

# CANCER PROMS: A SCOPING STUDY

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# Introduction

**This scoping study was commissioned by Macmillan Cancer Support to explore the potential role of Patient-Reported Outcome Measures (PROMs) in helping to progress their programme on Living With and Beyond Cancer and to inform the work of the national cancer task force.**

Macmillan's goal is to ensure that all people affected by cancer have access to well-planned support to cope with the longer-term consequences of treatment and recovery. In particular they wanted to know if there was a role for PROMs in monitoring implementation of the National Cancer Survivorship Initiative (NCSI) priorities, which are as follows:

- Ensuring all cancer patients have access to a recovery package based on holistic needs assessment and care planning
- Developing risk-stratified pathways of post-treatment management
- Promoting physical activity
- Understanding and commissioning improved management of the consequences of treatment.

PROMs are frequently used in research studies, but that is not our main concern here. Instead our aim was to examine the potential value or otherwise of PROMs to shed light on problems or gaps in service delivery and to inform patient care. Early pilot surveys had suggested that use of PROMs could help to uncover specific support needs of people living with and beyond cancer, leading to new ideas for improving services<sup>1</sup>. Macmillan believes there is a case for using these instruments more widely, both as a policy lever to determine priorities and to help plan service developments. We were asked to examine the potential for using PROMs in these ways and to recommend specific measures that might be used for these purposes. We tackled the task by reviewing relevant studies and conducting interviews with a small group of experts.

# What are PROMs?

PROMs are standardised questionnaires asking patients about their current health status. They are designed to elicit people’s subjective reports of the personal impact (outcomes) of illness and treatment, focusing mainly on physical functioning, ability to maintain daily activities, and emotional wellbeing – often referred to more generally as health-related quality of life. Their distinctive feature is that health is assessed by the person experiencing it, not by a doctor or anyone else <sup>2</sup>. The aim is to obtain important information that is not reflected in traditional clinical measures. This is done by asking respondents to describe their current state, by means of a structured interview or by completing a questionnaire, which can be either paper-based or electronic. The resulting reports can then be compared to previous measurements from the same individual or group (to measure change over time) or to those from a reference group or sub-groups (to compare against an external norm or standard).

PROMs can be applied alongside biomedical markers to assess outcomes at a defined point in time after a specific treatment, but they can also be used to monitor progress over a longer time period for people in recovery or those with chronic conditions. In certain cases, these instruments are used both as an initial screening tool and to monitor progress during and after treatment. This dual use happens most often in the treatment of mental health problems, such as anxiety or depression, but it may have wider applications, including in cancer care.

PROMs must be carefully developed and tested to conform to accepted statistical and psychometric standards, including evidence of validity, reliability and sensitivity to change. The best PROMs are developed with input from patients, ensuring that they cover topics that are salient and meaningful from the patient’s perspective. While they are intended primarily for use at two or more time points to measure health gain (or loss), for example before and after treatment, or at various time points during a period of illness or recovery, they can also be used to obtain a single snapshot of the prevalence of quality of life problems.

PROMs fall into three distinct types (Table 1). Some PROMs measure general health status regardless of the clinical diagnosis (generic PROMs), while others ask about health perceptions in relation to specific conditions (condition-specific PROMs). A third type are patient-generated measures, where patients are asked to define their own outcome goals and achievement of these is then assessed after a period of time.

**Table 1: Types of PROM**

Type	Examples
Generic	Medical Outcomes Study: SF-36 <sup>3</sup> ; EuroQol: EQ-5D <sup>4</sup>
Condition-specific	Osteoarthritis of the hip: Oxford Hip Score <sup>5</sup> ; Depression: PHQ-9 <sup>6</sup>
Patient-generated	Measure Yourself Medical Outcome Profile: MYMOP <sup>7</sup> ; Schedule for Evaluation of Individual Quality of Life: SEIQoL <sup>8</sup>

Most PROMs cover a number of quality of life dimensions or domains. For example, the widely used EuroQol measure (EQ-5D)<sup>4</sup> includes five domains (mobility, self-care, usual activities, pain/discomfort, anxiety/depression) and an overall rating of the respondent's health state. The results can be scored separately for each domain or summarised in a single index score to monitor variations and time trends or for ranking providers. The EQ-5D has been adopted by the Department of Health in England for inclusion in its national PROMs programme. EQ-5D is also included in NHS England's large general practice patient survey (<http://www.england.nhs.uk/statistics/category/statistics/gp-patient-survey/>), giving population data that can be used as a 'normal population' reference for comparison purposes. Condition-specific PROMs ask about issues relating to the specific problem (e.g. Have you had trouble washing or drying yourself because of your knee?). Like EQ-5D, results can be used descriptively or summed to produce a single score. Condition-specific measures tend to be more responsive to change than generic measures, but both types can be used to describe pre- and post-treatment health status and health gain.

Patient-generated measures are intuitively appealing, but they are not often used for large-scale data collection because it is harder to score and summarise the results. Their primary use is for facilitating the exchange of information in clinical consultations and in care planning for long-term conditions.

PROMs are distinct from patient experience or satisfaction questionnaires (sometimes referred to as PREMs – Patient Experience Measures) which aim to elicit patients' reports on the process of care rather than its effects. The national Cancer Patient Experience Survey for England is a well-known example of a PREM, focusing on cancer patients' reports on the quality of their interactions with staff and other aspects of the treatment or care process (<http://www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey>). PROMs and PREMs are sometimes used together to obtain a more complete picture of the quality and effectiveness of care.

Over the last few years the Department of Health in England has funded a programme of work to measure PROMs in elective surgery. The principal motivation for doing so, at least initially, was to assess the value, including value for money, of health care interventions and to identify poorly performing organisations. The government's aim was to focus attention on the outcomes of care, instead of just counting activity rates (e.g. numbers of operations performed). They were also keen to emphasise the importance of patients' evaluations of their health and its impact on quality of life to obtain a fuller picture of health gain than is available from traditional clinical indicators. It was hoped that commissioning would become outcomes-based, using financial incentives based on locally agreed indicators of healthcare quality, including PROMs<sup>9</sup>.

The national PROMs programme was introduced at a time when there was great optimism that choice and competition, including greater awareness of geographical variations in performance, would provide the necessary stimulus to improve the quality of care across the NHS. The intention was to measure and describe outcomes in a meaningful way to inform people's choice of provider. The government hoped that patients, GPs and healthcare commissioners would seek out those hospitals and clinicians that achieved the best outcomes. Outcomes data were to be published and hospitals were given financial incentives to attract patients, in the hope that this would drive up quality standards. Clearly this mechanism relies on the availability of choices and people's willingness to shop around. It also assumes that there are meaningful differences between hospitals and clinical teams in the quality of care provided.

At the same time as launching the experiment in routine data collection from elective surgery patients, the Department of Health instigated a programme of research to pilot the use of PROMs for patients with other conditions, including long-term conditions, mental health, coronary revascularisation and cancer care. Responsibility for the PROMs programme was passed to NHS England in April 2014 following the NHS reorganisation. Meanwhile other funding bodies, including Macmillan, have also commissioned work on PROMs and their uses.

The first PROMs were developed in the early 1970s and since then large numbers of generic and condition-specific measures have emerged, spawning a substantial academic industry with its own dedicated journals and conferences (e.g. International Society for Quality of Life Research (ISOQOL) and its journal *Quality of Life Research*).

