Title:

Feasibility and interest of the use of the national identification number of clients for the registration of treatment demand in Belgium: Preliminary results.

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Abstract:

Background: The avoidance of "double counting" is a continuous concern in the monitoring of the persons in treatment for a substance related disorder. Therefore, the Belgian TDI registration moved in 2011 from an anonymous registration towards a registration based on the use of the client's coded national identification number (NIN). In this presentation we aim to describe the implementation process of the use of the NIN and to present preliminary analyses of the correcting effect of this new procedure on the phenomenon of "double counting".

Methods: In 2011, clinicians of 69 Belgian treatment programs recorded the TDI variables and, if available, the NIN of the client. Records are registered into a database after the coding of the NIN by a Trusted Third Party. The coded NIN and the TDI variables are afterwards forwarded to the Belgian Focal Point for analysis.

Results: In 82.15% of the records is the NIN used as identification code of the client. We estimate that the registration of the NIN will allow to avoid a double counting of 7.3%.

Conclusions: The introduction of the NIN allows to adjust the Belgian TDI estimates for a substantial proportion of double counts. Critical factors in the implementation and use of the NIN, as well as future epidemiological opportunities will be addressed.

1. Introduction

In order to draw a clear European picture of the drug treatment demand, the treatment demand indicator has been set up by the EMCDDA in the context of the five key indicators which contribute to provide objective, reliable and comparable information at a European level concerning drugs, drug addiction and their consequences (European Monitoring Center for Drugs and Drug Addiction 2009).

One main problem in the treatment of substance related disorders (both dependency and abuse) is the large number of dropouts, with rates ranging from 60% to 80% of clients (Lopez-Goni et al. 2011). This can be explained by the fact that clients are mostly living in unstable contexts and difficult socioeconomic situation (unemployment, low education level, young age,...) (King and Canada 2004).

On the other hand, treatment for substance related disorders requires long term and repeated episodes of care to achieve the treatment objectives (recovery, stabilization, ...). Matching treatment settings, interventions, and services to an individual's particular problems and needs is critical to succeed (National Institute on Drug Abuse 2009).

The multiplication of treatment episodes of a client within a program or between different treatment programs can result in an overestimation of the number of treated persons. This problem, clearly identified in the EMCDDA TDI protocol 2.0., led to the recommendation to assign a unique identifier to individual client's data in order to avoid double counting (Simon et al. 2000).

The Belgian treatment demand registration started with an updated system in January 2011 based on a new national protocol (Conférence interministérielle Santé publique 2006;Interministeriële Conferentie Volksgezondheid 2006). In this registration system, importance was given to the use of the national identification number (NIN) as unique identifier for the registration of clients.

In this presentation, the legal and societal aspects of the use of NIN, as well as its operationalization, are presented. Secondly, preliminary results obtained after 1,5 year of registration are presented focusing on the use of the NIN and the advantages in the double counting aspect. Finally, future epidemiological opportunities will be addressed.

2. Belgian TDI protocol and the use of national identification number

The Belgian protocol set up in 2006 differs from the European one in several aspects. First, it extends the registration to alcohol related disorders as main substance whereas the European protocol only considers alcohol at the level of a secondary substance. Secondly, in Belgium, all treatment episodes followed by a client are required to be registered by the centre although only the last one should be reported to the EMCDDA.

To identify treatment episodes and link them to a particular client, the starting date of the episode is registered as well as the NIN of the client in treatment. To allow a certain flexibility in the registration, the client can be identified in three ways: 1) if the patient has a NIN, this one must be used in priority, 2) if the client is a foreigner without a national identity, the so-called "NIN-bis" or the passport number can be used, 3) if the client has no official documents or doesn't want to give its identification number, the birth date is used.

This protocol has been submitted to 2 sectorial committees ("health" and "national identification number") of the Belgian (federal) privacy commission and received its approval with the following remarks and recommendations (Comité sectoriel de la sécurité sociale et de la santé. Section "Santé" 2010; Comité sectoriel du Registre national 2011; Sectoraal comité van de Sociale Zekerheid en van de Gezondheid. Afdeling "Gezondheid" 2010; Sectoraal comité van het Rijksregister 2011). Considering the proportionality, the commission considered that the use of the coded NIN to follow a patient in time and between different treatment centers, the use of data related to the centers and the use of socioeconomic, treatment and addiction data are appropriate, relevant and not excessive considering the objectives. They recommended that these data are analyzed under the supervision of a medical doctor.

