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## Access to healthcare for undocumented migrants with communicable diseases in Germany: a quantitative study

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**Background:** Migrants without residence permits are *de facto* excluded from access to healthcare in Germany. There is one exception in relevant legislation: in the case of sexually transmitted infections and tuberculosis, the legislator has instructed the local Public Health Authorities to offer free and anonymous counseling, testing and, if necessary, treatment in case of apparent need. Furthermore, recommended vaccinations may be carried out free of charge. This study intends to comprehensively capture the services for undocumented migrants at Public Health Authorities in Germany. **Methods:** An e-mail survey of all Local Public Health Authorities ( $n = 384$ ) in Germany was carried out between January and March 2011 using a standardized questionnaire. **Results:** One hundred thirty-nine of 384 targeted local Health Authorities completed the questionnaire (36.2%), of which approximately a quarter ( $n = 34$ ) reported interaction with ‘illegal’ immigrants. Twenty-five authorities (18.4%) gave the indication to carry out treatment. This outpatient treatment option is mostly limited to patients afflicted with sexually transmitted infections with the distinct exception of human immunodeficiency virus/acquired immune deficiency syndrome. **Conclusions:** The study highlights the gap between legislation and the reality of restricted access to medical services for undocumented migrants in Germany. It underlines the need of increased financial and human resources in Public Health Authorities and, overall, the simplification of national legislation to assure the right to healthcare.

## Introduction

According to the latest published estimates, the number of undocumented migrants (UDM) in the European Union ranged between 1.8 and 3.8 million in 2008.<sup>1</sup> The residence status is an essential determinant for access to healthcare in European countries: although international agreements grant them the right to healthcare services,<sup>2–4</sup> UDM face serious obstacles in most countries.<sup>5</sup> According to national law, in many countries, UDM at least have access to emergency care, but the implementation and the access to everyday practice of health services are prevented.<sup>6–12</sup> Therefore, the provision of healthcare for migrants without residence permits continues to be an important topic in many parts of the world. In Germany, the number of third country

nationals without a valid permit was estimated between 100 000 and 400 000 in 2010, around 0.12–0.48% of the German population.<sup>13</sup>

Similar to asylum seekers and refugees, UDM are entitled under national law to receive basic medical care in case of pain, acute diseases or preventive care like vaccinations.<sup>14</sup> However, the German aliens’ legislation undermines the right to healthcare access for UDM: if a person without any kind of residence status is not able to afford private payment for healthcare, as is frequently the case, she/he is obliged to seek out a social welfare office first. There he/she must obtain a healthcare services eligibility certificate to receive free treatment.<sup>14</sup> During the process of authorization, the public official finds out about the applicant’s undocumented residence; he must report to the Aliens

Department ('Ausländerbehörde') which, subsequently, informs the police.<sup>15</sup> At that point, the UDM is at high risk of being deported to the country of his or her origin. There is, however, one important exception: the experiences from the human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) pandemic in the 1980's demonstrated the importance and success of voluntary 'low-threshold' facilities in contrast to the compulsory approaches previously applied in the control of epidemics.<sup>16</sup> Based on this experience, legislation on providing counselling and testing for patients with sexually transmitted infections (STI) or tuberculosis by local Public Health Authorities (LPHAs, 'Gesundheitsämter') was adopted in 2001 in the German Protection Against Infection Act ('IfSG', 'Infektionsschutzgesetz').<sup>17</sup> In Germany, the medical care system is mainly composed of hospitals and outpatient treatment arrangements financed by health insurances. As the least important pillar in the German healthcare system, LPHAs are under the responsibility of each administrative district ('Landkreis'), which then plays the main role in preventing infectious diseases, detecting infections at an early stage and preventing them from spreading to the general public. The Act includes the possibility of anonymous tests in every LPHA in each administrative area, funded by public resources in cases of apparent need. In addition, LPHAs may provide outpatient treatment in individual instances.<sup>17</sup> Moreover, the LPHA may carry out recommended vaccinations free of charge. LPHAs are financed through taxes; however, they receive only a small share (about 0.8%) of the total budget earmarked for the health system.<sup>18</sup> Medical confidentiality is prescribed by law<sup>19</sup>; hence, UDM could access medical care without fear of deportation after treatment. Because of altered legislation, this could become vitally important for migrants without access to regular healthcare. The legislator's official reasoning stresses not only the epidemiological need but also a 'social complementary function' of the LPHA with a particular view on specific population groups excluded from regular healthcare, such as the UDM. However, *de facto* it is up to the districts to deal with the implementation details and the diversity of medical services. This article examines the current practice of healthcare for UDM with communicable diseases in Germany. It explores whether healthcare for UDM is provided on a local level outside of the regular health system and under the conditions of the current complex body of legislation. This is the first quantitative study that intends to comprehensively capture the services for UDM in German local Health Offices.

