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.

Person-reported outcome measures (PROMs) and person-reported experience measures (PREMs) measure different things, 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, but most PROMs apply to only one condition, which limits their use. Different measures have been developed independently and do not work well together. 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. 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. However, it does not cover all aspects of health outcomes, experience and patient-centred care.

Response rates are affected by perceived relevance and ease of use. Most measures require a higher reading age than the average reading age of the UK population, which is about 9 years.
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. Inter-rater reliability studies identified the importance of using clear, unambiguous wording.

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. 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. It was also tested in comparison with 3-level version of EQ-5D in a hospital cardiovascular clinic, and in hip and knee replacement surgery.

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. The howRu and howRwe measures were both used in a census of 24000 care home residents in the UK, Australia and New Zealand.

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, and the Health Confidence Score (HCS). 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. These built on the author’s prior work about how spread and interoperability 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, each measure was developed in a similar way. 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.
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
| Name                        | Options             | Text used in survey                                                                 | Alias      | Notes                                                                 |
|-----------------------------|---------------------|------------------------------------------------------------------------------------|------------|-----------------------------------------------------------------------|
| **Quality of life**         |                     |                                                                                    |            |                                                                        |
| Health status               | None–extreme        | How are you today? (past 24 hours) Pain or discomfort How feeling low or worried        | howRu      | Health status (howRu) is sometimes referred to as health-related quality of life. This was the first in the family.17 |
| Pain/discomfort             |                     |                                                                                   | Pain       |                                                                        |
| Distress                    |                     |                                                                                   | Distress   |                                                                        |
| Disability                  |                     |                                                                                   | Disability |                                                                        |
| Dependence                  |                     |                                                                                   | Dependence |                                                                        |
| **Personal well-being**     | Strongly agree–disagree | How are you feeling in general? I am satisfied with my life What I do in my life is worthwhile I was happy yesterday I was NOT anxious yesterday | PWS        | 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           |                     |                                                                                   | Satisfaction |                                                                        |
| Worthwhile                  |                     |                                                                                   | Worthwhile |                                                                        |
| Happy                       |                     |                                                                                   | Happy      |                                                                        |
| Not anxious                 |                     |                                                                                   | NotAnxious |                                                                        |
| **Sleep**                   | Strongly agree–disagree | Thinking about your recent sleep pattern I go to sleep at the same time I wake up at the same time I wake up feeling refreshed I sleep well | Sleep      | Sleep hygiene is an important determinant of health and well-being.50 |
| Sleep at same time          |                     |                                                                                   | SleepTime  |                                                                        |
| Wake at same time           |                     |                                                                                   | Refreshed  |                                                                        |
| Wake refreshed              |                     |                                                                                   | SleepWell  |                                                                        |
| Sleep well                  |                     |                                                                                    |            |                                                                        |
| **Fatigue**                 | Strongly agree–disagree | Thinking about getting tired I usually have enough energy I do not tire too quickly I can usually concentrate well I can keep going if I need to | Fatigue    | Fatigue is a common presenting complaint in primary care and can have a large impact on quality of life.51 |
| Energy level                |                     |                                                                                    | Energy     |                                                                        |
| Tire quickly                |                     |                                                                                    | TireFast   |                                                                        |
| Able to concentrate         |                     |                                                                                    | Concentrate|                                                                        |
| Stamina                     |                     |                                                                                    | Stamina    |                                                                        |
| **Individual care**         | Strongly agree–disagree | How do you feel about caring for your health? I know enough about my health I can look after my health I can get the right help if I need it I am involved in decisions about me | HCS        | Health Confidence Score (HCS covers people’s confidence about looking after their own health.24 |
| Health confidence           |                     |                                                                                    | Knowledge  |                                                                        |
| Knowledge                   |                     |                                                                                    | SelfManage |                                                                        |
| Self-management             |                     |                                                                                    | GetHelp    |                                                                        |
| Access to help              |                     |                                                                                    | ShareDecision |                                                              |
| Shared decisions            |                     |                                                                                    |            |                                                                        |
| Diet management             | Strongly agree–disagree | How well do you look after yourself? I manage my diet well I manage my physical activity well I manage my weight well I manage my medication well | SelfCare    | Self-care, includes self-management of diet, physical activity, weight and medication.52 |
| Exercise management         |                     |                                                                                    | Diet       |                                                                        |
| Weight management           |                     |                                                                                    | Exercise   |                                                                        |
| Meds management             |                     |                                                                                    | Weight     |                                                                        |
| **Shared decisions**        | Strongly agree–disagree | Thinking about your plan I know the possible benefits I know the possible downside I know that I have choices I feel fully involved | SDM        | Shared decisions (SDM) covers patients’ involvement in clinical decisions, including their understanding of the choices and the risks and benefits of each.29 |
| Know benefits               |                     |                                                                                    | Benefits   |                                                                        |
| Know downside               |                     |                                                                                    | Downside   |                                                                        |
| Know choices                |                     |                                                                                    | Choices    |                                                                        |
| Fully involved              |                     |                                                                                    | Involved   |                                                                        |
| **Behaviour change**        | Strongly agree–disagree | Thinking about this behaviour I am able to do it (skills and tools) Nothing prevents me from doing it I choose to do it I do it without thinking | Behaviour  | Behaviour change covers capability, opportunity and motivation (conscious and unconscious) to change behaviour based on Michie’s COM-B model.54 |
| Capability                  |                     |                                                                                    | Capability |                                                                        |
| Opportunity                 |                     |                                                                                    | Opportunity|                                                                        |
| Conscious motive            |                     |                                                                                    | Motivation |                                                                        |
| Automatic motive            |                     |                                                                                    | AutoMotive |                                                                        |
| **Continued**               |                     |                                                                                    |            |                                                                        |
### Table 1  Continued

