



Register data in the evaluation and program planning of addiction treatment programs: Using Sweden as an example



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ABSTRACT

Data from large-scale registers is often underutilized when evaluating addiction treatment programs. Since many programs collect register data regarding clients and interventions, there is a potential to make greater use of such records for program evaluation. The purpose of this article is to discuss the value of using large-scale registers in the evaluation and program planning of addiction treatment systems and programs. Sweden is used as an example of a country where register data is both available and is starting to be used in national evaluation and program planning efforts.

The article focuses on possibilities, limitations and practicalities when using large-scale register data to conduct evaluations and program planning of addiction treatment programs. Main conclusions are that using register data for evaluation provides large amounts of data at low cost, limitations associated to the use of register data may be handled statistically, register data can answer important questions in planning of addiction treatment programs, and more accurate measures are needed to account for the diversity of client populations.

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1. Introduction

Evaluation of addiction treatment programs are often based on primary data collected during the evaluation process. Such program evaluations usually utilize data collection methods and data sources similar to those used in conventional social science research (Fitzgerald, 1998; Fitzpatrick, Sanders, & Worthen, 2004; Posavac & Carey, 2007; Royse, Thyer, & Padgett, 2009) with randomized controlled clinical trials or quasi-experimental study designs, utilizing standardized instruments and client interviews and document studies (Coleman-Cowger, Dennis, Funk, Godley, & Lennox, 2013; Jensen, Cushing, Aylward, Craig, Sorell, & Steele, 2011; Miller, Forcehimes, & Zweben, 2011; Spirito et al., 2011; Wong et al., 2011). Data on costs are sometimes included to evaluate the economic efficiency of programs or interventions (French, Fang, & Fretz, 2010; Yakshina, 2011) or observational data are collected to provide information regarding the “culture” of a

program (Ehrmin, 2005; Winkelmann, 2003). However, what has been used to a lesser extent, when evaluating addiction treatment programs, is data from existing large-scale registers (either alone or in combination by merging different government registry data bases) or data from management information systems (MIS).

Addiction treatment programs in Sweden are managed by a range of national, regional or local governments, private institutions and individual organizations. Usually these programs, collect register data regarding their clients and interventions, hence there is a potential to make greater use of such records for program evaluation. The focus of this article is to discuss the value of using large-scale registers in the evaluation and program planning of addiction treatment systems and programs. The approaches described here are also applicable to the evaluation of other services where large-scale register data is available.

The article will focus on Sweden as an example of a country where register data is both available and is starting to be used in national evaluation and program planning efforts. In addition, discussion of possibilities, limitations and practicalities when using large-scale register data to conduct evaluations and program planning of addiction treatment programs, in Sweden as well as in other countries is provided.

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The article is organized as follows: The first section provides a brief description of national registers available in Sweden. The second section is followed by a brief overview of prior human services research in Sweden using large-scale registers in the evaluation and program planning; specifically addiction treatment programs. The third section describes advantages and limitations when using large-scale registers in evaluation of addiction treatment programs, with suggestions as to how to respond to such limitations. The final section provides key conclusions.

2. Registers available for evaluation and program planning efforts in Sweden

In Sweden there are a large number of national-level registers in several areas such as: population demographics, education, health, welfare, social services, social insurance, compulsory care, employment, national security, accidents, occupations, working environment, retirement, criminal justice, traffic, housing, income, wealth, living conditions, real estate, enterprise, research, military service and elections. Some registers are used to produce official statistics, others are not. These registers contain specific data about individual citizens that can be used in evaluation and research. Further, many of these registers can be merged with other registers and data sources if data sharing agreements are in place to protect client confidentiality.

These registers are based on national, regional and local authorities' activities, such as the National Employment Agency, the Higher Education Authority and the National Board of Health and Welfare. A number of the authorities' registers are kept and provided by Statistics Sweden, which is a national authority. Due to operative, administrative or similar reasons, some registers are handled by the authorities themselves including the police registry managed by the Police Authority and healthcare registers administered by the National Board of Health and Welfare (NBHW). The latter are, for example, responsible for more than 100 national quality registers with data on health care within certain areas such as cancer, fractures, stroke and prenatal care (*The National Board of Health and Welfare (Socialstyrelsen), 2014*).