The proliferation of measures has led to the publication of guidelines for developing, assessing and choosing a PROM. For example, the US Food and Drug Administration (FDA) has issued guidance on the use of PROMs in regulatory procedures for medicines<sup>10</sup>. ISOQOL ([www.isoqol.org](http://www.isoqol.org)) outlines the following criteria to guide development of new PROMs or selection of existing ones:

- Having a clearly defined conceptual and measurement model
- Tested for its performance in respect of
  - reliability (the degree to which it is free from measurement error)
  - Internal consistency reliability (the degree of inter-relatedness among items in a multi-component measure)
  - test-retest reliability (produces consistent scores over time)
  - face validity (degree to which it measures the concept it is supposed to measure)
  - content validity (covers the most relevant and important aspects of the construct it purports to measure)
  - construct validity (degree to which scores are consistent with other relevant indicators or theories)
  - criterion validity (degree to which scores are an adequate reflection of an external gold standard)
  - responsiveness (ability to detect changes over time)
  - interpretability (degree to which the scores are meaningful and easily understood)
  - burden (time and effort required to administer and complete the instrument).

# PROMs for cancer care

There is a vast array of PROMs for potential application in cancer care. Whilst most emphasis has been on the use of PROMs for evaluating treatment options in clinical trials, some reviews have focused on the use of PROMs within routine care<sup>11,12</sup>. The use of PROMs within post-treatment initiatives is a more recent focus, with some developed specifically for that purpose<sup>13,14</sup>.

## Assessing needs and outcomes

A distinction must first be drawn between needs assessment instruments versus outcome measures for health-related quality of life. The latter are more suitable for comparative analysis across populations and thus are the type of PROMs that we consider here, given their potential for use in wider performance measurement and quality improvement as well as individual-level care. However two prominent cancer needs assessment instruments, which emphasise the immediate concerns of cancer patients shortly after diagnosis or during active treatment, are outlined here as a framework against which the ten selected PROMs may be evaluated.

The Concerns Checklist promoted by the NCSI, and the Distress Thermometer and Problem List from which it was developed (15), are tools for discussion about patients' immediate needs to inform clinical assessment and intervention. The domains covered by these instruments are relevant not only for assessing the short-term impacts of cancer treatment – which is their primary use – but they can also be used to highlight longer-term difficulties experienced by people living with and beyond cancer.

Part of the holistic needs assessment advocated via the NCSI, the Concerns Checklist enables patients to flag up issues affecting them within the past week that they would like to discuss with a health care professional. The tool begins with a general statement ('I have questions about my diagnosis / treatment that I would like to discuss') followed by a list of 56 specific concerns grouped under six domains:

- **Physical concerns** – 23 items, mainly describing symptoms but also including broader issues such as 'My appearance' and 'sexuality'
- **Practical concerns** – 9 items, including caring responsibilities, work/education, money and daily activities such as preparing meals
- **Family / relationship concerns** – 3 items on partner, children or other relatives/friends
- **Emotional concerns** – 9 items including difficulty making plans, loss of interest, depression and anxiety
- **Spiritual or religious concerns** – 3 items on loss of faith, loss of purpose in life, and feeling regrets/not being at peace
- **Lifestyle or information needs** – 9 items including diet, support groups, and exercise/activity.



The end of the Concerns checklist includes a visual analogue scale (VAS) where patients are asked to show the overall level of concern that they have felt over the past week on a scale from 1 to 10, with no descriptors to indicate the meanings of particular values.

The Concerns checklist emerged following refinement and validation within the UK of the *Distress Thermometer and Problem List*<sup>15</sup>. The Distress Thermometer was developed in the 1990s<sup>16</sup> and is promoted by the National Comprehensive Cancer Network (NCCN), an alliance of 25 cancer centres across the USA. The 'thermometer' is a visual analogue scale for reporting overall distress experienced within the past week, ranging from 0 ('No distress') to 10 ('Extreme distress'). The VAS is followed by the 39-item Problem List, with specific problems grouped under five headings that broadly overlap with those of the Concerns checklist: practical problems (6 items), family problems (4 items), emotional problems (6 items), spiritual/religious concerns (1 item), physical problems (22 items, including 19 of the same symptoms within the Concerns checklist as well as bathing/dressing, nose dry/congested and substance abuse). Respondents are asked to tick 'Yes' or 'No' for each item listed, with space provided at the end for a free-text response to 'other problems'.

While some effort has been made to use repeat measures of needs assessment tools as an outcome measure for evaluating specific interventions<sup>17</sup>, their main purpose is for screening to inform individual-level clinical care. In contrast, the ten PROMs described below were predominantly developed for research purposes and so lend themselves more readily to the comparative analysis necessary to evaluate health services providers and to inform policy.

However, the six domains of the Concerns checklist capture many of the difficulties faced by people living with and beyond cancer, as highlighted by the NCSI<sup>18</sup>. We have therefore used these six domains as a framework against which to evaluate the content of other PROMs used in cancer care (*Table 1*). We have added one additional domain, personal control, meaning a person's sense of influence over his/her daily life, which has emerged as a prominent theme in research we are currently conducting to develop an outcome measure for people with long-term conditions<sup>19</sup>.

# Top ten cancer PROMs

We describe below ten PROMs currently in use for cancer care. We have selected this 'top ten' to reflect the following features: the extent to which they have been psychometrically validated, their frequency of use, their use within current cancer surveys, and their potential relevance for managing the longer-term consequences of cancer. The ten instruments reviewed below and summarised in Table 2 include three generic, two mental health, four general cancer, and one cancer survivorship PROM, reflecting the broad range of outcome measures that may be applied in cancer care.

**Table 2: Comparison of domains in 10 PROMs used in cancer care\***

	Domains:	Physical	Practical	Family / relationship	Emotional	Spiritual / religious	Information needs	Personal control
<b>PROM</b>	<b>type</b>	symptoms, mobility, appearance, sexuality	daily activities, work, caring, travel, money	partner, children, friends	isolation, anger, sadness, worry	loss of faith or purpose in life	lifestyle, support groups, therapies	decision-making, confidence in self-management
EQ-5D	generic	2	2		1			
SF-36	generic	16	7	2	5			
IPQ-R	generic	14	1	2	6		5	14
PHQ-9	mental health	5			4			
HADS	mental health				14			
EORTC-QLQ-C30	cancer – general	18	4	2	4			
FACT-G	cancer – general	7	3	7	8	2		
CARES-SF	cancer – general	22	10	15	7		4	1
SDI	cancer – general	3	12	4	1			
QLACS	cancer survivorship	20	4	7	12	4		

\*Values refer to the number of items per domain within each questionnaire.

The ten PROMs compared in Table 2 are described below in terms of their purpose, content, and relevance for cancer care.

## Generic PROMs

These outcome measures are not specific to any particular disease but are designed to elicit a broader picture of overall health status.

### EQ-5D

The EuroQol five-dimensional questionnaire was developed in the late 1980s by the EuroQol Group, a collaboration between seven European institutions (mainly UK and Scandinavian) with particular expertise in health economics (4). It consists of a 5-item questionnaire that asks respondents to rate their current health status in each of five domains: mobility (walking about), self-care (washing and dressing), usual activities (including work, study, family and leisure), pain / discomfort, and anxiety / depression. Two versions of the questionnaire exist, one with three response options (e.g. 'I have no/some/a lot of problems doing my usual activities') and the other with five (e.g. 'I have no/slight/moderate/severe/extreme pain or discomfort'). The questionnaire may also be accompanied by a visual analogue scale, EQ-VAS that prompts respondents to rate their current health on a scale from 0 ('the worst health you can imagine') to 100 ('the best health you can imagine'). A single-index score can be calculated for comparing health status across groups, including normative populations. EQ-5D scores can be translated into QALYs for cost-effectiveness analysis.

