

Harm to Others from Substance Use and Abuse: The Underused Potential in Nationwide Registers



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Supplementary Issue: Harm to Others from Substance Use and Abuse

ABSTRACT: This article considers the potential in using nationwide registers to study harm to others from substance use and abuse. The advantages of using registry data include the opportunity to include the data on the entire population nationwide and continuously updated longitudinal datasets; they allow for studying small subpopulations and have little missing data. Personal identification numbers and family numbers enable linkage of data from different registers. Such datasets can include extensive information on individual and family levels. In this article, we provide an introduction to nationwide registers and explain how they can be applied to investigate two types of third-party harms: harm to children and harm to partners/spouses from substance use and abuse in parents and partners/spouses. Finally, we discuss challenges, benefits, and ethical considerations regarding the use of such data.

KEYWORDS: harm to others, nationwide registers, substance use and abuse, children, partners, cohort

SUPPLEMENT: Harm to Others from Substance Use and Abuse

CITATION: Lund and Bukten. Harm to Others from Substance Use and Abuse: The Underused Potential in Nationwide Registers. *Substance Abuse: Research and Treatment* 2015;9(S2) 33–38 doi: 10.4137/SART.S23545.

TYPE: Methodology

RECEIVED: June 29, 2015. **RESUBMITTED:** September 16, 2015. **ACCEPTED FOR PUBLICATION:** September 18, 2015.

ACADEMIC EDITOR: Gregory Stuart, Editor in Chief

PEER REVIEW: Four peer reviewers contributed to the peer review report. Reviewers' reports totaled 1,075 words, excluding any confidential comments to the academic editor.

FUNDING: Authors disclose no funding sources.

COMPETING INTERESTS: Authors disclose no potential conflicts of interest.

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Background

Substance use and abuse contribute not only to harm to the user but also to third parties. Current estimates of the prevalence and extent of harm to others from substance use and abuse may be unreliable partly because persons with substance use problems are less likely to respond to surveys.¹ Nationwide registers provide a unique opportunity to study harm to others from substance use and abuse that can contribute to more reliable estimates of the prevalence and extent of such harms. Registry data enable studying the entire populations for long periods of time; they often include large samples and are therefore well suited to study small patient groups and rare outcomes. Despite these advantages, registry data are rarely used to study harm to others from substance use and abuse. We aim to provide information that make more researchers aware of the possibilities with registry data, alone or in combination with survey data, to answer research questions on this topic in both clinical and general populations. We describe relevant registers and how they can be applied to investigate two types of third-party harm: (1) harm to children from *in utero* exposure to substances^{2,3} and from growing up with parents who use or abuse legal and/or illegal substances^{4,5} and (2) harm to spouses/partners. We also discuss challenges, benefits, and ethical considerations regarding the use of such data. It is beyond the scope of this article to cover how all

registers available across countries can be used to study harm to others from substance use and abuse. Instead, we use the Norwegian setting as an example of how nationwide registers can be applied to address such research questions. However, we also refer to examples from other countries.

Norway and several other countries use nationwide registers for administrative and statistical purposes. All individuals living in these countries leave traces in these registers during their life span. For instance, information on education is included in the educational registers and employment in the employment registers. Information on birth, marriage, divorce, migration, and death is included in the national registers,⁶ and information on physical and mental health is recorded in registers on primary and specialist health care.

While Norway and the other Nordic countries have a strong tradition in conducting registry-based research in general, there exist only a few examples of registry studies on harm to others from substance use and abuse. For instance, a Finnish study investigated whether children of mothers with substance abuse problems were hospitalized because of injury or illness more often than children whose mothers did not have substance abuse problems.⁴ The study was a population-based cohort study that used health care and social welfare registers. All children born in Finland in 1998–2009 and their mothers were included in the study, resulting in the information on



>50,000 pairs of mothers and children. The results showed that children born to mothers with substance abuse problems were hospitalized more often due to injuries and infectious diseases and were more often placed out of home.⁴ The association between maternal prescription opioid use and use of prescription opioids among their adolescent children was studied using the data from Statistics Norway and the Norwegian Prescription Database (NorPD). Almost 100,000 adolescents and their mothers were included in the study, and the results showed an association between maternal use of opioid analgesics and repeated use in their adolescent children.⁷

A common aspect of the abovementioned examples is that they are based on clinical populations, ie, only cases with problematic substance use are recorded in the registers: persons who have been in contact with either primary or specialist health care for the treatment of substance use problems and persons using prescription drugs with abuse potential. Substance use beyond that which results in treatment is not registered except from in Birth Registries, which include information on maternal substance use during pregnancy. One way to avoid this shortcoming is by combining the information from large population-based surveys, where respondents have provided their personal identification number (PIN) and consent for linkage of survey and registry data with registry data. Examples of such studies are the Nord-Trøndelag Health Survey (HUNT)^{8,9} and the Norwegian Mother and Child Cohort Study.¹⁰ Health surveys and other population surveys typically ask questions about frequency and quantity of substance use and allow for investigating harm from others substance use also in the general population.