In general, the healthcare registers are used for quality improvement, for outcomes assessment following delivery of treatments, interventions or programs, and for research within the health care sector, however less often with respect to treatment for substance use disorders. The information in these registers is protected according to the *Public Access to Information and Secrecy Act* (Swedish code of statutes 2009:400). However, some authorities, such as NBHW and Statistics Sweden, may disclose data from their registers for research purposes, through a written agreement for researchers wishing to access the information through an exception to the absolute secrecy in the Public Access to Information and Secrecy Act. Within NBHW there is a service function, Registry service, where researchers who plan to conduct research on the registry can find support. Other national authorities have similar service functions.

A prerequisite for providing the data is that research is approved by one of the six regional ethical review boards according to *The Ethical Review Act*, (Swedish code of statutes 2003:460). The Ethical Review Act requires review of research protocols that utilize data, specimens and other media (e.g., photographs) from human subjects which may be highly sensitive (e.g., personal information concerning offenses against the law).

3. Prior studies on the use of large-scale registers in evaluation and program planning in Sweden

There is a vast body of evaluation studies in Sweden based on large-scale data registers, primarily in medicine, and including

epidemiology (e.g. Bergman, Olsson, Carlsten, Waern, & Fastbom, 2007; Johnell & Fastbom, 2008; Johnell, Weitoft, & Fastbom, 2009; Lazarinis, Kärrholm, & Hailer, 2011) and psychiatry (e.g. Björkenstam, Ljung, Burström, Mittendorfer-Rutz, Hallqvist, & Weitoft, 2012; MacCabe et al., 2010; Tidemalm, Waern, Stefansson, Elofsson, & Runeson, 2008; Wahlbeck, Westman, Nordentoft, Gissler, & Laursen, 2011). There are somewhat fewer evaluations and research on utilization of addiction treatment programs based on large-scale registers, however, in recent years there are significantly more studies being conducted with these data (see for example, K. Armelius & B.Å. Armelius, 2010; B.Å. Armelius & K. Armelius, 2011; Ericsson, Bradvik, & Hakansson, 2014; Gerdner, 2004; Grahn, Chassler, & Lundgren, 2014; Hakansson & Berglund, 2013; Hakansson, Schlyter, & Berglund, 2008, 2011; Larsson & Leiniö, 2012; Lundgren et al., 2012, 2013, 2014; Blom-Nilsson, Lundgren, & Chassler, 2014; Rognli, Håkansson, Berge, & Bramness, 2014; Storbjörk & Room, 2008).

As the articles presented in this special issue illustrate, register-based studies of addiction treatment programs, generally focus on long-term results, retention, recidivism, relapse, attrition, criminality and mortality (e.g., Ahacic, Damström-Thakker, & Kåreholt, 2011; Bukten, Skurtveit, Waal, & Clausen, 2014; Chen, Wu, Su, Chou, & Lin, 2010; Gjestad, Franck, Lindberg, & Haver, 2011; Grahn et al., 2014; Huang et al., 2011; McCowan, Kidd, & Fahey, 2009; Padyab, Grahn, & Lundgren, 2015; Soyka et al., 2012). Literature specifically focusing on methodological issues when using large-scale registers in research and evaluation is less common (Thygesen & Ersbøll, 2014). However some studies in the field of evaluation of addiction treatment have paid extra attention to such methodological questions (e.g. Simon, 2012; Xiao et al., 2011). This article intends to contribute to this field by discussing the benefits, limitations and considerations when using register data in evaluation and program planning of addiction treatment programs.

Prior research points at possibilities as well as limitations when using large-scale registers in human services studies. Swedish and Scandinavian studies about the use of large-scale registers for human services address aspects such as: the strength of studying entire populations (Gliksch & Dreyer, 2007; Olsen et al., 2010; Thygesen & Ersbøll, 2014) to ensure adequate coverage and generalizability (Neovius et al., 2011) as well as the importance of the content, quality and completeness of the information collected to ensure reliability and validity of the measurements (Djurhuus, Skytthe, & Faber, 2010; Gliksch & Dreyer, 2007; Sund, 2012). In the subsequent sections we present a summary of advantages and limitations of using register data based on previous research combined with our own experiences within this area.

4. Advantages and limitations when using large-scale registers in evaluation and program planning of addiction treatment programs

The pros and cons of using large-scale registers have been known within epidemiological research for some time. The discussion in the two following sections is based on a summary by the Danish epidemiologists Thygesen and Ersbøll (2014), which we have adapted and expanded to the evaluation of addiction treatment programs.

4.1. Advantages of register-based data in evaluation/program planning

There are a number of advantages in using register-based data in the evaluation of addiction treatment programs. One of the main advantages of using register data for evaluation purposes is that the register provides large amounts of data at low cost since data

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