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EDITORIAL



The use of patient-reported outcomes (PROs) in cancer care: a realistic strategy

THE POTENTIAL USES OF PATIENT-REPORTED OUTCOMES

Patient-reported outcomes (PROs) (i.e. any information on the status, health condition, health-related behaviour or health care experiences directly assessed and reported by the patient, without the response being interpreted by a clinician or a third party)¹ are promising in terms of improved patient monitoring. PROs make health care professionals more aware of symptoms and the clinical course of a given condition, and make patients more comfortable because they have a real-time connection with their care team. Various studies have demonstrated that this improves survival and quality of life, extends the cancer treatment tolerability period, detects recurrence earlier and reduces hospitalizations and emergency visits.²⁻⁴ Consequently, the systematic use of PROs in routine cancer care is highlighted as an effective approach to standardizing cancer practices. When collected during routine cancer care, PROs can be used to meet four objectives (Figure 1).

For clinical trials, they represent a cost-effective data collection system providing invaluable evidence of the impact of new treatments on patients' symptoms, status and quality of life in real life and clearly highlighting patient's experience with the evaluated drug or management (objective 1). In the case of the patient–health care professional relationship, PROs may help to monitor and assess treatments. They can also improve the patient's self-management of their disease, all improving the customization of cancer care (objectives 2 & 3). Finally, PROs may support new value-based care assessments contributing to public health rankings and new payment methods (e.g. pain management in an inter-hospital comparison) (objective 4).

As oncologists and quality measurement experts using them, we would like to point out that their developments currently require resolution of implementation issues before the four goals they pursue are actually achieved and fully contribute to improving the quality of care.

According to recent studies, the PRO content of past trial protocols was often incomplete or unclear due to difficulties in collecting data by patients, resulting in superfluous research.⁵ The data collection burden for clinicians has also limited their use in many cases regardless of the objective pursued.^{6,7}

PROS IN ROUTINE CARE: IMPLEMENTATION ISSUES

Implementation issues are identifiable at every step in initiating PROs.

- Data collection. PROs are now collected through valid questionnaires, while at the same time new remote data collection methods have been developed (e.g. apps or connected devices) as evidenced in many systems like the Capri application introduced at Gustave Roussy for monitoring patients receiving oral therapy (Figure 2).⁴ Despite this progress, the data collection of PROs remains a major problem. The completion of questionnaires increases the patients' workload, often in a context of fatigue and anxiety, and introduces interpretation problems. Certain situations such as non-compliance may also be underestimated. All of these problems increase the risk of low response rates, the exclusion of some sub-populations and data reliability concerns. Collecting and answering the relevant information also constitute a burden for clinicians given the time and effort involved. Likewise, infrastructure requirements represent an important investment (a PRO software system should include an interface to allow patients to self-report; automated e-reminders to patients to self-report; automated e-alerts when severe or worsening symptoms are reported by patients). Lastly, a disruption in workflow can limit their frequency of use. For instance, some health care organizations encourage patients to complete questionnaires at home before their medical appointment, but workflow adjustments involve numerous operational tasks such as instructing patients on how to log onto and manage the portal, potentially time-consuming for both distressed patients and swamped health care professionals.
- Data analysis. Results have to be standardized to facilitate comparisons between health care organizations or over time in a given health care system. In both cases, differences in patient characteristics (e.g. patient acuity status or comorbidities and age) and health care organization particularities (e.g. level of resources such as the number of beds) may skew results. If PROs are used as quality measurements (i.e. standardized and evidence-based measures of health care quality), they must also present metric qualities (i.e. construction and criterion validity, reproducibility) in order to generate reliable comparisons, which represent another constraint.
- Translating assessment into improvement. The ability to move from assessment time to improvement actions,

