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Measure what we want: a taxonomy of short generic person-reported outcome and experience measures (PROMs and PREMs)

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ABSTRACT

Introduction Health and care systems are complex and multifaceted, but most person-reported outcome and experience measures (PROMs and PREMs) address just one aspect. Multiple aspects need measuring to understand how what we do impacts patients, staff and services, and how these are affected by external factors. This needs survey tools that measure what people want, are valid, sensitive, quick and easy to use, and suitable for people with multiple conditions.

Methods We have developed a coherent family of short generic PROMs and PREMs that can be used in combination in a pick-and-mix way. Each measure has evolved iteratively over several years, based on literature review, user inputs and field testing. Each has has a common format with four items with four response options and is designed for digital data collection with standardised analytics and data visualisation tools. We focused on brevity and low reading age.

Results The results are presented in tabular format and as a taxonomy. The taxonomy is categorised by respondent type (patient or staff) and measure type. PROMs have subdomains: quality of life, individual care and community; PREMs have subdomains: service provided, provider culture and innovation. We show 22 patient-reported measures and 17 staff-reported measures. Previously published measures have been validated. Others are described for the first time.

Discussion and conclusions This family of measures is broad in scope but is not claimed to be comprehensive. Measures share a common look and feel, which enables common methods of data collection, reporting and data visualisation. They are used in service evaluation, quality improvement and as key performance indicators. The taxonomy helps to organise the whole, explain what each measure does and identify gaps and overlaps.

INTRODUCTION

Surveys, completed by patients or staff, are widely used in tailoring care, quality improvement, evaluation and population health management. They need to cover the things that matter most to those completing them and other stakeholders. The challenge is to do this in a simple easy-to-use way, while recognising the complexity inherent in the health domain.[1]

Person-reported outcome measures (PROMs)[2–4] and person-reported experience measures (PREMs) measure different things,[5] with only weak correlation. PROMs measure people's perception of their own situation; PREMs measure their perception of services provided. PROMs are a form of personal history and are of clinical value, but PREMs are usually anonymous, because people can be reluctant to criticise those they depend on. Individuals may choose to identify themselves in PREMs, but the default is not to.

PROMs and PREMs may be condition-specific or generic. Two-thirds of health and care expenditure is for people living with three or more chronic conditions,[6] but most PROMs apply to only one condition, which limits their use. Different measures have been developed independently and do not work well together.[7] For example, in some measures a high score is good, in others high is bad. Scale ranges vary, such as 0–1, 0–10, 0–48 or 0–100.

Generic measures work for all types of patients, treatments and conditions. They are based on the idea that people want similar things, such as good health and well-being, excellent service, supportive communities and organisations, care and innovations that meet their needs.

Care quality is assessed in terms of structure, process and outcome.[8] Our focus is on outcome as perceived by patients and staff. Perceived outcome is only one aspect of a complex whole, although broader than the traditional definitions of PROMs and PREMs.[9] However, it does not cover all aspects of health outcomes, experience and patient-centred care.[10]

Response rates are affected by perceived relevance and ease of use.[11] Most measures require a higher reading age[12] than the average reading age of the UK population, which is about 9 years.[13]

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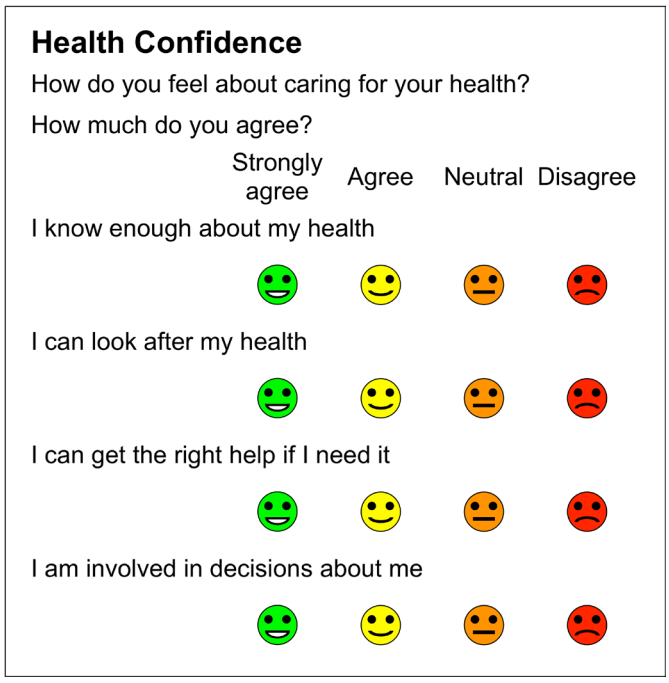

Figure 1 The Health Confidence Score: an example of a measure.

BACKGROUND

This work has had a long gestation. During the 1970s, the author worked with Rachel Rosser to evaluate computer systems in a London hospital using a short staff-reported classification of disability and distress.[14] Inter-rater reliability studies identified the importance of using clear, unambiguous wording.[15]

During the mid-2000s, interest in PROMs and PREMs increased, as exemplified by Darzi's NHS Next Stage Review *High Quality Care for All*, which recommended their wide use.[16] Unfortunately, existing tools were not well suited to routine use, having been used mainly in pharmaceutical clinical trials, where respondents have few time limitations and only one condition.