The use of the services of the eHealth-platform (an authorized institution acting as Trusted Third Party for the coding of the NIN) was considered mandatory. The reversible coding of this number was accepted in order to achieve quality control and to return the data to the data provider.

Furthermore, clients have to be informed (orally or by a letter) about the objectives of the registration, the type of data collected, the use of the data, the responsables and, their right to access and correct registered data. Clients can refuse (in writing) to be registered.

The committees also stressed the need for technical and organizational security measures to guarantee the security of data and illicit access or accidental destruction of data.

3. Improvement of the registration in terms of double counting

In 2011, 3,613 treatment episodes were registered in the Belgian TDI by 69 different treatment programs. Among those, 82.2% (n=2,968) were made using the NIN, 17.3% (n=626) using the birth date and 0.4% (n=19) using the identification numbers for foreigners.

This repartition varies largely in function of the treatment centre. In hospitals (38 programs), where the NIN is asked at the admission, 94.1% of the records (n=1,672) are using it. In centers with a convention with the national health and disability insurance institute (22 programs), where the client can be reimbursed from his treatment, 82.1% of the records (n=1,361) are made via this number. In the other centers (9 programs), where normally no identity information is asked at the client, only 47.9% of the treatment episodes (n=580) are registered using the NIN.

Table 1 provides an overview of the TDI database with the different records and clients identified. At the first step, all records based on the NIN are extracted. At step 2 we identified 48 duplicates (1.6%): the same person is found at the same date in the same institution. These doubles can be due to a correction procedure. This is because the centre cannot correct their records once they are registered in the database. To correct the record, the centre can make a second registration with the same 3 variables (program, NIN and start date). Only the last record registered based on these 3 variables is included. Next (step 3), one record of each client is kept for each center. We proceed with this step because we assume that the control for doubles at centre level can be made easily and that these 166 records can be easily identified in a TDI database without NIN. Finally, in order to evaluate the proportion of doubles avoided by doing the registration with the NIN at step 4, we consider the number of different patients, entered in more than one centre (n=200) compared to the total number of patients registered at least in one center (n=2754). We can thus estimate that 7,3% of the records are doubles compared to a normal protocol registration. This proportion can be larger if there is no good intra-center identification solution.

Table 1: Types of records and clients observed in the database in 2011

Step	Condition	Ν	%	Outcome
0	All records in the database	3,613		
1	NIN used	2,968		645 not uniquely identified clients
2	Different program & different start date & different NIN	2,920		48 doubles records (same client, same program, same start date)
3	Different NIN & different program	2,754		166 records of same clients registered in the same program
4	Different NIN	2,554		200 records of transferred clients between centers

Source: Belgian Treatment Demand Indicator Register (2012)

4. Perspectives for the use of the national identification number in the TDI registration

The use of the NIN in the TDI registration protocol of Belgium is a success with more than 80% of the records uniquely identified during the first year of registration.

First, this identifier allows us to avoid about 7% of multiple registrations reported to the EMCDDA. Secondly, this variable will provide the possibility of a longitudinal analysis of client's pathways to drug treatment at national level.

Regardless of the indisputable benefit, an efficient registration necessitates a continuous time consuming investment in terms of informing and reassuring field workers about the interest, security and anonymity of the use of the NIN. The following arguments are thereby considered to be important.

The use of the NIN is the only identifier providing a correct and unique national identification of the clients. Furthermore, this registration enables a longitudinal follow-up of their patients. Finally, only correct estimations result in correct public policy recommendations.

The NIN is managed correctly, safely and anonymously. This system is not being used to list drug addicts in Belgium, no link can be made with other databases without a formal advice of the privacy commission, the coding of the number is made by a trusted third party.

The centers are supported both technically and "clinically" in the shift from an anonymous registration towards a practice where the NIN is registered during the face-to-face interview in order to find a good way to present the study, to ask the NIN and the other variables and keeping the trust in the medical team.

Succeeding in this new TDI registration – in all its aspects - creates opportunities to use this database as a starting point for linkage with other NIN-based registries (death certificates, Infectious diseases registries, health insurance registries, ...) in order to provide epidemiological indicators (Drug related deaths, drug related infectious diseases, comorbidity, drug related health expenditures ...), in a productive, qualitative, effective, and cost effective manner.

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