

Evaluation of Sources and Types of Patient-Reported Outcome Data for Healthcare Research

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BACKGROUND

- There is growing interest in using patient-reported outcome (PRO) measures.
- PRO measures can complement clinical measures to improve the quality of healthcare.
- The amount of PRO data being captured by healthcare databases is unknown.

OBJECTIVE

To systematically identify sources that capture PRO measures and the types of PRO data that are captured in healthcare databases.

METHODS

PRO data were categorized into 9 dimensions of health status¹: physical function, symptoms, global perceptions of health, psychological well-being, social well-being, cognitive function, roles / activities, attitude to self / personal constructs, and satisfaction with care.

A systematic review was conducted in B.R.I.D.G.E. TO DATA[®] (www.bridgetodata.org), an international resource of database profiles.

- 175 database profiles were individually reviewed.
- The PRO category and specific data subcategory (e.g., symptoms - appetite) were extracted and quantified as frequency. The presence of PRO information were recorded as Yes, None, Optional (i.e., reporting by patients is optional), or Custom (i.e., PRO data collection can be specified by each investigator).
- For each PRO measure, characteristics of databases that captured the PRO measure were also reviewed and quantified (Table 1).

Table 1. Examples of Data Fields Used in Profiles (by Category)

Category	Data Fields
Summary	Database description, Database source, Years covered, Population type, Date of last update
Population Dynamics	Population size, Sample weights – Extrapolation factors
Demographic Data	Age, Gender, Date of birth, Death recorded, Other demographic data
Physician & Practitioner Info	Physician ID & Specialty, Pharmacy ID
Diagnoses/Signs & Symptoms	Diagnosis data , Diagnoses coded (coding systems), Max. number of codes, Physical exam findings, Environmental exposures, Behavioral data elements
Procedures	Procedure data, Procedures coded (coding systems), Laboratory information
Drug Information	Drug data, Drug dosage, Drug coding system(s), Additional drug information
Economic Data	Type of cost data (if applicable)
Validation & Linkage	Data validation, Access to medical records, Linkage to other databases
Administrative Data	Database contact data, Database usage restrictions, References of studies using/describing the database

The data fields marked in red in Table 1 indicate the most common fields likely to contain data on PRO measures in the database profiles.

RESULTS

A review of 175 database profiles in B.R.I.D.G.E. resulted in the identification of 42 (24%) databases that collect data on ≥1 of the nine dimensions of PRO measures (Figure 1). One of these databases [Pharmaceutical Assistance Contract for the Elderly (PACE, USA)] allows optional reporting by patients, and three databases [MediGuard (USA), PHARMO Record Linkage System (Netherlands), and Saskatchewan Health, Multiple Linkable Population Databases (Canada)] collect PRO-related data upon request. Physical function (n=27), symptoms (n=26), and psychological well-being (n=22) were the most frequently collected PRO measures.

Figure 1. The number of databases profiled on www.bridgetodata.org that collect data on patient-reported outcomes (PRO) [175 Database Profiles worldwide as of May 21, 2012]