The author identified a need for a simple PROM that could be used on smartphones and tablets. This led to the development of the *howRu* health status measure, which evolved from Rosser's classification. This was tested in a telephone survey of 2751 people living with long-term conditions, in comparison with 12-item Short Form Survey.[17] It was also tested in comparison with 3-level version of EQ-5D in a hospital cardiovascular clinic,[18] and in hip and knee replacement surgery.[19]

After the Stafford Hospital scandal, the financial crash and change of government, political interest turned to patient experience (PREMs). The *howRwe* patient experience measure was developed along the same lines as *howRu* to be quick and easy-to-use routinely. It was tested in an orthopaedic presurgical assessment unit.[20] The *howRu* and *howRwe* measures were both used in a census of 24 000 care home residents in the UK, Australia and New Zealand.[21 22]

Person-centred care and new care models became a key focus during the mid-2010s. Wessex AHSN selected *howRu* and *howRwe* for use in the evaluation of the North East Hampshire and Farnham NHS Vanguard project, also known as *Happy, Healthy at Home*. This eventually used 17 different surveys with more than 2800 respondents. Explicit objectives included improved personal well-being and health confidence, which led to the development of the Personal Well-being Score (PWS) based on ONS4,[23] and the Health Confidence Score (HCS).[24] Social prescribing and care navigation also attracted attention and evaluation funding, leading to related measures of loneliness, community cohesion and social determinants of health.

During the same period, Wessex AHSN was tasked with evaluating and promoting the spread of digital health innovation, which stimulated the development of innovation adoption measures.[25] These built on the author's prior work about how spread[26 27] and interoperability[28] are impacted by both technical and non-technical factors (eg, culture).

The aim of this paper is to describe the resulting family of generic measures, organised as a taxonomy. A taxonomy allows for measures to be viewed and compared, gaps identified and the body of work improved and developed further.

METHODS

The author with colleagues has developed a family of short generic PROMs and PREMs to capture a broad range of patient and staff perceptions of quality of life, healthcare services, wider determinants of health, digital and service innovations. These measures share a common format and scoring scheme. They are picked and mixed as required to create longer surveys for different purposes in quality improvement, impact evaluation and as key performance indicators (KPIs).

All measures are generic, suitable for most situations and clinical conditions, irrespective of case-mix, across health and social care. They can be completed on paper, smartphone, tablet, PC or via text message or voice.

Using criteria set out in the literature,[29–32] each measure was developed in a similar way.[17] None of the work was commissioned formally or grant-funded. The author had full editorial control.

In outline, the approach used was as follows:

1. Recognise the need for a new measure, based on user feedback and other insights. All measures were developed to meet actual or perceived needs.
2. Review the relevant literature and identify key themes.
3. Develop prototypes, based on a common format of four items per measure and four response options per item.
4. Discuss, revise and field test with users, colleagues and other stakeholders.

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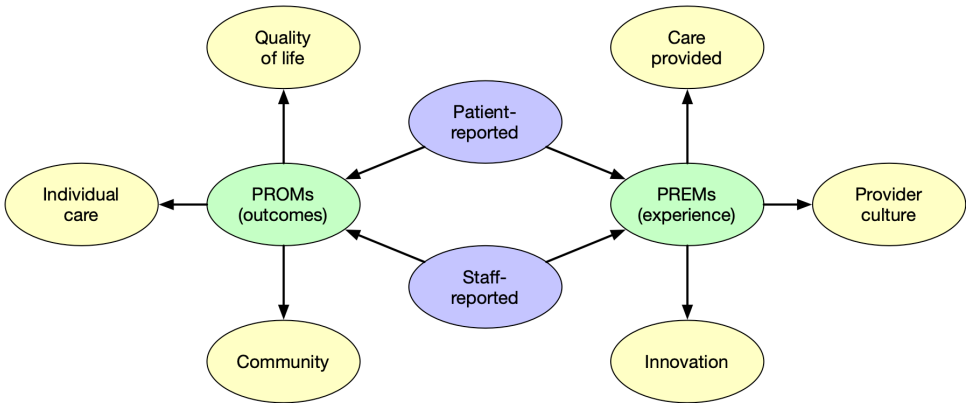

Figure 2 Top levels of the taxonomy. PREMs, person-reported experience measures; PROMs, person-reported outcome measures.

5. Iterate, adapt, evolve and further test. This involved dozens or in some cases hundreds of iterations before all issues were resolved.
6. Evaluate the measure for distribution (eg, skewness and kurtosis), internal reliability and construct validity.
7. Publish in peer-review journal.

The common format, with four items (questions) and four response options, is not a rigid rule and exceptions may be allowed to the number of items or options, although none is shown in this paper.

The Health Confidence Score (figure 1) provides an example of the look and feel, showing the title, preamble and instructions, items (lines), options (columns), colour and emojis.[24]

Items

Each item measures perception of one characteristic or theme in a measurement domain. Most domains have a well-understood ideal. Item wording needs to capture different aspects of the domain in ways that people readily understand.

Particular attention was given to word count and readability. These were calculated using the word count and readability statistics included in Microsoft Word. In this paper, we use the text in the tables herein, including footnotes, with each item label treated as a separate sentence. The survey preamble and options are excluded, because the preamble is usually tailored to the local context and option repetition depends on administration mode (eg, the options should always be visible to the user). The readability measure is the Flesch Kincaid Grade (FKG), which estimates US school grade.[33] As a guide, the reading age of a text is FKG plus five.

Options

The following option sets are used:

- None, a little, quite a lot, extreme (none–extreme)
- Strongly agree, agree, neutral, disagree (strongly agree–disagree)
- Hardly ever, occasionally, sometimes, always (hardly ever–always)
- Excellent, good, fair, poor (excellent–poor).

