORI on behalf of NHS England, asking people to report on their experience of their GP practice. The questionnaire is available in paper and online formats.

Data from the survey are freely available from web platform, with analysis possible at both the CCG and GP practice level. Full questionnaire contains 62 questions, including the EQ5D.

A major downside is that response rates to the survey are low; for example there was a 32.5% response rate to the 2014/15 survey.

Questions we would recommend as measures for the MCP contract (12 in total):

- Q21-Q24: experience of last GP/nurse appointment
- Q28-Q29: overall experience
- Q32-Q33: self-management support
- Q36-Q39: care planning.

## The table below maps the shortlisted tools against our selection criteria

	Usefulness	Meaningfulness	User Friendliness	Feasibility	Responsiveness	Validity	Reliability	Wide-spread usage	Low cost
CARE	2	1	2	2	1	0	0	1	2
IntegRATE	1	2	2	2	?	1	1	?	2
CollaboRATE	1	2	2	2	1	2	2	1	2
P3CEQ	1	2	1	1	?	?	?	?	2
GP survey	2	2	1	1	2	0	0	2	2

0 = Criterion not met  
 1 = Criterion partially met  
 2 = Criterion strongly met  
 ? = Unknown

Some tools are still in development. Some criteria are therefore difficult to assess at this time.

## Recommended measurement tools

### 3. Measures for carers

# ASCOT-Carerer SCT4

## Name of tool: Adult Social Care Outcomes Toolkit (ASCOT) for Carers SCT4

### Description:

A seven-item tool covering the following domains of social care-related quality of life (SCRQoL):

- Control over daily life
- Occupation
- Social participation and involvement
- Personal safety (as a result of the caring role)
- Self-care
- Time and space to be yourself
- Feeling supported and encouraged.

SCT4 is still in development and currently can only be obtained, along with guidance and data collection tools, by contacting:

[ascot@kent.ac.uk](mailto:ascot@kent.ac.uk).

### Pros:

- Captures aspects of SCRQoL that are valued by carers
- Language is easy to understand, and the tool is short
- ASCOT-Carerer questions are included in the annual Personal Social Services Survey of Adult Carers in England (SACE)
- Potential for use in practice as well as outcome measurement.

### Cons:

- May require close working with ASCOT team – it is not an off-the-shelf solution and is still in development
- ASCOT will need to be consulted to determine whether a licence is needed
- Risk of duplication if people have already carried out SACE survey, which may affect whether willingness to complete.

## Name of tool: Carer Experience Scale

### Description:

A six-item tool to measure the carer experience, focusing on care-related quality of life. Covers the following dimensions:

- Activities outside caring
- Support from families and friends
- Assistance from organisations and government (amount of)
- Fulfilment from caring
- Control over the caring
- Getting on with the person cared for

Designed for use in economic evaluations, and is part of a suite of capability-based questionnaires that also includes ICECAP-A (see slide 40).

### Pros:

- User friendly: small number of questions; easy to understand language
- Interrogates how people feel about their caring role
- No cost to use.

### Cons:

- Doesn't measure carer's physical and emotional wellbeing, looking instead at 'care-related quality of life'
- Designed as a research instrument, suitability for practice settings is unclear
- Cannot be used to quantify an overall quality of life score.



# Carer STAR

## Name of tool: Carers STAR™

### Description:

Arranged on a star format this tool asks respondents to rate their situation in seven different domains:

- Health
- The caring role
- Managing at home
- Time for yourself
- How you feel
- Finances
- Work

The tool is designed to be completed in conversation with a practitioner and can be used as an assessment, review and measurement tool.

### Pros:

- Brief, at seven questions
- Can be used as an assessment and review tool to ensure consistency across a service, and potentially to improve practice
- Easy to understand language and graphics
- Has been tested and developed in conjunction with different groups of carers.

### Cons:

- Only available under paid licence; training for all staff using the tool is compulsory
- Designed to be completed as part of key work, rather than as a self-complete questionnaire
- No overall quality of life score can be calculated.

See also: slide 44 for versions of this tool developed for older people and people with long term conditions

# The table below maps the shortlisted tools against our selection criteria

	Usefulness	Meaningfulness	User Friendliness	Feasibility	Responsiveness	Validity	Reliability	Wide-spread usage	Low cost
ASCOT-Carer	2	2	1	1	1	2	2	2	1
CES	1	2	2	?	?	2	2	?	2
Carer STAR	2	2	1	1	2	2	2	?	?