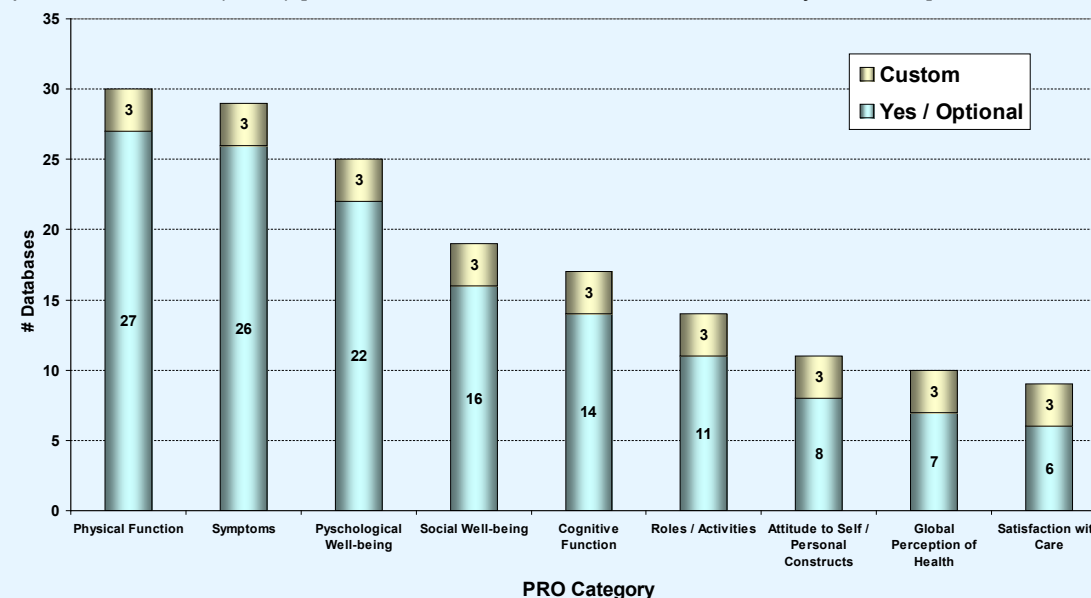


Table 2 lists common examples of subcategories that were identified for each PRO category.

Table 2. Examples of Common PRO Measures Collected by Databases

PRO Category	Examples of Common PRO Measures
Physical Function	Activities of daily living Physical function / Disability Physical activity / Exercise
Symptoms	General symptoms / Self-diagnoses Sleep quality / patterns Nutrition; Vision; Allergies
Global Perception of Health	Health status Quality of life Major health problems
Psychological Well-being	Behavioral / Substance abuse Anxiety / Stress Mental Health; Depression; Suicidality
Social Well-being	Psychosocial Social attitudes / Relationships Sexual behaviors
Cognitive Function	Cognition Communication Learning / Comprehension / Memory
Roles / Activities	Pursuits / Hobbies Roles in household Socioeconomic activities
Attitude to Self / Personal Constructs	Life satisfaction Attitude to body image / weight Social influences
Satisfaction with Care	Satisfaction with care Financial effects on care Access to care

- ✓ The majority of databases in B.R.I.D.G.E. found to report PRO data are longitudinal (n=24) and/or cross-sectional (n=16), particularly survey data (n=19), and in populations of <200,000 (Table 3).
- ✓ US databases (n=24) had the highest frequency of collecting PRO data.
- ✓ Canadian databases collecting PRO data focused heavily on physical function, psychological and social well-being.
- ✓ Database characteristics varied among PRO categories:
 - Databases collecting cognitive function data primarily included populations from specialty institutions, and data on patients' role/activities were commonly obtained from (non-institutionalized) outpatients.
 - Medical/claims records were also frequent sources for data on symptoms and cognition.
 - Global perception of health data were often from database populations of 0.5-1 million.

Table 3. Excerpt from B.R.I.D.G.E. TO DATA[®] comparing data elements with PRO measures and economic data in 3 selected databases

