JOURNAL OF ETHNICITY IN SUBSTANCE ABUSE
https://doi.org/10.1080/15332640.2019.1664962
Taylor & Francis
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Migration and ethnicity related indicators in European drug treatment demand (TDI) registries

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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

Introduction

Knowledge gap

Disparities in the provision of (mental) health care and substance use treatment (SUT) for migrants and ethnic minorities (MEM in what follows) have been documented extensively across the continents (Kirmayer, 2012; Saloner & Lê Cook, 2013; WHO, 2016) but to a much lesser extent in Europe (De Kock, 2019; Domenig, Fountain, Schatz, & Bröring, 2007; EMCDDA, 2013a, Lemmens, Dupont, & Roosen, 2017). Horyniak, Melo, Farrell, Ojeda, & Strathdee (2016) found that prevalence estimates of hazardous/harmful alcohol use among forced migrants ranged from 17% to 36% in camp settings and 4%–7% in community settings and that male sex, trauma exposure and symptoms of mental illness were commonly identified correlates of substance use. Missinne and Bracke (2012) in turn

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found that, independent from residence status, the broader population of persons with a migration background displayed more depressive symptoms compared to the general populations in 23 EU member states. Moreover, only a minority of European member states offer full access to health services to undocumented migrants (Cuadra, 2012).

The second European Union Minorities and Discrimination Survey (FRA, 2017) observed that Roma[1] - the largest ethnic minority in Europe - respondents experienced the highest rates of discrimination in access to health care compared to other national and ethnic minorities. The SRAP (2012) study on harmful substance use among Roma in turn concluded that poverty, segregation, low access to education, employment and health services are important factors that contribute to substance use in the six studied Roma communities in Italy, Bulgaria, Romania, Spain, Slovenia, and France.

Preliminary Belgian studies among non-national SUT clients identified disparities compared to their national client counterparts: lower retention rates, later first admittance, underrepresentation of females compared to their national client counterparts (Derluyn et al., 2008), overrepresentation in substitution treatment, underrepresentation of intra-European clients compared to their presence in the general population (Blomme, Colman, & De Kock, 2017). An additional analysis of the same data compared the profile of clients registered as Belgians, EU nationals and non-EU nationals in the Belgian Treatment Demand Indicator (TDI) registry (2012–2014) and identified less referral by general practitioners and lower socio-economic status, especially among third country clients (available on request to the author).

TDI is the largest reliable drug-related data set in Europe (Montanari et al., 2019). It informs about met (Ritter, Mellor, Chalmers, Sunderland, & Lancaster, 2019) treatment demand[2] (as opposed to unmet treatment demand). The objective of the TDI is to collect information in a harmonized 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, p. 16).

However, although coverage of the register has improved significantly between 2011 and 2019, not all services active in or related to drug treatment demand participate in the registration (Antoine, De Ridder, Plettinckx, Blanckaert, & Gremeaux, 2016). Furthermore, in the third TDI

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[1] The term Roma encompasses diverse groups, including Roma, Gypsies, Travellers, Manouches, Ashkali, Sinti, and Boyash. Roma is the term commonly used in EU policy documents and discussions.

[2] The first actor who defined a common protocol for collecting data on people entering drug treatment was the Pompidou Group (PG), who coordinated studies at city level (in Dublin and London in 1991) and a developmental project in 11 cities and the creation of a European expert group which met several times to discuss and agree on the methodological guidelines. (TDI protocol 3.0)

protocol (2012), the "nationality" variable was omitted at the European Monitoring Center for Drugs and Drug Addiction (EMCDDA) level and consequently some countries no longer register it.

Privacy versus equality

General recommendation 32 of the Committee on the Elimination of all Forms of Racial Discrimination (CERD) states that "the principle of nondiscrimination requires that the characteristics of groups be taken into consideration." Moreover, the European Commission against Racism and Intolerance (ECRI) (in Simon, 2012) specifies that "it is difficult to develop and effectively implement policies without good data." ECRI defines equality data as "statistics broken down by citizenship, national/ethnic origin, language and religion" (Farkas, 2017a, p. 36).

In the context of HIV-related surveillance among migrants, a report of the European Center 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.

To protect European citizens from these potential harms, the General Data Protection Regulation (GDPR, 2016) regulates the collection and processing of personal data. The GDPR explicitly prohibits the collection of ethnicity related data but also provides quite an array of exceptions including "substantial public interest," "vital interests of the data subject" and "public health" relevance (art. 9). Furthermore, the collection and processing of (pseudo)anonymized data (Custers et al. 2012, p. 345) is not prohibited when working with unidentifiable unique encrypted personal numbers (Van Baelen, De Ridder, Antoine, & Gremeaux, 2018) and as long as the "purpose specification principle" (and subsequent informed consent) is respected.

Farkas – in a report on equality data gathering commissioned by the European Commission – argues that "no Member State imposes an absolute prohibition of ethnic data collection. In all Member States, the collection of ethnic data takes place in accordance with the Data Protection Directive" (2017a, p. 14).[3] Farkas rated the EU-28 member states equality

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[3] For detailed country information we refer to the full country reports (Farkas, 2017c).

Table 1. Equality data score as presented in Farkas (2017b).

		Equality data gathering score (Farkas, 2017b)			
Country	Regulated	Valid	Reliable	Comprehensive	Used
Austria	red	red	orange	yellow	red
Belgium	red	yellow		yellow	yellow
Bulgaria	orange	orange	red	green	red
Croatia	yellow	orange	orange	light green	red
Republic of Cyprus	red	red	red	orange	red
Czechia	red	orange	orange	yellow	red
Denmark	red	red	yellow	yellow	orange
Estonia	orange	orange	orange	orange	red
Finland	green	green	green	green	light green
France	red	orange	yellow	yellow	red
Germany	red	red	yellow	yellow	orange
Greece	red	red	orange	yellow	red
Hungary	light green	orange	orange	orange	orange
Ireland	yellow	light green	yellow	yellow	yellow
Italy	red	yellow	orange	yellow	orange
Latvia	red	orange	orange	orange	red
Lithuania	red	orange	orange	orange	red
Luxembourg	red	orange	orange	yellow	red
Malta	red	red	orange	orange	red
Netherlands	light green	green	green	green	yellow
Poland	red	orange	orange	yellow	red
Portugal	orange		yellow	yellow	red
Romania	red	orange	orange	orange	yellow
Slovakia	red	orange	red	red	red
Slovenia	red	orange	red	orange	red
Spain	orange	orange	orange	orange	red
Sweden	red		orange	light green	red
UK	green	green	green	green	green

Explanatory note:
The gray scale represents respectively from black to light gray the following colors (Farkas, 2017b, p. 5–6):
- Red (Score 01–19): Major weaknesses;
- Orange (Score 20–39): Areas of Weaknesses;
- Yellow (Score 40–60): Mixed areas of strengths & weaknesses;
- Light green (Score 61–80): Areas of strengths;
- Green (Score 81–100): Major strengths.