| Name                              | Options                  | Text used in survey                                                                 | Alias            | Words (FKG) | Notes                                                                 |
|-----------------------------------|--------------------------|------------------------------------------------------------------------------------|------------------|--------------|----------------------------------------------------------------------|
| **Adherence**                     |                          |                                                                                   |                  |              |                                                                     |
| Remember                          | 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 |
| Go on if I feel bad               |                          |                                                                                   |                  |              |                                                                     |
| Go on if I feel better            |                          |                                                                                   |                  |              |                                                                     |
| Treatment satisfaction            |                          |                                                                                   |                  |              |                                                                     |
| **Acceptance of loss**            |                          |                                                                                   |                  |              |                                                                     |
| New capability                    | 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 |
| Recognise loss                    |                          |                                                                                   |                  |              |                                                                     |
| Change activity                   |                          |                                                                                   |                  |              |                                                                     |
| Move on                           |                          |                                                                                   |                  |              |                                                                     |
| **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                         |                          |                                                                                   |                  |              |                                                                     |
| Social status                     |                          |                                                                                   |                  |              |                                                                     |
| Housing                           |                          |                                                                                   |                  |              |                                                                     |
| Enough money                      |                          |                                                                                   |                  |              |                                                                     |
| **Loneliness**                    |                          |                                                                                   |                  |              |                                                                     |
| People to talk to                 | 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 confide in              |                          |                                                                                   |                  |              |                                                                     |
| People to help                    |                          |                                                                                   |                  |              |                                                                     |
| Do things with others             |                          |                                                                                   |                  |              |                                                                     |
| **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                   |                          |                                                                                   |                  |              |                                                                     |
| Trust each other                  |                          |                                                                                   |                  |              |                                                                     |
| Share information                 |                          |                                                                                   |                  |              |                                                                     |
| Help each other                   |                          |                                                                                   |                  |              |                                                                     |
| **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                      |                          |                                                                                   |                  |              |                                                                     |
| Respected at home                 |                          |                                                                                   |                  |              |                                                                     |
| Safe outside                      |                          |                                                                                   |                  |              |                                                                     |
| Respected outside                 |                          |                                                                                   |                  |              |                                                                     |
| **Loneliness (ONS)**              | Harshly agree–disagree   | 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                 |                          |                                                                                   |                  |              |                                                                     |
| Feel left out                     |                          |                                                                                   |                  |              |                                                                     |
| Feel alone                        |                          |                                                                                   |                  |              |                                                                     |
| Feel lonely                       |                          |                                                                                   |                  |              |                                                                     |

FKG, Flesch Kincaid Grade.
### 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. |
| Kind                        | 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 covers how well services collaborate.                                                                           |
| 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**        | Strongly agree–disagree     | Thinking about how you use your data                                               | Privacy    | 37 (4.5)    | Privacy covers patients’ perceptions of data protection, sharing and information governance.                                       |
| 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**              | 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.                                         |
| Digital confidence          |                             | Digital devices include computers, smartphones and tablets                          | DCS        | 36 (6.8)    | Digital confidence assesses people’s confidence in using digital apps and similar devices.                                         |
| 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 covers understanding of and confidence in using 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  |             |                                                                                                                                       |
| **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.                                   |
| 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.
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.

**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 ensure 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.
### 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.88 |
| Physical needs        |                    | Physical care needs                  | PhysicalNeed|             |                                            |
| Distress              |                    | Pain and/or distress                 | Distressed|             |                                            |
| Unpredictable        |                    | Unpredictable needs                  | Unpredictable|         |                                            |
| Challenging           |                    | Behaviour problems                   | Challenging|             |                                            |
| **Individual care**   | 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.