#### **Uptake and use within cancer:**

Owing to its simplicity and the fact that it is not disease-specific, the EQ-5D is widely used. It is currently included within the UK's national GP Patient Survey, and it was a component of both the national cancer PROMs survey (20) and the electronic Patient-reported Outcomes from Cancer Survivors (ePOCS) system<sup>21</sup>.

### SF-36

The SF-36 is a short-form questionnaire stemming from the much longer Medical Outcomes Study, developed in the USA by the RAND corporation in the 1980s and widely used around the world, including the UK<sup>3</sup>. The SF-36 expanded upon earlier MOS short-form questionnaires of 18 and 20 items in order to improve their precision. Responses to the 36 items are grouped into eight sub-scales: physical functioning (10 items), role limitations due to physical problems (4 items), bodily pain (2 items), general health status (5 items), vitality (4 items on energy/fatigue), social functioning (2 items), role limitations due to emotional problems (3 items), and mental health (5 items); additionally a single item asks respondents to rate their change in health status in comparison to a year ago. The eight sub-scales can be combined into two summary scales, one on physical health (comprised of the physical problems, role limitations – physical, bodily pain, and general health status sub-scales) and the other on mental health (comprised of the vitality, social functioning, role limitations – emotional, and mental health sub-scales). Each of the sub-scales and the two summary scales are presented as a numerical score ranging from 0 to 100, with higher numbers representing better health. Reference values from normative populations are available for comparison. The SF-36 is not designed to produce an overall single score, making it potentially more difficult to interpret than single-index PROMs. Nonetheless it is widely used and therefore allows for comparison across health conditions and populations.

#### **Uptake and use within cancer:**

The SF-36 is the most widely used measure for health-related quality of life in a wide range of conditions. It has been used extensively as an outcome measure when evaluating cancer treatments across various tumour sites, including the longer-term consequences of cancer<sup>22,23</sup>.

## IPQ-R

The Revised Illness Perception Questionnaire<sup>24</sup> built on the previously developed IPQ<sup>25</sup> to assess a patient's likelihood of coping with illness based on five components of his/her perception of it: illness identity, perceptions of cause, illness time-line, consequences of illness, and one's sense of control/ability to cure an illness. The IPQ-R is presented in three distinct sections. The first section on illness identity prompts respondents to state whether or not they have experienced each of 14 symptoms (e.g. pain, nausea, fatigue, upset stomach), and if yes whether or not they believe the symptom to be related to their illness. The second section combines questions on illness duration and expectations of improvement (6 items), consequences / severity of illness (6 items including financial burden and the impact of one's illness on others), sense of personal control over illness (6 items), confidence in treatment to cure illness (5 items), sense of understanding one's illness (5 items), cyclical nature of illness (4 items), and emotional response to illness (6 items). All 38 questions in section two are answered on a five-point agree/disagree scale, with some questions negatively worded (e.g. 'Nothing I do will affect my illness') and so requiring reverse scoring. The third section asks respondents to evaluate 18 potential causes of their illness, again with a choice of five levels of agree/disagree responses. This section also prompts a free-text response where people list the three most important factors that they believe caused their illness, which are not restricted to the 18 potential causes already listed.

### **Uptake and use within cancer:**

Although used much less extensively than the EQ-5D and SF-36, the IPQ-R has been validated amongst UK patients following treatment for oesophageal cancer<sup>26</sup> and was used within the ePOCS study<sup>27</sup>. It has also been used more recently with children following cancer treatment<sup>28</sup>.

## Mental health PROMs

### PHQ-9

The Patient Health Questionnaire is used for clinical assessment of common mental disorders<sup>6</sup>. The PHQ-9 is the module for depression, based on the nine criteria for depression defined in the DSM-IV. Respondents are asked to rate how often they have been affected by each of the nine listed problems (e.g. sleeping too much, having little energy, poor appetite, feeling bad about oneself) during the last two weeks, with each response scored from 0 ('Not at all') to 3 ('Nearly every day'). An additional question asks respondents to rate how difficult any of the identified problems have made it for them to undertake work and home responsibilities or to get along with other people.

### **Uptake and use within cancer:**

The PHQ-9 serves as both a diagnostic tool and as a marker of severity of depression, which is correlated with functional status, number of disability days taken, and the use of healthcare. Within cancer care the PHQ-9 is predominantly used for screening purposes, or alternatively to validate other assessment tools such as the Distress Thermometer<sup>29</sup>. One of its items informed content of an electronic patient-reported outcome system (ePRO) for distress management recently trialled amongst cancer patients in the USA<sup>30</sup>. It is used routinely in the UK as part of the Improving Access to Psychological Therapies (IAPT) programme<sup>31</sup>.

## HADS

The Hospital Anxiety and Depression Scale<sup>32</sup> consists of 14 questions, each asking respondents to rate how often they have had certain feelings (including tension, restlessness, panic, cheerfulness, and loss of interest in one's appearance) within the past week on a scale from 0 ('Not at all') to 3 (e.g. 'Definitely'/'Very often'/'Nearly all the time'). Scores are calculated for each of the two sub-scales, anxiety and depression, which are comprised of 7 items each. Some questions require reverse scoring (e.g. 'I can laugh and see the funny side of things'). Higher scores indicate a higher degree of clinically significant anxiety / depression.

### **Uptake and use within cancer:**

HADS is one of the most widely used and validated measures of anxiety and depression, used around the world, including the UK. Like the PHQ-9 it may be used in its own right to assess distress amongst cancer patients<sup>33</sup> or alternatively to validate other measures of distress<sup>34</sup>.

## Condition-specific PROMs

### **EORTC-QLQ-C30 (version 3.0)**

The European Organisation for Research and Treatment of Cancer – Core Quality of Life Questionnaire was developed in the 1980s specifically for cancer patients<sup>35</sup>. Its primary intended use was to assess quality of life for patients undergoing active cancer treatment and participating in clinical trials. The core questionnaire consists of 30 questions grouped within several sub-scales concerning function (15 items covering physical, role, cognitive, emotional, and social) and symptoms (13 items covering fatigue, pain, nausea/vomiting, breathlessness, sleep interference, loss of appetite, constipation, diarrhoea, and financial impact). The five physical function items are presented in the present tense (e.g. 'Do you need to stay in bed or a chair during the day?') with four response options ranging from 1 ('Not at All') to 4 ('Very Much'). The remaining functional and symptom questions are evaluated within the past week and are scored on the same four-point scale. The last two items are global health status ratings ('How would you rate your overall health / quality of life during the past week?') and are scored on a seven-point scale from 1 ('Very poor') to 7 ('Excellent'). Higher scores within the functional and global health status domains equate to better quality of life, but for the symptom domains a higher score represents worse quality of life due to more severe symptoms.

### **EORTC-QLQ site-specific modules**

The core questionnaire is intended to be supplemented by additional modules developed for specific tumour sites and their associated treatments, or alternatively for specific issues or populations (e.g. modules for 'Information' and 'Elderly cancer patients'). To date 19 modules have been validated and are available for use, with a further 12 modules in development. The modules for the most common cancers are widely used, for example EORTC-QLQ-BR23 (breast cancer), EORTC-QLQ-CR29 (colorectal cancer), EORTC-QLQ-LC13 (lung cancer), EORTC-QLQ-PR25 (prostate cancer). As these modules are specific to tumour site, questions vary in their content and emphasis; the lung cancer module focuses almost exclusively on symptoms and side effects of treatment, while the colorectal cancer module contains a section on the impact of a stoma bag and the breast cancer module covers concerns over sexuality and body image. Most module questions are evaluated within the past week and are framed within the same four-point scale as the core questionnaire (1 for 'Not at All' to 4 'Very Much'), although some items concerning weight loss/gain and sexual activity are evaluated across the past four weeks.