This list is extensible. For example, we could also use:

- Agree, neutral, disagree, strongly disagree (agree–strongly disagree)
- Strongly agree, agree, disagree, strongly disagree (strongly agree–strongly disagree).

Options are usually ordered left to right, from best to worst. We use colour coding and emoji (both of which are optional), from best (eg, green smiley face) to worst (eg, red sad face). Emoji are tailored to the meaning of each option set, using a choice from: grin, smile, neutral (straight mouth), unhappy and miserable.

All items are optional. In most cases the recall period is now. Many PROMs use recall periods with questions such as: "how often have you experienced X" during the last week or month. However, many people find recall difficult (eg, most people find it hard to remember what they had for dinner 2 or 3 days ago).[34] These measures avoid specifying a recall period other than today or yesterday.

Scoring

A high score is always good, which aids consistent understanding of results. This rule is followed even when the name of an item or measure implies that it measures something undesirable.

For items about individuals, the scoring system is from 0 (worst) to 3 (best). For populations, the mean item score is transformed to a 0–100 scale using the formula: (mean item score)×100/3. For example, responding *strongly agree* to *I know enough about my health* scores 3 on the 0–3 individual scale and 100 on 0–100 population scale; *disagree* scores 0 on both scales.

Most measures comprise a group of four items. A summary score is calculated for each measure as the sum of the item scores. Assuming four items, at the individual level this gives a 13-point scale from 0 (4×worst) to 12 (4×best). For populations, the mean summary score is shown on a scale from 0 to 100, using the formula: (mean summary score)×100/12. A summary score is not calculated if any item score is missing.

Using a common 0–100 scale for item and summary mean scores enables direct comparison of the results. A

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Table 1 Patient-reported outcome measures

Name	Options	Text used in survey	Alias	Words (FKG)	Notes
Quality of life					
Health status	None–extreme	How are you today? (past 24 hours)	howRu	24 (2.6)	Health status (howRu) is sometimes referred to as health-related quality of life. This was the first in the family.[17]
Pain/discomfort		Pain or discomfort	Pain		
Distress		Feeling low or worried	Distress		
Disability		Limited in what you can do	Disability		
Dependence		Require help from others	Dependence		
Personal well-being	Strongly agree–disagree	How are you feeling in general?	PWS	29 (3.7)	Personal Well-being Score (PWS) is based on the Office of National Statistics ONS4. Unlike ONS4 all items are worded positively, and it has a summary score.[23]
Life satisfaction		I am satisfied with my life	Satisfaction		
Worthwhile		What I do in my life is worthwhile	Worthwhile		
Happy		I was happy yesterday	Happy		
Not anxious		I was NOT anxious yesterday	NotAnxious		
Sleep	Strongly agree–disagree	Thinking about your recent sleep pattern	Sleep	29 (0.9)	Sleep hygiene is an important determinant of health and well-being.[50]
Sleep at same time		I go to sleep at the same time	SleepTime		
Wake at same time		I wake up at the same time	WakeTime		
Wake refreshed		I wake up feeling refreshed	Refreshed		
Sleep well		I sleep well	SleepWell		
Fatigue	Strongly agree–disagree	Thinking about getting tired	Fatigue	27 (3.9)	Fatigue is a common presenting complaint in primary care and can have a large impact on quality of life.[51]
Energy level		I usually have enough energy	Energy		
Tire quickly		I do not tire too quickly	TireFast		
Able to concentrate		I can usually concentrate well	Concentrate		
Stamina		I can keep going if I need to	Stamina		
Individual care					
Health confidence	Strongly agree–disagree	How do you feel about caring for your health?	HCS	38 (1.9)	Health Confidence Score (HCS covers people's confidence about looking after their own health.[24]
Knowledge		I know enough about my health	Knowledge		
Self-management		I can look after my health	SelfManage		
Access to help		I can get the right help if I need it	GetHelp		
Shared decisions		I am involved in decisions about me	ShareDecision		
Self-care	Strongly agree–disagree	How well do you look after yourself?	SelfCare	28 (4.2)	Self-care, includes self-management of diet, physical activity, weight and medication.[52]
Diet management		I manage my diet well	Diet		
Exercise management		I manage my physical activity well	Exercise		
Weight management		I manage my weight well	Weight		
Meds management		I manage my medication well	MedsMan		
Shared decisions	Strongly agree–disagree	Thinking about your plan	SDM	28 (3.8)	Shared decisions (SDM) covers patients' involvement in clinical decisions, including their understanding of the choices and the risks and benefits of each.[53]
Know benefits		I know the possible benefits	Benefits		
Know downside		I know the possible downside	Downside		
Know choices		I know that I have choices	Choices		
Fully involved		I feel fully involved	Involved		
Behaviour change	Strongly agree–disagree	Thinking about this behaviour	Behaviour	29 (1.0)	Behaviour change covers capability, opportunity and motivation (conscious and unconscious) to change behaviour based on Michie's COM-B model.[54]
Capability		I am able to do it (skills and tools)	Capability		
Opportunity		Nothing prevents me from doing it	Opportunity		
Conscious motive		I choose to do it	Motivation		
Automatic motive		I do it without thinking	AutoMotive		