## Methods

The survey was conducted through the email distribution of a 10-page questionnaire. The nationwide survey targeted all 384 LPHAs. Aiming to achieve a maximum response rate, methodological remarks made by Dillman<sup>20,21</sup> have been considered within the planning and implementation of the survey. Accordingly, all administrative heads were approached and asked to forward the questionnaire to the staff member of the institution who would most likely have had contact with UDM. All administrative heads were identified over the institutions' websites and received a personal letter. Further support was requested from the German Cities' Council ('Deutscher Städtetag') that represents all German communities. Even after the Council had been approached twice, it did not respond to the authors requests. The questionnaire was developed for this study and pre-tested in cooperation with employees of five LPHAs. The considered health authorities were randomly selected and are located in smaller towns and in larger cities. Among the institutional staff positive and negative attitudes were encountered towards the topic of investigation. Following the completion of the questionnaire, all pre-testers were called and asked to provide open and frank feedback about clarity, logical flow and

comprehensiveness of the questionnaire, providing the opportunity of a 'Retrospective-Think-Aloud'. During the pre-test, the author was advised to limit the study to email distribution (rather than using regular mail or fax) by LPHA staff. It was expected that email distribution would raise the willingness to participate. Eventually, the questionnaire underwent a final revision to accommodate the suggestions made at the pre-testing stage. The final version of the questionnaire contained 20 questions with the following emphasis: (i) contact, treatment and documentation; (ii) handling of patients without legal residence status; (iii) relevant activities of the LPHA and (iv) assessment of the local situation. Most points can be characterized as closed questions with multiple choice response options. Almost all questions had a commentary option. The questionnaire concluded with an open question. Participants were asked to share their ideas on opportunities for improvement with respect to the medical service delivery to UDM at the respective LPHA. Regardless of the responses given in the questionnaire, the participating health authorities were asked to share records of an individual case, provided that the responding employee had the authorization to share information about personal professional experience with UDM. All respondents were offered to receive the results of the study upon request. In the absence of any remuneration, this was intended as an incentive for participation. The accompanying letter explicitly asked the responders to complete the questionnaire regardless of their actual experience with UDM. The questionnaire's configuration followed the advice of experts for empirical research. This included an appealing front cover, a clear layout and an optimal scope for the questionnaire. The time for the completion of the questionnaire varied between 10 and 15 min, depending on the extent of interaction with UDM and the type and scale of services provided. All questionnaires were anonymized. Also, anonymity was guaranteed, so that individual questionnaires could not be linked to particular LPHAs. Return of completed questionnaires via email, fax or mail was offered. The questionnaires were distributed in mid-January 2011. Participants were asked to return the completed questionnaire within 6 weeks, and a reminder was sent out 2 weeks after the deadline. Another 2 weeks later, a personal reminder and another copy of the questionnaire were sent out—asking the LPHAs to return the answers within 3 weeks. Because of the limited increase in the response rate following the first reminder, the authors abstained from sending out yet another reminder. Though Dillmans 'Tailored Design Method' highlights the relevance of financial incentives, this was not provided. Neither would the financial resources of the study allow a respective approach nor was it considered appropriate, as the institutional policies of the LPHAs would not permit their staff to accept any grants.

## Results

### Response rate

One hundred thirty-nine of 384 targeted LPHAs completed and returned the questionnaire (36.2%). This number falls short of the 44% response rate of the last comprehensive survey of all LPHAs in 2001, which was supported by the Federal Ministry of Health.<sup>16</sup> There was no systematic East-West difference perceived, yet substantial differences between the response rates of different federal states were observed. Disregarding few exceptions, mainly the LPHAs of three federal states denied participation with reference to the reluctant attitude of the German Cities' Council. The return rate of the targeted LPHAs in small cities and of those located in large cities statistically represents their share of all LPHAs across Germany. The return rate of LPHAs in metropolises with  $\geq 500\,000$  citizens ( $P < 0.05$ ) exceeded the statistically representative number (table 1). Overall, the LPHAs located in main cities, representing a population of about 11 million people (13.4% of the

German population), had a response rate of 70% and are thus overrepresented in this survey.