### ***Uptake and use within cancer:***

The EORTC is a collaboration of cancer research centres across Europe including Britain; the core questionnaire was thus designed to work within a range of cultural settings<sup>35</sup> and has been widely used internationally including in the UK. In 2009-2010 the Patient-Reported Outcome Measurement Group at the University of Oxford reported on the extensive use and validation of the EORTC-QLQ questionnaires for four common cancer types: breast<sup>36</sup>, colorectal<sup>37</sup>, lung<sup>38</sup> and prostate<sup>39</sup>. The core questionnaire and its relevant tumour-specific module were recommended as a PROM of choice for potential piloting within the NHS in all four cancers. However the authors noted that the bulk of evidence focused on their use in clinical trials for patients undergoing active treatment, and that as post-treatment recovery becomes a more prominent issue the EORTC-QLQ modules might not sufficiently capture quality of life changes over the longer term. Recent work suggests that this PROM does capture issues of importance in the post-treatment phase, but the domains it assesses are somewhat limited<sup>40</sup>.

### **FACT-G (version 4)**

The Functional Assessment of Cancer Therapy – General (FACT-G) is the American counterpart to the EORTC-QLQ-C30 (41). It has been validated internationally and used as an outcome measure within UK populations (42). Developed around the same time, it also follows a modular approach of a core questionnaire supplemented by site-specific PROMs. The 27 items of FACT-G are grouped within four clearly defined domains: emotional well-being (6 items, including a question on satisfaction with how one is coping with illness), functional well-being (7 items emphasizing ability to work and general enjoyment of life), physical well-being (7 items focused on symptoms and side effects of treatment), and social/family well-being (7 items focused on perceived support from and communication with family and friends, including a question on satisfaction with sex life). All questions are answered with reference to the past 7 days using a five-point scale from 0 ('Not at all') to 4 ('Very much'). Disease-specific modules are answered using the same scale and contain around 10-12 items in addition to the core questionnaire.

**Uptake and use:** Like the EORTC-QLQ-30, the FACT general and module questionnaires were recommended for piloting within the NHS for all four cancer types reviewed by the Patient-Reported Outcome Measurement Group at Oxford in 2009-10. Tumour-specific modules were included within the UK national cancer PROMs pilot (20). FACT has been extensively used and validated; however it may also require further assessment for its suitability as a measure of longer-term recovery.

## CARES-SF

The Cancer Rehabilitation Evaluation System – Short Form was derived from the original CARES questionnaire containing 139 items. The short-form version<sup>43</sup> contains 59 ‘problem statements’ that are evaluated with reference to the last month including today on the extent to which each applies to the respondents. Responses are on a five-point scale ranging from 0 (‘Not at all’) to 4 (‘Very much’), and respondents are also prompted to indicate whether or not they want help on each of the problem statements. The first 36 questions are always to be completed and span domains of physical concerns, psychosocial, medical interaction, sexual issues, financial problems, and symptoms / side effects (e.g. weight gain, diarrhoea, lack of bladder control). The remaining 23 questions are only answered if relevant to the respondent and concern the impact of cancer on children, employment, sexual intercourse, marriage / dating, chemotherapy, radiation therapy, ostomy and prosthesis. The end of the questionnaire has space for up to five additional cancer or treatment-related problems to be listed as free-form text. In contrast to the EORTC and FACT questionnaires, the developers of CARES-SF aimed to capture broader domains relevant to survivorship, with wider-ranging questions (for example, items on finance and travel). A global score can be calculated from the responses.

### ***Uptake and use within cancer:***

CARES-SF is used much less frequently than the EORTC or FACT questionnaires; it is included but does not feature prominently in recent reviews of cancer PROMs. However it was noted in an earlier review<sup>36</sup> that CARES-SF has demonstrated responsiveness to change in patients over time, potentially increasing its relevance for use in long-term monitoring. It has also been used to validate other cancer PROMs, including the Social Difficulties Inventory that was developed in the UK<sup>44</sup>.

## SDI

The Social Difficulties Inventory was developed in the UK in response to a perceived lack of existing instruments for sufficiently addressing cancer patients’ everyday problems in routine clinical practice<sup>44</sup>. Its 21 items were developed in consultation with patients through interviews and focus groups, after review of existing cancer PROMs including those above. Responses refer to the past month and are scored on a four-point scale ranging from 0 (No difficulty) to 3 (Very much difficulty). Domains for four sub-scales include Physical ability (5 items on independence, daily activities, mobility and recreation), Providing for the family (5 items on work, finance, and planning for the future), Contact with others (3 items on communication and isolation) and Undefined (3 items on sexual matters, discrimination and holidays), with a further 5 single items on caring and supporting others, body image, living conditions, and ‘other’.

### ***Uptake and use within cancer:***

The SDI was referred to in the 2010 NCSI Vision for its potential as a screening tool in identifying cancer patients that are in greatest need of support<sup>18</sup>. It was one of six measures included in the trialling of the ePOCS system (alongside the IPQ-R, EQ-5D, SF-36, EORTC-QLQ-C30 and QLACS, below), and one of two quality of life measure (alongside the EQ-5D) included in the UK national cancer PROMs survey<sup>20</sup>.

## Survivorship PROMs

### QLACS

Developed relatively recently, the Quality of Life in Adult Cancer Survivors<sup>45</sup> is a 47-item questionnaire based on in-depth interviews with people living with and beyond cancer. Domains are grouped within 'general' and 'cancer-specific' quality of life concerns. 'General' domains include negative feelings (4 items), positive feelings (4 items), cognitive problems (4 items), pain (4 items), sexual interest (2 items), energy/fatigue (4 items), sexual function (2 items), and social avoidance (4 items). 'Cancer-specific' domains include financial problems (4 items), positive effects of cancer on one's outlook (4 items), distress related to fears of cancer heritability in family members (3 items), appearance (4 items), and distress related to fear of cancer recurrence (4 items). Statements are evaluated with reference to the past four weeks and scored on a seven-point scale from 1 (never) to 7 (always).

### ***Uptake and use within cancer:***

In reviews of PROMs specifically for cancer survivorship<sup>14</sup>, QLACS features prominently. In a 2009 report published by Macmillan<sup>46</sup> it was recommended as the PROM of choice for assessing quality of life in people living with and beyond cancer, although the Impact of Cancer (IOC) measure<sup>47</sup> was also reviewed favourably in terms of evidence for psychometric robustness and coverage of domains appropriate for a wide range of cancer survivors. Along with the EORTC-QLQ-C30, the QLACS was highlighted in the 2010 NCSI Vision for understanding outcomes in individuals and was included in the ePOCS feasibility study. Recent work<sup>48</sup> however highlights gaps in its use with younger cancer patients.



# How are PROMs data collected?

PROMs data can be collected in a variety of ways:

- Sample surveys
- Population surveys
- Cohort studies
- Centrally organised routine data collection
- In-clinic data collection.

Examples of each of these are outlined below.

## Sample surveys

The feasibility of collecting PROMs data from people living with and beyond cancer in the UK was first assessed in a panel survey including people with various types of illness and none, which found that those recovering from cancer were significantly more likely to report poor health outcomes than people with no history of cancer<sup>49</sup>. This was then followed by a Department of Health funded survey of patients with breast, colorectal and prostate cancer and non-Hodgkin's lymphoma<sup>20,50</sup>. Participants who had been diagnosed and treated for any of these cancers between one and five years previously were identified through three cancer registries and a random sample of these (4,992 patients) was sent a questionnaire through the post. This included the EQ-5D, the Social Difficulties Inventory (SDI) which covers broader quality of life domains including the social consequences of cancer<sup>44</sup>, and relevant modules of the Functional Assessment of Cancer Therapy (FACT) instrument<sup>41</sup>. The survey also included questions about experience of treatment and care, co-morbidities, physical activity, psychological issues, demographic information and space for free-text comments.