Continued

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Table 1 Continued

Name	Options	Text used in survey	Alias	Words (FKG)	Notes
Adherence	Strongly agree–disagree	Do you follow treatment instructions?	Adherence	32 (3.1)	*Adherence* includes remembering to take medications, have treatment and to follow instructions, given side effects or recovery, and satisfaction.[55]
Remember		I remember to do it	Remember		
Go on if I feel bad		I do not stop if I feel bad	TakeIfBad		
Go on if I feel better		I do not stop if I feel better	TakeIfGood		
Treatment satisfaction		I am happy with my treatment	TreatSatis		
Acceptance of loss	Strongly agree–disagree	Have you learnt to live with what's happened?	Loss	32 (0.5)	Acceptance of loss covers how people cope with loss, learn to live with events, including recognition of capabilities and change, how to do things differently and to move on with life, along the lines of the grief cycle.[56]
New capability		I know what I can and cannot do	CanDo		
Recognise loss		I see how my life has changed	Recognition		
Change activity		I do things differently now	Activity		
Move on		I have moved on	MoveOn		
Community					
Social determinants	Strongly agree–disagree	Thinking about how you live	SDOH	31 (2.4)	Social determinants of health impact health and care outcomes but are outside the clinical system. Education, self-esteem, housing and poverty play a major role in determining peoples' health outcomes.[57]
Education		I have had a good education	Education		
Social status		I am valued for what I do	Status		
Housing		I am happy about where I live	Housing		
Enough money		I have enough money to cope	Poverty		
Loneliness	Strongly agree–disagree	Thinking about your friends and family	Loneliness	31 (2.4)	Loneliness is an important determinant of health and well-being. This measure focuses on peoples' perception of loneliness and their social relationships in a positive way.[58]
People to talk to		I have people to talk to	Companion		
People to confide in		I have someone I can confide in	Confidant		
People to help		I have people who will help me	PeopleHelp		
Do things with others		I do things with others	JoinIn		
Neighbour relationships	Strongly agree–disagree	Thinking about your neighbours	Neighbours	19 (3.2)	Neighbour relationships, community cohesion and social capital are impacted by how well people know, trust and help each other.[59]
Know each other		We know each other	KnowNeighs		
Trust each other		We trust each other	TrustNeighs		
Share information		We share information	NeighsShareInfo		
Help each other		We help each other	NeighsAssist		
Personal safety	Strongly agree–disagree	Thinking about your personal safety	PersSafety	30 (4.8)	Personal safety covers physical safety (eg, from injury) and emotionally safety (from verbal abuse or discrimination), which may occur either inside your own home or when you go out.[60]
Safe at home		I feel safe at home	SafeHome		
Respected at home		I feel respected at home	HomeRespect		
Safe outside		I feel safe outside home	SafeOut		
Respected outside		I feel respected outside home	RespectOut		
Loneliness (ONS)	Hardly ever–always	How often do you	LonelinessONS	17 (0.0)	This measure is included as an alternative to loneliness (above), based on guidance from the Office of National Statistics (ONS).[61]
No one to talk to		Have no one to talk to?	NoFriends		
Feel left out		Feel left out?	Isolated		
Feel alone		Feel alone?	Alone		
Feel lonely		Feel lonely?	Lonely		

FKG, Flesch Kincaid Grade.

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Table 2 Patient-reported experience measures

Name	Options	Text used in survey	Alias	Words (FKG)	Notes
Care provided					
Patient experience	Excellent–poor	How are we doing?	howRwe	18 (2.2)	Patient experience (howRwe) covers peoples' perception of the care and service provided by a specific service in terms of compassion, communication, access and organisation.[20]
Kindness		Treat you kindly	Kind		
Listen/explain		Listen and explain	Talk		
Prompt		See you promptly	Prompt		
Organised		Well organised	Organised		
Service integration	Strongly agree–disagree	How well do services work together?	Integration	35 (2.9)	Service integration captures how well services collaborate.[62]
Services talk together		Services talk to each other	Talk		
Service knowledge		Staff know what other services do	Aware		
Repeat story		I do not have to repeat my story	Repeat story		
Services work together		Different services work well together	PartOfTeam		
Provider culture					
Privacy	Strongly agree–disagree	Thinking about how we use your data	Privacy	37 (4.5)	Privacy covers patients' perceptions of data protection, sharing and information governance.[63]
Data are safe		My data is kept safe and secure	SecureData		
Data shared as needed		My data is only shared as needed	ShareData		
Can see/check data		I can see and check my data	CheckData		
Happy about data use		I am happy about how my data is used	DataSatis		
Innovation					
Digital confidence	Strongly agree–disagree	Digital devices include computers, smartphones and tablets	DCS	36 (6.8)	Digital confidence assesses people's confidence in using digital apps and similar devices.[64]
Digital usage		I use a digital device frequently	DigitalUse		
Peer usage		Most of my friends use digital devices	PeerUse		
Access to help		I can usually get help if I am stuck	Supported		
Confident digitally		I feel confident using most digital devices	DigitalConf		
Product confidence	Strongly agree–disagree	How do you feel about (this product)?	PCS	25 (4.7)	Product confidence coversunderstanding of and confidence in using a specific innovation, application or product.[65]
Frequent user		I use it frequently	ProductUse		
Confident user		I feel confident using it	SelfAssured		
Know benefits		I know the potential benefits	Positives		
Know problems		I know potential problems	Negatives		
User satisfaction	Strongly agree–disagree	What do you think of (this product)?	UX	33 (0.5)	User satisfaction focuses on people's perception of how much an innovation is useful and easy to use, availability of help and overall satisfaction.[66]
Helps me		It helps me do what I want	HelpsMe		
Easy to use		It is easy to use	EasyToUse		
Can get help		I can get help if I need it	Support		
Product satisfaction		I am satisfied with this product	ProdSatis		
Digital readiness	Strongly agree–disagree	New ideas in this field of work	DigitalReady	30 (4.4)	Digital readiness covers how ready people are to use digital innovations and their innovativeness.[67]
Digital use		I use a digital device frequently	DigitalUser		
Confidence		I feel confident using most digital devices	DigitalConf		
New ideas needed		New ideas are needed	OpenToIdeas		
Keep up to date		I keep up with new ideas	WellInformed		

FKG, Flesch Kincaid Grade.

