

The Role of Patient Reported Outcomes (PROs) in Healthcare Policy Making

Authors: Hariprasad Esam, Ravi Kishore, Shivaprasad Singuru, Ankita Sawant, Shilpa Mendon, Amit Dang
MarksMan Healthcare Solutions, HEOR and RWE Consulting, Navi Mumbai, India

Patients - Experts of their experience of disease

- Patients are the most valuable and authoritative source of information on outcomes such as health-related quality of life, functional status, symptom and symptom burden and health behaviours.¹
- Unfortunately patients have remained an untapped resource in assessing the quality of healthcare and of long-term support services. Even traditionally the only information collected from patients were feedback on satisfaction or experience with care.¹

Patient - An untapped resource so far - Why?

- Conventional medicine adopts the disease-centered model of clinical care that is directed at making patients "feel better".^{2,3}
- In contrast the patient-centered approach focusses on improving the biological aspects with psychological and social considerations.²
- Today, the usage of Patient-Reported Outcome Measures (PROM) is recognized as an efficient quality improvement tool.⁴

PROM - A valuable tool

- Initially the use of PROM was restricted to research that culminated in some regulatory bodies mandating their use.⁴
- Role of PROMs later expanded from facilitating patient-clinician communication to evaluating the quality of healthcare services.⁴

Potential of PROMs for improving clinical care

- Provides clinical information for medical decision-making.
- Identifies patient's areas of concern unrecognized by the provider.
- Contributes information for pre-planning of visits by the patient care team.
- Assist clinicians in monitoring patient status longitudinally.
- Provides an important source of information about treatment response.⁵

Countries where PROMs has been implemented in routine practice

- Till date the use of PROMs is restricted to England, Sweden and parts of the US.
- In England, the government has been the driving force in their attempt to make accessible to the public, comparisons of provider's performance.⁴

Swedish rheumatology quality registry - Established in 1995

- Established in 1995, the Swedish rheumatology quality registry contains data on over 66000 patients, about 85% of people in Sweden with rheumatoid arthritis.
- Each patient is provided with a personal identifier to access the registry and input information into a user friendly "dashboard" on both disease specific and general measures of function and health.
- The PROMs enables clinicians to provide more appropriate and patient centred care. The system is also useful in guiding treatment, sharing decision making and self-management.
- Patient benefit the most by this engagement as they feel empowered and confident in managing and controlling their condition. The improved confidence translates into better clinical response.⁶

US primary care model: HowsYourHealth.org - Developed in 1994

- The HowsYourHealth system was developed in 1994 and disseminated on the internet since 1999 at no cost to primary care practices.
- Patient enters data from home or within the doctor's office by ticking in boxes in response to questions on their function, diagnosis, symptoms, health habits, preventive needs, capacity to self-manage chronic conditions and their experiences of care.

- The system has been endorsed by several medical specialty organizations and used by hundreds of practices in the US and Canada.⁶

National PROMs programme in England for elective surgery

- In England, from April 2009, all providers (NHS hospitals, independent sector treatment centres, private hospitals) treating NHS patients for any elective procedures had to compulsorily participate in the national PROMs programme.
- It required all patients to complete a pre and post-operative questionnaire.
- The postoperative questionnaire included overall view of results of surgery, extent of improvement if any and reports on adverse outcomes.
- With the help of this report providers were identified and compared to show whether or not any provider's outcome was significantly different from what would be expected. Results were publicly reported online at the NHS Trust level.⁷

Challenges in successful implementation of PROMs⁷

1. Practical theme-inadequate resources allocated to implement PROMs. Collecting PROMs data takes people away from other activities and therefore additional staff time needs to be resourced to render this process feasible.
2. Attitudinal issues - suspicion among healthcare professionals about the motives in adopting PROMs.
3. Methodological issues - specific scientific concerns frequently asked by the professionals on the measurement properties of PROMs.
4. Conceptual issues - difficulties among professionals in comprehending the nature of subjective measurement.

Lessons for policy makers

- Professionals must be provided with necessary training and greater practical and methodological support to ensure better collection and interpretation of PROMs data.⁷
- Ensure that healthcare professionals, such as nurses, physicians, pharmacists and allied health professionals are engaged at a much deeper level.⁷
- More focus is needed on inter-provider comparisons so as to achieve improvements in the care of whole patient groups (e.g., all patients undergoing hip replacement surgery within a hospital system).⁷

Indian scenario - Where are WE?

- Concept yet to catch up in India.⁸
- Clinicians and regulatory bodies has given minimal importance to PROMs.⁸
- India has a strong and widespread generic market. Thus PROM implementation in clinical trials should be made mandatory for pharmaceutical companies to prove their label claims.⁸
- Data obtained from PROs in clinical trials can be useful in making health-related decisions at all levels in India.⁸

REFERENCES

1. Brennan RN, Dubow MJ. Available at: http://www.qualityforum.org/.../FAST_FORWARD_-_PATIENT_REPORTED_OUTCOMES.
2. Refolo P et al. European Review for Medical and Pharmacological Science 2012;16:1319-23.
3. Snyder CF et al. Qual Life Res. 2012 Oct;21(8):1305-14.
4. Black N. BMJ. 2013 Jan 28;346:f167
5. Broderick JE et al. eGEMs (Generating Evidence & Methods to improve patient outcomes) 2013;1(1). Available at: <http://repository.academyhealth.org/egems/vol1/iss1/12>
6. Nelson EC et al. BMJ 2015;350:g7818
7. Boyce MB, Browne JP. Available at: <http://www.qualitymeasures.ahrq.gov/expert/expert-commentary.aspx?id=48933>
8. BN V et al. Value in Health 2015;18(3):A102