A good response rate of 68% was achieved, but certain sub-groups (those aged over 85 and those in the most deprived group) were somewhat less likely to return completed questionnaires<sup>20</sup>. In general respondents reported good quality of life scores, albeit not quite as good as those in a general population sample, but a substantial minority clearly had on-going problems. Nearly half the respondents (47%) said they worried about recurrence of their cancer, more than a quarter (27%) were afraid of dying, and 20% had moderate or severe difficulties with mobility or usual activities. Bowel, urinary and sexual problems were common among colorectal and prostate patients, leading to worse quality of life scores. Those with other long-term conditions in addition to cancer tended to report worse scores than those without.

Nearly a third of respondents to this survey took the opportunity to record free-text comments on the questionnaire and analysis of these provided explanatory context for the PROMs scores<sup>50</sup>. Issues mentioned included the emotional impact of cancer, poor experiences of treatment and care, effect of comorbidities, treatment side-effects, social difficulties, and other physical and psychological problems. The fact that about one in five patients had ongoing problems several years after their initial treatment came as a surprise to many clinicians and policymakers, highlighting the need to review services for cancer patients after the immediate treatment period.

Respondents to the survey were sent a further identical questionnaire one year after the first one. The follow-up survey achieved an excellent response rate of 85%, but there was very little difference between the results of this second survey and the earlier one, confirming the earlier impression that a significant minority of cancer patients experienced long-term problems<sup>51</sup>. The case for examining recovery pathways and tailoring support for those experiencing ongoing problems was clearly made.

## Population surveys

Cross-sectional sample surveys such as those described above can provide a useful snapshot of the experience of people living with cancer, but the numbers of participants were too small to make reliable comparisons between centres for which larger samples are required. To address this a large population survey of colorectal cancer patients was organised to gather fuller data on their quality of life and the factors that influence it<sup>52</sup>. As before, patients were identified through the national cancer registry service. All those who had been diagnosed with colorectal cancer between 12 and 36 months previously were sent a questionnaire. The questionnaire included EQ-5D, FACT, and SDI PROMs, together with questions about treatment, disease status and other long-term conditions.

Responses were obtained from 63% (21,802) of 34,467 patients. A third of respondents reported no problems on any of the EQ-5D domains, but on average PROMs scores were worse than those from a general population. The most commonly-reported problems were pain, discomfort and disruption to daily activities. Patients with rectal cancer had worse scores than those with recto-sigmoid or colon cancer. Poorer quality of life was most marked in the younger age group. Nearly one in five of these had problems with incontinence or sexual difficulties. In some cases the problems had a very serious effect on their quality of life, for example inability to leave the house due to problems with bowel control. The study drew attention to the need for risk-stratified pathways and improved care coordination to tackle these problems.

Similar population surveys are now being undertaken with patients undergoing treatment for gynaecological cancers (cervix, ovary and uterus), bladder cancer and prostate cancer. Final reports from these studies were not available at the time of writing. A Department of Health-funded study has also looked at the potential for using PROMs to understand the needs of people with various long-term conditions by gathering data in general practice<sup>19,53</sup>. Initial response rates were much lower (38%) than for the cancer surveys, suggesting this would not be an efficient method to identify cancer patients.

## Cohort surveys

The population surveys described above are cross-sectional and therefore cannot provide a complete picture of quality of life changes from diagnosis to recovery. A prospective longitudinal cohort study was therefore designed to fill this knowledge gap. Funded by Macmillan, the CREW (Colorectal Wellbeing) study is following 1,000 people with colorectal cancer over a period of five years to plot the natural history of health-related quality of life following colorectal cancer treatment<sup>54,55</sup>.

Participants in the CREW study were recruited from 30 NHS cancer treatment centres across the UK after their initial cancer diagnosis but before commencing treatment. Those who agreed to participate were given a baseline questionnaire to complete at home prior to surgery, with follow-up questionnaires at 3, 9, 15, 24, 36, 48 and 60 months after surgery. These questionnaires contain a battery of standardised PROMs, including the EORTC-QLQ-C30 (quality of life scale)<sup>35</sup> and its colorectal cancer subscale EORTC-QLQ-CR29<sup>56</sup>, the Supportive Care Needs Survey (SCNS-SF34)<sup>57</sup>, the Quality of Life in Adult Cancer Survivors scale (QLACS)<sup>45</sup>, the Personal Wellbeing Index<sup>58</sup>, and the EQ-5D, plus other questions about personal, emotional and environmental factors, utilisation of health resources, health co-morbidities, lifestyle and self-management capabilities. Recruitment began in 2010 and data collection is currently at the 36 month stage. It took somewhat longer than anticipated to recruit the required number of participants, but the study eventually succeeded in securing participation from 78% of eligible patients with colorectal cancer (n=1,056)<sup>59</sup>. No results were available at the time of writing.

## Centrally organised routine data collection

Four elective surgical procedures were selected to launch the Department of Health's national PROMs programme because it was felt that these discrete, one-off operations would be relatively easy to track. Patients on the waiting list for surgery could be readily identified, administration of follow-up questionnaires is relatively straightforward, contact details are usually accurate, suitable PROMs had been identified, and data linkage to facilitate case-mix adjustment was possible. The intention was to evaluate and learn from routine PROMs collection among surgical patients before expanding the programme to encompass a wider range of conditions<sup>2</sup>.

The national surgical PROMs programme, launched in 2009, monitors outcomes of care for patients undergoing hip replacement, knee replacement, hernia repair and varicose veins surgery. Data collection is mandatory – all acute hospitals providing any of the four operations are required to participate. They must invite everyone undergoing these procedures (i.e. a census, not a sample) to complete a questionnaire before their operation, though patients may decline to participate if they wish. Those who complete the pre-surgery questionnaire are then sent a postal questionnaire three to six months after their operation to measure changes in their health status.

A single generic PROM (EQ-5D) is included in all questionnaires, together with condition-specific PROMs for three of the four diagnostic groups – Oxford Hip Score<sup>60</sup>, Oxford Knee Score<sup>61</sup>, and Aberdeen Varicose Veins Questionnaire<sup>62</sup>. No suitable condition-specific PROM was available for hernia patients so they complete the EQ-5D only. The questionnaires include some additional items asking about the respondent's health, including whether they have pre-existing conditions such as arthritis or diabetes, and about their experience of receiving treatment. Results from this continuous survey are collated, linked with data from the Hospital Episode Statistics (HES) information, case-mix adjusted, and published at regular intervals on the website of the Health and Social Care Information Centre (HSCIC) <http://www.hscic.gov.uk/proms>).

Response rates have been very good to date – the latest round achieved 77% for the pre-operation questionnaire and 73% for the post-operation one, an excellent result for a postal survey. Not surprisingly, the results show that most patients experience improvements in their health-related quality of life, especially those undergoing hip or knee surgery where more than 80% of patients report better health six months after undergoing the procedure.

A number of researchers have used the surgical PROMs dataset to explore key questions about variations between providers, health inequalities, and the factors influencing quality of life outcomes. For example, one study looked at the association between health gain (measured by changes in PROMs scores after surgery) and the availability of wider choice of provider<sup>63</sup>. They hypothesised that provider choice would have the greatest beneficial effect in areas where competition was fiercest. They looked at changes in disease-specific health status before and after hip replacement using Oxford Hip Scores and related this to the relative concentration of hospitals in different parts of the country, but found no evidence of a relationship between the two. The study authors concluded that hospital market concentration (as a proxy for competition) had no significant influence on the outcome of hip replacement.