data gathering (including but not limited to ethnicity related data) as presented in Table 1.[4]

At least eighteen of the EU-28 member states regulate equality data gathering in their privacy legislation insufficiently, resulting in dispersed interpretation and adding to the taboo around this type of data gathering. Farkas (2017a) further specifies that ethnicity data gathering is not absolutely prohibited in any of

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[4] (Farkas, 2017b, pp. 12–21) rated equality data gathering by means of a fixed set of indicators as:

- regulated (in sensitive data exemptions allowed as per Directive 95/46/EC and in anti-discrimination legislation and the existence of equality data legislation or guidance);
- valid (consultation of populations, coverage of groups, use of self-definition);
- reliable (nationally comparable, regular data collection, number of actors collecting data, controls and disaggregation);
- comprehensive (presence of population estimation and data on employment, education, housing, health, poverty/social exclusion, crime victimization, discrimination complaints, discrimination cases, outcomes of discrimination cases), use of equality data to promote equality in practice (official national monitors (discrimination, equality, integration), official local monitors (discrimination, equality, integration, proof in discrimination cases, use of remedies & sanctions, planning for equality or positive actions, law- and policy-making, evaluation of anti-discrimination legislation).

the member states and that even in France – often cited as a member state with absolute prohibition of this type of data gathering – ethnicity data-gathering is possible by means of the exceptions in privacy legislation.[5]

Health-related data enjoys an even higher level of protection in the EU (Convention 108, Article 6). As is the case in GDPR, the 2019 Recommendation on the protection of health-related data (CM/Rec(2019)2) stresses in its preamble that data gathering should always "aim to serve the data subject, enhance the quality and efficiency of care, and to enhance health systems where possible."

This recommendation subsequently advises member states to ensure that its principles are enshrined in law and brought to the attention of the authorities responsible for healthcare systems with the main aim of developing secure and interoperable information systems. The recommendation aims at limiting data processing for specified purposes. As is the case for the GDPR, it includes exceptions related to "reasons of public health, such as the protection against health hazards, humanitarian action or in order to ensure a high standard of quality and safety for medical treatment, health products and medical devices, subject to the conditions provided for by law" and "reasons of substantial public interest" (2019, p. 5).

A report on "ethnic statistics" and data protection commissioned by the Council of Europe (Simon, 2007, p. 21) specifies that:

> The concept of public interest applies to all areas of public action, and so leaves legislators relatively substantial scope for removing certain sensitive data from the protection authorities' control. It also specifies that scientific research and public statistics are areas where reasons of public interest apply. This opens the way to the collection of data which might seem to be prohibited.

Indeed, "public interest" in GDPR and the health-related data recommendation are broad and open to interpretation. Nevertheless, although "public interest" theoretically opens the way to (secondary) use of migration and ethnicity related data for research or official purposes, it is rarely invoked by the member states to register or process this data.

Research question

Monitoring scientifically sound migration and ethnicity related indicators among SUT clients (on a voluntary basis) can be argued to be

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[5] A French constitutional decision did indeed forbid the inclusion of variables on race and religion in administrative files but it did not rule on the de facto inclusion of geographic origin or previous citizenship (available in public statistics) and language related indicators. Farkas concludes that "It is conceivable that as a result of the Constitutional Council decision, French judicial interpretation is not compliant with the EU Data Protection Directive concerning the collection of ethnic data, inasmuch as it denies the right to individuals to consent to the processing of data concerning their ethnic origin while providing a mechanism that generates such data without their explicit consent" (Farkas, 2017a, p. 14).

indispensable for identifying health disparities and for understanding and acting upon the needs of diverse client populations. The aim of this study is subsequently to identify:

1. What MEM-specific treatment demand trends could be identified in the EU-28 member states in the national drug reports?
2. Which migration and ethnicity related indicators were used in EU-28[6] TDI registries in 2017?

Identifying migration and ethnicity related indicators will allow us to assess their analytical capacity to capture complex ethnicity and migration related characteristics and treatment demand trends, their compliance with General Data Protection Regulation (GDPR) and their subsequent transferability to other European contexts.

Methods

National report analysis

To identify trends concerning drug treatment demand among MEM in the EU-28 member states we screened the 2014 national drug reports submitted by the EU-28 member states to the EMCDDA by means of the following queries: ethn*, minorit*, migra*, nationali*, foreign, roma, asylum, refugee. The 2017 reports that are available online contained little to no information on treatment demand trends[7] among MEM whereas not all 2015 and 2016 reports were available online, as the result of large changes in the reporting system in 2015.[8]

I subsequently focused on the 2014 reports[9] for in-depth analysis and disseminated a survey to identify the indicators that were used in 2017 (see below). Full paragraphs including the search terms were listed and read per country. The information was then coded with the intent of framework analysis (Gale, Heath, Cameron, Rashid, & Redwood, 2013). The framework codes emerged from the gathered data and are used for the subheadings of this paper: vulnerable populations, treatment demand, drug-related crime, prison populations, health/risk behavior data, social correlates and accessibility.

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[6] Austria, Belgium, Bulgaria, Croatia, Republic of Cyprus, Czechia, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, Netherlands, Poland, Portugal, Romania, Slovakia, Slovenia, Spain, Sweden, UK (England and Wales, Northern Ireland, Scotland).

[7] The internal document *Guide for reporting to EMCDDA 2015* states that the chapter on 'social correlates and social reintegration' – included in all 2014 reports – will no longer be separately included, but integrated in the treatment chapter in the reporting system as from 2015.

[8] The reporting guidelines of EMCDDA are re-discussed year by year.

[9] All 2014 reports are based on 2013 data. Subsequently, if no year is mentioned in the results section, data refer to 2013.

Survey on migration and ethnicity related variables in treatment demand indicator registries

To identify how EU-28 member states monitor migration and ethnicity related variables, an online survey[10] was distributed to the EU-28 member states via the Reitox National Focal Points by means of a request of the Belgian National Focal Point (Sciensano). The European Reitox National Focal Points (NFP) are responsible for submitting the treatment-based (including TDI data) drug reports to EMCDDA on a yearly basis.

The survey questions aimed at identifying ethnicity and/or migration related variables registered by means of the 2017 national TDI protocols. The full survey is available upon request to the author. The survey was open from 10th to 31st of April 2019. Two reminders were sent by the Belgian National Focal Point. Two days before closing the survey, the researcher sent an extra reminder and called all heads of the national focal points that had not completed the survey to provide the relevant data.

