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Monitoring refugee health

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Kayvan Bozorgmehr^{1,2}, Claudia Hövener³

¹ Department of Population Medicine and Health Services Research, School of Public Health, Bielefeld University, Bielefeld, Germany

² Section for Health Equity Studies and Migration, Department of General Practice and Health Services Research, University Hospital Heidelberg, Heidelberg, Germany

³ Robert Koch Institute, Berlin
Department of Epidemiology and Health Monitoring

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Monitoring refugee health: Integrative approaches using surveys and routine data

The Federal Health Reporting of the future will face the challenge of considering not only social developments such as demographic ageing but also the increasing diversity of society, for example with respect to migration. Since the first focus report on 'Migration and Health' has been published by the Federal Health Reporting in 2008 [1], major advances have been made in the underlying data sources. Health monitoring at the Robert Koch Institute, amongst other efforts, has been further advanced to increase its sensitivity to migration [2]. However, the inclusion of certain migrant groups has remained a challenge. Representative health studies currently do not systematically take into account migrant workers in precarious employment, people without an official residence permit and refugees. Particularly in the case of refugees, there are obvious structural weaknesses that have resulted in an incomplete information base. Germany has been a destination for people seeking international protection to varying degrees since the 1990s. Despite this, nationwide data that are comparable over time and space on the health and care of this migrant population are virtually non-existent.

There are many reasons for this gap. During the asylum procedure, refugees are initially accommodated in central, state-run reception facilities before being transferred to collective accommodation run by each district. During this process, they are not registered in official population registries and are hence practically not accessible by conventional sampling approaches. This group of people is

extremely diverse with respect to their country of origin, languages spoken, reasons for fleeing and route taken, as well as residency prospects and socioeconomic background. It is therefore impossible to conduct surveys without a linguistic, cultural and contextual adaptation of survey instruments. In addition, due to the high level of migration dynamics and spatial displacement, there is no overview of the entire refugee population (denominator population), which is an essential parameter for health monitoring among refugees [3]. There are also substantial limitations when using routine healthcare data. During their initial stay at central, state-run reception facilities, refugees usually receive primary medical care in the facilities' own outpatient clinics. However, routine data is not collected and collated uniformly in these. Those who use regular, external healthcare services, while staying at a reception facility or after transfer to the districts, are only identifiable as refugees in health insurance provider data in regions which provide refugees with an electronic health card (eGK). At the same time, refugees are generally only issued an eGK after leaving the reception facilities. This can be up to 18 months after their arrival in Germany or when the entire asylum application process has been completed.

Due to these factors, data on refugee health and provision of care remains incomplete and is based almost exclusively on local individual studies and surveys of limited duration that are generally incompatible with the principles of health reporting. An important exception is the survey

of refugees established in 2016 by the Institute for Employment Research (IAB), the Federal Office for Migration and Refugees (BAMF) and the Socio-Economic Panel (SOEP), which uses a sample from the Central Register of Foreigners to supplement the established SOEP surveys. While this data source provides information on the living situation of refugees, the number of indicators on health and healthcare provision is limited.

The situation is similar in many other European countries. A review analysing the integration of migrants into health information systems and the availability of corresponding data in the European Region of the World Health Organization (WHO) revealed that only 23 of the 53 WHO member states have systematic and routine approaches to collecting health data on migrants [4]. Countries with nation-wide standardised registers were able to examine key aspects of health such as mortality, life expectancy and morbidity as well as collect data relating to pregnancy and childbirth for refugees, and compare these to other groups such as people with a migrant background or those without a migrant background. Nevertheless, there was a lack of feasible approaches to a systematic inclusion of migrants and particularly refugees in existing health surveys that would allow the collection of self-reported and more complex aspects of health. In many cases, systems for recording notifiable infectious diseases were the only sources of routinely available data with which to assess the health of refugees. Routine medical data from individual clinics were also frequently used, yet such data allowed only limited comparisons with other settings.

How can we ultimately improve the availability of information on the health of refugees as well as the integration

of this information into health reporting at municipal, state and federal levels? This question, which is highly relevant internationally, is addressed by the two articles in this issue from different, yet complementary, perspectives by presenting experiences from two projects supported by national funding programmes [5].

Biddle *et al.* describe an approach based on a targeted, group-specific sampling and recruitment which enables health monitoring among refugees living in collective accommodation by integrating them into health surveys. Jahn *et al.* describe an innovative approach to using routine medical data in reception facilities, which is based on the principle of distributed computing. Both approaches create new information resources that enable the integration of the target group in terms of the visibility of relevant health aspects in settings that have not yet been systematically considered. However, sustained use of this information in health reporting will require a structural consolidation of these approaches at national, federal state and municipal levels.

Corresponding author

Prof Dr Kayvan Bozorgmehr
Department of Population Medicine and Health Services Research,
School of Public Health, Bielefeld University, Bielefeld, Germany
P.O. Box 10 01 31
33501 Bielefeld, Germany
E-mail: kayvan.bozorgmehr@uni-bielefeld.de

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Editors

Johanna Gutsche, Dr Birte Hintzpeter, Dr Franziska Prütz,
Dr Martina Rabenberg, Dr Alexander Rommel, Dr Livia Ryl,
Dr Anke-Christine Saß, Stefanie Seeling, Dr Thomas Ziese
Robert Koch Institute
Department of Epidemiology and Health Monitoring
Unit: Health Reporting
General-Pape-Str. 62–66
12101 Berlin, Germany
Phone: +49 (0)30-18 754-3400
E-mail: healthmonitoring@rki.de
www.rki.de/journalhealthmonitoring-en

