

Toward a new generation of quality registries for neurodevelopmental disorders: the example of NEUROPSYK

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Abstract

Swedish healthcare quality registries are tools for the evaluation and improvement of clinical services and population-based research. There are presently 11 national quality registries that focus on psychiatric disorders; but none cover all neurodevelopmental disorders (NDDs) as defined by the *International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10)* and the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)*. Health care professionals have called for more user-friendly; time-saving; and clinically informative registers.

To fill this gap, the NEUROPSYK Quality Register was established in 2014 by the Center of Neurodevelopmental Disorders at Karolinska Institutet. Initially, this was a clinical register of child and adolescent psychiatry for the Stockholm County Council.

The main objectives of NEUROPSYK are to improve the assessment of and interventions used for individuals with NDDs by doing the following: 1) supporting adequate follow-up related to the implementation of existing regional and national guidelines for assessment and treatment; 2) providing clinical decision-making aids; and 3) conducting large-scale clinical epidemiological research. The registry incorporates all legal requirements for quality registries in Sweden.

NEUROPSYK includes patients of all ages diagnosed with NDDs per the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*. These diagnoses include autism spectrum disorder, attention-deficit/hyperactivity disorder, intellectual disabilities, communication disorders, specific learning disorders, and motor disorders. Medication and behavioral interventions are recorded and patient outcomes over time are measured with the economical and user-friendly Clinical Global Impression tool, the Global Assessment of Functioning instrument, and patient-reported health-related quality of life.

NEUROPSYK minimizes administrative work for health care professionals because it is integrated with structured digital patient records, thereby increasing the likelihood of high coverage and data quality. NEUROPSYK combines several strengths to exemplify a new generation of quality research registers for use in psychiatry and other areas of health care.

Keywords: Autism; ADHD; epidemiology; implementation; quality management; assessment; psychiatry; register; neurodevelopmental disorders

Read more about NEUROPSYK: <http://ki.se/en/kind/neuropsyk-quality-registry-for-neurodevelopmental-disorders>

Background

Approximately 10% of the general population is affected by neurodevelopmental disorders (NDDs) (1). Recently, NDD diagnoses have increased markedly in Sweden and elsewhere in the world, which has posed a challenge to many health care providers. For example, between 2001 and 2011, the prevalence of diagnosed autism spectrum disorder (ASD) increased 3.5-fold among Stockholm children

between the ages of 0 and 17 years (2). The increase in the prevalence of ASD without intellectual disability was almost 8-fold, from 0.14% to 1.10%. In addition, the prescription of methylphenidate for attention-deficit/hyperactivity disorder (ADHD) increased from 1.2% in 2006 to 4.6% in 2014 among males between the ages of 10 and 17 years (3). In Sweden in 2014, a total of 58,600 individuals with ADHD were treated pharmacologically (4).

Regional and national health care authorities in Sweden have generated clinical guidelines for the assessment and treatment of NDDs to improve evidence-based practice and comparable services across providers and regions (5-7). However, no systematic means have yet been implemented to determine whether recommended diagnostic and treatment procedures are followed, and individuals in the health care system are not being tracked across their NDD diagnoses, ages, and types of service providers. To achieve this goal locally, regionally, and nationally, data about health care, outcomes, and patient pathways are needed. One efficient strategy to use to obtain this is the implementation of healthcare quality registries (QRs).

QRs in Sweden serve as important tools for the evaluation and improvement of health care services, and they provide a primary data source for epidemiological and longitudinal research (8-10). QRs contain individualized information about patients' diagnoses, diagnostic assessments, medical interventions, treatment outcomes, and patient-reported outcome measures. In 2016, a total of 108 different national QRs were approved and

monitored by the Swedish Association of Local Authorities and Regions (11). Eleven of these QRs included psychiatric disorders. With the exception of children with ADHD, a majority of patients with NDDs are not included in the existing registries at all (Table 1). For example, individuals with ASD in the normative intelligence range are not yet included in current QRs, and there are no QRs to cover any language or speech disorders. Most current registers cover only certain NDD diagnoses (e.g., only ADHD), only patients referred to a specific type of organization (e.g., child and adolescent psychiatry), or only adults. Long-term follow-up of patients' pathways in health care is needed throughout childhood and adolescence and into adulthood. Information is needed from the different professions involved (e.g., pediatricians, neurologists, psychologists, speech therapists) as well as from different care units (e.g., pediatric units, habilitation centers, child- and adolescent psychiatry, speech therapy, adult psychiatry). Hence, there is a need to implement a registry that covers the full health care pathways and outcomes for patients with all NDDs across their lifetimes.