Results

Identified vulnerable populations in TDI

20 out of the 28 national drug reports of 2014 identify MEM populations that they describe as specifically vulnerable for problem use or remarkably prevalent in treatment demand registries.[11] Eight country reports[12] did not single out a specifically vulnerable MEM population. At least three (France, Malta, UK) of those countries are reported to explicitly mention the inclusion of MEM populations in social exclusion policies. The UK report explains that there are no statistically representative samples available to report about these populations whereas the Polish report explains that no data is available. The German report in turn indicates that “data on the prevalence of addiction behavior among people with a migration background is generally insufficient” (p. 71[13]).

Populations denominated as “not having the nationality of the member state” are most prevalent, including but not limited to Greek nationals in Cyprus, Vietnamese and Chinese nationals in Ireland (in addition to traveler populations), Portuguese nationals in Luxembourg, homeless non-

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[10] The full questionnaire is available upon request to the author. The relevant wording of the questions is reported in the results section.

[11] Note that MEM that were only reported about in drug-related crime or judicial statistics are not accounted for in this section.

[12] UK, Poland, Denmark, Greece, Portugal, France, Finland, Malta.

[13] In the results section I only refer to pages in the 28 national reports. These reports are fully available and were consulted via http://www.emcdda.europa.eu/publications-database_en?f%25255B0%25255D=field_series_type%253Aname%3ANational%20reports&f%5B0%5D=field_pub_date%3A2014

nationals in Hungary, and undefined non-nationals in Austria and Italy. Roma populations are the second most mentioned across the reports, mainly in Central and Eastern European but also in the Baltic member states.[14]

Problem users with a Russian background (identified by means of their language or as a "former USSR national") are the third most mentioned population, more specifically in the Baltic states and Germany.

Besides these three categories, the Dutch report highlighted vulnerabilities among non-western migrants, the Swedish report speaks of "foreign-born," the German and Belgian reports identify populations with a "migration background". The German report is in fact the only report that includes a clear definition of "migration background."[15]

Treatment demand

Half ($n = 14$) of the 2014 national drug reports observe numerical trends in treatment demand among MEM mainly based on nationality registration. Table 2 presents the full paragraphs that include MEM related TDI data.

Notwithstanding the fact that half of the countries report numerical treatment demand trends among varying MEM, these numbers are often left insufficiently contextualized because they report inconsistently concerning comparisons with general population presence (other than the Danish, Cyprus and German reports) and whether the numbers represent over- or underrepresentation. The majority of the data is not aggregated per treatment type nor at other levels (except for the Estonian report).

Most importantly the migration or ethnicity related variables are not analyzed in relation to other correlates (i.e., employment, gender, education, housing) and countries do not always identify longitudinal trends. The "Social exclusion and drug use" parts of the 2014 reports often include a break-down by employment and education but this is not related to ethnicity or migration related indicators in the TDI data. Reports do identify specific socio-economic vulnerabilities in these populations (i.e., the Swedish report concerning nationalities of homeless populations and low employment among third country nationals in the Dutch report) by means of references to other studies.

Only the Irish report specifically identifies an in-depth study of treatment demand among a MEM (sub)populations concerning the above mentioned

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[14] Lithuania, Slovakia, Slovenia, Czechia, Romania, Bulgaria

[15] p. 156 *The term, "People with migration background" includes people who came to Germany after 1950 and foreign nationals born in Germany (including refugees), late repatriates and naturalised persons as well as their children* (Ruf & Walter-Hamann 2014)."

Table 2. Treatment demand MEM-trends in the EU-28 national drug reports of 2014.

GR	In 2013 unemployed users comprise 64.3% of all users who approached drug services. 8.8% of all users approaching treatment services were homeless users at the reporting year**. 7% of users approaching various therapeutic services in 2013 have foreign nationality**. (p. 80)
DA	**A minor proportion of the drug users receiving treatment are foreign citizens, amounting to a little over 6% in 2011**. The proportion of clients of foreign nationality receiving treatment almost corresponds to the proportion of foreign nationals in the population as a whole. (p. 39)
BG	The general characteristics of the persons demanding drug-related treatment in 2013 can be expressed as follows:
	predominantly male (81.1%), **predominantly Bulgarian (81.8%),** General average age – 29.5 years of age, predominantly secondary education (56.2%), predominantly heroin (70.1%), predominantly daily use (56.4%), predominantly injecting (64.4%), average age at the time of first use of primary drug – 19.6 years of age. (p. 60)
	The relative share of the individuals who have demanded treatment and who do not belong to the main ethnos of the country has increased more than twice since 2007 and over the past 3 years remained within the 17–18% break, which can be explained by the fact of the addition of the persons who demanded treatment in the prisons, where the percentage of the minority groups is much higher. (p. 63)
CY	In 2008, a remarkable decrease of opiate HRDUs occurred, partly attributable to some significant changes in the population used for the estimate, such as a lower number of demands for treatment, a lack of prison data and a significant decrease of foreign nationals recorded in treatment. (p. 39)
	In particular, as in previous years, foreign nationals accounted for the majority of high risk opiate users (estimated at about 60% of all opiate HRDUs in 2013) (p. 42).
	Regarding the nationality of clients recorded in treatment in 2013, 879 out of 1092 were Cypriot nationals**. Nationals of other countries amounted to 205, the majority of whom were EU nationals (135), mainly Greek nationals**. (p. 52).
	As in previous years, **significant differences occur in risk behavior prevalence when stratified by nationality**. As in the case of heroin as primary drug, both injecting and sharing practices are more prevalent among foreign nationals (27.5% of Cyprus nationals with heroin as primary drug reported ever shared, as compared to 41% of EU nationals). (p. 61)
DE	Data from the various recent studies (MoSyD, SCHULBUS, JDH-Study Berlin) confirms that in a comparison of adolescents from Muslim parent households with other adolescents of the same age, those with a Muslim background use cannabis and illegal drugs much more rarely. (p. 43)
	The data available on the prevalence of addiction behavior amongst people with a migration background is generally insufficient. In addition, this population group is too heterogeneous to enable generally applicable statements to be made as to the addictive behavior of its members. Rather, the group must be further differentiated into specific sub-categories. Individual study results are available for the addictive behavior of migrant adolescents. In a cross-sectional study, Bermejo and Frank (2014) collected data on alcohol consumption amongst older persons with Turkish, Spanish and Italian migration backgrounds, as well as amongst repatriates. Overall risky consumption was reported by 9% of respondents. Repatriates had the highest level (11.4%) and the Turkish group - in which most people, namely 70.2% are abstinent - had the lowest level (5.3%). Looking at persons who consume alcohol, the highest value for risky consumption was recorded in the Turkish group (17.6%). Alcohol consumption of older persons with a migration background is below the average values for Germans. The findings indicate that persons who consume alcohol from abstinence based cultures are more likely to develop problem consumption patterns. (p. 71)
	In 2013, 78.2% (2012: 78.7%) of all outpatient clients N = 67,03059 with drug problems recorded within the framework of the German Statistical Report on Treatment Centers for Substance Use Disorders were male. 50.2% (2012: 50.3%) of all treated patients were between 15 and 29 years of age. 83.3% (2012: 83.2%) of them were of German nationality**, 3.2% (2012: 3.0%) were from other countries of the European Union (EU), 8.4% (2012: 8.6%) from non-EU countries such as Turkey or the former Soviet Union (unknown nationality: 5.1%).** Since living conditions of the clients vary considerably depending on the main diagnosis or the drugs used, the characteristics presented in Table 5.4 are broken down by main drugs. (p. 104)
	In outpatient and inpatient addiction treatment (Künzel et al. 2013), the proportion of these people in outpatient treatment was most recently estimated at 16.8% and the proportion of those in inpatient treatment was estimated at 13.0%. These figures, however, are not only related to persons addicted to illegal drugs but also, for example, to alcohol and tobacco dependent persons (p. 156)