### Contacts to UDM

Approximately one-quarter (24.6%) of the responding LPHAs reported having contact to 'illegal' immigrants. LPHAs located in cities with more than 100 000 inhabitants have significantly more contact with migrants without legal residence status than LPHAs located in smaller cities ( $P < 0.05$ ). Nineteen percent of these authorities stated that they record the legal residence status of their clients. The majority, however, was unable to reliably quantify the contacts with UDM and solely provided personal estimates. Twenty-four of the 34 LPHAs which reported having contact indicated the number of UDM that received medical services in 2009. Less than one-quarter of the responding LPHAs have shown efforts to make medical testing and counselling services for 'illegal migrants' known to the target group. More than two-thirds (71%) of the LPHAs that actually showed an effort also reported contact with UDM. The overwhelming majority (91%) of the LPHAs that did not interact with UDM failed to engage themselves in specific outreach campaigns. The survey showed a correlation between city size and outreach campaigns: The bigger the city, the more likely efforts are being undertaken to reach out to this vulnerable group.

### Treatment

Twenty-five LPHAs (18.4%) reported to have provided treatment in the framework of the 'IfSG', whereas the majority of 111 institutions (81.6%) denied this. Of the 25 institutions reporting to have provided treatment, 14 stated that there had been UDM among those treated, whereas five did not respond and six denied this.

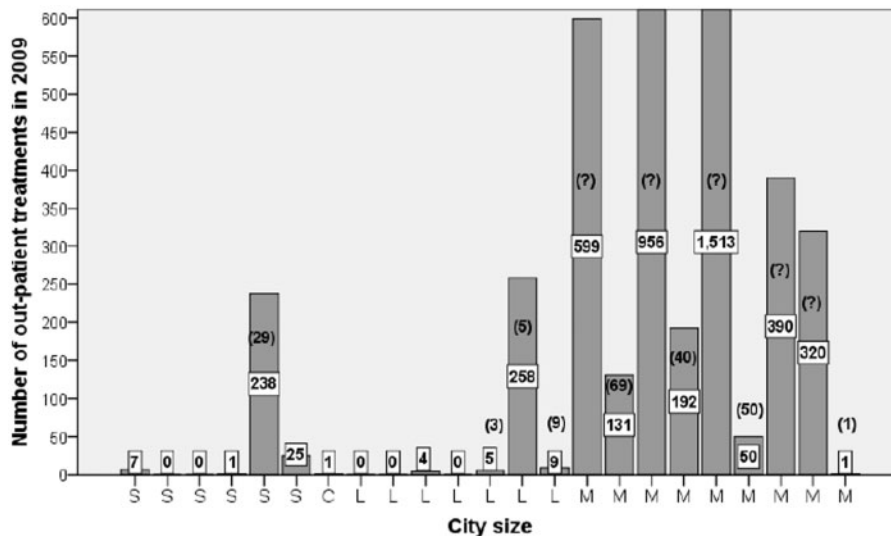
**Table 1** Response rate according to city size

City size (inhabitants)	Number of addressed LPHAs	Number of responses	Response rate
Small town (<50 000)	213	74	35.2%
City (<100 000)	75	18	22.7%
Large city (<500 000)	66	24	36.4%
Metropolis ( $\geq 500 000$ )	30	21	70%
Unknown origin		2	
Total	384	139	36.2%

Furthermore, 53% of the LPHAs reporting interaction with UDM also reported provided treatment. The survey results show that those LPHAs are largely located in the biggest cities (metropolises) and only very few of the health authorities in areas with population numbers below 100 000 carry out treatment. If all patients who were treated in the framework of the 'IfSG' regardless of their legal status are considered, 23 institutions reported patient numbers between 0 and 1513 (figure 1). Patient numbers of 50 or more are predominantly reported from institutions located in metropolises. The survey also reveals that anonymous HIV counselling and testing make up the largest share of the services provided. The majority (91.6%,  $n = 120$ ) of the responding LPHAs pointed out that 'free of charge and anonymous HIV-testing' is provided.

