

Migration & ethnicity related indicators in European drug treatment demand (TDI) registries

Knowledge gap

- **Emerging evidence on disparities** in health & substance use treatment (SUT) for migrants and ethnic minorities (MEM) in the EU
 - **Limited health access** for undocumented migrants in EU member states (Cuadra, 2012)
 - **Belgian substance use treatment:** lower retention, significant relation nationality x type of service and referral types, lower socio-economic status in treatment, underrepresentation of EU nationals & non-EU females (Derluyn et al. 2008, Blomme et al. 2018, De Kock et al. 2019)
- **Little monitoring of migration and ethnicity related disparities** in (mental) health and SUT (access)
 - At least 18 of the EU-28 member states regulate equality data gathering insufficiently in privacy legislation & there is little to no data available in health (Farkas, 2017)

→ **Belgian policy oriented research project on 'mapping & enhancing SUT for MEM'**
(www.Belspo.be, DR 84/00) (February-October 2019)

Main analytical challenges

- **GDPR prohibition** on collecting and processing ethnicity related data (art. 9)
 - Except 'substantial public interest' & 'public health' (Simon et al. 2007; 2012)
- **'categorising' may work to reify disparities** in health (Varcoe et al. 2007)
 - See for instance 'blacks' & 'Hispanics' categorisation in USA epidemiological studies (De Kock et al. 2017)
- Juxtaposition of **privacy versus equality** in the EU

Premise: protecting individual privacy and the right to equal treatment are two sides of the same coin: pursuing the integrity of all individuals (including privacy and equal treatment) in society in line with the Universal Declaration of Human Rights



Treatment Demand Indicator (TDI)

- Standardisation initialised by the **Pompidou group** over two decades ago and continuously sustained by **EMCDDA and the National Reitox Focal Points**
- **GOAL:** “The objective of the Treatment demand indicator is to collect information in a harmonised and comparable way across all Member States on the number and profile of **people entering drug treatment** (clients) during each calendar year” (TDI protocol 3.0, 2012, p. 16).
- **largest reliable drug-related dataset** in the EU (Montanari et al., 2019)
- **Administrative and epidemiological data** (not a client ‘file’)
- Since **3.0 protocol**, no ‘nationality’ or other migration or ethnicity related indicator

2014 EU-28 drug treatment reports

“What MEM-specific treatment demand trends can be identified?”

by using search terms: ethn*, minorit*, migra*, nationali*, foreign, roma, asylum, refugee

2014 EU-28 drug treatment reports (1/2)

- Qualitatively identified **vulnerable populations**:
 - 20/28 identify vulnerable MEM populations
 - Populations ‘who do not have the nationality of the member state’
 - Roma populations (Central & eastern member states)
 - Problem users with a Russian background (Baltic state & Germany)
 - ‘non-western migrants’, ‘foreign-born’, ‘migration background’

2014 EU-28 drug treatment reports (2/2)

“What MEM-specific treatment demand trends can be identified?”

- **treatment demand**

- 14/28 observe numerical trends
- **Unclear relation with prevalence & whether numerical trends represent over- or underrepresentation**

- **Health correlates**

- **Social correlates**

- **drug-related crime & prison populations**

Analysed in other datasets / surveys

- **Accessibility** discussed in all reports, **but not in relation to MEM**

Survey on migration & ethnicity related indicators in 2017

via Sciensano, the Belgian Reitox Focal Point

“Which migration / ethnicity / nationality related indicators were included in the 2017 national TDI protocol?” (survey April 2019)

- **68% response rate** of mainly Reitox National Focal Point staff members

Nationality (n=10)
Birthplace (n=6)
European-Union / not-European-Union (n=5)
Ethnicity (n=5)
Nationality at birth (n=4)

- Registration method: **provider ticks one or several predefined categories**
- **Coverage issues:** total service coverage, identifiable clients (i.e. by means of national identification number [NIN])