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**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 an 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.
## 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? With staff?                            | 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**  |               |                                                                                      |                      |             |                                                                      |
| Services talk together   | Strongly agree–disagree | How do you work with other services? Services talk to each other | IntegStaff           | 35 (2.9)    | Service integration (staff) asks how staff perceive collaboration with other services. Staff perceptions often differ from those of patients. |
| 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 |          | We feel part of the overall care team                                                | PartOfTeam           |             |                                                                      |
| **Patient confidence**   |               |                                                                                        |                      |             |                                                                      |
| Patient knowledge        | 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 |
| Self-management          |               | They know enough about their health                                                   | PatSelfM             |             |                                                                      |
| Patient access           |               | They can look after their health                                                      | PatGetHelp           |             |                                                                      |
| Shared decisions         |               | They can get the help they need                                                       | PatSDM               |             |                                                                      |
| They are involved in decisions about themselves |          |                                                                                      |                      |             |                                                                      |
| **Provider culture**     |               |                                                                                        |                      |             |                                                                      |
| Staff relationships      | Strongly agree–disagree | Thinking about colleagues in other services We know each other | 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       |               |                                                                                        | KnowOthers           |             |                                                                      |
| Rely on each other       |               |                                                                                        | Rely                 |             |                                                                      |
| Share information        |               |                                                                                        | ShareData            |             |                                                                      |
| Help each other          |               |                                                                                        | HelpOthers           |             |                                                                      |
| **Shared decisions**     | Strongly agree–disagree | Thinking about your patients’ choices They know the possible benefits | StaffSDM             | 26 (3.7)    | Shared decisions (staff) address staff perceptions of shared decision-making in general, as opposed to that for individual patients.10 |
| Patients know benefits   |               |                                                                                        | BenefitStaff         |             |                                                                      |
| Patients know risks      |               |                                                                                        | DownsideStaff        |             |                                                                      |
| Patients know choices    |               |                                                                                        | ChoicesStaff         |             |                                                                      |
| Fully involved           |               |                                                                                        | InvolvementStaff     |             |                                                                      |
| They know the possible downside |          |                                                                                      |                      |             |                                                                      |
| They know that they have choices |          |                                                                                        |                      |             |                                                                      |
| They are fully involved  |               |                                                                                        |                      |             |                                                                      |
| **Patient safety**       | Strongly agree–disagree | Thinking about patient safety Adverse events are rare | 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           |               |                                                                                        | AdverseEvents        |             |                                                                      |
| Systems are safe         |               |                                                                                        | SafeSystems          |             |                                                                      |
| Open about errors        |               |                                                                                        | Honest               |             |                                                                      |
| Learn from mistakes      |               |                                                                                        | LearnMistakes        |             |                                                                      |
| **Staff safety**         | Strongly agree–disagree | Thinking about your own safety I feel safe at work | 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             |               |                                                                                        | SafeAtWork           |             |                                                                      |
| Respected at work        |               |                                                                                        | WorkRespect          |             |                                                                      |
| Safe outside             |               |                                                                                        | StaffSafeOut         |             |                                                                      |
| Respected outside        |               |                                                                                        | StaffRespectOut      |             |                                                                      |
| **Privacy**              | Strongly agree–disagree | Thinking about how we use patient data Patient data kept safe and secure | Privacy             | 37 (4.5)    | Privacy covers patients and staff perceptions of information governance including data protection, data sharing, subject access and satisfaction.83 |
| Data are safe            |               |                                                                                        | SecureData           |             |                                                                      |
| Shared as needed         |               |                                                                                        | ShareData            |             |                                                                      |
| Patients check data      |               |                                                                                        | CheckData            |             |                                                                      |
| Happy about data use     |               |                                                                                        | DataSatis            |             |                                                                      |
| **Innovation**           |               |                                                                                        |                      |             |                                                                      |

Continued
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                               | ITCConfidence |             |                                                                                                                                       |
|                              |                       | I enjoy learning new applications                        | LearnApps    |             |                                                                                                                                       |
|                              |                       | I can get help if I am stuck                             | CanGetHelp   |             |                                                                                                                                       |
|                              |                       | I can solve most problems if stuck                       | SolveITproblems |           |                                                                                                                                       |
| Learning apps                 |                       |                                                          |             |             |                                                                                                                                       |
| Can get help                  |                       |                                                          |             |             |                                                                                                                                       |
| Solve IT problems             |                       |                                                          |             |             |                                                                                                                                       |
| Product confidence            | Strongly agree–disagree | How do you feel about this product?                     | POS         | 25 (4.7)    | Product confidence covers staff understanding 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.                   |
| 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.
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 satisfy 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.

The response options form an ordinal scale, which suggests that non-parametric statistics should be used. However, interval or ratio scales are needed for health economic calculations, such as quality-adjusted life year or Load calculations. 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. 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. 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. 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 ±1.96(SD/√n)=±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. Five have been described in the literature (digital confidence, user satisfaction, innovation readiness, innovation process and behaviour change). three have been described in the specific context of residential care homes (work well-being, job confidence and service provided) 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. 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, social prescribing, care home services 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.

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. 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). FHIR Questionnaire and Questionnaire Response resources support the use of surveys in day-to-day care and clinical research. LOINC supports the structure and content of assessment surveys. LOINC and SNOMED CT (UK Edition) codes have been allocated for some measures (eg, houRu and HCS) and applications for the others are underway.

**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

| 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.
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 cover 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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