TABLE 1. Overview of quality registries that include patients with psychiatric disorders in Sweden

Registry name	Registry focus	Diagnoses included	Ages	No. of patients in registry (n)	Completeness (%)
Bipolär	Bipolar disorders	Bipolar disorders	All ages	8373	28%
BUSA	Attention-deficit/hyperactivity disorder	Attention-deficit/hyperactivity disorder and attention deficit disorder	All ages	5689	10%
ECT	Electroconvulsive therapy	Not specified	All ages	3664	89%
HabQ	Habilitation services	Cerebral palsy, autism (low functioning), and other not specified diagnoses	Children	Cerebral palsy, 569; autism, 345; others, 1120	No information
Kvalitetsstjärnan	Psychosis and schizophrenia	Psychosis and schizophrenia	Adults	3000/year	No information
NEUROPSYK	Neurodevelopmental disorders	Autism spectrum disorders, attention-deficit/hyperactivity disorder and attention deficit disorder, dyslexia, Tourette syndrome, stuttering, etc.	All ages	896	No information
PsykosR	Psychosis and schizophrenia	Psychosis	All ages	7923	23%
RIKSÄT	Eating disorders	Eating disorders	All ages	2600/year	90%
Rättpsyk	Forensic psychiatry	Not specified	Adults	1728	86%
SBR	Addictive behavior	Addiction (e.g., opiates)	Adults	4078	15%
SIBeR	Internet treatment	Depression, phobias, etc.	All ages	No information	No information
Q-BUP	Child and adolescent health care	All diagnoses	Children	0	0%

Information about the number of patients in each registry and the registry's completeness has been retrieved from that registry's annual report or from the National Board of Health and Welfare (Completeness 2015 - Comparisons between Swedish Healthcare Quality Registries and government-administered health registries)

Objectives

The NEUROPSYK Quality Register was established in 2014 by the Center of Neurodevelopmental Disorders at Karolinska Institutet, and it initially and formally considered a clinical register of child and adolescent psychiatry for Stockholm County Council. The register's objective is to collect data for all patients who receive diagnoses within the NDD categories of the DSM-5 regardless of service provider or age, in the country of Sweden (Table 2).

Current ICD-10 diagnoses are converted with the use of the recommended ICD-10 diagnosis synopses from the DSM-5. This includes ASD, ADHD, intellectual disabilities, communication disorders, specific learning disorders, and motor disorders (see Table 2). Due to the considerable comorbidity between these types of conditions and other psychiatric and somatic disorders, it is advantageous to include all NDD diagnoses and co-existing disorders in the same registry to enable follow-up for

all patients who are not included in other QRs at present. Service providers who are included or planned to be included are the following: child and

adolescent psychiatry, adult psychiatry, habilitation services, speech therapy providers, pediatric neurology and medicine, and clinical genetics.

TABLE 2. International Statistical Classification of Diseases and Related Health Problems; 10th Revision diagnoses included in NEUROPSYK

DSM-5 Category	ICD-10 diagnoses as defined in DSM-5	Other relevant ICD-10 diagnoses included
Intellectual disability	F70; F71; F72; F73; F79	
Communication disorders	F80.9; F80.0; F80.8	F98.5
Autism spectrum disorders	F84.0	F84.5; F84.1; F84.9
Attention-deficit/hyperactivity disorder	F90.2; F90.0; F90.1; F90.8; F90.9	
Learning disorders	F81.0; F81.1; F81.2	
Motor disorders	F82; F98.4; F95.2; F95.1; F95.0; F95.8; F95.9	
Other neurodevelopmental disorders	F88; F89	