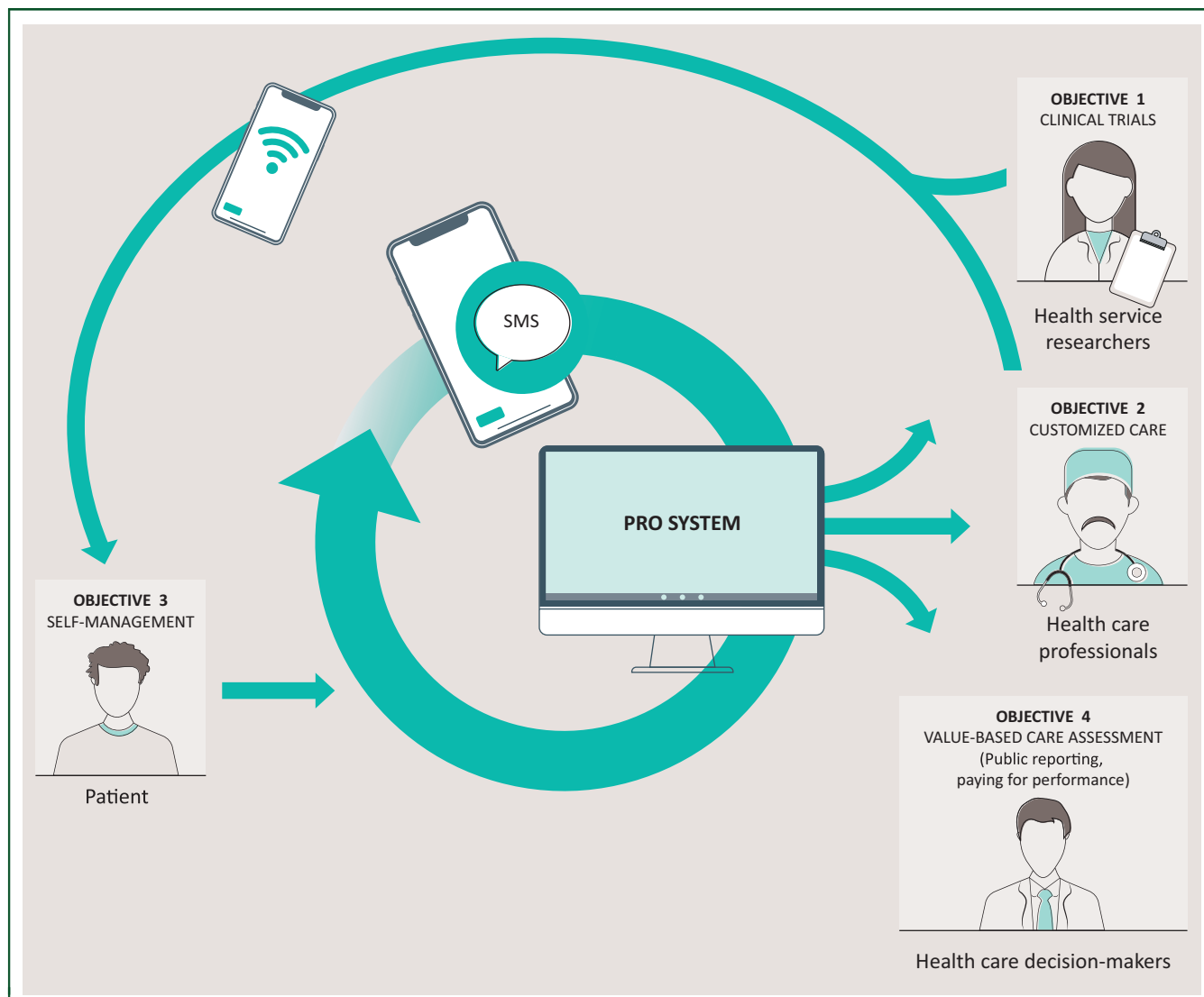


Figure 1. The four objectives for using PROs in cancer care.
PROs, patient-reported outcomes.

which qualifies the ‘actionable’ nature of PROs, can also raise concerns, given that some results cannot be spontaneously translated into improved actions. For instance, it may turn out that no effective treatment exists with regard to the improvements outlined in the PRO assessment or that the individual action is difficult to assess based on an average evaluation. All of these issues must be overcome before considering effective use of PROs. It involves defining a realistic strategy in their development.