Norwegian Setting as an Example

Linking data on individual and family levels. All Norwegian residents are assigned a unique PIN. The PIN enable the linkage of information on the individual level between several registers and survey data that include information on education, marital status, employment, physical and health, and crime. Similarly, unique family numbers enable the linkage of information between family members, such as information between parents and their children, between siblings, and between partners/spouses.

Studying harm to others from substance use and abuse using only information from registers. When using only registers to study harm to others from substance use, the study population is usually clinical populations, such as persons in treatment for alcohol or drug use disorders or persons who are dispensed prescription drugs with abuse potential.^{2,7,11} For example, several government registers were used to investigate the effect of parental alcohol abuse on children during the formative years.¹¹ Parental alcohol abuse was associated with children experiencing parental violence, family separation, and being placed in foster care and with several negative long-term outcomes, such as self-destructive behaviors, increased risk of unemployment, teenage pregnancy, and hospitalization due

to violence.¹¹ In another study, information from the Swedish Medical Birth Registry was used to study the association between the maternal use of benzodiazepines and/or benzodiazepine receptor agonists during pregnancy and neonatal outcomes and congenital malformations in children. The results showed that children born to mothers who had used these drugs were at increased risk of preterm birth and low birth weight, but the drugs did not seem to have strong teratogenic potential.¹² To study the mortality in infants born to women using methadone during pregnancy, an Australian study used probabilistic record linkage of three New South Wales registers: the Registry of Births, Deaths and Marriages; the client database from the Pharmaceutical Drugs of Addiction System; and the Midwives Data Collection.¹³ Linkage was possible through the use of name, address, and hospital numbers. The data were deidentified before the researchers received the data, but separate unit record files with a project number were created to allow for remerging. The study showed that infant mortality was higher among infants whose mothers used methadone during pregnancy compared with the infants of all other mothers. This example shows that there are possibilities for registry linkage also in countries without PIN and family numbers.

While studies addressing substance use and abuse, using the register-only approach, usually only identify clinical populations, some exceptions exist. For instance, the use and abuse of prescription drugs with abuse potential can be identified in national prescription databases, and information can be used to investigate the use of prescription drugs with abuse potential among adults and outcomes in their children and partners. A study using information from Statistics Norway and the NorPD showed that the repeated use of opioid analgesics among mothers contributed to the increased risk of their children also becoming repeated users of opioid analgesics.⁷ Similarly, using information from the Medical Birth Registry of Norway (MBRN) and the NorPD, another study showed that parents' previous use of hypnotics was associated with the chance that children who were less than three years old were dispensed with the hypnotic alimemazine.¹⁴

Studying harm to others from substance use and abuse using information from both registers and surveys. For studies that investigate harm to others from substance use and abuse in the general population, combining survey and registry data may be a useful approach. Some population and health surveys ask respondents to provide their PIN and permission for linking information from surveys and registers. Some of these surveys include questions on tobacco, alcohol, and illegal drug use, which would otherwise be difficult to identify among persons not in treatment for a substance use problem, and information about their substance use, therefore, would not be included in nationwide registers. Apart from some notable exceptions, few use the possibility with the linkage of information from surveys and registers to study harm to others from substance use and abuse. One such exception is a study



of the association between adolescent alcohol use and future disability pension. In this 39-year follow-up study of about 50,000 men conscripted for military service in 1969–1970,¹⁵ the respondents completed the questionnaires that included information on family and social background; school performance; health, mental, and behavioral factors; and tobacco, alcohol, and illegal drug use. Recipients of disability pensions were identified using the National Social Insurance Board and the Longitudinal Registry of Education and Labor Market Statistics. The results showed that alcohol use in adolescence, particularly risk use, was associated with the increased risk of becoming the recipients of disability pension.¹⁵ In this study, father's drinking behavior was only used as one of several covariates. Nevertheless, it provides an example of how information from surveys and registers can be linked to study harm to others from substance use and abuse. The approach has also been applied to study other types of third-party harm. For example, to study the association between parental mental health problems and children's dependence on public welfare in young adulthood, youth-health survey data were linked with registry data from Statistics Norway and the Norwegian Social Insurance Administration Registers. The results suggest that exposure to parental mental health problems increases the adolescents' risk of becoming welfare recipients in young adulthood, but that perceived social support from others can be a protective factor.¹⁶