Discussion on monitoring based on survey responses

“How do you think monitoring migration & ethnicity in TDI could be enhanced?” (survey April 2019)

1. Reliable indicators and registration in national TDI registries (n=5)

For instance, Three or more indicators:

1. **First generation:** 'nationality' used in 1/3 of the registries (ISO 3166)
2. **Second generation: i.e.** 'birth place mother' (and father) (i.e. European Labour force, health & social surveys, EU-SILC)
3. **Access to health:** a or several language related questions (i.e. PISA questionnaire: home language)

→ Consultation of member states on interpretation of indicators (i.e. 'nationality' versus 'country of citizenship', modes of registering 'ethnicity', etc.)

→ Supporting professionals in good registration



2. Use of unique identifiers in the TDI dataset (n=3)

- Resolves the issue of not possessing a national identification number (NIN)
- Can resolve the issue of delivering identifiable datasets to the data processing responsible (i.e. Reitox national focal point)

3. Database linkage (n=2)

- (!) Only if appropriate safeguards are in place
- Only possible with appropriate identifiers
- Bias from linkage errors, privacy preservation, data preparation

4. Stratify available TDI data (n=2), but also multi-indicator & multivariate analysis

- Multivariate analysis including i.e. living situation, socio-economic situation, gender
- Multi-indicator analysis comparing treatment demand to for instance prevalence rates and other (survey) data to allow for tiered drug treatment policy making (i.e. national health surveys) (Ritter et al., 2019)
- Analysis of two or more migration / ethnicity related indicators (i.e. nationality, birthplace mother, home language) allows to disentangle seemingly static groups

Conclusion (1/2): sensitive and prohibited?

- **Sensitive yes, prohibited no**

“ registration can work to reify, perpetuate and spread into the area of healthcare politically driven notions and categories of nationalism which exclude certain groups” (Helberg-Proctor, 2017)

- At the national level

- need for including **equality grounds** (i.e. ethnicity) in law or offering operationalising guidelines by national data protection agencies
- Need for conducting a **Data Privacy Impact Assessment for** the inclusion of new indicators in TDI by Data Protection Officers (DPO's)

Conclusion (2/2): 'do no harm' = purpose specification

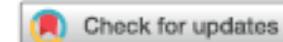
- **Informed consent:** data subjects are less reluctant to give information if they know the purpose (i.e. combatting discrimination, Eurobarometer, 2015)
- **TDI purpose specification (at national level):** not only 'documenting and counting' but also informing policy making
- i.e. 2018 UK 'National Drug Treatment Monitoring System' protocol:
"Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities"

In a nut-shell

European Centre for Disease Prevention and Control (ECDC) (2011, p. 13) cautions that

“[This type of data gathering] should ‘do no harm’ (...). This means that if data are collected about ‘migrants’ it should be done with the intention of benefiting migrants and it should be possible to provide evidence that this is the case or, at least, that no harm befalls them as a result of this data collection.”

- reliable indicators
- multi indicator and multivariate analysis
- purpose specification & informed consent
- data privacy impact assessment & appropriate safeguards



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ABSTRACT

The knowledge about substance use and treatment among migrants and ethnic minorities is scarce in the European Union. In light of recommendations to optimize data gathering and processing, the aim of this paper is to identify which migration and ethnicity related indicators are used in the EU-28 treatment demand indicator (TDI) registries. We present results of a systematic TDI report analysis and an online survey. Because of the importance of the principles of subsidiarity and proportionality in the European Union, we base the discussion of the results on survey responses of experts in the member states. We subsequently discuss considerations related to 1) optimizing migration and ethnicity related indicators in TDI and other drug related indicator protocols, 2) using unique identifiers, and 3) enhancing purpose specification and informed consent. These suggestions are formulated against the backdrop of the General Data Protection Regulation (GDPR) as well as the growing need to ground comprehensive drug treatment policies in tiered modelling and multi-indicator analysis.

KEYWORDS

Migration and ethnicity related indicators; drug treatment data; GDPR