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mean score 100 occurs if all respondents chose the best option (the ceiling) and 0 if all chose the least desirable option (the floor). It is unlikely that an individual score will be confused with a population mean score, because they use different ranges.

Taxonomy

A taxonomy was developed as a way of organising and classifying the measures, to explain the range and scope of measures to others and to identify gaps and overlaps.

A taxonomy is a system for classifying multifaceted, complex phenomena according to common conceptual domains and dimensions.[35] It is a hierarchy of things or concepts in which each node (other than the root) has a single parent and any number of sibling and child nodes. Each node is a specialisation or sub-class of its parent (inheritance).

The development of the taxonomy followed an iterative process similar to that used to develop its components. Key criteria were simplicity, coherence and inheritance.

Patient and public involvement

Many patients, health staff and members of the public took part in focus groups during the development of these measures. They helped test and refine early versions of the measures. Most focus groups were informal. Papers which describe the development and validation of specific measures provide more details of patient and public involvement for those measures.

This paper does not report identifiable data about any individuals or groups.

RESULTS

The taxonomy

The results use the taxonomy as an organising principle or framework. Figure 2 shows the top levels.

Patient-reported and staff-reported measures cover the same domains, but there are important differences between them. It helps to consider these roles separately. Patients are subjects of care, but staff provide care (eg, clinicians, admin staff and volunteers) within an organisational structure. Staff see many patients and the data collection process is usually simpler. Many staff-reported measures were adapted from patient-reported measures.

At the next level, the two broad categories of measure are person-reported outcome measures and person-reported experience measures.

Person-reported outcome measures

PROMs refer to the impact on individuals as perceived by the rater. They include measures of:

- Quality of life
- Individual care
- Community

Quality of life measures include people's health status, personal wellbeing, fatigue and sleep patterns. These are usually about patients, recorded by patients themselves or proxies on their behalf.

Individual care measures include health confidence, shared decision-making, self-care, behaviour change, adherence to treatment (eg, medication) and acceptance of loss. Individual care is typically based on interactions between patient and clinician (staff); both groups have their own perception of the outcome, which may differ.

Community measures include external and environmental factors such as social determinants of health, loneliness, neighbour relationships and personal safety. This is mainly related to how and where people live.

Person-reported experience measures

PREMs measure people's perception of the service provided. There are three domains:

- Care provided
- Provider culture
- Innovation

Care provided covers both individual services and the way that services work together. Patients and staff have views about the quality of care provided.

Provider culture measures aspects of each health and care organisation's policies and practice. Staff have more direct knowledge and experience of the culture than patients.

Innovation focuses on the impact of specific innovations, such as digital health applications and new ways of working. Staff are invariably involved and patients less frequently.

Tables

Details of each measure are shown in tables 1–4.

Each table is set out with six columns:

1. *Name*: a short easy to understand name or label. The name is usually positively worded, but not always. For example, the health status (*howRu*) measure has an item for *pain or discomfort*. Here, the best (highest) score comes from having no pain. The English language is better at describing some aspects negatively.
2. *Options*: the response options easure how much the respondent currently perceives some thing to be a problem. Many measures ask about agreement with positively worded statements using a scale from *strongly agree* to *disagree*.
3. *Text used in survey*: text as presented to the respondent. In practice each survey also contains a preamble. This is not shown here, because it is usually context-specific and contains locally-specific instructions and context.
4. *Alias*: a short unique alias name used in computer processing. This does not contain spaces; it uses UpperCamelCase to separate natural words and component parts.
5. *Words (FKG)*: the number of words and Flesch Kincaid readability grade.
6. *Notes*: brief description and reference to a publication about each measure or the most influential source that influenced its development.

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Table 3 Staff-reported outcome measures

Name	Options	Text used in survey	Alias	Words (FKG)	Notes
Quality of life					
Health status	None–extreme	How are you today? (past 24 hours)	howRu	24 (2.6)	Health status (howRu), when reported by staff is the same as when reported by patients.[17]
Pain/discomfort		Pain or discomfort	Pain		
Distress		Feeling low or worried	Distress		
Disability		Limited in what you can do	Disability		
Dependence		Require help from others	Dependence		
Work well-being	Strongly agree–disagree	How content are you in your job?	WWS	36 (2.7)	Work Well-being (WWS) was adapted from the personal well-being score,[20] focusing on the job people do. It measures job satisfaction.
Job satisfaction		I am satisfied with my job	JobSatis		
Worthwhile job		I am valued for what I do	WorthwhileWork		
Happy at work		I was happy yesterday* at work	HappyAtWork		
Not anxious at work		I was NOT anxious yesterday* at work	NotAnxiousAtWork		
Assessed need	None–extreme†	How are they doing?	howRthey	34 (3.5)	Staff or carer assessment of patients with dementia and frailty being cared for at home or in residential care homes.[68]
Physical needs		Physical care needs	PhysicalNeed		
Distress		Pain and/or distress	Distressed		
Unpredictable		Unpredictable needs	Unpredictable		
Challenging		Behaviour problems	Challenging		
Individual care					
Job confidence	Strongly agree–disagree	How confident do you feel in your job?	JCS	35 (1.9)	Job confidence (JCS) was adapted from the health confidence score,[24] focusing on how confident people feel in their work role.
Knowledge		I know enough about my job	JobKnow		
Self-management		I can manage my work	JobManage		
Access to help		I can get help if I need it	JobHelp		
Shared decisions		I am involved in decisions that affect me	JobDecisions		

*Work wellbeing: previous working day.
†Assessed need: quite a lot needs one person most of the time; extreme needs two people.