0 = Criterion not met  
 1 = Criterion partially met  
 2 = Criterion strongly met  
 ? = Unknown

# Practical considerations for implementation

## The literature provides insights into sampling considerations, including the issue of who to sample

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- Sample patient cohorts rather than the entire population. Outcomes for variables such as quality of life and state of mind will be different for patients than for the wider population as a whole.
- Take a representative snapshot of the patient cohort each year, rather than tracking the same patients for multiple years. This will ensure service level improvements are accurately captured.
- There are a number of variables that need to be controlled for when sampling: not just demographics and number/type of health conditions, but also the frequency with which a patient accesses care and the types of care the patient receives.

Different conditions require different frequencies of care interaction and have different recovery times. Post-treatment surveying will need to allow for this, so that patients' responses are collected at the right time for improvements that are the result of treatment to be captured by the survey.

## Sampling issues also include how to reach people

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Identifying a sample prior to distributing the survey is less resource-intensive than over-sampling and then balancing responses later. Over-sampling would require more time spent collecting the larger number of responses, plus time analysing the data and removing surplus responses.

### **Sampling considerations for particular survey types:**

#### **E-survey**

- Could be difficult to access older people – 17% of Dudley and Sandwell residents haven't used the internet in the last 3 months, and the vast majority of these non-users are old (65 years or over).

#### **Phone survey**

- Phone surveys struggle to reach a sufficient number of currently employed people.

#### **Point of contact**

- Would have ready access to entire patient cohort – but would need some sort of check in place to avoid over sampling any particular population groups.

# There are different ways of administering tools; evidence and experience suggests this may have to be done at the point of contact

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## Postal

- Postal surveys tend to get the lowest response rates (around 10%).

## E-survey

- Tend to get higher response rate than postal surveys (up to 20%);
- But not everyone has internet access or uses it regularly.

## Phone survey

- This would need to be subcontracted out, and is the most costly option.

## Point of care

- Likely to get the highest response rate, as you will have a 'captive audience';
- Access to full patient cohort, with control over who responds.

## Ethical considerations

Haringey CCG had initially planned to administer its PROMs/PREMs through a postal survey. But this opened up ethical complications: the CCG would have to obtain each person's consent to access their contact details (so that the questionnaire could be posted out). So instead they chose to administer at the point of care. Questionnaires are distributed by general practices and patients can either complete them in clinic or take them away and return using a pre-paid envelope. They also offer online completion.

# There are two main options for administering at the point of care, both have strengths and weaknesses

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## Giving the questionnaire to the patient to complete independently

- + People may feel they can be more honest with their responses when they are provided anonymously;
- + People completing the survey independently avoids creating any extra demands on practitioners' time;
- Practitioners aren't available to help people with any difficulties in responding.

## Questionnaire is integrated into the patient assessment

- + The PROM/PREM can support routine patient assessment and management and people to be more involved in their care;
- May require additional time by practitioners to be committed to each assessment;
- The practitioner's presence could influence the patient's responses.

# However data is captured, the CCG will have to consider whether it manages the survey in-house or commissions an external partner

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## Paper vs electronic surveys

- Paper-based responses would need to be manually uploaded by staff; entering and 'cleaning' data by hand is time-consuming.
- Electronic responses could automatically feed into a centralised database, and wouldn't require any cleaning.
- There are IT platforms available which allow practitioners and people to access the information in real time (eg. through personalised dashboards). They can also aggregate data at a team or organisational level.

The team developing the Long Term Conditions Questionnaire trialled the instrument using paper-based and online surveys. They found they got better response rates with paper-based surveys. Many people who were targeted with the electronic version didn't even open the email that was sent to them.

Haringey CCG commissioned Quality Health to administer and manage their survey. They found working with a specialist patient survey company "hugely valuable" and would definitely recommend this option to Dudley. Administration of the survey has been the most challenging aspect of the work to embed PROMs and PREMs into their outcomes-based contract, and Quality Health's involvement has made this more manageable.



## Some tools may need to be adapted before you use them

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### Language

Many of the tools we have recommended have been developed within the healthcare context. We have given priority to those that are transferable across health and social care but there are very few tools that can be used across both settings.

Language may therefore need to be adapted in some cases to ensure suitability in different contexts (eg. social care, mental health) and with different groups.

### Shortening tools

Some tools may contain items of more/less interest. In order to reduce the burden of completion, you might want to select only some of the questions contained within a particular tool for use.

In such cases, permission may be required from tool developers. Where tools have been validated, this would alter psychometric properties for 'whole tool' use.