DSM-5; Diagnostic and Statistical Manual of Mental Disorders; Fifth Edition Category

ICD-10; International Statistical Classification of Diseases and Related Health Problems; 10th Revision

Methods

Unlike traditional Swedish QRs, NEUROPSYK is integrated with patient medical records and requires minimal administrative work for health care professionals. This curtails any unnecessary workload and increases the likelihood of both high coverage of the target population and data validity. For all consenting patients, a limited number of essential and informative health measures are retrieved automatically. This allows for an accessible system that requires minimal administration. NEUROPSYK was first implemented in the largest Swedish county (Stockholm) through integration with the medical record software “Take Care,” which is used by both private and county council managed care units. Every 24 hours, data for the chosen variables are retrieved from the patient record database and sent via a secure health care connection to the registry platform, where they are saved and can be used for feedback to care providers on different levels. For example, service management can easily access online statistics related to resources used, treatments administered, and improvement in global functioning and quality of life over time for different patient groups.

In addition to information about the patient (e.g., personal identity number, ICD-10 diagnosis), the registry includes data about each episode of patient contact with the care provider, including the following: the date of each visit, the profession(s) involved in the care (e.g., physician, psychologist, social worker, special education teacher), and the type of visit (e.g., home visit, group treatment, individual consultation) (Table 3). In addition, the registry includes information about what pharmacological treatments were prescribed (ATC codes) and the defined daily dose. Other treatments and interventions are coded using the Swedish classification of health interventions (i.e., the KVÅ

code, which may refer to neuropsychiatric assessment, cognitive behavioral treatment, or patient education in a group). Process measures (e.g., medications, types of behavioral intervention), outcome measures (e.g., Clinical Global Impression, Global Assessment of Functioning), and patient reported data (e.g., EQ-5D/DISABKIDS) are included.

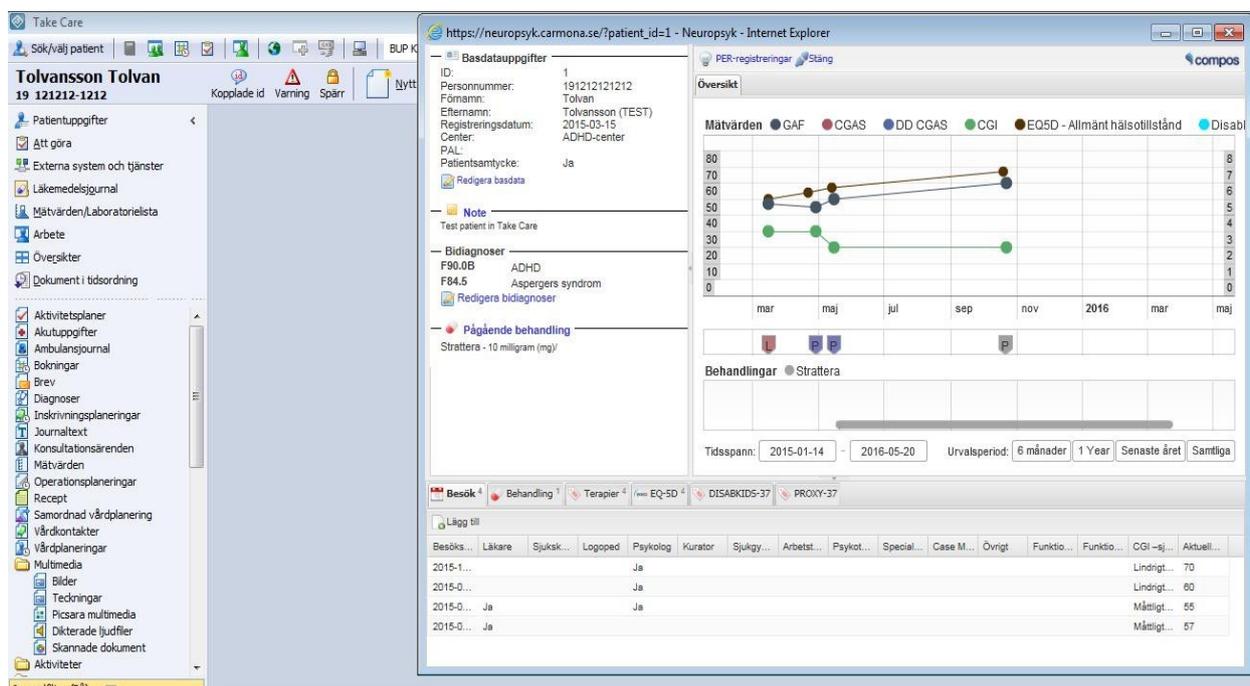
NEUROPSYK also provides patient overviews, which are useful for clinical routines and easily accessible from the medical record through a single sign-on for authentication. The overview includes the patient’s diagnoses as well as his or her current health status (i.e., Global Assessment of Functioning), quality of life (i.e., EQ-5D/DISABKIDS), medications, interventions, and health care contacts over time (Figure 1). The patient overview can be used to plan and follow up on interventions for the patient.