Patient-reported measures

Figure 3 shows patient-reported outcome and experience measures.

Table 1 describes PROMs; table 2 describes PREMs.

Staff-reported measures

Staff-reported outcome and experience measures are summarised in figure 4.

Staff-reported outcome measures are described in table 3. Staff-reported experience measures are described in table 4.

Table 5 summarises the number of measures by rater (patient-reported and staff-reported) and type (PROM or PREM). The expanded taxonomy is provided as a online supplementary file 1.

DISCUSSION

The need for generic measures with a broad scope is increasingly recognised, in particular for older people with long-term conditions.[36] This taxonomy is, as far as we know, the most comprehensive, coherent framework or taxonomy of short generic measures that has been published. It is unusual in covering both patient-reported and staff-reported measures as well as PROMs and PREMs. It also covers external factors that affect health and well-being, and those that affect the spread of health innovations.

A possible limitation of our approach is that it is based primarily on the work of a single author. The measures were not developed as part of a grant-funded research programme in an academic setting, nor for use in clinical trials. Some people may consider this to be a strength on the basis that theories should emerge from bottom-up, empirical experimentation. However, each measure has been strongly influenced by existing theories and paradigms.

Four response options may also be regarded as a limitation, but this is not our experience. The best option (the ceiling) can be thought of as being as good as it gets. If used appropriately this does not produce a ceiling effect, whereby the measure is unable to detect valuable improvements. A floor effect (the worst option) is more problematic, because things can always get worse. In general, if a respondent is at the floor, this calls for remedial action.

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Table 4 Staff-reported experience measures

Name	Options	Text used in survey	Alias	Words (FKG)	Notes
Care provided					
Service provided	Excellent–poor	What do you think about the service we provide?	StaffHowRwe	20 (4.2)	Service experience (staff) asks how staff perceives the service their team provides. Adapted from the howRwe experience measure.[20]
We are kind		Treat people kindly	StaffKind		
We listen/explain		Listen and explain	StaffTalk		
We are prompt		See people promptly	StaffPrompt		
Well organised		Well organised	StaffOrganised		
Service integration	Strongly agree–disagree	How do you work with other services?	IntegratStaff	35 (2.9)	Service integration (staff) asks how staff perceive collaboration with other services. Staff perceptions often differ from those of patients.
Services talk together		Services talk to each other	TalkStaff		
Service knowledge		We know what other services do	AwareStaff		
Care planning		We consider other services when planning care	CarePlanning		
Part of team		We feel part of the overall care team	PartOfTeam		
Patient confidence	Strongly agree–disagree	How confident are patients in caring for their health?	PatHCS	38 (2.9)	Patient confidence asks how staff perceive patients' health confidence as a population. If staff report on individuals, they should use HCS as a proxy.[24]
Patient knowledge		They know enough about their health	PatKnowledge		
Self-management		They can look after their health	PatSelfMan		
Patient access		They can get the help they need	PatGetHelp		
Shared decisions		They are involved in decisions about themselves	PatSDM		
Provider culture					
Staff relationships	Strongly agree–disagree	Thinking about colleagues in other services	StaffRelns	21 (2.9)	Staff relationships impact on how well different groups of people work together for a common good, as explored by Gittell's work on relational coordination.[69]
We know each other		We know each other	KnowOthers		
Rely on each other		We rely on each other	Rely		
Share information		We share information	ShareData		
Help each other		We help each other	HelpOthers		
Shared decisions	Strongly agree–disagree	Thinking about your patients' choices	StaffSDM	26 (3.7)	Shared decisions (staff) address staff perceptions of shared decision-making in general, as opposed to that for individual patients.[53]
Patients know benefits		They know the possible benefits	BenefitStaff		
Patients know risks		They know the possible downside	DownsideStaff		
Patients know choices		They know that they have choices	ChoicesStaff		
Fully involved		They are fully involved	InvolvementStaff		
Patient safety	Strongly agree–disagree	Thinking about patient safety	PatSafety	25 (3.3)	Patient safety focuses on clinical aspects of safety including adverse events and cultural attitudes towards safety and learning from incidents.[70]
Adverse events		Adverse events are rare	AdverseEvents		
Systems are safe		Our systems are safe	SafeSystems		
Open about errors		We are open if things go wrong	Honest		
Learn from mistakes		We learn from our mistakes	LearnMistakes		
Staff safety	Strongly agree–disagree	Thinking about your own safety	StaffSafety	25 (1.7)	Staff safety. Staff need to feel safe from being attacked by patients or bullied by managers within the organisation and outside.[71]
Safe at work		I feel safe at work	SafeAtWork		
Respected at work		I feel respected at work	WorkRespect		
Safe outside		I feel safe outside work	StaffSafeOut		
Respected outside		I feel respected outside work	StaffRespectOut		
Privacy	Strongly agree–disagree	Thinking about how we use patient data	Privacy	37 (4.5)	Privacy covers patients and staff perceptions of information governance including data protection, data sharing, subject access and satisfaction.[63]
Data are safe		Patient data kept safe and secure	SecureData		
Shared as needed		Patient data only shared as needed	ShareData		
Patients check data		Patients can see and check their data	CheckData		
Happy about data use		I am happy about how patient data used	DataSatis		
Innovation					