As well as encouraging competition between NHS providers, the government wanted to increase capacity and choice by encouraging private providers to enter the market for elective surgery. There was much concern in some quarters that standards might be worse in the private treatment centres than in the NHS ones. The existence of the elective surgery PROMs pilot (prior to the rollout of the national programme) enabled a comparison of outcomes achieved by NHS and private providers<sup>64</sup>. The results showed only minor differences between the two types of provider, with most patients reporting good, very good or excellent outcomes, regardless of where they were treated.

Factors external to the health system, such as socio-economic and environmental influences, do seem to make a difference to how quickly people are treated and how well they recover<sup>65,66</sup>, but somewhat surprisingly these and other studies<sup>67-70</sup> suggest that there is in fact a great deal of uniformity across the country in quality of life outcomes after these procedures. Instead of the expected variations in the quality of care, all providers appear to be performing at similar levels of competence producing similar results.

## In-clinic data collection

There is a great deal of interest in the potential to use PROMs in regular patient care to monitor progress during and after treatment. The development of electronic methods for collecting and analysing data makes this a much more practical possibility. Paper and pen surveys are cumbersome and relatively expensive to administer. Analysis of the results requires separate data entry and analytical expertise, often leading to considerable delays in producing results. For instance, there is a time lag of about 18 months before results from the national surgical PROMs programme are available on the HSCIC website. Online surveys that can provide automated data collection, instant analysis and feedback in a well-presented comprehensible format (unlike the HSCIC data which is impenetrable to non-experts) could provide a much more efficient and effective means of generating valuable information for both clinicians and patients.

A recent UK study investigated the feasibility of collecting PROMs data from cancer patients electronically. The ePOCS system (electronic Patient-reported Outcomes from Cancer Survivors) was intended as a cost-effective way to collect PROMs data at regular post-diagnostic time points<sup>21,27,71</sup>. The system uses a secure questionnaire administration tool, accessed via a public-facing website, and responses can be linked to cancer registry data. In the pilot study patient monitoring and communications were semi-automated via a tracker database, and communication with patients took place primarily by email.

The ePOCS system was designed and tested in a hospital setting using research nurses to recruit patients with breast, colorectal and prostate cancer. Participants were invited to complete PROMs within six months of their cancer diagnosis and then again at nine and fifteen months. A pilot study was carried out using the following measures: EQ-5D, Illness Perception Questionnaire<sup>24</sup>, Medical Outcomes Study Short-Form questionnaire (SF-36)<sup>3</sup>, Social Difficulties Inventory<sup>44</sup>, Quality of Life in Adult Cancer Survivors Scale (QLACS)<sup>72</sup> and relevant modules of the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC-QLQ)<sup>56,73,74</sup>.

Of 1,152 eligible patients approached, 636 agreed to participate, a response rate of 55%. Like the postal surveys, agreement to participate was lower among older and less affluent patients. Most of those who did take part liked the system and found it easy to use. Linkage with cancer registry data was achieved for all participants. The experiment demonstrated the feasibility of gathering PROMs data electronically<sup>59</sup>.

A group of clinicians based in the north of England is using electronic surveys for monitoring post-treatment recovery following shoulder surgery. Called PROMs 2.0 this project is looking at ways in which the national surgical PROMs programme might be transformed by the use of electronic in-clinic data collection. Both clinicians and patients are enthusiastic about its potential (<http://proms2.org/>). Further research will be required to assess the validity and utility of this type of system for managing the care of individual patients.

Some research has been conducted to address the important question of whether inclusion of PROMs in routine clinical practice leads to improvements in cancer care. A recent systematic review looked at 24 controlled trials addressing this issue<sup>12</sup>. There was some evidence of positive effects, but wide variability in the design and use of the interventions and outcome measures limited the extent to which firm conclusions could be drawn. Another review of use of PROMs with palliative care patients found evidence of improved emotional and psychological outcomes, but there was no effect of this type of feedback on overall quality of life scores<sup>75</sup>.

Nevertheless, many experts remain convinced that use of PROMs in regular patient care is the way forward, recognising that a number of challenges will need to be overcome<sup>76</sup>. For example, the establishment of 'virtual' clinics using PROMs has been mooted, enabling remote monitoring to avoid unnecessary hospital appointments. Patients could be called up only when their PROMs scores indicate unmet needs for specialist help, potentially leading to more efficient use of resources and a reduction in the 'treatment burden' for patients.

This type of approach is currently being evaluated in a five year multi-centre study funded by the National Institute for Health Research (NIHR). The eRAPID study (Electronic patient self-Reporting of Adverse events: Patient Information and aDvice) is inviting patients attending cancer centres in Leeds, Bristol and Manchester to complete PROMs online at home. Their reports are immediately available in their hospital records so clinicians can monitor them to improve and streamline care. The system offers online advice to support self-management and alerts are triggered if serious problems occur so patients can be contacted immediately when necessary.

# What can PROMs be used for?

It is important to consider carefully how the outputs will be used before planning PROMs data collection. Decisions about where and in what way the information will be gathered, when and from whom, are likely to vary according to its intended purpose.

In theory PROMs can be used for a variety of purposes, the most common of which is as an outcome measure in clinical trials to evaluate medical interventions and technologies. They can also be used to monitor performance across specialties, organisations, departments or whole systems, and in clinical care to inform diagnosis, treatment and provider choice<sup>2</sup> (Table 3).

**Table 3: Potential uses of PROMs**

Level of aggregation	Purpose	Relevance
<b>Health system</b>	System-wide performance assessment	To monitor variations in health outcomes between population sub-groups and provider organisations
	Determining value for money	To determine the extent to which the current pattern of service provision is delivering good value for money
<b>Commissioners</b>	Procurement/contracting	To encourage providers to monitor health outcomes and to incentivise better care
	Monitoring quality	To use as a key performance indicator to monitor health outcomes and value for money
<b>Provider organisation/ specialty</b>	Clinical audit	To better understand patients' needs and assess how well these are being met by the organisation
	Quality improvement	To help plan innovations, monitor progress and incentivise staff
<b>Clinical trials</b>	Trial recruitment	To screen for eligibility for participation in trials and for use as a baseline measure
	Trial outcomes	To measure outcomes in intervention and control groups
<b>Clinical care</b>	Screening and diagnosis	To help make a diagnosis, including co-morbidities and impact on quality of life
	Health needs assessment and monitoring	To improve communication, identify needs for self-management support and monitor how the patient is getting on
	Choosing providers	To select 'the best' provider for an individual patient
	Choosing treatments and self-management support	To inform patients to facilitate shared decision making and personalised care planning

So what has been achieved to date in respect of the aspirations listed in Table 3? Our conclusions are summarised overleaf.



## Variations and value for money

Various sources, including the NHS Atlas of Variation in Healthcare (<http://www.rightcare.nhs.uk/index.php/nhs-atlas/>), have revealed wide differences in the performance of hospitals around the country in relation to various conditions. This led to calls to monitor and compare quality of care in different provider organisations, one of the main reasons for implementing routine collection of PROMs. However routine measurement in elective surgery has revealed few differences in PROMs scores across the country, begging the question of whether the programme is worthwhile. If everywhere is delivering similar quality, what is to be gained from measuring it continuously? Periodic surveys may be all that is needed, and they are considerably cheaper to organise. The national PROMs programme in elective surgery is currently under review by NHS England and presumably these questions will be addressed. The future of the programme may be threatened if the various stakeholders cannot point to evidence of beneficial impact.