(*continued*)

EE	**Most of the persons receiving drug addiction treatment (over 80%), just like in the previous year, were Russians, the percentage of other nationalities was less than 10%.** In 2013, the percentage of Estonians who sought treatment for the first time was somewhat larger amounting to almost 20%. 38% of all people who sought treatment lived in Tallinn and Harju County and 59% in Ida-Viru County. However, among the persons who sought treatment for the first time, the percentages of patients living in Tallinn or Harju County and the Ida-Viru Country were reversed - 59% of the people who sought treatment lived in Tallinn or Harju County while 38% lived in Ida-Viru County (p. 38)
GR	According to the data from two low threshold services run by OKANA and KETHEA, the profile of their clients (n = 2 552) is as follows: The vast majority were men (80%), the mean age of those approaching KETHEA low threshold service (n= 379) was 37 years, on average, about one out of three were immigrants, more than half (55%) were homeless and 77.5% were unemployed. (p. 78) **In 2013 unemployed users comprise 64.3% of all users who approached drug services. 8.8% of all users approaching treatment services were homeless users at the reporting year. 7% of users approaching various therapeutic services in 2013 have foreign nationality. (p. 80)**
SK	Heroin was mainly distributed from suppliers to consumers through Roma families that apply a similar modus operandi as Albanian organized crime groups. In Central and Eastern Slovakia, heroin continued to be sold in minimum quantities to relatively closed groups of consumers. **A majority of heroin consumers were individuals of Roma origin involved in its distribution, and/or long-term heroin addicts.** (p. 145)
LV	**Approximately one third (35.2%) of drug users treated in 2013 are Latvians, about one half (50.6%) are Russian speaking, one in ten (10.2%) drug users have not provided information on their nationality, but 7.6% of drug users treated in 2013 represent other nationalities**. Among those first-treated patients whose nationality has been indicated, the proportion of Latvians is bigger than among previously treated patients (44.6% and 30.8% respectively). (p. 58)
LU	The male/female ratio of the PDU population is stable at 4:1. **During the last ten years the proportion of indexed non-native PDU has shown strong variations but a clearly increasing tendency since 2003. The population of non-native drug users largely consists of Portuguese nationals, whose proportion is not consistently lower than the one observed in general population**. (p. 74)
RO	Data for HIV infection show double prevalence among IDUs, compared to the previous year. In terms of the socio-demographic indicators, these define, both for IDUs benefitting from treatment services and for IDUs benefitting from needle exchange programs, an extremely vulnerable population, in terms of lack of subsistence means, low level of education, **ethnical component (high prevalence of Roma sub-population in the needle exchange programs) and anomic behaviors (commercial sex, drug related crimes etc.).** (p. 6)
PT	The analysis of socio-demographic characteristics of patients who went in 2013 to the different drug addiction treatment structures continue to be mostly male (74% to 88%), aged 35–44 years (22% to 52%) and 25–34 years (18% to 44%), middle age varying between 30 and 40 years. **Continue to be predominantly individuals of Portuguese nationality (93% to 100%)** and singles (48% to 71%). (p. 73)
IE	**The incidence of treated problem substance use among the Traveler community was three times that among the general population in 2010** (523 per 100,000 vs 173 per 100,000). [elaborate study of types and trends] (p. 61)
MA	**The majority of all treated clients were Maltese Nationals during 2013 (97%),** the same as that for 2011 and 2012. The number of Maltese first treated clients was reported at 94%, the same percentage as in 2012 and a slight decrease of 3% from 2011 (97%). Treated clients coming from other EU countries in 2013 remained stable at 2% of the entire service using population as in 2011 and 2012. (p. 49)

contexts: it documents treatment demand in a specific population, comparing trends among traveler clients to trends in the general population.

Drug related crime and prison populations

Whereas only half of the country reports include data and trends about MEM drug treatment demand, more ($n = 18$) reports include information about drug-related crime or nationalities in judicial statistics. The type of data reproduced includes foreign arrestees, convictions of non-nationals, non-nationals detained with drugs, prison population data, drug-related crime, and aggravated narcotic offenses. Some countries reported quite high non-national prison populations (Cyprus: 50%) or non-national involvement in drug-related crime as reflected in prison populations (Finland: 39%, Spain: 1/3, Portugal: 28%) while other countries report that these numbers decline and/or have always been quite low (Czechia: 9%, Italy: 17% [but also over 30% unknown], Greece: 8%, Bulgaria [no numbers]).

However, no real trends can be discerned because country reports do not report uniformly and numbers are rarely presented in relation to a broader context. It is for example unclear whether the populations included in these drug related crime or judicial statistics do or do not overlap or are related to trends in treatment demand data. This is for instance particularly the case for the populations denominated as "ethnic Albanian" in the reports of Slovakia, Czechia and Croatia as well as Russian populations in Finland, ethnic Vietnamese in Slovakia and non-EU nationals in Italy, Spain, and Luxemburg.

Only the Romanian and Lithuanian reports mention that Roma populations in the capital are involved in both drug markets and problematic use of heroin but this is not documented with numbers. Similarly, the Irish report gives insight in a prison subpopulation with Asian backgrounds, detained for involvement in cannabis production but identified as having been lured by human traffickers and forcedly involved in cannabis cultivation. Lastly, the Slovakian report notes that "distribution of heroin to users is obviously provided by Roma families" (p. 19) but does not include references to numbers, observations or the relation of this statement to treatment demand.

Some country reports (i.e., Luxemburg, Sweden) emphasize that no real trends among non-nationals involved in drug related crime can be discerned. The French report does not include numbers but does report that data is available per nationality about different types of offenses, convictions, types of procedures, nature and duration of the sentences (p. 147).

