Role of Social Media in Patient Reported Outcomes Research

**Development of PRO Research**

**Origin**

- **1975**
  - Mette’s use of PRO using disease-specific clinical databases to test quality systems that were established in Sweden
- **2000**
  - PRO as a reimbursement mechanism for accountability with case organizations introduced to some parts of the EU
- **2009**
  - Mandate to use PRO in patient outcome for certain elective surgical patients with National Health Services (NHS) if applied in UK

**Social Media and PRO Research**

- Establishing and reporting the evidence for clinical product evaluation based on social media and rarely PRO developed need to be standardized for the content validity

**Challenges in Using Social Media as a Source for PRO**

- **The PRO is measured using an instrument consisting of a questionnaire plus the information and documentation that support its use.**
- **The PRO measurement instrument or tool can be either general in nature or disease-specific, but the combination of generic and disease-specific PRO measurements is often used in clinical studies.**
- **The National Institute of Health (NIH) introduced a research design of PRO measurement information systems to develop, validate, and standardize instruments for PROs that are relevant to the common medical conditions.**

**The Other PRO Challenges**

- **There is a lack of consensus in the terminology and methodologies of the PRO measurement while establishing the guidelines.**
- **The complexity in defining the domain-based items and setting up methodology of PRO measurement for generic or disease-specific health status.**
- **There is confusion over to what extent any new guidance should be prescriptive or descriptive.**

**Our Perspective on PRO Research**

- **Evaluation**
  - Healthcare is moving towards value-based systems, where improving the quality of life and longevity is a good clinical practice. Thus, there is a need to use PRO to enable health-care professionals to understand and improve their services.
  - The publication of data based on PROs is likely to find its way onto social media and patient websites, and such information is of interest to both patients and patient advocacy groups alike.

**Conclusion**

- As social media has a great potential to impact the patient care in the future through increasing mobile technology usage, it would definitely assist the generation of PRO for a quality and informed decision of healthcare practitioners.