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Louise Biddle^{1,2}, Maren Hintermeier¹,
Amir Mohsenpour², Matthias Sand³,
Kayvan Bozorgmehr^{1,2}

¹ Section Health Equity Studies and Migration,
Department of General Practice and Health
Services Research,
University Hospital Heidelberg

² AG Population Medicine and Health Services
Research, School of Public Health,
Bielefeld University

³ GESIS Leibniz Institute for the Social
Sciences, Mannheim

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Monitoring the health and healthcare provision for refugees in collective accommodation centres: Results of the population-based survey RESPOND

Abstract

To date, the integration of refugees in German health surveys is insufficient. The survey RESPOND (Improving regional health system responses to the challenges of forced migration) aimed to collect valid epidemiological data on refugee health status and healthcare provision. The core elements of the survey consisted of a population-based sampling procedure in Baden-Württemberg, multilingual questionnaires and a face-to-face approach of recruitment and data collection in collective accommodation centres with multilingual field teams. In addition, data on the geographical locations of accommodation centres and their structural quality were obtained. The results indicate a high overall health burden. The prevalence of depression (44.3%) and anxiety symptoms (43.0%) was high. At the same time, high unmet needs were reported for primary (30.5%) and specialist (30.9%) care. Despite sufficient geographical accessibility of primary care services, frequent ambulatory care sensitive hospitalisations, i.e. hospitalisations that could potentially have been avoided through primary care (25.3%), as well as subjective deficits in the quality of care, suggest barriers to accessing healthcare services. Almost half of all refugees (45.3%) live in accommodation facilities of poor structural quality. Collecting valid data on the health situation of refugees is possible through a combination of targeted sampling, multilingual recruitment and survey instruments as well as personal recruitment. The presented approach could complement established procedures for conducting health surveys and be extended to other federal states.

HEALTH MONITORING · REFUGEES · SURVEY · ACCESS BARRIERS · QUALITY OF CARE

1. Introduction

Due to experiences before, during and after flight, refugees (Info box 1) face specific health risks, which makes an efficient healthcare response after arrival in Germany crucial. International studies show that providing care for mental health issues, chronic diseases, serious infectious diseases as well as for pregnant women is particularly important [1].

Ensuring that refugees in Germany receive adequate healthcare is challenging. The legal norms of the Asylum Seekers Benefits Act ('Asylbewerberleistungsgesetz', AsylbLG) limit care to the 'treatment of acute illnesses and pain conditions' (§4 AsylbLG). Children and pregnant asylum seekers are exempt from this regulation and further services can be accessed on a case-by-case basis (Section 6 AsylbLG). Nevertheless, this regulation has been shown

Info box 1

In this article, the term 'refugees' refers to all people who have applied for asylum at the German Federal Office for Migration and Refugees (BAMF) – regardless of the outcome of their asylum application – as well as people admitted to Germany for resettlement in accordance with the Geneva Refugee Convention of the United Nations High Commissioner for Refugees (UNHCR).

Info box 2

The publication by Bozorgmehr et al. [6] defined 'people with a migrant background' according to the definition of the International Organisation for Migration (IOM) as 'a person who moves away from his or her place of usual residence, whether within a country or across an international border, temporarily or permanently, and for a variety of reasons' [7].

to prevent asylum seekers from receiving needs-based care [2, 3]. In addition, language, financial, geographical or structural factors can also act as barriers to accessing adequate healthcare for refugees [4]. Moreover, it is not only access to healthcare but also the circumstances in the host country after migration which are of great relevance to the health of refugees. Factors such as an insecure residency status, satisfaction with the living situation and opportunities for social and economic participation can influence health and well-being [5].

Against this backdrop, population-based data are particularly important in determining healthcare needs. In addition to routine clinical data, data from surveys and interviews at national or regional levels form an essential part of national data systems. Only they can provide reliable information on the frequency of certain diseases as well as potential access barriers. Furthermore, data on residential locations which are used in household surveys can also be used, for example to assess geographical barriers to accessing healthcare. However, a recent analysis of health data available for people with a migrant background (Info box 2) in Europe found that the current utilisation of survey data is insufficient [6]. This is partly due to the fact that this population group – which is considered "hard-to-reach" for research purposes – is often under-represented in population-based studies. In Germany, further problems arise when recruiting refugees for health monitoring surveys. On the one hand, refugees cannot be identified in population registers, as these only record data on nationality and do not provide information on legal status. On the other hand, reporting can be delayed, which is why refugees who have recently arrived and who often live in initial reception or

collective accommodation centres are under-represented in population registers. Furthermore, people with a migrant background are regularly excluded from studies if the surveys are exclusively in German.

In Germany, the task of collecting and evaluating information on the health of the population lies with the Robert Koch Institute (RKI), amongst other actors. National data on the health status, access to care services, but also on other relevant indicators such as the health behaviour of children, adolescents and adults living in Germany are regularly collected through several interview and examination surveys within the context of health monitoring at the RKI. Over the past two decades, increased efforts have been made to integrate individuals with a migrant background in the German Health Interview and Examination Survey for Children and Adolescents (KiGGS) and the German Health Interview and Examination Survey for Adults (DEGS1). Such efforts have included oversampling of participants without German nationality, providing multilingual questionnaires and targeted public outreach to recruit people with a migrant background [8]. Since 2016, the RKI has been working more intensively on migration-sensitive recruitment and data collection procedures as part of the Improving Health Monitoring in Migrant Populations (IMIRA) project [8]. However, the samples for these surveys are recruited based on data from the population registration office, which do not adequately represent refugees and asylum seekers in initial reception and collective accommodation centres in Germany [9].