We have already spoken to the developers of LTCQ (the long term conditions PROM) about this, in case you select this tool. They are happy in principle for Dudley to select only certain questions, but would like to know which questions were selected and why, as this would contribute to their understanding of how the tool can be used in practice.

ICF can provide further support and advice if/when Dudley consider adapting language of, and shortening, selected tools.

# Some people may face barriers to completing PROMs and PREMs; there are various challenges that may need to be addressed

## READING PROMs

### Challenges

It is not easy to judge who will struggle because reading issues are often hidden. PROMs with more detail and harder words can be intimidating.

### Possible solutions

Ensure questionnaires are written in plain language and user-tested before administration. If possible, services should offer support to complete questionnaires or encourage people to find somebody to support them (eg. a family member or friend).

## UNDERSTANDING PROMs

### Challenges

Certain question types and phrasing in PROMs are particularly difficult:

- Questions requiring long memory
- Questions with too many response options
- Questions that try and address many things at once
- Scales with a large number of options

### Possible solutions

Select questionnaires without too many of the above question types and with consistent questions and response options.

## FORMAT OF PROMs

### Challenges

The look of a PROM can make it seem intimidating and hard to use. Complicated formatting includes text that is inconsistently aligned, unclear fonts, small font sizes, a lack of white space and non-prominent headings.

### Possible solutions

Select a PROM that most closely adheres to these guidelines and/or work with somebody with experience in accessible information.

## Some patients may not be able to self-complete; there are considerations to take account of when using proxy completers

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- Some patients may be unable to complete PROMs themselves due to certain physical disabilities or cognitive impairment. One solution for this is to use a ‘proxy respondent’ who is familiar with the patient’s current status (eg. family member/carer).
- The research in this area shows that self-reported and proxy-reported outcomes can differ, with proxies reporting lower quality of life than patients themselves report (Rand and Caiels, 2015).
- The extent of agreement between proxies and patients is affected by how observable the aspect of health being assessed is; the proxy’s familiarity with the health condition; the closeness of the relationship between proxy and patient; and the burden of care being experienced by the proxy (Rand and Caiels, 2015; Sneeuw et al, 1999).
- We would suggest that proxies are asked to answer ‘as if they were the patient’ rather than from their own judgement of the patient. There seems to be closer agreement between patient and proxy views when this question format is used (Pickard and Knight, 2005).

## There are also barriers and facilitators for effective use of PROMs in routine practice

	Barriers	Facilitators
Practical	Lack of time/money/human resources to collect, analyse, and use data; lack of IT/statistical support.	Integrating into consultation; ensuring user friendliness; management being deeply involved and appreciating additional burden on staff.
Methodological	Nature and design of tools (eg. lack of responsiveness); meaningful interpretation of score change.	Making data presentation meaningful to practitioners – eg. using graphics; and illustrating clinically important change.
Practitioner attitude	Not valuing holistic view of patient; concern about patient confidentiality; fear of performance measurement; concern over validity of tools measuring patient care.	Education <b>PLUS</b> guidance; being transparent about objectives; selecting tools in consultation with practitioners – to ensure they are meaningful to their practice (note: patients often have different priorities to practitioners).
Achieving impact	No new information provided; intrusion on patient privacy; negative effect on interaction and practitioner-patient relationship; narrowing focus of consultation; distressing questions.	Recognising potential to improve communication, patient education, shared decision-making, care planning, screening, and disease progression/response to treatment.

Sources: Boyce and Browne (2013); Boyce et al (2014); Greenhalgh et al (1999)

## Case study example: Pennine MSK Partnership

### Background

- Pennine MSK Partnership is a single organisation (a prime provider) providing integrated musculoskeletal services to the population of Oldham through an outcomes-based contract; it has been in existence since 2006.
- The standard measures in their outcomes-based contract do not include PROMs; they do include the Friends and Family Test, PALS and complaints data though.
- Instead PROMs are linked to specific quality improvement targets, proposed by the provider, which then form the basis of a CQUIN payment. Once an area for quality improvement has been agreed, specific PROMs are chosen to assess the impact of improvement work undertaken.

### Learning from Pennine MSK

- **Link measurement to improvement.** Agree which behaviours or ways of working you want to change, define improvement goals, and then choose measurement tools to track whether improvements are being made. This way of approaching measurement helps to drive a service improvement focus, rather than measuring for the sake of it.
- **What you do with the information is as important as what you gather** and how. Again the key issue here is provider engagement; providers are far more likely to use data (eg. to improve services) when they see it as relevant and useful.