### Counselling

One hundred thirteen institutions explained what counselling in the field of STI and HIV/AIDS would encompass. More than half (51.3%) of all LPHAs selected more than one option; 55.8% of all responding LPHAs reported referrals to aid organizations and 37.2% referrals to other service providers for legal counselling. As much as one-fifth ( $n = 23$ ) of 113 authorities had offered or would offer outpatient treatment (20.4%). Fifteen of these 23 LPHAs had already reported that they had carried out ambulatory treatment. If one considers the additional comments section to the questionnaire ( $n = 58$ ), some reoccurring remarks warrant further attention as they provide insight into common practices of the LPHAs: frequently, reference was made to 'arrangements with specialized physicians or hospitals' ( $n = 20$ ), and it was pointed out that decisions would be made on a case by case basis without a standardized procedure ( $n = 9$ ). The problem associated with the treatment of HIV/AIDS patients is explained: 'HIV-treatment cannot be made available because of its prohibitive costs'. Some notable differences exist between tuberculosis and STI regarding the services offered to UDM. Applying the chi-square test, statistically significant differences can be found only for outpatient treatment services: These depend on contacts to UDM or the number of treatments already provided ( $P < 0.05$ ). In cases of tuberculosis, outpatient treatment is offered frequently (chi-square test:  $P < 0.05$ ). However, regional disparities exist: half of the LPHAs providing outpatient treatment for tuberculosis patients ( $n = 32$ ) have their seats in cities with less than 100 000 inhabitants. STI (including HIV/AIDS) ( $n = 23$ ) are treated by significantly fewer



**Figure 1** Number of outpatient treatments in 2009 by LPHAs ( $n = 23$ ). S, small city; C, city; L, large city; M, metropolis. (), number of outpatient treatments of UDM in 2009; (?), number of treatments of UDM is unknown

**Table 2** LPHAs categorized according to their approach to UDM

Categories	I	II	III
Title	No contact, lack of awareness	Rare contact, little knowledge	Frequent contacts
Description	Have never had contact before, not yet thought about it: ergo no supply structure	Rare contact to immigrants, specific knowledge about legal environment for UDM does not exist, decisions are made on a case-by-case basis	Frequent contacts to patients without health insurance, UDM are only one group among other vulnerable people
Dimensions	(i) <100 000 inhabitants (ii) No contact (iii) No outreach campaigns	(i) <5 to 10 contacts or treatments/year (ii) Case-by-case decisions (iii) Do not gather information on clients' residence status	(i) ≥100 000 inhabitants (ii) ≥5 contacts with UDM in 2009 (iii) Conduct outreach campaigns
Additional clustering	(iv) No in-house treatment (i) Small city (80.6%) (ii) Head of office responded (85.9%)  (iii) No referral or affiliations with other institutions or organizations (iv) Duty to report UDM to foreigners' office is answered in the affirmative or not clear (77.1%)	(i) Small town or rural area (ii) Contacts with UDM in form of anonymous testing (iii) No treatment of other diseases	(iv) Do not share information with police (i) Metropolis (ii) In-house treatments of STIs and tuberculosis (59.1%) (iii) In-house treatments of other diseases  (iv) Good evaluation of the situation in the own department (at least to a certain extent) (80%)
Frequency of total (n = 138)	72	18	22
Percentage	52.2	13	15.9

LGHAs (21.7%) in smaller cities. HIV/AIDS and STI patients are more frequently referred to aid organizations than tuberculosis patients.

### *Duty to report (section 87 Germany's Residence Act)*

One hundred eight LPHAs chose to respond to the point regarding the sharing of their clients' personal data with the foreigners' office when they suspected the person of illegal residence in Germany. The majority denied the practice or elaborated that data would be passed on only after consultation with the patients ( $n = 50$ , 46.3%), though 15 authorities confirmed sharing data (13.9%). In addition, 43 authorities made use of the comments option. Forty-two remarks fall under one of the following three categories: (i) no experience with UDM, (ii) case-by-case decision and (iii) due to the anonymous test and counselling service, the residence status of the clients is unknown. The majority of the LPHAs (26 out of 42) stated that they are not able to answer the data sharing question as they lack relevant experiences. Authorities that provided outpatient treatment passed on patient data less frequently ( $P < 0.05$ ; for overview of results see table 2).