Relevant registers for studying harm to others from substance use and abuse. *The Medical Birth Registry of Norway.* The Medical Birth Registry of Norway (MBRN) includes information on all births in Norway since 1967.¹⁷ It is based on compulsory notification on all births and late abortions from 12 weeks of gestation and includes information on the mothers' health before and during the pregnancy, complications during pregnancy or birth, such as the use of prescription drugs during pregnancy, complications at or after birth, and diagnoses or malformations in the child. If the mother provides it then information on the mother's and father's occupation and smoking and drinking habits are registered. Information is registered in a separate form during the routine visits of general practitioners and midwives during pregnancy, and the pregnant woman brings the form with her to the hospital where she is giving birth. The midwife registers additional information about the birth, and other relevant information is included until the baby is discharged from the hospital. From 1998 and onward, data have also included information on congenital conditions for infants transferred to neonatal wards after birth.

The Norwegian Prescription Database. The Norwegian Prescription Database (NorPD) includes information on prescription drugs dispensed at pharmacies to all individuals in Norway not living at an institution.¹⁸ The database includes information from 2004 and onward and is updated on a monthly basis. The database includes detailed information on the patient, the prescriber, the prescribed prescription drug,

and the pharmacy where it is dispensed. The following information is available about the patient: PIN, month and year of birth, gender, and residence (municipality and county). For the prescriber, the registry information includes prescriber ID, year of birth, gender, profession (medical doctor, dentist, etc.), and prescriber specialization if the prescriber is a medical doctor. For the dispensed prescription drugs, the following information is recorded: prescription ID, date of dispense, number of packages dispensed, price, and defined daily doses (DDD) dispensed. The DDD is the assumed average maintenance dose used for an adult person for the main indication of drugs.¹⁹ Prescription drugs are recorded according to the Anatomical Therapeutic Chemical classification system at five levels: anatomic main group, therapeutic main group, therapeutic subgroup, chemical therapeutic subgroup, and chemical substance.¹⁹ Registered information about the pharmacy where the prescription drug is dispensed includes county number and name, municipality number and name, and pharmacy number and name.

The Norwegian Patient Registry. The Norwegian Patient Registry (NPR) was established in 1997.²⁰ From 2008, information has been registered on the individual level. The registry has several purposes, including contributing to research. Information on admission to hospitals and treatment in specialist health care is registered in the NPR. The registry includes codes for the International Classification of Diseases (ICD 10). With regard to harm to others from substance use and abuse, information on mental and behavioral disorders and injuries is of particular interest. Information on what type of treatment people in specialist health care receive is also included, as is information on where and for how long they receive treatment.

The KUHR Database. The KUHR database (control and reimbursement to practitioners in primary health care for seeing and treating patients) includes information on the main reason for contact with a general practitioner in primary health care.²¹ Codes for International Classification of Primary Care (ICPC) and information on which diagnoses are the cause of contact with primary health care and date of the visit are included. Harm to others from substance use and abuse and ICPC codes for mental health problems, injuries, and social problems are of particular interest. Examples of social problems include relationship problems with partner or parents and partners' or parents' behavioral problems. In addition to ICPC codes, ID, age, and municipality number of the patients are registered. For the reporting person or unit, the following information is registered: ID, type of business/profession, and municipality number. For treatment, the following information is registered: the time of treatment and fares for completed treatment, which offer information on what type of treatment the patient received.

The Norwegian Cause of Death Registry. The Norwegian Cause of Death Registry includes information about persons



who, at the time of death, are located in Norway and persons registered as living in Norway who die while abroad.²² The aim of the registry is to follow trends in the causes of death over time. For instance, it allows for monitoring whether death by suicide increases or decreases over time. All deaths in Norway must be reported to the Cause of Death Registry. Medical doctors write the death certificates and are obliged by law to send information on cause of death to the registry. Information is then processed and encoded according to ICD. The registry includes information about ID, gender, age, municipality of residence, and cause and place of death. For the cause of death, special circumstances, such as suicide, drug-related problem, and murder, are included. If an injury caused the death, information about where (eg, nursing home, school, and sports arena) the injury occurred and what activity (eg, sport or work) caused the injury are included. In cases with an autopsy, details from the autopsy are included.²²

The Norwegian Social Insurance Administration Registers (FD trygd). The Norwegian Social Insurance Administration Registers (FD trygd) include information on sickness absence, disability pension, unemployment, social welfare, marital status, number of births, and single provider benefits.²³ The data allow for calculating the amount of benefits received within a certain time period. Information has been registered on individual level since 1992 and is continuously updated.