Continued

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Table 4 Continued

Name	Options	Text used in survey	Alias	Words (FKG)	Notes
IT capability	Strongly agree–disagree	Using information technology (IT) at work.	ITC	31 (4.7)	Staff IT capability assesses how staff feel about using IT at work, in terms of confidence, learning, getting help and solving problems.
IT confidence		I feel confident using IT	ITconfidence		
Learning apps		I enjoy learning new applications	LearnApps		
Can get help		I can get help if I am stuck	CanGetHelp		
Solve IT problems		I can solve most problems if stuck	SolveITproblems		
Product confidence	Strongly agree–disagree	How do you feel about this product?	PCS	25 (4.7)	Product confidence covers staff understanding of and confidence to use a specific innovation, application or product.
Frequent user		I use it frequently	ProductUse		
Confident user		I feel confident using it	SelfAssured		
Know benefits		I know the potential benefits	Positives		
Know problems		I know potential problems	Negatives		
User satisfaction	Strongly agree–disagree	What do you think of this product?	UX	33 (0.5)	User satisfaction focuses on people's perception of how much an innovation is useful and easy to use, availability of help and overall satisfaction.
Helps me		It helps me do what I want	HelpsMe		
Easy to use		It is easy to use	EasyToUse		
Can get help		I can get help if I need it	Support		
Product satisfaction		I am satisfied with this product	ProdSatis		
Innovation readiness	Strongly agree–disagree	New ideas at work	Innovativeness	28 (4.3)	Innovation readiness (staff) covers where people and organisations fall on the innovativeness spectrum.
New ideas needed		New ideas are needed in my field	Open		
Keep up to date		I keep up with new ideas	Informed		
We back new ideas		My organisation supports new ideas	Receptive		
We make ideas work		My organisation makes new ideas work	Capable		
Innovation process	Strongly agree–disagree	Thinking about this project	NPT	35 (2.3)	Innovation process is based on Normalisation Process Theory (NPT) in terms of how well innovations are implemented.[72]
Vision is followed		The original vision is being followed	Vision		
Plan to make it work		We all thought about how to make it work	Planning		
We work together		We all act to make it work	Collaboration		
Reflection		We all think about how to keep it going	Reflection		

HCS, Health Confidence Score.

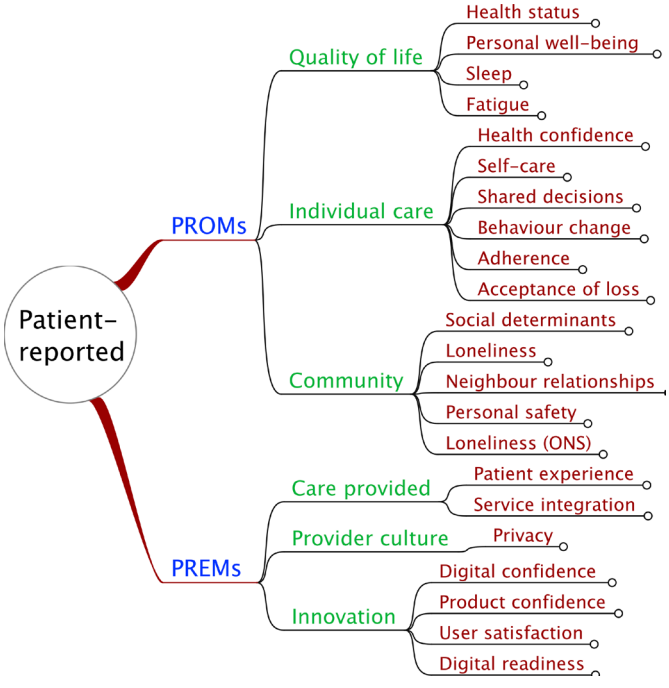

Figure 3 Summary of patient-reported outcome (PROMs) and experience (PREMs) measures.

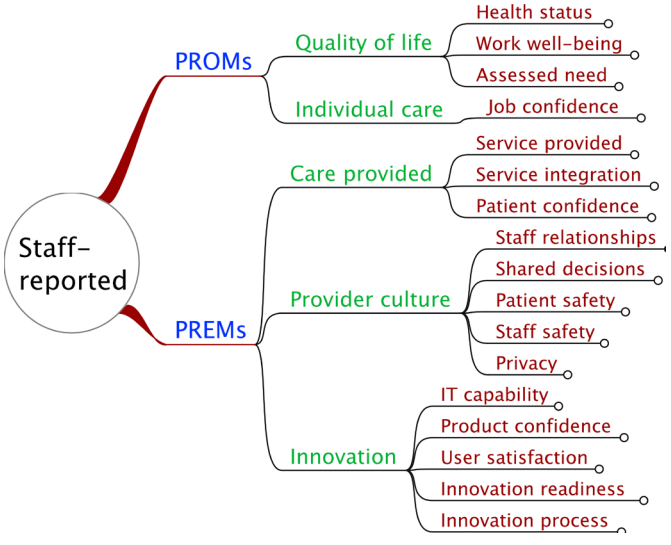

Figure 4 Summary of staff-reported outcome and experience measures. PROMs, patient-reported outcome measures; PREMs, patient-reported experience measures.

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Intermediate options can be regarded as being less good than the ceiling and less bad than the floor, respectively.