Health correlates and high risk drug using behaviors

Those country reports that include MEM numerical drug treatment demand trends[16] more often also included specific information on correlated health risks and risky drug use, compared to countries that did

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[16] Greece, Denmark, Bulgaria, Cyprus, Germany, Estonia, Slovakia, Latvia, Lithuania, Luxemburg, Romania, Portugal, Ireland, Malta.

not observe these trends. Some country reports observe that among persons newly registered with infectious diseases a certain proportion consists of non-nationals. Concerning HIV in Sweden, 12 of 14 newly registered HIV cases among persons who inject drugs (PWID) in 2013 were reported to have been infected abroad. But the total number is low and declining. In Bulgaria and Slovakia these numbers were similarly low, respectively 12 and 5%. In Greece, between 2011 and 2013, 23% of newly infected HIV were non-nationals (p. 60). Concerning HCV (Hepatitis C) in Cyprus, the majority of HCV positives (23 out of 39 cases) were non-nationals (1/2 Greek, 1/4 other EU, 1/4 non-EU).

Additionally, in Estonia, the prevalence of infectious diseases in 2013 among Tallinn PWID was higher among those with a Russian nationality. Also in Estonia, 70.2% of the overdose victims (mainly fentanyl-related) were ‘ethnic Russians’ ($n = 78$). However, overdose deaths were generally declining. In Italy, 9% of the overdose deaths involved non-nationals. This was the case for 27% of the overdose deaths in Luxemburg. Additionally, a decreasing number of victims of Portuguese nationality was observed in Luxemburg.

High risk drug use related behavior was also accounted for in some of the reports. A lower starting age for illegal substance use was reported among Roma in Czechia. In Cyprus, most high risk drug users were non-nationals and in 2013 injecting and sharing practices became more prevalent in this population. In Estonia too, injecting drug users mainly had a Russian nationality. Higher injecting prevalence was also observed among female travelers compared to male travelers in Ireland, while when leaving gender unaccounted for, injecting practices were similar to those in the general population.

Social correlates

Half of the countries that report on treatment demand[17] in varying MEM populations, mention social correlates to problem drug use among MEM populations. Homelessness, unemployment, low education and being undocumented are the social correlates that are most mentioned in these country reports. The Dutch report for instance reports that “the proportion of non-Western migrants among the homeless people was 40%” (p. 83) whereas the Swedish report notes that among homeless non-nationals

> “one fourth had no other known problem besides their lack of housing, compared to 14% of the Swedish-born. The most usual reason for being homeless in the foreign-born group is not being approved on the regular housing market” (p. 71) and “the

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[17] Greece, Denmark, Bulgaria, Cyprus, Germany, Estonia, Slovakia, Latvia, Lithuania, Luxembourg, Romania, Portugal, Ireland, Malta.

> income gap has increased. Poverty is increasingly more common among immigrants" (p. 67). These correlates are equally mentioned in nine country reports that did not include an analysis of treatment demand among MEM.[18]

Four country reports quote survey data that indicates higher unemployment among non-Western migrants (Netherlands), concurrence of risk factors (substance use, homelessness) (Spain) and higher unemployment among non-nationals compared to nationals (Austria, Latvia). However, as mentioned above, none of the reports study these issues as correlates in the available TDI data (see Table 2).

Access

All EU-28 2014 country reports refer to national strategies intended to increase the accessibility of SUT services. Countries such as Czechia, Austria, Poland, Estonia and Romania mainly focus on increasing the geographical availability of opioid substitution treatment to assure equitable access. Country reports also focus on targeting especially vulnerable populations such as drug using prison populations (i.e., Bulgaria, Spain, Denmark) and HIV positive substance users (i.e., Lithuania, Greece, Latvia, Luxemburg, Slovakia).

Moreover, country reports mention universal health coverage for all citizens (i.e., France, Denmark, Bulgaria, Slovakia, Portugal) enabling access to SUT. Nevertheless, not all citizens have access to SUT, especially not when persons demanding treatment do not have a national identification number or social security number (i.e., Croatia). However, only the German, Luxemburg, Irish, and UK reports specifically mention MEM populations when discussing accessibility. None of the country reports (except for the French) make reference to the degree of access to drug treatment for undocumented MEM.

Migration and ethnicity related indicators in treatment demand registries

The survey had a response rate of 68%, including two additional respondents who provided information via telephone and sent documentation to the researcher. Data was collected about 19[19] of the EU-28 member states. Respondents all were staff members and researchers, mainly and as intended of the Reitox National Focal Points.

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[18] Austria, Czechia, Lithuania, Netherlands, Poland, Slovenia, Sweden, Croatia, Spain.

[19] Belgium, Bulgaria, Cyprus, Czechia, Finland, France, Greece, Ireland, Italy, Latvia, Lithuania, Luxemburg, Poland, Portugal, Slovakia, Spain, Sweden, The Netherlands, United Kingdom (England). No data available on Austria, Croatia, Denmark, Estonia, Germany, Ireland, Hungary, Malta and Romania.

Table 3. The five most often registered indicators in 2017 national TDI protocols identified by survey respondents.

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

Concerning the **indicators used**[20], all respondents answered the question "which migration/ethnicity/nationality related indicators were registered in the 2017 national TDI protocol?" Considering that only two respondents chose the "other" option (see below) we presume that the answer options had sufficient coverage. The used indicators are listed in Table 3.

Two respondents answered that they did not record migration or ethnicity related variables. One respondent answered that this data is not available and that "only the number for foreigners is available". Five respondents only ticked one option whereas the other respondents indicated that they cover two to three indicators. Only one respondent indicated recording "birthplace/nationality mother or father" and one respondent reported recording a language related question.

Concerning the **methods of registration**[21], the majority of the respondents ($n = 12$) indicate that "providers tick one or several predefined categories." Three respondents indicate that open answers by the provider are also available in addition to predefined ticking. One respondent reported that only an open ended registration is possible.

All respondents reported insufficient **coverage** of the ethnicity and migration related indicators[22] because of a low number of services that register TDI or a low number of identifiable clients in TDI registries. In some countries, most government funded SUT services register TDI. In most countries, SUT services consist partly of private services that often do not register TDI. Furthermore, TDI registration is often not mandatory which is why some services sometimes do not register it. Respondents also observe that many clients are not registered with a national identification number (NIN), especially those clients with a migration background and those who do not have a NIN such as undocumented migrants. A respondent specified for example that:

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[20] "Birthplace, European/not-European choice, Nationality at birth, Nationality, Language related question, Birthplace/nationality of mother, Birthplace/nationality of grandmother, Birthplace/nationality of father Birthplace/nationality of grandfather, Ethnicity, I don't know, None, Other (Please specify)."

[21] Based on the question *"Can you specify how migration/nationality/ethnicity related indicators were mainly registered in the 2017 national TDI protocol?"*

[22] Based on the question *"Please name the (types of) services of which (you think) registered nationality/migration/ethnicity related in 2017"* and *"Are clients registered with a national identification number in drug treatment in your country?"*

Table 4. Summary of how survey respondents believe monitoring migrant and ethnic minority presence in drug treatment could be enhanced.