NEUROPSYK can also be used for register-based research, provided that ethical approval is obtained for a specified research project and that the registry board has accepted the project. In principle, any researcher can access NEUROPSYK, and the same roles apply as for any Swedish QR. For example, the registry can be used to study characteristics of outpatients diagnosed with NDDs (e.g., trajectories, comorbidities, functioning, disability pension, quality of life). Furthermore, studies of the transition from child and adolescent health care to adult health care for persons with NDDs and adherence to clinical guidelines can be performed. Studies of the effects of perinatal and other environmental factors on NDDs can occur with the use of information from other QRs and national health statistics.

TABLE 3. Data retrieved from patient records in NEUROPSYK

Variable	Description
Patient identification and diagnosis	
Personal identity number	Unique 10-digit number including information about birthday (YYMMDD) and sex (male/female)
International Statistical Classification of Diseases and Related Health Problems, 10th Revision diagnosis	Primary and additional diagnoses
Care provider–related information	
County	County where the caregiver is located
Health care unit/department	Caregiver unit unique identity number
Type of visit	Home visit, group treatment, telephone contact, etc.
Visit date/contact date	All types of visits or contacts (consultations, home visits, phone calls, etc.)
Number of professionals meeting patient	Maximum of 5 professionals per visit
Professions involved in the consultation	Type of professions involved in patients' care (e.g., physician, psychologist, occupational therapist, social worker, special education teacher, speech therapist)
Treatment and interventions	
Anatomic Therapeutic Chemical classification system (ATC code)	Pharmacological treatment
Defined daily dose (DDD)	Amount of each medication taken each day
Klassifikation av vårdåtgärder code (KVÅ code)	Swedish classification of health and medical interventions
Clinician-rated measures	
Global Assessment of Functioning (GAF)	Assessment of functioning for adults
Children's Global Assessment Scale (CGAS)	Assessment of functioning for children 0 to 18 years old
Children's Global Assessment Scale for Developmental Disabilities (DD-CGAS)	Assessment of functioning for children 0 to 18 years old
Clinical Global Impression-Severity (CGI-S)	Severity of the condition
Patient reported measures	
EQ-5D	Self-reported health-related quality of life for adults
DISABKIDS	Proxy or self-reported health-related quality of life for children and adolescents

FIGURE 1. Patient overview



The variables in the registry were selected on the basis of current clinical guidelines and in response to the consensus of a reference group. The reference

group consisted of 20 clinicians, stakeholders, and registry and information technology experts as well as policy makers (e.g., psychiatrists, pediatricians,

psychologists, speech therapists, researchers, managers, health care officials, experts on quality registries and information technology). The process started in 2011, with four reference group meetings held to discuss aims, variables, and technological solutions. Further discussions were held in smaller working groups, and a board consisting of 12 members was formed. The NEUROPSYK board has representatives from health care (i.e., child and adolescent psychiatry, adult psychiatry, pediatric units, habilitation centers, speech therapy, and school nurses), research (i.e., psychiatrists, pediatricians, and psychologists), information technology experts, and non-governmental organizations. The register adheres to all legislative requirements for national QRs in Sweden, which are mainly delineated in the Swedish Patient Data Act. NEUROPSYK is a formally approved care register of the Stockholm County Council, and it has also been accepted by the Swedish Association of Local Authorities and Regions.