Answering any survey question involves four cognitive steps: (1) understand the question; (2) retrieve relevant information from memory; (3) judge which response option fits best and (4) responding in a way that fits the judgement. There is always a risk that raters may satisfice by doing one or more of these suboptimally, to save effort. This can give rise to a number of effects such as acquiescence bias, primacy effect and non-differentiation. This risk is greater in surveys answered in private, where there is no other person present to sense-check the responses, if a survey is long or difficult, seen as a chore or not regarded as relevant.[37]

The response options form an ordinal scale, which suggests that non-parametric statistics should be used.[38] However, interval or ratio scales ares needed for health economic calculations, such as quality-adjusted life year or Load calculations.[39] We have explored the generation of multi-attribute interval weightings using pairwise comparisons with the PAPRIKA(Potentially All Pairwise RanKings of all possible Alternatives) method.[40] In the absence of such weightings, we ascribe unweighted integer values to these options to calculate mean scores for item and summary scores of populations. In ideal situations (eg, people in good health), the distributions of these measures are skewed to the top, but summary scores for people with long-term conditions show a distribution which is close to normal.[17 23 24] In practice, we find that parametric and non-parametric statistical tests produce very similar results.

It is useful to identify the minimally important difference (MID) between two sets of measurements. Half a SD is a widely used criterion at the individual level.[41] So, for a summary score, if SD=20 on 0–100 scale (which is typical), the MID=0.5 (SD)=10. For populations, sample size (n) is a key variable, so if n=64 and SD=20 the 95% CI is $\pm 1.96(SD/\sqrt{n})=\pm 4.9$.

Carers or informal care givers form a special case, sharing aspects of both patients and staff; they are not discussed here, but will be considered in a future paper. There is no prohibition on people using measures that are not explicitly designed for them. For example, any measure may be completed by a proxy, but if so this should be recorded.

Four of these measures (health status, health confidence, personal well-being and experience) have been validated psychometrically at the time of writing.[17 20 24 24] Five have been described in the literature (digital confidence, user satisfaction, innovation readiness, innovation process and behaviour change),[25] three have been described in the specific context of residential care homes (work well-being, job confidence and service provided)[42] and the process is underway for others. We encourage other validation studies.

Practical implementation always needs to consider the whole end-to-end process, not only what measures to use and why, but who, where, when and how.[43] This includes ensuring that people are asked to complete surveys, that all the stakeholders involved understand what is being asked and why and that all aspects of survey management, including supporting technology and analytics, are properly resourced. Results may be reported at the individual level to tailor individual care, or aggregated to measure the performance of specific services or user needs.

These measures have been used with success in commissioning services and in the evaluation of new care models,[44] social prescribing,[23] care home services[21 22 42] and in digital health evaluation, including self-care for people with diabetes and detection of atrial fibrillation (AF).

Innovation measures have been mapped to the Nonadoption, Abandonment and failure to Scale-up, Spread and Sustain framework (NASSS), which uses the lens of complexity theory to explain and avoid failures of digital health innovations.[45]

PROMs may be thought of as patient history, form part of the clinical record and inform patient care. However, identifiable data are subject to strict information governance, requiring compliance with the General Data Protection Regulation (GDPR), Health Insurance Portability and Accountability Act (HIPAA) and similar laws and regulations.[46] In practice, to avoid issues of information governance, many PROMs are collected anonymously.

Widespread use of PROMs and PREMs requires integration with electronic health records and other health IT systems. This needs semantic interoperability using standards such as Fast Health Interoperability Resources (FHIR) and coding schemes such as Logical Observation Identifiers and Codes (LOINC) and Systematised Nomenclature of Medicine Clinical Terms (SNOMED CT).[28 47] FHIR Questionnaire and Questionnaire Response resources support the use of surveys in day-to-day care and clinical research.[48] LOINC supports the structure and content of assessment surveys.[49] LOINC and SNOMED CT (UK Edition) codes have been allocated for some measures (eg, *howRu* and HCS)[17 24] and applications for the others are underway.

Table 5 Summary count of measures

	PROMs	PREMs	Total
Patient-reported	15	7	22
Staff-reported	4	13	17
Total	19	20	39

PREMs, patient-reported experience measures; PROMs, patient-reported outcome measures.

CONCLUSIONS

This paper describes a family of generic PROMs and PREMs for routine use and in evaluation. This family of measures has a broad scope but is not claimed to be comprehensive.

The measures are described in tables and organised as a taxonomy. The taxonomy is categorised by respondent (patient or staff) and type (PROMs or PREMs). We describe 22 patient measures and 17 staff measures. Some

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are described here for the first time. These measures may be used to help tailor individual care, and at aggregate level for evaluation and accountability.

PROMs are grouped under categories for quality of life, individual care and community. PREMs have categories for service provided, provider culture and innovation. All of the measures share the same form, with four items with four response options. The measures are short with low reading age. They can be used to build short questionnaires for different purposes, using common survey management, data analytics, data visualisation and reporting tools. This flexibility allows practitioners to select measures on a pick-and-mix basis to meet their local needs.

LAY SUMMARY

This paper describes a family of short generic PROMs and PREMs, designed for use in combinations in a pick-and-mix way. PROMs cover quality of life, individual care and community; PREMs cover service provided, provider culture and innovation. Common properties of these measures include specialty-independence, brevity, ease of use, low reading age, a common format, data collection, reporting and data visualisation methods. They are used in tailoring care, quality improvement, service evaluation and as KPIs.

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