Reliable indicators and registration in TDI ($n = 5$)
It is sensitive and/or prohibited by law ($n = 3$)
Use of unique identifiers in the TDI dataset ($n = 3$)
([pseudo]anonymous) database linkage ($n = 2$)
Stratify available TDI data ($n = 2$)

> Registering ethnicity is illegal in [member state]. Our TDI data is pseudo-anonymised and cannot be linked to other register data. Birthplace, Nationality at birth, Nationality, Mother tongue, Birthplace/nationality of mother and Birthplace/nationality of father are available in the national population register and by applying data permissions for specific studies, it would be possible to link this data to general health care registers. They are not, however, very useful for assessing drug-disorders because of under-reporting.

Lastly, we asked respondents in an open ended question how they believe monitoring MEM presence and trajectories in drug treatment could be enhanced in their country. Clearly, the registration of these types of indicators is considered sensitive or even prohibited in some countries, as demonstrated in the quote below.

> It is very difficult in [member state] to get data through studies on migrants, non-nationals, not to speak of ethnicity which is a taboo subject. To any attempt to do so will be opposed the fear of discrimination. The only possible approach for these subjects seems to carry out qualitative studies.

Answers to this question are very diverse but complement one another. Four respondents did not provide answers on how to enhance registration or data processing. Respondent answers were categorized and are summarized in Table 4. These answer categories are used to structure the discussion. The discussion is based on these survey responses because of the importance of proportionality and subsidiarity in the European Union. This means that in domains in which the European Union does not have exclusive competence, member states are expected to initialize change and that EU action shall not exceed what is necessary to achieve the objectives of the Treaties. In other words, a discussion on how to enhance TDI registration and data processing, can only be initiated based on the perspectives of national experts in the field.

Discussion: A heated debate

In light of public interest, our results demonstrate that over half of the 2014 national drug reports observe trends in treatment demand and highlight important social correlates to harmful substance use and treatment demand among MEM. Nevertheless, the reports insufficiently contextualize specific numbers or substantiate and explain trends clearly to be able to act upon them. Eastern and Central European countries clearly observe disparities among Roma and general populations but cannot pinpoint reasons and ways forward because of inconsistent data and a lack of harmonized processing guidelines. This is similarly the case for Russian speakers in Latvia, Estonia, Germany and more recently in France (Jauffret-Roustide, Serebroskhaya, & Chollet, 2017) as well as non-nationals in Cyprus, Ireland, Luxembourg, Hungary, Austria, Sweden, and Italy.

Moreover, persons defined as having a migration background (at least one parent with other nationality/birthplace) are identified as specifically vulnerable in Belgium and Germany. Lastly, it should be mentioned that trends in treatment demand among the growing group of intra-European migrants, asylum applicants and undocumented migrants in Western, Northern and Southern European countries are left unstudied in the 2014 country reports. Indeed, the data used in these reports dates back about five years at the moment of writing. Nevertheless, new (intra-European) migration movements had already initiated due to the accession of Central and Eastern-European countries in the EU in 2007. Although irregular third country arrivals in the EU only peaked in 2015, the number was already growing in 2013.

Even though the research domain of SUT among MEM is still limited in the European context there are clear indications of disparities in these populations across the EU-28 member states. Subsequently, ethnicity and migration related data gathering in TDI could be argued for on the basis of public interest if privacy regulations are respected. In what follows, we first elaborate on the ways survey respondents believe monitoring MEM presence and trajectories in drug treatment could be enhanced and then discuss the importance of purpose specification and subsequent informed consent.

Sensitive and prohibited?

Three respondents indicated in the survey that this type of data collection is sensitive or prohibited in their country. This type of data collection is indeed the subject of heated debate in Europe, mainly because of its ethical implications for the populations being registered and “categorized” (Jacobs et al., 2009). The main argument of proponents of migration and ethnicity related data gathering is based on a perceived need for documenting (in)equalities related to (health) rights of population groups (Krizsán, 2001) whereas opponents mainly refer to concerns about privacy (Should treatment data aggregated at migration or ethnic background level be made available and if so to whom?) and self-determination (What will be the consequences of lumping individuals together in categories of persons with a migration background?) (Varcoe, Browne, Wong, & Smye, 2009).

Especially in the health domain it has been argued that it 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 et al., 2017). We have argued elsewhere that the analysis of static ethnicity related categories in epidemiological research that lacks the consideration of correlates and consequent analysis of cross-categories can indeed work to reify and stigmatize subpopulations (De Kock, Decorte, Vanderplasschen, Derluyn, & Sacco, 2017).

However, it appears that European member states interpret the GDPR and its predecessors very differently and as a result only a minority registers such data in health, census or other registries. The main problem appears to be that national legislation and resultant regulations do not contain specified definitions of the equality grounds (i.e., "race," "ethnicity"). As a consequence, member states insufficiently regulate the indicators and processing of equality data in the light of public interest. It should be noted that in the EU-28 only two countries - UK and Ireland - collect data on ethnicity with the aim to implement positive action (Escafré-Dublet & Simon, 2011).

In any case and in conformity with the GDPR, National Data Protection Authorities should regulate and control compliance with the lawfulness of data processing and should supervise that "processing is necessary in order to protect the vital interests of the data subject or of another natural person" (GDPR, 2016, art. 6). Furthermore, the GDPR requires that before data registration and processing takes place, a Data Privacy Impact Assessment be made and that Data Protection Officers at the organizational level secure that no direct or indirect harm is inflicted upon data subjects as a result of data registration or processing.

This implies that advocates of minority rights and anti-discrimination policy on the one hand and proponents of personal data protection on the other hand should not per definition take opposite stands. Moreover, protecting individual privacy and the right to equal treatment can be considered 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.

Reliable indicators in TDI

Five respondents indicated that more reliable registration could enhance monitoring MEM in European SUT. The fact that nationality was most reported by survey respondents to be registered in national TDI registries is a direct result of its inclusion in the second TDI protocol. The strength of already having the nationality variable integrated in at least one third of the EU-28 national TDI protocols should not be underestimated, considering the compatibility needs when making changes in a registration protocol in the interest of longitudinal analysis (Krizsán, 2001). With sufficient coverage (both in terms of client totals as in terms of treatment services covered) it can give insight in the specific group of first generation migrants in SUT (i.e., an estimated half of the 2018 MEM population in Belgium). Even if coverage is limited, member states could choose to monitor registration shortcomings scrupulously in order to report on parts of their TDI datasets. The nationality indicator does need rewording in specific national contexts (and with answer options conforming to ISO 3166 including a "none" option) because in some EU countries "nationality" could be interpreted as an ethnicity related indicator (i.e., Cyprus, Romania, Estonia).

Nevertheless, the nationality variable is indeed a flawed proxy to cover all migration and ethnic backgrounds because it does not capture the complexity of migrant generations or (multiple) self-definitions (Hunt, 2017; Kolind & Hunt, 2017). Additionally, the "European/non-European" indicator reported to be used in at least three member states is insufficiently valid considering the changing composition of the EU member states and the difference between countries pertaining to the EU on the one hand and European countries on the other hand.