A REALISTIC STRATEGY OF DEVELOPMENT

Existing guidelines help to define this strategy in the use of PROs in clinical trials⁸ or in personalized cancer care.⁹⁻¹¹ Such guidelines highlight the importance of: (i) informing patients that PROs can direct care and prompt responses to their feedback; (ii) defining strategies for limiting the work involved in data collection (e.g. by selecting valid measures easily implemented by the patient and determining how the data will be collected and who will receive the results); and

(iii) producing results that can be easily interpreted by clinicians (e.g. the PROs can be risk-stratified based on severity so that clinicians can manage patients with the greatest needs while monitoring other patients who may require assistance at some point).

Recent initiatives also provide insight into steering clinical and organizational practices. For instance, the remote monitoring system Capri highlights the role of nurse navigators in processing the information generated by PROs. Their work involves advising patients in terms of self-management, directing them to various ambulatory health care professionals and contacting oncologists when required, thereby alleviating the burden of data collection for the latter.¹² These initiatives highlight that a PRO’s platform without organization to treat the data can lead to unsustainable and critical situations.

These guidelines and insights are part of a realistic strategy to implement PROs. Such a strategy is essential to appropriately utilize PROs in clinical trials and personalized cancer care. By applying this strategy, databases based on

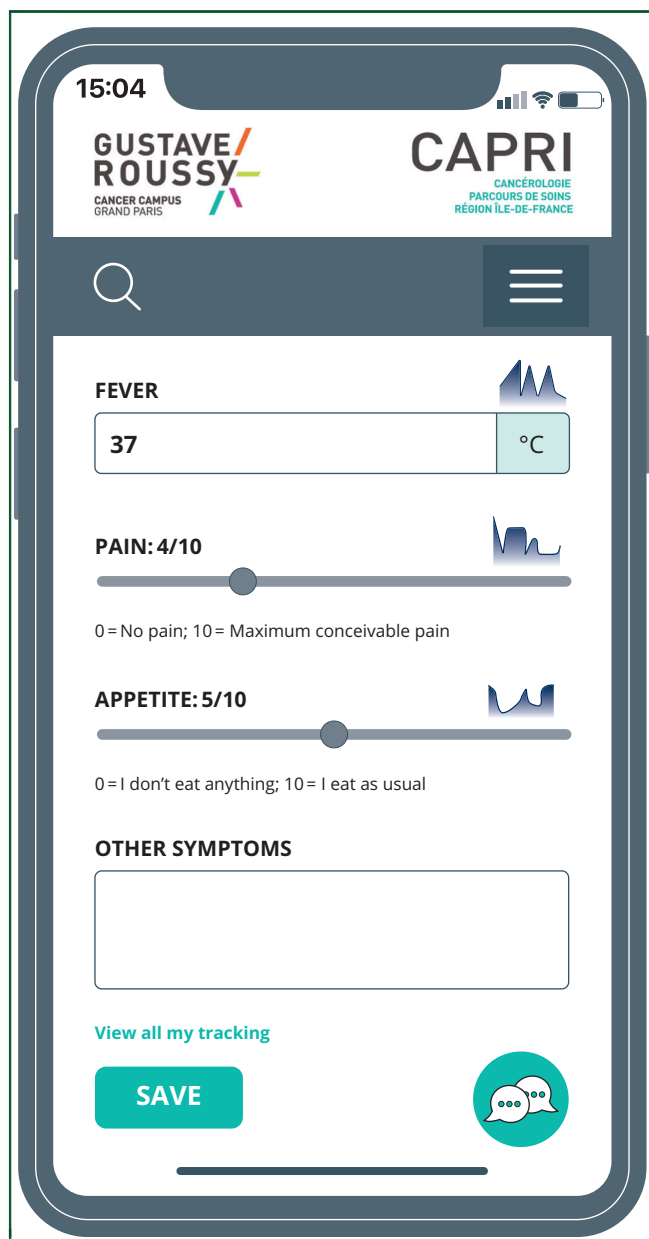


Figure 2. A typical PRO platform.
PROs, patient-reported outcomes.

patient information will also increase, and PROs can eventually be used as quality indicators.^{13,14} In all cases, it is in the field that the effective role of PROs will be confirmed to improve the patient experience, the quality of care and patient outcomes.

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