The German Institute for Economic Research's (DIW) 'IAB-SOEP-BAMF Panel', a survey specifically designed to collect information from refugees, is sampled based on

the Central Register of Foreign Nationals (AZR). The AZR is kept by the Federal Office for Migration and Refugees (BAMF) as a police register and contains detailed information on the legal status and place of residence of refugees arriving in Germany. Using this as its basis, the IAB-SOEP-BAMF Panel is able to draw a representative sample of refugees in Germany [10]. However, this survey is primarily concerned with socioeconomic aspects such as educational status and the integration of refugees in the labour market. The survey includes questions on general and mental health status [5], but little attention is given to other health-related matters. Questions on utilisation of services are not included, except for a few variables on the uptake of outpatient and inpatient care.

In order to close these gaps in the availability of survey data, a data collection approach was developed as part of the project 'Improving regional health system responses to the challenges of forced migration' ([RESPOND](#)) in 2016. Funded by the Federal Ministry of Education and Research (BMBF), this project set out to conduct a population-based health survey among refugees in initial reception and collective accommodation centres. This paper presents the project's methodological approach as well as selected results regarding health status, utilisation of healthcare services and quality of care. Furthermore, data on the accommodation situation, the quality of accommodation and the geographical accessibility of primary healthcare are reported.

2. Methodology

The present survey was designed as a population-based, cross-sectional study and conducted as part of the RESPOND

project. The target population was defined as adult refugees living in initial reception centres (EA) and collective accommodation centres (GU) in the state of Baden-Württemberg at the time of the survey.

2.1 Questionnaire development

Drawing on previous feasibility studies [11–13] and using established instruments, a questionnaire was developed that covers essential dimensions of health status, healthcare utilisation, quality of care as well as sociodemographic information and adequately takes into account the specific context and living conditions of refugees. A description of the questionnaire development, including a detailed overview of instruments used, has been published previously [14]. Only a selection of the most important indicators will therefore be presented below.

Health status was assessed using instruments from the European Health Interview Survey (EHIS; general health, pain, chronic diseases) [15] as well as scales for depressive symptoms (PHQ-2; depression) [16] and symptoms of general anxiety disorders (GAD-2) [17]. Both PHQ-2 and GAD-2 scores above a cut-off of three were considered as indicating a depressive or anxiety disorder respectively [16]. Utilisation of healthcare services was assessed based on EHIS instruments (use of specialist and general medical services), the EU Statistics on Income and Living Conditions (EU-SILC; unmet needs) [18] and the German Health Interview and Examination Survey for Adults (DEGS; advice on health behaviour) [19]. Variables of health status, utilisation of healthcare services, quality of care and perceived distance from health services were dichotomised for the analysis ([Annex Table 1](#)).

Basic DEGS and EHIS sociodemographic items were supplemented with an adapted version of the MacArthur Scale (subjective social status) [20], as well as questions related to legal status, health insurance status and length of stay in Germany (Annex Table 1). With regard to 'nationality' and 'mother tongue' variables, only categories that described at least 2% of the participants were considered in the evaluation, remaining answers were categorised as 'other'. Levels of education were recorded based on the questions of EHIS on school education and vocational qualification and combined in a separate classification into three educational levels. An adapted MacArthur Scale of subjective social status (SSS) in Germany was divided into low SSS (levels 1–4), medium SSS (levels 5–6) and high SSS (levels 7–10) [20, 21].

A number of aspects related to quality of care were examined. On the one hand, ambulatory care sensitive hospitalisations (ASH) were assessed using questions on specific clinical diagnoses and hospitalisations due to these conditions [22]. These are hospitalisations for diseases that are considered potentially avoidable given effective primary care and can therefore be considered as an indicator of the quality of primary care. These are also referred to as 'avoidable hospitalisations'. In addition, the World Health Organization (WHO) Responsiveness Scale was used to assess non-technical aspects of quality of care in the dimensions of cleanliness, respectful treatment, confidentiality, autonomy in decision-making, communication, choice of provider and waiting time during the last appointment [23]. As the WHO Responsiveness Scale specifically focuses on assessing a patient's most recent appointment, responses from individuals who had not been to see a doctor were

excluded. The questionnaire also included a question on the abuse of medicines from the Structured Clinical Interview for DSM-5 (SCID; medication abuse) [24]. Possible geographical barriers to accessing care were captured using a subjective evaluation of the distance to different care services (pharmacies, primary and specialist care providers, hospitals), taken from the European Patient's Forum (EPF) study [25].

The questionnaire was developed in English and German and then translated into Albanian, Arabic, Persian, French, Russian, Serbian and Turkish using a TRAPD (Translation, Review, Adjudication, Pretesting and Documentation) approach. Two independent professional translations were brought into a joint discussion, and an interdisciplinary translation and research team was then tasked with the synthesis of both texts [26]. A cognitive pre-test was conducted for several questionnaire items to ensure comprehensibility [27]. The final version of the questionnaire comprised 68 questions.

An instrument was developed to quantify the quality of housing in terms of its structural condition (small-area housing environment deterioration, SHED) and validated in a separate study [28]. Drawing on the Broken Windows Index [29], this instrument measures the condition of (1) window panes and glass, (2) walls and roof, (3) litter, (4) graffiti inside and outside the building, and (5) external spaces on the basis of five observer-based assessments. The instrument has been shown to be highly reliable when conducted in the form of independent individual ratings [28]. In the context of this study, however, it was used as a rating by a team, as the joint work on site did not create an independent, but a combined impression of the resi-

dential environment. A sixth question assessed the general living environment as a global rating. Following Z-standardisation and 0–1 normalisation of the individual results for the purpose of comparability, the variables collected on the quality of accommodation were converted into an overall score. Facilities were divided into quintiles based on the overall score in order to examine accommodation quality based on the distribution of people living in the centres.