A way forward concerning monitoring second generation migrants could be the inclusion of an indicator concerning birthplace of mother to the example of European surveys (i.e., European Labor force, health and social surveys, EU-SILC) and a language related question (mother tongue, home language [i.e., International PISA questionnaire] and possibly a third language related question). A minimum, medium and in-depth registration scenario for TDI is subsequently proposed in Table 5 below.

The use and processing of these indicators in European surveys and their acceptance in the EU-28 member states that partake in the surveys, indicates validity and conformity vis-à-vis current national privacy regulation. Additionally, the use of these indicators could be generalized to other registries (i.e., national health surveys) which could contribute to data comparability and multi-indicator analysis. These indicators are not intended to capture self-identification but rather to capture the situation of objectifiable social groups. It should be noted that self-identification (see below) is an added value for qualitative understanding but has been described in literature to be insufficiently discriminatory to capture migration backgrounds (Perrin, Dal, & Poulain, 2015).

A second way forward is the consultation of Eastern and Central European member states to collaboratively (with member state representatives and targeted populations) consider the inclusion of ethnicity related (in combination with other) indicators. This issue will become increasingly important because inequalities among Roma populations are no longer only a concern in Central, Eastern and Baltic European countries but increasingly require attention in Western, Northern and Southern European countries too (AC Company, 2005; ERRC, 2017).

Table 5. Proposal for minimum, medium, and in-depth registration.

Type of registration	Number of indicators	Indicators	Analytical capacity
Minimum	2	Nationality Country of birth	National/non-national specifiable per country First migration generation
Medium	3 or 4	Country of birth mother (Country of birth father)	Second migration generation
In-depth	5 or 7	Mother tongue Home language A third language related question	Integration Health access Ethnicity related language use

Concerning registration of the indicators, **self-definition** is considered to do most justice to the right of self-determination and to define ethnicity and migration background (Aspinall, 2017; Krizsán, 2001; Varcoe et al., 2009). The definition of ethnicity and migration background by thirds such as the police and justice actors should therefore be evaluated critically because the resulting numbers may not be correct and possibly harm the data subject and/or depicted populations (Krizsán, 2001). However, self-definition complicates data collection and analysis (lack of uniform and exclusionary units of analysis), especially in the SUT context. Also, it has been argued that strict self-definition is arguably the best method or sufficiently valid when the purpose is to analyze the impact of perception by others (i.e. perceived and structural discrimination) (Ringelheim & De Schutter, 2010, p. 135).

Our results demonstrate that the majority of TDI data is registered by means of the provider ticking predefined categories. The option of open-ended self-identification alongside the choice of predefined categories, is a valuable addition to ticking predefined categories, in line with the right to self-determination.

Multivariate analysis in TDI datasets

Two respondents indicated that the in-depth analysis of current TDI datasets will be sufficient to gain more insight into treatment demand among MEM populations. Indeed, some current TDI datasets already hold the potential for informing positive action towards certain MEM populations. However, identifying complex patterns and trends in treatment demand and nuancing the identification by means of migration and ethnicity related indicators, requires intersectional analysis (Agirdag & Korkmazer, 2015; De Kock et al., 2017). Indeed, only relating identified populations in one-on-one relations to health risks, risky drug use behavior, drug-related crime or prison-populations is insufficient because it provides little information on real treatment demand trends. Furthermore, it could in fact harm the population being described by adding to stigma or discrimination. Madeira, Pereira, Gama, & Dias (2018) for instance found that perceiving MEM as a threat or risk to public health (i.e., concerning HIV among high drug users as mentioned in some reports) is indicative for health providers self-reported bias in treatment, a bias directly related to lower quality treatment.

This implies the analysis of two sets of combined variables. First, the processing of at least two and preferably more reliable migration and ethnicity related variables (see Table 5) will allow for contextualizing the seemingly static categorization of individuals in groups or populations. Indeed, individual data should not be used only to characterize a group but also to identify combined characteristics as well as longitudinal trends and subgroup changes.

Second, migration and ethnicity related variable analysis should be studied intersectionally in combination with covariates such as living situation, education, employment and gender in relation to treatment demand (Giritli Nygren & Olofsson, 2014). This combined study will give in-depth insight into both the construct of ethnicity, the impact of migration/ethnicity and might broaden micro-centred epidemiological studies by explaining treatment demand trends (Carliner, Delker, Fink, Keyes, & Hasin, 2016; Kapilashrami, Hill, & Meer, 2015). The "guide for assessing health needs and health protection resources" developed with the support of the European Health program (Makonnen, 2016) could be a valuable resource in addition to the EMCDDA processing and reporting guidelines.

Moreover, it should be noted that none of the 2014 national drug reports compare treatment demand to population based prevalence rates among MEM besides the German and the Swedish reports. In this context, Ritter et al. (2019) argue for the deployment of models that include treatment demand and need (substance use prevalence) when estimating real treatment gaps for the purpose of local treatment planning. These models should also allow us to distinguish between drug types, age groups and drug use severity (Ritter et al., 2019, p. 25) and focus on subsequent "tiered" modeling based on multi-indicator analysis for targeted service planning.

A way forward in the European context could be to a priori add additional purposive sampling strategies to the National Health Surveys in order to routinely collect data in representative MEM samples on (spectra from harmful to recreational) substance use prevalence or setting up targeted surveys that complement general population studies, to be included in the national drug reports. Furthermore, the currently used indicators (i.e., nationality, birthplace, EU/not-EU) should always be contextualized by means of representation in the general population or other population based studies. It would also be informative if country reports could inform consequently on why specific information is not provided (i.e., the UK report mentioned that representative datasets were not available).

The use of unique identifiers in the TDI datasets

The use of unique identifiers in the TDI datasets was suggested by three survey respondents to better monitor treatment demand among MEM. If a unique identifier is not available (i.e., first letters of name and first two numbers of birthday), data cannot be analyzed at the individual disaggregated level (disabling the study of correlates). The growing group of undocumented migrants for instance that do not possess NIN (yet) are not identifiable in datasets if NIN is the only identifier used. A last way forward in order to not rely on NIN, could thus be the consideration to create unique (pseudo)anonymized TDI identifiers for each client.