Gathering PROMs data from every cancer centre in the country is certainly feasible, as the studies outlined above have demonstrated, but making reliable comparisons between centres is challenging, not least because patients sometimes receive care from more than one centre and from primary care as well. Comparing providers' performance without taking account of disease severity and other factors that may affect recovery can be misleading and will almost certainly be mistrusted, so risk stratification and case mix adjustment is necessary. This would presumably have to be done separately for each type of cancer and sub-group. Cancer treatment is not usually elective, so value for money assessments derived from system-level monitoring may be less relevant than for elective surgery. Treatment comparisons are better done by means of randomised controlled trials.

Given current resource constraints, it seems unlikely that NHS England will want to expand the current PROMs programme to encompass cancer unless there are very strong grounds for doing so. The case for expansion will be strengthened if the current round of large-scale surveys find evidence of variations in the quality of cancer care, but the methodological challenges will remain.

## Commissioning

NHS England intends that Clinical Commissioning Groups should make use of PROMs data in their commissioning plans, but our search for evidence of CCGs actively using PROMs data in their procurement, contracting or monitoring processes for cancer care has drawn a blank. Most CCGs are still at an early stage of development and some still struggle to make sense of any clinical data, let alone PROMs, but a few interesting models are beginning to emerge, not least Staffordshire's programme to transform cancer and end of life care.

A partnership between four CCGs and Macmillan Cancer Support, this aims to provide personalised, coordinated care for cancer patients across a population of about a million people. Details of how the programme will be implemented are not currently available, but the intention is to gather PROMs data from all local providers as a management tool to identify needs and monitor progress. Described by Bob Ricketts, Director of Commissioning Support Strategy at NHS England, as "the biggest demonstration of outcomes-based population commissioning anywhere in the NHS", this programme will test the utility of PROMs in the management of a large-scale cancer programme aimed across a single local health economy – a unique experiment which should generate useful learning. The Staffordshire initiative should be carefully evaluated.

## Clinical audit and quality improvement

The cancer surveys described in this report have helped clinicians to better understand the needs of people living with and beyond cancer, including their psychosocial needs (77). Similar surveys conducted in hospitals or by specialty groups could play a powerful role in collaborative audits by groups of cancer specialists. Many groups of clinicians around the country are already using PROMs to inform and evaluate their clinical practice, but we are unsure about the extent to which this is happening in cancer care. Given concerns about the unrecognised long-term consequences of cancer treatment, this type of activity would seem to be worth encouraging.

Choice of PROMs for use in these quality improvement programmes must be done carefully. Use of inappropriate measures or ones that are too complex and hard to interpret could lead to confusion. Some of the PROMs focusing on longer-term recovery were developed only recently and have not yet been well tested. Further validation studies may be required.

Several international initiatives are working to build consensus on the most suitable measures for specific clinical topics, including the International Consortium for Health Outcomes Measurement (ICHOM) [www.ichom.org](http://www.ichom.org) (which has a group working on prostate cancer), the Patient Reported Outcome and Quality of Life Instruments Database (PROQOLID) [www.proqolid.org](http://www.proqolid.org), and the Patient Reported Outcomes Measurement Information System (PROMIS International) <http://www.nihpromis.org/science/PROMISGlobal>. These may help to narrow down the choice.

## Clinical trials

Incorporation of PROMs to evaluate quality-of-life outcomes in clinical trials is already becoming commonplace, yielding useful knowledge on the comparative effectiveness of various therapies, including cancer treatments. The use of PROMs in clinical trials should be encouraged, but cumulative learning from these would be greatly enhanced if investigators could agree on a limited set of measures for widespread use. Systematic reviews and meta-analyses often fail to draw firm conclusions on clinical effectiveness due to the plethora of outcome measures that cannot be combined. More standardisation would be a great help.

## Clinical practice

Evidence shows that personalised care planning, in which patients with long-term conditions work together with clinicians to agree goals and actions as part of a recovery package for supported self-management, can lead to better health outcomes<sup>78</sup>. PROMs could be used as part of such a package to monitor progress and evaluate the outcomes. They could also be useful for informing patients about treatment or support options and recovery pathways as part of a shared decision making process<sup>79</sup>. This is already happening to some extent. For example, GPs in North Yorkshire are initiating discussions with their patients about PROMs to encourage them to think about which treatments would be most appropriate for them – <http://www.valeofyorkccg.nhs.uk/rss/index.php?id=proms>.

PROMs are unlikely to be used as a diagnostic tool in cancer because better methods exist, but they could be useful for health needs assessment (including self-management support), for identifying treatment side-effects and for post-treatment monitoring with individual patients. PROMs data can be incorporated into decision aids to inform patients about the likely benefits and harms of alternative treatments or management options<sup>80</sup>. Some cancer decision aids are available on NHS websites (<http://sdm.rightcare.nhs.uk/pda/>), but more are needed. These can be incorporated into clinical record systems making them readily available at appropriate decision points.



Electronic means of data collection are obviously the way forward and current studies evaluating online monitoring and virtual clinics will produce valuable evidence on how to integrate this approach into routine practice. These will need long-term investment and support if they are to be sustainable. It will be crucial to get commissioners on board with this work at an early stage. More work is also needed to test out ways of presenting the data electronically and on paper so that it is easily understood by both clinicians and patients, and is clinically relevant<sup>81-84</sup>.

The problems inherent in making reliable comparisons between cancer centres will have to be overcome before PROMs data could be used to select providers – no easy task because of the heterogeneity of cancer patients and the challenge of making meaningful adjustments for case-mix. For the same reasons, the search for global indicators is likely to be fruitless. Work is currently under way to develop methods for combining data from several different PROMs instruments, but the process is highly technical<sup>85</sup>. For routine use in cancer care it would make more sense to try to obtain agreement on a core set of PROMs for widespread use.

The use of PROMs in clinical care has great potential, but many clinicians still need to be convinced of their validity and utility<sup>86</sup>. If they are to make use of them in clinical practice, they will want reassurance that the process can be fitted into care pathways without causing disruption. While the use of PROMs for care management looks most promising, the benefits of their use in regular clinical care have not yet been adequately demonstrated in rigorous trials. This should be a priority for further research.

## Multi-purpose PROMs

Multi-purpose applications of PROMs data, for example using it for clinical care purposes and then aggregating it for performance measurement, remain largely aspirational at present<sup>87</sup>, but in mental health the Improving Access to Psychological Therapies (IAPT) programme is making strides in this direction. This large-scale national programme for treating people with anxiety and depression has shown how PROMs – in this case PHQ-9, GAD-7 (88) and CORE-10 – can be used both as a clinical tool to inform the management of individual patients, and as key performance indicators across a programme that treats nearly half a million patients each year<sup>31</sup>. This has been achieved by adopting a standard minimum data set that can provide meaningful information for both clinicians and patients, including PROMs collected at each appointment. PROMs scores are used both as screening tools, to confirm a diagnosis, and as outcome measures, to assess recovery rates. Up-to-date information on individuals' progress is used to plan interventions. The IAPT programme is beginning to generate impressive results<sup>31, 89-91</sup>.

A number of challenges must be overcome before this multi-purpose use of PROMs can be achieved in cancer care, not least building trust and commitment among clinicians and patients. It is not sufficient to just gather data and publish it. To achieve this it will be necessary to demonstrate impact. For example the national cancer patient experience surveys have stimulated improvements in patient care, especially in relation to information and communication. These improvements were the result of effective leadership at both national and trust level, careful dissemination of results to staff, employment and training of clinical nurse specialists, positive support from medical staff, and a commitment to act on the 'quick wins' ([www.candocancercare.org](http://www.candocancercare.org)). Similar efforts will be required to capitalise on the learning from PROMs.