## Discussion

This survey's results show the gaps in healthcare provision for UDM, even for state covered communicable diseases. Overall, few LPHAs have contact to UDM, and a minority of them provides treatment at their facilities. Also, HIV/AIDS patients cannot be treated or financed for a longer period. This shows that the German model, which mandates local health authorities to bridge the healthcare gap for population groups excluded from the regular system, has a limited effectivity even concerning its main targets: STI, tuberculosis, and prevention of communicable diseases (vaccines). The survey results might over-represent the number of interactions between LPHAs and UDM. LPHAs from large urban centres that play a more prominent role in the provision of healthcare to UDM compared with those in smaller towns and cities returned the questionnaires more often. The low response rate in some federal states prevents a description of the respective local situations. Nevertheless, neither informal expert interviews nor the scientific literature suggest that the recent situation would differ from what was found in the participating federal states. Those LPHAs that did not complete the questionnaire are mainly located in rural areas with low population densities. Therefore, it is likely that a higher response rate would not create substantially divergent results. It can

be presumed that a higher response rate would predominantly have raised the number of completed questionnaires from those LPHAs with little or no contact to UDM. A response rate of  $n = 104$  from those LPHAs without UDM contact can still be considered as sufficient. Furthermore, in the light of limited resources, the actual investigation may have been perceived as an offense to current structures and practice. The skewed response rate might be caused by the fact that LPHA employees in smaller towns and cities often have limited legal awareness about the entitlements of UDM. The complex body of legislation and the implicit threat of deportation for UDM induce uncertainty for duty bearers and UDM: the duty bearers in many cities and towns remain unclear about their obligation to provide services, eliminating the possibility of proactively raising awareness among the intended beneficiaries. Without knowing about their entitlements, vulnerable groups remain excluded from all health services. The impact of an unclear legal environment on the usage of healthcare services by UDM is also described for other European countries.<sup>22–26</sup> Torres-Cantero *et al.*,<sup>26</sup> for example, found that after legal changes in Spain with free medical care at equal terms for all immigrants, the same level of health services utilization existed between legal or UDM.

Even though LPHAs are local government organs, they are not allowed to pass on information about their patients to other state bodies such as the public authorities responsible for foreigners as this would violate medical confidentiality. In reality, concerns about the administrative law might overshadow all other legal and ethical aspects. Additionally, one needs to be mindful that the German debate about 'illegal immigration' is ideologically charged and highly polarizing.<sup>27,28</sup> This was expected to have an impact on the return rate of the quantitative survey as well, which at the end reached a satisfactory 36%.

The exclusive focus on the medical response to a diagnosed ailment often proves to be insufficient as underlying problems are ignored. The health status of immigrants could be improved more effectively with preventive care aimed at vulnerable groups such as children and pregnant or breast-feeding mothers. Chronic health issues and living conditions need to be considered in the counselling and medical treatment process. With regard to STI, treatment at LPHA facilities was mainly provided by the LPHAs in the big cities or metropolises. The treatment of tuberculosis lacked a similar divide. One reason could be the long tradition of care giving by the Public Health Services to people suffering from tuberculosis that dates back almost a century and transcends the boundaries of urban life.<sup>29</sup> Another reason could be the more

traditional family structure in rural areas with infrequent occurrence of STI and a higher level of stigmatization of affected persons. Predominantly, the LPHAs located in smaller towns pointed out their limited financial and human resources. They also put forward their perception that there is no demand for services beyond those currently provided. The situation for those infected with HIV/AIDS proves even more worrying. UDM are not receiving treatment for the virus, at least not for an extended period. Also, early diagnoses and a timely treatment start are in no way ensured for UDM. Immigrants that lack health insurance have to be aware of the testing facilities in the public health centres, which are free of charge and anonymous. They require counselling that includes treatment options in the event of a positive test result.

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### Key points

- Complexity and ambiguity of legislation hinder access to health service.
- UDM infected with HIV/AIDS are *de facto* excluded from treatment for the disease.
- Pro-active awareness and nationwide promotion of the Public Health Authorities' services are essential for early diagnosis.

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