2.2 Sampling

This study had no access to the AZR data so a separate sampling frame was constructed. Sampling was carried out at the level of accommodation centres. After arrival and registration by the BAMF, refugees are accommodated in initial reception centres of the federal states. At the point of data collection, refugees were allowed to stay in these centres for a maximum of six months, with the exception of persons from so-called ‘safe countries of origin’ (Section 47 Asylum Act, AsylG). Refugees with good prospects of being allowed to stay in the country may then be transferred to collective accommodation centres at regional level. In the initial reception centres, the reception authorities at the federal state level are responsible for accommodation; the responsibility for refugees in collective accommodation centres and follow-up accommodation lies with the regional and district authorities.

A list of all initial reception centres in the state as well as anonymised occupancy lists at the room level was established in co-operation with the Ministry of the Interior of Baden-Württemberg and the responsible regional councils. A two-stage random sample was drawn from a total of

twelve centres. In the first stage, six of the twelve centres were selected with a probability proportional to accommodation occupancy and responsible authority. In the second stage, a random selection was made at room level so that 25% of the residents were included in the sample. This self-weighting approach results in an equal selection probability for each person within the sampled population.

The sampling procedure for collective accommodation centres has been described in detail previously [14]. All lower-level reception authorities were contacted in order to obtain a list of all collective accommodation centres ($N=1,933$), as well as the corresponding occupancy figures, of the 44 districts of Baden-Württemberg. This was done in cooperation with the Ministry of Social Affairs and with the consent of the County Association (Landkreistag) of Baden-Württemberg. At the time of the survey, a total of 70,634 refugees were living in collective accommodation centres. A random sample proportional to the population was drawn at the level of accommodation centres, balancing on the number of refugees in the district as well as accommodation size. A total of 65 centres were drawn to include a net sample of 1% of all refugees at district level.

An additional benefit of manually collating the sampling frame at the level of collective accommodation centres was the possibility of identifying geographical locations. The geo-coordinates of 1,786 centres were determined. As some authorities did not provide geo-information, 7.6% ($n=147$) of centres from five urban and rural districts were excluded from geographical analysis because their addresses could not be determined.

2.3 Study implementation

Specifically trained, multilingual research staff collected the data between February and June 2018. Refugees living in the centres were contacted at least one week in advance by the staff or responsible social workers at the centre to inform about the purpose and time of the visit. In order to reach a large proportion of the residents, each centre was visited on two consecutive days. In the course of field visits, the research staff completed questionnaires on accommodation quality for each accommodation centre in the sample.

All people living in sampled facilities were personally informed about the study by multilingual field teams on site and invited to participate ('door-to-door recruitment' [30]). Standardised, multilingual audio messages were also used. Criteria for inclusion in the study were being at least 18 years old and proficiency in at least one of the nine study languages. Illiterate people were included in the study if they confirmed that someone could help them fill out the questionnaire. Potential participants received a questionnaire and a leaflet with study information in one of the nine languages, as well as non-monetary, unconditional incentives (notebooks, pens and colouring pads/crayons for children). Respondents could choose between returning the completed questionnaire in person to the research team or, alternatively, returning it by post in a pre-paid envelope. In addition, an online version of the questionnaire (using a personalised QR code) was also made available. If people were approached who could not participate in the study or did not meet the inclusion criteria, the reason for non-participation, their gender and language were documented.

2.4 Weighting

The RESPOND data was weighted to improve the accuracy of the sample when making estimates regarding the total refugee population. The weights were calculated using data on gender, age group and region of origin from Baden-Württemberg's asylum statistics [31]. For country of origin, data on asylum applications from 2016 to 2018 (quarters 1 to 4) were available. For gender and age group, statistics were only available for one quarter each of 2016 (Q2), 2017 (Q4) and 2018 (Q3). These asylum application statistics can only approximate the true composition of the refugee population, as first-time applicants before 2016 as well as applicants that apply for asylum more than once are generally not recorded. To enable weighting with a complete data matrix, missing values were imputed using the 'mice' package in R [32]. The complete data matrix was then used to calculate calibration weights. Data on gender, age and region of origin were adjusted to the distribution of these variables in the asylum statistics, taking into account the sample design and using 'iterative proportional fitting' (raking technique) [33].

2.5 Data evaluation

Descriptive statistics of the weighted data are used to determine physical and mental health status, utilisation of health services, unmet needs, quality of care as well as the perceived geographical distance to healthcare services. For this purpose, prevalence of each indicator, including 95% confidence intervals, are presented by gender (health status and utilisation) or by type of

To date, the integration of refugees in German health surveys is insufficient.

accommodation (responsiveness and perceived geographical distance). These analyses were carried out with STATA version 15.1.