FIELD NAMES	China Health and Nutrition Survey (CHNS) (China)	Manitoba Population Health Research Data Repository: Long Term Care (Canada)	National Survey on Drug Use and Health (NSDUH) (USA)
Database Type	Longitudinal Population Database Cross-sectional Population Data Population Surveys – general (all diseases/all drugs) [Each individual wave is cross-sectional and covers a variety of categories, including health and nutrition.....(more)]	Longitudinal Population Database Drug and Diagnosis Data	Cross-sectional Population Data Population Surveys – specific (selected diseases & / or drugs) (U.S. national survey specific to the use of illicit drugs (including non-medical use of prescription drugs), tobacco, and alcohol and the presence of mental health)
Database Source	Survey Data Questionnaires include: Household Survey Health and Nutrition Survey (Child, Adult) Physical Activity Body Image and Mass Media Behaviors and Practices Community Survey Health and Family Planning Facility Surveys	Other (An admission/separation form is completed for each resident by all Manitoba personal care homes and is submitted to Manitoba Health for processing in the Master Registration System Information. The LTC MDS Tool is used to collect information from residents in all Winnipeg personal care homes for clinical assessment and care planning purposes.)	Survey Data A scientific random sample of households is selected across the United States. Each selected person represents more than 4,500 United States residents.
Years Covered	1989 - 2009 (The 2011 surveys are currently in progress)	1973 - Present	1971 - Present
Patient Type	Outpatient/Non-institutionalized Other (Household residents; community information)	Other (Population in long term care facilities, including personal care homes)	N/A
Database Population Size	<200,000 (In 1989 CHNS included 3,795 households. In 1991, 1993, 1997, and 2000, the number of households participating was 3,616, 3,441, 3,875, and 4,403, respectively.....(more)]	~200,000 (In case of MDS, approximately 5,000 clients for the period 2004/05 to 2006/07)	N/A (NSDUH is not comparable across all years back to 1971. The 2010 public use file contains 57,873 records due to a subsampling step used in the disclosure protection procedures.)
Other Demographic Data	Yes Examples include - Occupation; education; income; benefits (working household members); how daily time is spent; diet / nutrition status; marriages; birth preference; mass media and body images; household size and composition; living arrangements; care of children / elders; housing conditions; land ownership; household asset ownership (limited); detailed community economic, social, and demographic infrastructure data; GPS data.	Yes (Individual person (de-identified); multiple records per person - multiple admission/separation dates, including stays in progress (no separation date); limited postal code and municipality code information.)	Yes Survey questions include those on: history of moving residences; criminal record/traffic violations; perceived overall health; pregnancy history; hospital stay history; medical history; attitudes towards substance abuse; history of selling drugs; religious influences; social influences; attitudes towards parents; attitudes towards school; media exposure to alcohol/drugs; school/work policies on alcohol/drugs; and accessibility to substances.....(more)
Diagnosis Data	Yes These include: Clinical exams (limited) with blood pressure measurement; Disease history (all members - past 4 weeks); First menstruation (girls aged 9+); Eating disorders (girls age 12+); Physical measurements (all children). Regarding disease history data - symptoms, severity, duration of illness, and course of action are collected.	Yes; however, diagnostic information is not reliably coded. The MDS Assessment contains biopsychosocial and Activities of Daily Living (ADL) assessment information. This database can be used for health status analyses of such residents; for example, to assess changes over time in ADL, cognitive performance, functioning for independent activities of daily living (IADL), clinical characteristics, profile of risk, and falling.	Yes This survey collects information on substance use disorders, mental illness, and behavioral data. Data on medical history are also recorded.
Behavioral Data Elements	Yes These include: smoking, tobacco use, alcohol consumption, diet / nutrition intake measurements; physical activity, activities of daily living; birth control practices; drinking water, sanitation.	Yes (Where data are linkable)	Yes Data collected include: use of & cause for use of illicit drugs; alcohol, and tobacco; perceived risk by amount of substance use; attitudes towards danger/risk; driving habits; effect on home/school/social/work life & physical danger while using substances; encounters with police/court; coping behaviors; sleep; appetite; suicidality; time spent acquiring drugs; time & location of use of substance; attempt to set limits or stop use of substance.
Drug Data	Other (Data are only available for tobacco, tea, water, caffeine, alcohol, soft drinks, food consumption/use, and some price data on drugs.)	Yes (Drug prescription information is stored in the Nursing Home Drug Data housed at MCHP)	Yes The survey questions are specific to the use of illicit drugs (including non-medical use of prescription drugs), tobacco, and alcohol
Cost Data	Yes	Yes (Where data are linkable)	Yes
Linkage to Other Databases	No However, linkage occurs between CHNS waves to the Master longitudinal CHNS files	Yes Via identification numbers of both patients and physicians (encrypted to ensure confidentiality)	No

LIMITATIONS

This analysis was done using databases/registries currently profiled within B.R.I.D.G.E. TO DATA[®]. More profiles of healthcare data sources are continually being added to this resource.

CONCLUSION

Within 175 database profiles reviewed in B.R.I.D.G.E. (international resource of database profiles), physical function and symptoms are currently the most frequently collected PRO data types, while patient satisfaction with care, and global perceptions of health are least likely to be collected. Reporting PRO data has become increasingly important for healthcare; however, this study shows that only about a quarter of databases reviewed collect any PRO data. With increasing interest in these data, the likelihood is that this proportion will increase and the methods for collecting them may be instructive for database design.

Reference: 1. Fitzpatrick R, Davey C, Buxton MJ, Jones DR. Evaluating patient-based outcome measures for use in clinical trials. Health Technology Assessment. 1998;2:14.

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