Statistics Norway. Statistics Norway administers several registers with extensive information on socioeconomic conditions, such as detailed information on education and employment. The National Registry enables the linking of data between family members. This allows for studying how substance use or abuse of one family member may affect other family members over time. Statistics Norway also administers data from child protective services.²⁴

The Norwegian Police Registers. The Norwegian police registry includes information on all registered criminal cases, such as information on identified offenders, and forms the basis of the official Norwegian crime statistics. The registry includes information from all the Norwegian police districts from 1992 and onward. The Norwegian crime registry is based on individual codes for every offense²⁵ and includes >600 different codes.²⁶ The crime codes include information on both the offense in question and corresponding paragraphs of the Penal Law. The registry provides data on four prosecuting decisions: formal charge leading to conviction, formal charge leading to acquittal, fines, and other. Convictions are decisions where a person is found guilty of a crime in the court of law.²⁶ Every single offense committed at one particular occasion is registered separately²⁶; the same person can, therefore, be registered with several convictions during a single day. For instance, the same individual can be convicted both for driving under the influence and for stealing a car.

The Norwegian Prison Registry. The Norwegian Prison Registry was founded in 1992 and is administered by the

Correctional Service of Norway.²⁷ The registry include extensive data on persons who have been imprisoned in Norway, including age, gender, convictions and sentences, and the actual time spent in prison, both for persons detained on remand and for those who are convicted.

Studying harm to children and partners from substance use and abuse using registry data. In this article, we have limited third parties to children and partners experiencing harm from substance use and abuse in parents and spouses/partners, respectively. Next, we describe in more detail how registry data can be used to study such third-party harm.

Harm to children from in utero exposure to maternal substance use and abuse. The MBRN can be used to identify harm to children from *in utero* exposure to substance use and abuse. To study the short-term neonatal outcomes from *in utero* exposure to substance use and abuse, medical birth registers can be used, either alone or in combination with other registers and/or surveys. For instance, to study the association between maternal cigarette smoking and risk of stillbirth and death in the first year of life, a Danish study combined survey data and data from the Danish Medical Birth Registry.²⁸ The results showed that exposure to tobacco smoke *in utero* increased the risk of stillbirth, and infant mortality was almost twice as high in children born to mothers who smoked during pregnancy. To investigate long-term outcomes from *in utero* exposure to maternal substance use and abuse, information from the Medical Birth Registry must be linked with information from other registers or/and surveys. For instance, the KUHR, the NPR, and the NorPD can be used to identify if *in utero* exposure to, for example, alcohol, tobacco smoking, or prescribed opioid painkillers increases the risk of diseases, infections, or concentration problems. Other registers can be used to examine if *in utero* exposure to different substances increases the risk of poor performance in school and not completing school (education database), being unemployed (Statistics Norway and FD trygd), criminal behavior (the Norwegian police and prison registers), and premature death (the Cause of Death Registry).

Harm to children from growing up with parental substance use and abuse. Harm to children from growing up with parental substance abuse can be studied using the registry data alone or in combination with survey data. Parents in treatment for substance use problems can be identified through one or more registers, such as the NPR and the NorPD. The database on primary health care may also be used to identify parents with substance use problems.

Information from the NPR, the KUHR, and the NorPD can be used to study the mental health and substance use problems in adolescents and young adults. Taken together, these registers identify contact with, and treatment in, primary health care, specialist health care, and medicinal treatment for mental health and/or substance use problems. Information from registers can also identify if parental substance use or abuse is associated with the increased risk of injuries in their

children. Poor academic performance and dropout of school and unemployment can be studied using the education registry and FD trygd, respectively.²⁹ Data on child welfare can be obtained from Statistics Norway and allow for studying whether children who grow up with parental substance use or abuse are at increased risk of being placed in foster care. Information from the crime registry can be used to identify whether children who grow up with parental substance use/abuse are at increased risk of being charged or convicted for criminal acts. Finally, through the Cause of Death Registry, it is possible to identify if children who grow up with parents with substance use problems are at increased risk of dying at a young age by suicide, from overdose, or by accidents. For example, results from a study that used several government registers showed an association between parental substance abuse and attempted suicide among children as that in young adults.^{11,30}

Harm to partners from substance use and abuse. The registers also enable studying harm to spouses/partners from substance use and abuse. Registry data alone or in combination with survey data can be used to investigate the association between the substance use or abuse of spouses/partners and the risk of mental health problems, physical injuries, and unemployment both in clinical subgroups and in the general population. One way to study this in the general population is by linking information in registers with information in surveys, which includes information about the respondent's substance use. For instance, a study that compared the effect of divorce on mental health in heavy-drinking and lower consuming couples used PIN and family numbers to identify the couples/spouses.³¹ Using information from two waves of the HUNT, the study showed that divorce affected the couples with at least one heavy drinker more than the couples with a low consumption. Other studies could apply the approach described above to identify the couples but could get more detailed and continuously updated information on mental health and other outcomes over time, using information in registers. The rich information available in linked datasets also allows for controlling for moderating, mediating, and confounding factors, such as parental mental health and social inequality.