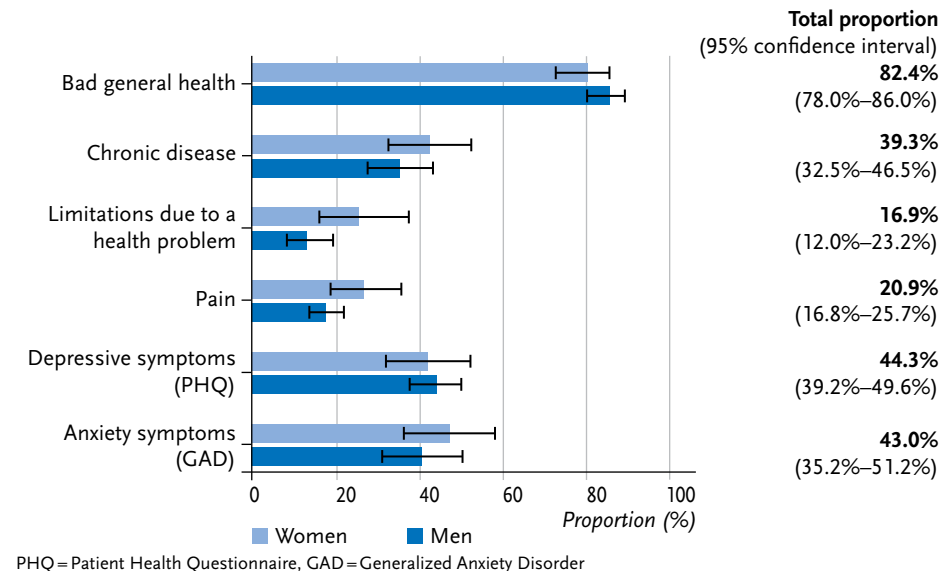
To calculate the distance to primary care services, geo-data on general medical practices from the publicly available database of the Association of Statutory Health Insurance Physicians (Kassenärztliche Vereinigung) of Baden-Württemberg were used. Geo-information software (QGIS) was used to determine the nearest practice, which was then assigned for each centre based on linear distance and using the 'nearest neighbour analysis'. As refugees usually do not have their own car, calculating travel time by public transport or on foot is particularly important. The travel times (walking, driving and public transport) were calculated using the Google Maps Distance Matrix API (last calculation: 19 June 2020, 07:00) [34]. Google Maps' Distance Matrix API offers the advantage of simultaneous requests

for several data points. Travel time and date were randomly selected for a working day.

3. Results

A total of 560 adult refugees (response rate 39.2%; [Annex Figure 1](#)) took part in the study, of which 411 (73.4%) of which lived in collective accommodation centres, with the remaining 149 (26.6%) living in initial reception centres. The response rate was calculated according to the recommendations of the American Association for Public Opinion Research (AAPOR) [35]. Almost one third ($n=158$; 31.3%) of the sample were women, more than half ($n=253$; 51.4%) were under 31 years of age. The primary regions of origin were West Asia ($n=134$; 26.7%), South Asia ($n=128$; 25.5%) and West Africa ($n=120$; 23.9%). Educational status was mixed, but the subjective social status in Germany

Figure 1
Self-reported, weighted prevalence of health issues and symptoms by gender (with 95% confidence intervals)
Source: RESPOND Study 2018



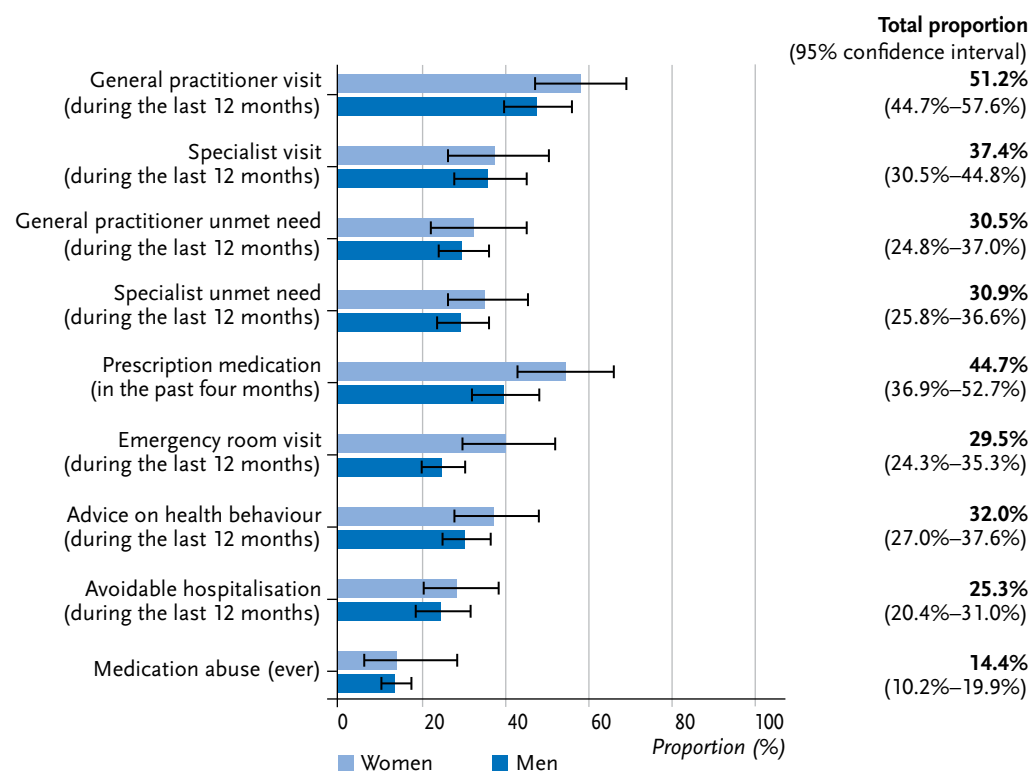
was predominantly ($n=277$; 70.7%) assessed as being low. More than half of participants had already been in Germany for more than one year ($n=253$; 55.8%), but the majority ($n=281$; 62.2%) still had asylum seeker status. In initial reception centres, there was a tendency toward shorter length of stay in Germany and a more uncertain asylum status. Half of the participants ($n=240$; 52.2%) held an electronic health card ([Annex Table 2](#)).