# Case study example: Haringey CCG

## Background

- Haringey is one of five London CCGs developing a new valued-based model of commissioning. The work so far has focused on three populations: people with multiple long term conditions; frail older people; and people with diabetes.
- The work started with an extensive programme of engagement, exploring with service users and local residents what outcomes they want their health services to achieve, and then prioritising these. Measures were then identified for each of the priority outcomes; some outcomes mapped neatly onto existing tools and data, others didn't. Where there wasn't existing data or a suitable tool, they devised their own survey question to address this.
- The result was a composite questionnaire for each population group, bringing together items from several existing measurement tools with their newly devised questions. The questionnaires were then reviewed by service providers and subjected to cognitive testing before use.
- The CCG commissioned Quality Health to administer and manage the survey, and the collection of a baseline is nearing completion. They had initially assumed the survey would be postal, but ethical complications have meant that it had to be administered at the point of care. It has taken them four months to capture 8,000 surveys.
- Haringey intends to link PROMS and PREMS to contract payment; they are already doing this in Camden for diabetes services.

## Case study example: Haringey CCG (continued)

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### Learning from Haringey

- Above all, measurement must be meaningful, and so the power of measures depends on the quality of the engagement process that underpins their selection. Patient-defined outcomes don't always map neatly onto existing tools, but don't let that be a reason not to measure them.
- Haringey found it useful to segment their population in order to focus on groups of people with similar needs. They were doubtful that a population-level approach would produce meaningful data, or that it would be capable of measuring change over time.
- Measures chosen must relate to outcomes that are relevant to people who use services, and must be things that providers have an influence over. Involve providers in the development process so that all measures and tools are owned by them.
- There have been concerns that gathering outcomes and experiences at a system level might lead providers to 'pass the buck', because it wouldn't be possible to link poor findings to particular services. But the CCG has chosen to stick with their approach because they want to drive shared responsibility for outcomes.
- Given how much work has been involved in gathering the baseline, Haringey are now considering re-measuring every two years (rather than every year as they initially planned).

# Case study example: Bedfordshire CCG

## Background

- Bedfordshire CCG has a contract with Circle to manage all musculoskeletal services in Bedfordshire, which uses outcome measures.
- Patients are asked about their experiences one-on-one at the clinic, generally post experience. Patients are given an electronic form to complete in the practitioner's presence. Little measurement is done as follow-up work is after the point of contact.
- Response rates have been good. However, Circle has had problems gathering information relating to the extended care pathway (ie. what happens when patients progress to other services following treatment).

## Learning from Bedfordshire CCG

- Giving the patient a survey to complete in person, to fill in while still with the practitioner, ensures high response rates (when patients were left to complete a survey alone, post-appointment, a higher proportion left without completing it). Using iPads has also been found to drive up response rates.
- It has been difficult for one provider to track a patient's progress as they transition through different stages of the care pathway, due to underdeveloped data sharing mechanisms between different providers and some territoriality.
- There are some concerns that a patient's relief post-treatment might be inflating positive feedback, although the existence of such a phenomenon hasn't been verified.



# Next steps

## In terms of next steps, we would recommend Dudley CCG to:

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- Review the tools that we have recommended against the outcomes of your public consultation; tools should be selected which capture those things that matter most to people who use services and the wider community.
- Take all tools which you are considering building into the MCP contract to the public and your providers, giving them opportunity to review and comment on them. Be prepared to revise your approach if these tools are considered unsuitable for any reason.
- Give thought to how PROMs and PREMs can be used to drive transformation, as well as assessing it. For example, is there scope for embedding PROMs and PREMs into the routine delivery of care and support?
- Work with providers to ensure clarity and shared expectations about how PROMs and PREMs data will be used – eg. for service planning, quality improvement. This includes considering how data will be fed back to providers, and what support will be given for them to make sense of, and use data effectively.
- Remember that ICF have budgeted 5 days of time to provide ongoing support and advice, as you progress with the commissioning of the MCP. We can use these days flexibly to provide targeted follow up on key issues if these are needed. Our team includes a specialist health economist who we can draw on for advice on technical issues (eg. sampling, population stratification). We can also put you directly in touch with any of the people we interviewed if you want a more detailed conversation with them.
- Bear in mind that some of the tools we have recommended cannot be used immediately ‘off the shelf’. For some you may need to complete a licensing agreement (even if the tool itself is free), and/or those using the tool may need to undergo training. If you want to use specific questions rather than tools in their entirety, you will probably need to liaise with the researchers/organisations that developed them to get their agreement to do this.
- Consider how this work can be shared more widely, especially with other vanguards who are developing outcomes-based contracts. ICF would be delighted to work with you to disseminate the findings from the project.