Lastly, database linkage (i.e., TDI and population registries) for gaining insight in treatment demand, as suggested by two respondents, could be problematic and holds the risk of harmful use of datasets (i.e., small and identifiable subsets, opening the possibility for linkage to judicial databases in insufficiently regulated data environments). Database linkage is reported to be rare in the domain of ethnic data collection in Europe (Farkas, 2017a,b,c) and to our knowledge limited in the drug treatment domain (Van Baelen et al., 2018). Moreover, linkage of population-based administrative data is limited by many methodological challenges such as bias from linkage errors located in the data linkage environment, privacy preservation procedures in data preparation and the choices of linkage methods.[23]

Additionally, in the niche domain of MEM in drug treatment, database linkage is likely to be unreliable because it requires clients to be registered with a unique identifier that is equally identifiable in other databases such as a national identification number (NIN). Persons with a different nationality have been reported to be more often registered without a NIN (i.e., 40.72% non-identifiable third country and 37.51% European clients in 2012–2014 datasets compared to 23.86% of Belgian clients).

Although database linkage could offer insights in high quality subsets of data, it would be advisable at this moment to limit data analysis on this specific topic only to TDI datasets. Only member states that have high quality datasets (valid indicators, coverage etc.) and that provide sufficient safeguards for the privacy of data subjects should consider linkage of TDI to other datasets for further analysis.[24]

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[23] In the Netherlands for instance some argue that while ethnicity is included in the health domain to combat disparities, it might be intertwined with and contribute to these very societal dynamics which produce health inequalities. This was similarly argued for by Epstein (2007) in stating that the political context in the US shaped scientific practices related to ethnicity and race in health, as exemplified in US based epidemiological studies (De Kock et al., 2017).

[24] More information on TDI database linkage in other domains can be found in Van Baelen et al. (2018).

"Do no harm": Purpose specification and informed consent

Rallu and colleagues (2004) argue in favor of data collection regimes that do not simply aim to document and count but that clearly and explicitly aim at implementing positive action in the light of equality regulations (in Escafré-Dublet, 2011). Indeed, the raw data can be misleading if the data are not considered in relation to other characteristics such as age, sex and SES (WHO, 2010, p. 8). Subsequently, it is essential to consider **purpose specification** scrupulously.

The TDI protocol 3.0 describes the purpose of data collection as follows: "gain insights into the characteristics, risk behaviors and drug use patterns of people with drug problems in the community, and to help to estimate trends in the extent (prevalence and incidence) and patterns of problem drug use" (2012, p. 17). One could however argue to take this a step further and include, to the benefit of (and to explicitly protect) the populations involved (and their subsequent willingness to provide data) the purpose of combatting inequities and disparities. The 2018 UK "National Drug Treatment Monitoring System" protocol for instance, introduces with the following sentence: "Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities." This addition to the protocol could be decided upon on the level of a member state or the EU level.

Purpose specification in turn is closely intertwined with **voluntary informed consent** by the data subject. Studies do indeed observe that persons identifying with stigmatized populations are often "reluctant" to identify as such out of fear of stigmatization (Varcoe et al., 2009). This in turn results in their underrepresentation in statistics. However, the nature of data collection methods and use of data without proper purpose specification (i.e., invalid proxy by interpreting only language to identify "ethnicity," "choosing" nationality in census contexts, involuntary ethnicity registration in police statistics etc.) are likely to influence this suspicion.

Moreover, the 2015 Eurobarometer asked whether individuals would support providing personal details on an anonymous basis if it could help to combat discrimination in their country and 72% were in support regarding data on "ethnic origin" (Makkonen, 2016). Although individuals with a Roma background were less favorable, still over half of the surveyed respondents with this background, were in favor. Although it can be time intensive for service providers, it is advisable for the national TDI protocols to include a clear statement on purpose specification to support the service provider responsible for registration in explaining it to the client.

Purpose specification and informed consent could thus be translated in 1) specifying the purpose of TDI (at member state or EU level) and 2) involvement of target populations in defining variables and subsequent involvement of, for instance, the ombudspersons for Minority Rights in the member states. Indeed, the quality of the data highly depends on the data supplier's interest in the produced data (Krizsán, 2001, p. 281).

Conclusion

Treatment demand trends and socio-economic contexts of MEM populations are very diverse across the national contexts of the EU-28 member states and consequently do not always allow for comparisons. However, the current study demonstrates that the TDI dataset – as a result of the efforts of standardization initialized by the Pompidou group over two decades ago and continuously sustained by EMCDDA and the National Reitox Focal Points – provides a valuable tool when it comes to identifying treatment demand trends across the EU-28 countries. The existence of this dataset enables knowledge transfer across the countries and informs joint policy planning without interfering with the principles of subsidiarity and proportionality.

Although some respondents expressed legitimate concerns related to privacy legislation, the majority of survey respondents in the current study formulated complementary measures to enhance trend monitoring concerning MEM drug treatment demand. Because of the importance of the principles of subsidiarity and proportionality in the European Union, I focused the discussion of the results on the suggestions made by survey responses of Reitox National Focal point staff members. Departing from the idea that drug (treatment) policy is best based on "tiered modeling" (Ritter, 2019), this paper suggests to focus prioritarily on the use of reliable migration and ethnicity related indicators in TDI and other drug related indicator protocols, multivariate and cross-category TDI analysis, the use of unique identifiers and purpose specification in the TDI protocol.

Providing guidelines and support on how the existent data can be enhanced, processed and safeguarded as well as continuously improving the quality and coverage of the dataset might allow the member states to relate prevalence rates (health surveys), treatment demand and data on social correlates to identify meaningful trends and inform targeted service planning.

Processing TDI data should always comply with the GDPR, thereby avoiding increased stigma of specific populations and preventing harm for data subjects resultant of data collection and processing. In the light of growing political conservatism and identity politics in the European Union, the GDPR requirement of providing a Data Privacy Impact Assessment and consequently identifying safeguards to reduce the risks of migration and ethnicity related data registration and processing, is key. This paper could be a point of departure for developing such an Impact Assessment.

In conclusion, this paper argues, together with other European scholars and policy makers (Farkas, 2017a; Ringelheim, 2011) for the necessity to include scientifically sound migration and ethnicity related indicators that allow us to monitor (changing) MEM (sub)populations in the drug treatment domain and for processing this data intersectionally, in light of the specific purpose of serving their (public) interest.

Acknowledgments

Many individuals have contributed to this work and helped in conceptualizing the discussed issues, although they may not agree with all the views, interpretations and conclusions in this paper. Lies Gremeaux and Jerome Antoine (Sciensano, Belgian National Focal Point) provided very useful input and comments to the early and advanced versions of this paper and were key in disseminating the survey to National Reitox Focal Points. Hannah Vermaut (UNIA, Belgian Equality Body) provided comments on an early version of this paper based on her insight and expertise.

Declaration of interest statement

The views, interpretations and conclusions set out in this publication are those of the author and cannot be considered to reflect the views of the Belgian Science Policy Office. The answers of staff members of the National Focal Points do not necessarily reflect the official position on the discussed topics of these respective National Reitox Focal Points.

Funding

The author was funded by a grant of the Belgian Science Policy Office (DR/84 - MATREMI: Mapping and Enhancing substance use treatment for migrants and ethnic minorities).

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