3.1 Health status

After weighting the data, 82.5% of refugees reported either a moderate, poor or very poor general health status. In addition, 39.3% of respondents reported a chronic illness, 16.9% a limitation due to a health problem and 20.9% suffered from severe to very severe pain. There was a tendency towards a higher prevalence of health limitations as well as pain among female refugees ([Figure 1](#)). The prevalence of depressive symptoms was 44.3%, and 43.0% for symptoms of anxiety ([Figure 1](#)).

The results of the RESPOND study indicate a high health burden, while at the same time showing high unmet needs.

Figure 2
Self-reported, weighted utilisation and quality of health services by gender (with 95% confidence intervals)
Source: RESPOND Study 2018



Primary care services are accessible geographically, but quality indicators suggest other access barriers.

3.2 Utilisation of healthcare services

In the twelve months prior to the survey, 51.2% of refugees had visited primary and 37.4% specialist care services. Almost one third of refugees reported unmet needs (foregone health services), both in primary and specialist care. 29.5% of refugees had made use of emergency care in the past twelve months, whereas just under half had received prescription medication during the four weeks prior to the study. For both emergency care and prescription medication, there was a clear trend towards a greater utilisation by female refugees. One third of respondents had received advice from their doctor regarding their health behaviour in the twelve months prior to the study (Figure 2).

3.3 Quality of care

One quarter of refugees stated having been in inpatient treatment in the twelve months prior to the survey due to medical conditions which, with adequate primary care, should not have required hospitalisation (avoidable hospitalisations). In addition, 14.4% of respondents reported having been addicted to prescription drugs or having taken more of a drug than they had been prescribed at least once in their life. Reported responsiveness of care varied by type of healthcare service and accommodation type (collective accommodation/initial reception centre; Figure 3). The best ratings were given for respectful treatment and cleanliness, while choice of provider and waiting time received the worst

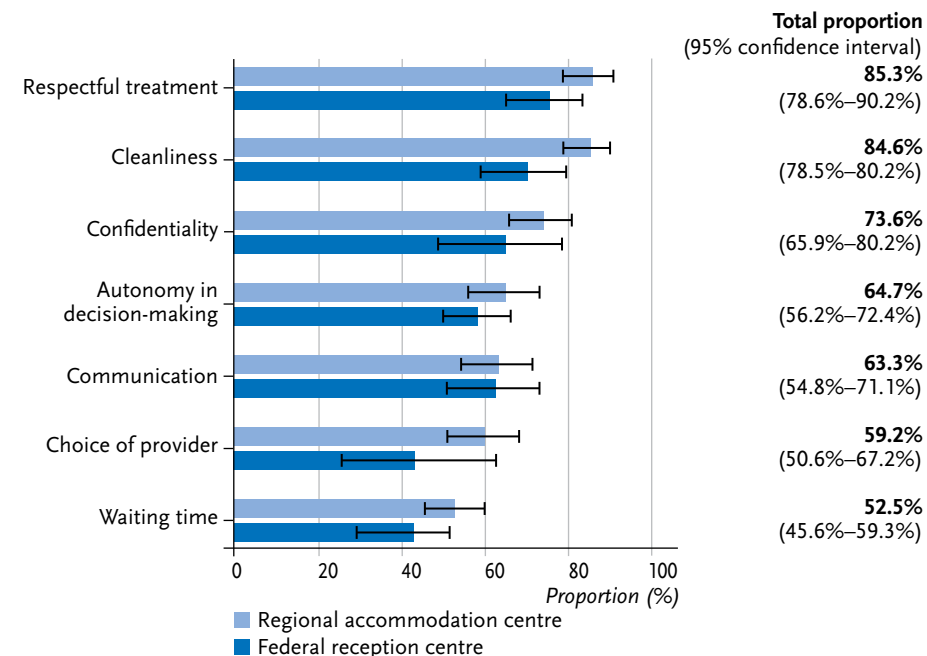


Figure 3
Quality of care perceived as good or very good (responsiveness) by type of accommodation (weighted, with 95% confidence intervals)
Source: RESPOND Study 2018

Table 1
Number of regional accommodation centres (GU) and federal reception facilities (EA) according to accommodation quality in quintiles as well as their respective number of residents
Source: RESPOND Study 2018

Quality of accommodation in quintiles	GU (n=56)		EA (n=5)		Total (n=61)		Residents (n=5,092)	
	Number	%	Number	%	Number	%	Number	%
Q1 (very high)	40	71.4	1	20	41	67.2	1,423	27.9
Q2 (high)	12	21.4	2	40	14	23.0	1,297	25.5
Q3 (average)	2	3.6	0	0	2	3.3	26	0.5
Q4 (low)	1	1.8	0	0	1	1.6	41	0.8
Q5 (very low)	1	1.8	2	40	3	4.9	2,305	45.3
Total	56	100.0	5	100.0	61	100.0	5,092	100.0

Q=quintile, GU=regional accommodation centre, EA=federal reception centre

Almost half of all refugees (45.3%) live in accommodation facilities of poor structural quality.

ratings. When compared to the initial reception centre setting, there was a tendency towards a subjectively better assessment of care services for respondents in collective accommodation across all responsiveness domains; this tendency was particularly clear for cleanliness (Figure 3).