Challenges and benefits with studying harm to others from substance use and abuse using registers. Using information from registers for research purposes is not without challenges. For instance, changes in how information is entered into the registers can cause gaps in time series, making the information before and after the changes incompatible. Another disadvantage is that researchers do not directly affect which data are collected and available in the registers.

Gaining access to register data can be both time-consuming and expensive. Approval from the regional committees for medical and health research, and sometimes the Norwegian Data Protection Authority, is required in such research projects. In addition, approval from the different data owners must be obtained. Researchers should never have

access to data while they still include PIN. Therefore, after all other approvals have been obtained, applications are sent to Statistics Norway, which is usually responsible for data linkage. This can be a time consuming process, and getting access to data may take years. Furthermore, the price of data linkage can be substantial. Data owners are to be paid a fee for access to data. The highest cost is usually the cost of linkage. Because research groups do not receive a cost estimate until the application has been submitted to Statistics Norway, it is challenging to set up realistic cost estimates for such projects.

Apart from these limitations, registers enable studying third-party harm from substance use and abuse in a way that would be difficult, if not impossible, using survey data alone. Obvious benefits are that in contrast to most surveys, registers typically include information on entire populations, or entire subsets of populations, and most are continually updated and longitudinal. Furthermore, the opportunity to link data on the individual level and between family members through the use of PIN and family numbers is usually not available with survey data. Other advantages are the attrition rate and the negligible nonresponse. For instance, while respondents in survey studies may decline to participate in follow-up studies,¹ this is less of a problem with registry studies, which include continuously updated information on everyone included in the study, as most registers are not based on consent. Furthermore, while in surveys some respondents may refrain from answering all questions, especially concerning sensitive issues, registry entries are usually complete.

In cases where researchers are interested in collecting a representative sample within subpopulations, such as persons with rare or special conditions, they can be identified through registers and contacted for participation in survey studies, given that ethical approval is granted. For instance, to study the association between welfare deficiencies, mental health problems, and drug use in a representative prison population, a random sample was drawn from the official registry on prison inmates and respondents were then contacted and asked to participate in a level-of-living survey.³² Furthermore, when consent to match survey data to registry data is included in survey studies,^{8-10,33} this enable longitudinal follow-up using nationwide registers is allowed. This approach is less time and cost consuming than gathering follow-up data with interviews or questionnaires. Information from registers can also be used to improve survey studies: background information, such as demographics, may be obtained from registers instead of from the interviews or questionnaires and save both time and money.

Ethical Considerations

Most registry data used for research purposes in Norway are regulated under the Statistics Act. The law states that registry data should only be used for statistical and research purposes, and results should be published without political consideration.⁶ In datasets that include a large number of variables on



the individual level, there is always the possibility that persons can be identified. This risk increases when data from several registers and/or survey data are linked. While all such research projects are evaluated by ethical committees, researchers have a responsibility not to request more information than necessary in order to answer the research questions in the project. For instance, not all research projects need information on exactly where the study participants live in the country, where they receive treatment for injuries, mental health or substance use problems, where prescription drugs were dispensed, or where they died. Furthermore, in most projects, exact birth date is not necessary. By conducting studies according to these principles, research projects will have sufficiently comprehensive data to answer its research questions and at the same time reduce the risk that individuals can be identified.

Conclusion

While there is great potential for conducting research on harm to others from substance use and abuse based on registry data, relatively few use this approach to address such research questions. This article gives an introduction to nationwide registers and explains how they can be used to study harm to others from substance use and abuse. We have shown that registry data allow for studying entire populations or subsets of populations over long time periods, with no or minimal attrition, and that the PIN and family numbers used in most registers allow for the linkage of information from several registers on the individual level and family level. We hope that this will inspire more researchers to use registry data in their work with harm to others in the future.

Author Contributions

Wrote the first draft of the manuscript: IOL. Contributed to writing of the manuscript: IOL, AB. Jointly developed the structure and arguments for the article: IOL, AB. Made critical revisions and approved the final version: IOL, AB. Both authors reviewed and approved of the final manuscript.

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