Pilot project

Starting in 2013, five care units participated in the development of registry routines and technological solutions. In 2015, the registry was integrated with the medical record system in Sweden's largest county (Stockholm), and the QR was used by five pilot units as a regional system. The development process was done in close collaboration with each of the five public and private health service representatives and providers, interested organizations, and existing psychiatric registries in Stockholm County Council and beyond (e.g., BUSA, a national quality registry for structured follow-ups of patients with ADHD both children and adults; see Table 1). The development of the registry was guided by legal experts from the Stockholm County Council to ensure compliance with the legal requirements related to patient rights and data safety.

The pilot use of this registry was an iterative process that involved technicians, multi-professional clinicians from various departments, and researchers. The following objectives were kept in mind: 1) to optimize information technology and connect to the electronic clinical file system in clinical reality; 2) to enhance user feasibility; 3) to generate automatic informative statistics and reports for clinicians; 4) to collect experiences with the adequate implementation of the register into existing clinical routines; 5) to encounter and solve user reservations; and 6) to examine the use of the registry in terms of clinical and research utility and validity.

NEUROPSYK is currently operating as a regional quality registry in Stockholm County so that its feasibility can be examined; the eventual goal is to

implement it as a national QR. As of October 2016, NEUROPSYK contained more than 1000 patients with NDDs who were enrolled from 13 different units.

Future plans and developments

An evaluation of the pilot project is planned that will focus on validation, data quality, and the user experience. Another objective is to develop a way for this system to integrate with the national platform, with the goal of transferring data from patient record systems all over Sweden into NEUROPSYK. The recruitment of care providers from all over Sweden as well as the training of clinicians in how to assess global functioning is ongoing. A long-term goal is to collect more data regarding which diagnosis-specific standardized instruments are most often used by clinicians. We are continuously lobbying for structured variables to be created by the county councils for this purpose.

Feedback from patients and their family members is invaluable to improve quality of care. In NEUROPSYK, web-based questionnaires assess patient-reported outcome measures related to health status, quality of life, and satisfaction with care via a home computer or a tablet in a health care waiting room. Outcomes of patient-reported measures can be used for planning, treatment, and follow-up before, during, and after consultations. However, the collection of patient-reported measures has not been implemented in most of the participating care providers; this is planned for the future.

Conclusions

QRs in Sweden are unique resources to improve the quality of healthcare and to provide large amounts of data for epidemiological research. Despite these benefits, QRs have been criticized for increasing administrative work for health care professionals. Managers and health care recipients have called for more user-friendly and time-saving systems for following up on the quality of care received. As a result, a new generation of QRs with a higher degree of integration with patients' medical records is emerging. NEUROPSYK is an example of the next generation of QRs, and it has been developed with the aim of providing an efficient tool for the improvement of health care. NEUROPSYK includes real-time follow-up evaluations of health care interventions; this differs from traditional QRs, which record patient responses via separate web-based forms that may be separated from the health care experience being assessed by weeks or months. With the use of real-time information related to actual treatment pathways for these patients, improved collaboration among different health care

units and professions can be achieved and may result in reduced waiting times, the earlier discovery of NDDs, and earlier intervention. The continuous collection of relevant clinical data from both public and private providers will also make it possible for health care authorities and politicians to optimize health care by allowing for the more effective allocation of resources to the care of children with NDDs and their families.

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Conflict of Interest statement/disclosure

None of the authors reports a direct conflict of interest related to this article. Bölte discloses that he has, in the last 5 years, acted as an author, consultant, or lecturer for Shire, Medice, Roche, Eli Lilly, Prima Psychiatry, GLGroup, System Analytic, Kompetento, Expo Medica, and Prophase. He receives royalties for textbooks and diagnostic tools from Huber/Hogrefe, Kohlhammer, and UTB. Borg has received compensation as a member of the scientific advisory board of Astra Zeneca.

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