3.4 Quality of accommodation

In total, the 560 respondents were accommodated in 63 different centres. The quality of accommodation of 61 of them was assessed and calculated, and covered five initial

reception centres and 56 collective accommodation centres. With a possible spectrum from very high (value=0) to very low (value=6) accommodation quality, collective accommodation received a better average rating of 1.0 (median=0.5; min. 0.0; max. 4.8) than initial reception centres with an average of 2.7 (median=1.7; min. 0.5; max. 5.2). However, when the accommodation size is taken into account, 45.3% of refugees lived in three accommodation centres that all received very low ratings for accommodation quality (lowest quintile) (one initial reception centre, two collective accommodation centres) (Table 1).

Figure 4
Distance to pharmacies, general practitioners, specialists and hospitals perceived as 'close enough' by type of accommodation (weighted, with 95% confidence intervals)
Source: RESPOND Study 2018

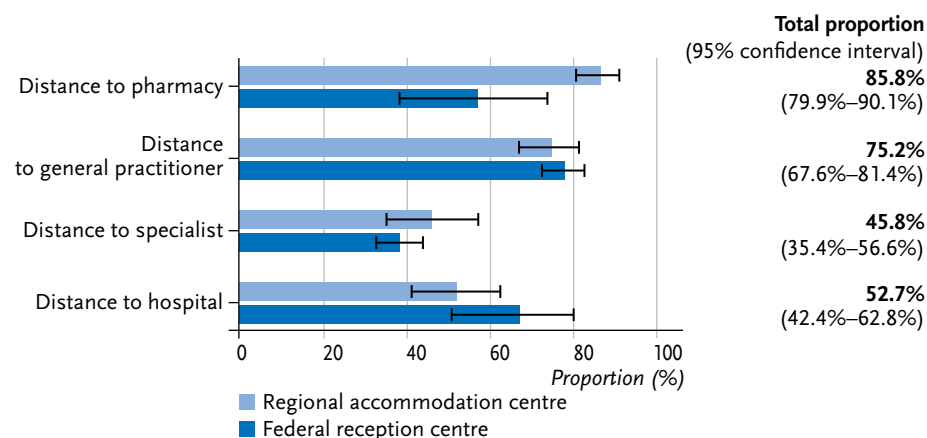
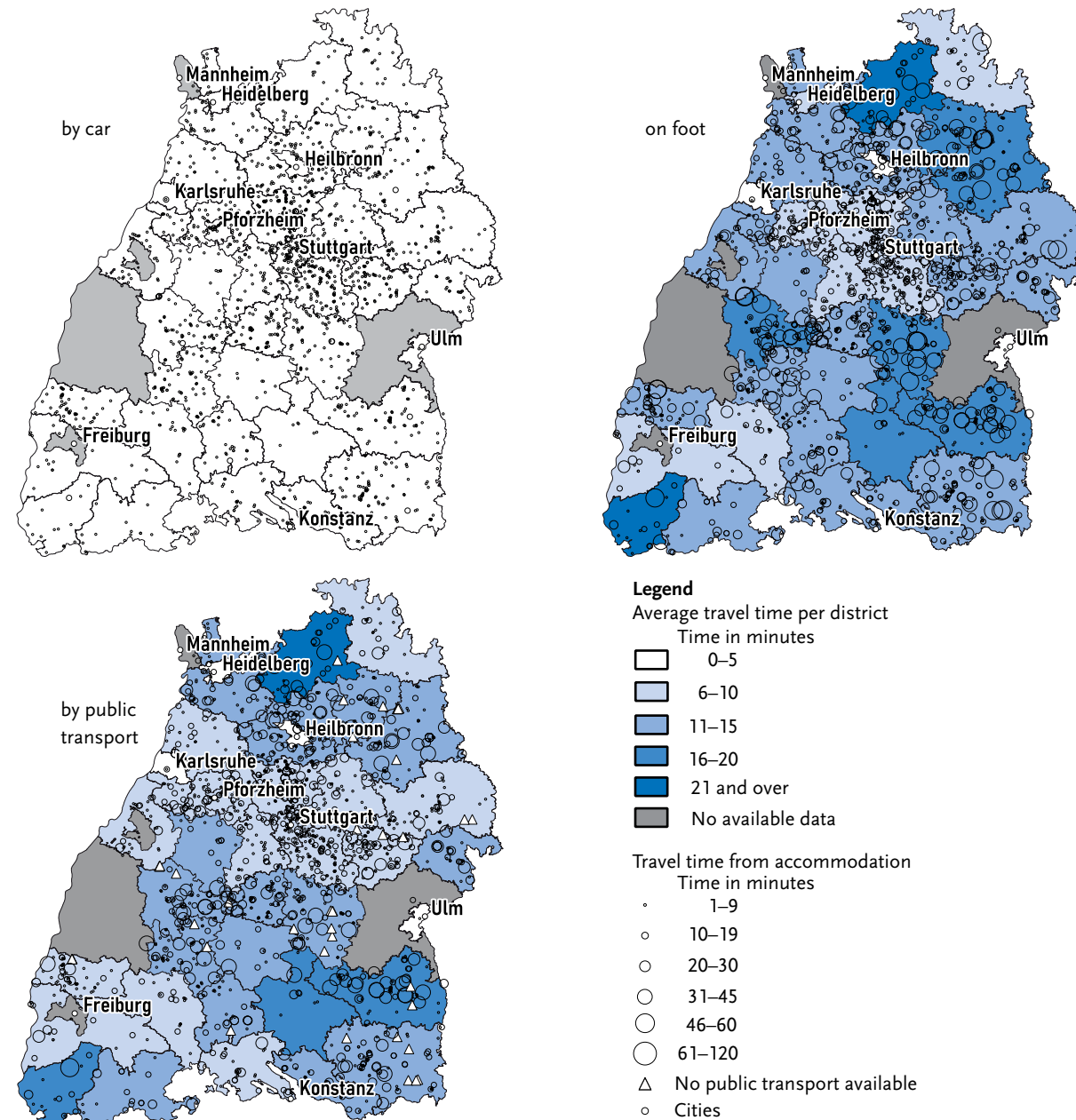


Figure 5

Travel time (in minutes) to the nearest primary care practice per accommodation and mean travel time per district by car, on foot and by local public transport

Source: RESPOND Study 2018



The collection of valid data on the health of refugees should be continued and extended to other federal states.