# Recommendations

We were asked to make recommendations on how Macmillan Cancer Support could use PROMs to achieve its priorities in cancer care. We believe a bottom-up approach would be most fruitful, encouraging clinicians and patients to make greater use of these tools for clinical audit and in regular care. The value of PROMs should be judged by the extent to which they contribute to better care for patients. They have a potentially useful role in drawing attention to quality of life issues that might otherwise be missed, but the extent to which this additional knowledge leads to the provision of more effective support for people living with and beyond cancer needs to be tested in the real world of clinical practice.

In our view a focus on the clinical coal-face is likely to be more productive than trying to persuade NHS England to extend the national PROMs programme to encompass cancer alongside elective surgery. A mandatory top-down initiative would have to overcome numerous practical problems, including financing and staffing the programme, persuading clinicians and patients to participate, agreeing suitable 'before' and 'after' measurement points, developing tailored methodologies for different tumour sites, tackling the complexity of case-mix adjustment, sorting out how to make reliable comparisons between cancer centres, dealing with publication delays, and so on.

There is also a case for carrying out more cross-sectional and longitudinal surveys to improve understanding of the needs of people living with and beyond cancer, focusing on different tumour sites, but these would not need to be carried out very frequently. Recent studies and those currently under way have already contributed a great deal to understanding of patients' needs. While additional surveys could certainly add to the stock of knowledge, the priority now is to implement strategies for meeting the needs that have already been identified.

It is important to remember that PROMs are designed to measure health status and health-related quality of life. They are not the best tools for measuring specific lifestyle changes, such as smoking or physical exercise, for which direct questions about smoking status or activity levels are more appropriate. However, PROMs can be used alongside these other items in the same questionnaire, where necessary.

We suggest the following priorities for action:

**1. Use PROMs to monitor and evaluate recovery packages:**

PROMs should be trialled alongside existing needs assessment tools to help in developing personalised care plans, monitoring individuals' progress and evaluating outcomes. The data should be collected and analysed electronically, using interfaces such as those developed for the ePOCs or eRAPID projects described above.

**2. Use PROMs data to develop risk-stratified care pathways:**

Existing data from PROMs surveys could be used to identify patients' support needs, to design appropriate interventions and to target individuals according to their level of risk. Ongoing monitoring using PROMs data could be used to evaluate the impact of the interventions. The IAPT programme in mental health uses a stepped care model together with PROMs indicators to ensure that patients are signposted to appropriate care. This approach should be examined to see if it could be adapted for use in cancer care.

**3. Use PROMs data to inform patients about treatment, management and support options:**

Findings from PROMs surveys could be incorporated into electronic patient decision aids to provide information about prognosis, support options and likely outcomes to inform shared decision making. As part of this effort there is a need to test different ways of presenting PROMs data. The aim should be to maximise their meaningfulness for non-specialists to encourage their use in clinical care by both clinicians and patients.

**4. Encourage use of PROMs for clinical audit and collaborative improvement projects:**

Collaborative audits and data sharing would be greatly facilitated if agreement could be reached on a core set of PROMs. Macmillan and/or the cancer task force should convene a meeting of interested parties to agree priorities for further application of PROMs. The group could review existing PROMs, starting with our top ten, with the aim of recommending a core set of measures for use as key performance indicators.

**5. Test the use of PROMs in virtual clinics for remote monitoring:**

Macmillan should consider funding further research into the efficacy and cost-effectiveness of virtual clinics where patients are encouraged to complete PROMs online to enable remote monitoring, avoiding unnecessary hospital appointments.

**6. Use of PROMs to inform commissioning strategies and as key performance indicators:**

Currently there appears to be very little use of PROMs by commissioners of cancer care, but as the shift towards outcomes-based commissioning gathers momentum there is likely to be growing interest in the potential contribution of PROMs. The Staffordshire programme to transform cancer and end of life care may provide valuable learning of direct relevance to this issue. We suggest that this programme should be carefully evaluated to capture and build on their experience and explore the various ways in which PROMs could be used in commissioning.

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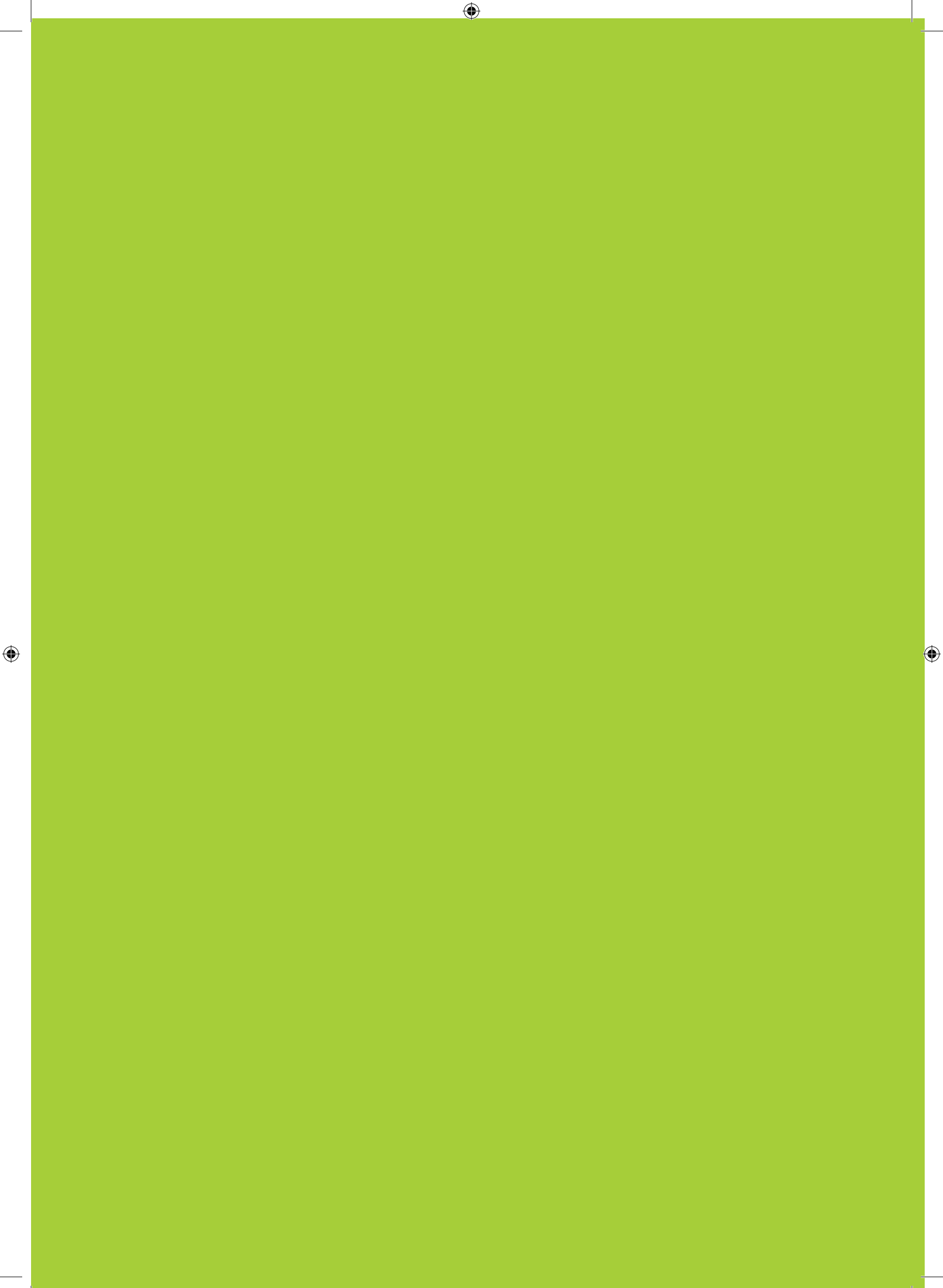
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