3.5 Geographical distance to healthcare services

85.8% of refugees stated that a pharmacy was close enough to their accommodation. 75.2% said that primary medical services were close enough, while the same was true of only 45.8% for a specialist practice and 52.7% for a hospital. Pharmacies tended to be judged as being 'close enough' more frequently by refugees in collective accommodation centres, while hospitals were judged as 'close enough' more frequently by refugees in reception centres (Figure 4).

Figure 5 shows the actual distances from all collective accommodation centres in Baden-Württemberg to the nearest primary care practice. The mean travel time by car was 2.7 minutes (standard deviation 2.1; min. 0; max. 18.7). All collective accommodation centres were within 30 minutes of the nearest practice by car (Figure 5); only about 90% of the centres had a practice within 30 minutes walking distance (Figure 5). The mean walking time was 13.2 minutes (standard deviation 15.5; min. 0; max. 119.3).

91% of accommodation centres had a practice within a 30-minute journey by public transport (Figure 5). The average travel time by public transport was 11 minutes (standard deviation 11.03; min. 0; max. 97.08), yet 41 accommodation centres were not connected to the public transport network. For these 41 accommodation centres, the travel time on foot was at least 60 minutes, and the walking distances were between 4.5 and 10 kilometres each way. The travel time by car from these accommodations to the nearest primary care practices was nine minutes on average (standard deviation 2.8 min. 4.2; max. 18.7), with locations ranging from five to just under 16 kilometres away. In addition to the 41 accommodation centres mentioned, another

40 accommodation centres had more than 45 minutes travel time from the respective nearest practice, both on foot and by public transport.

4. Discussion

The RESPOND study is characterised by its population-based sampling procedure, multilingual questionnaires based on established instruments and personal contact with respondents, relevant authorities and institutions. This made it possible to obtain reliable epidemiological data on the health status, access to and quality of healthcare as well as important aspects of the living and housing environments of refugees. In general, refugees have a high overall health burden. For example, 44.3% report depressive symptoms, a very high figure compared to the general population in Germany (10.1%) [36], which points to a high need for health and psychosocial services. In other areas, such as limitations in everyday life due to a health problem, the figures for refugees (16.9%) are also higher than for the general German population (6.6%) [37]. Direct comparisons are difficult because of the differences in age and gender composition between the two populations. Important insights can nonetheless be gained from such comparisons, which should be improved through the use of population standardisation in future studies.

The high mental health burden of refugees in Germany has been shown previously by analyses based on the IAB-SOEP-BAMF panel [5, 38]. However, when considering the burden of physical illnesses, the two studies come to different conclusions: compared to the population living in Germany, the IAB-SOEP-BAMF panel [38] records a lower

burden, while the RESPOND study shows a higher burden. To a certain extent, this can be explained by the fact that the RESPOND study mainly captures recently arrived refugees (since 2016), whereas the IAB-SOEP-BAMF panel analyses were based on a sample of refugees which arrived in Germany between 2013 and 2016. In addition, RESPOND is the first study which facilitated population-based insights on utilisation, accessibility and quality of care for refugees – topics not covered by the IAB-SOEP-BAMF panel.

The majority of refugees had used healthcare services in the twelve months prior to the survey. However, a high number of respondents reported foregone care. The comparatively high prevalence of avoidable hospitalisations also points to an insufficient coverage of primary care services. With regard to the quality of care experienced (responsiveness), the overall assessment of cleanliness and respectful treatment were good, but assessments of choice of provider and waiting time showed room for improvement. Compared to a study of patients with chronic illnesses in outpatient care in Germany [39], refugees in the RESPOND study rated every domain of responsiveness as worse. A close analysis of the responsiveness of the healthcare system for refugees, including a qualitative analysis of the possible reasons for differences between the different domains from the perspective of those affected, is urgently needed to comprehensively assess how refugees experience the quality of care.

Important insights were also gained with regard to the quality of accommodation facilities. While the majority of centres visited were in good or acceptable structural condition, a disproportionately large number of refugees were living in large accommodation centres which were in poor

condition. Findings from existing research in Germany shows that structurally poor housing conditions can negatively impact refugee's mental health [40]. In addition, the international literature points to links between the quality of accommodation, occupancy density and physical health, particularly in relation to the worsening of chronic diseases such as asthma and the spread of infectious diseases [41].

The COVID-19 pandemic has made explicit the importance of the link between the housing conditions of refugees and their health: in centres with better conditions and lower occupancy levels, authorities had better opportunities to comply with physical distancing, isolation and quarantine requirements, thereby being more effective in controlling the pandemic [42]. The implementation of existing standards for the accommodation of refugees should be re-examined with respect to the structural quality of buildings, occupancy density, geographic location and cleanliness. In addition, further research on the impact of different housing and living conditions on the health of refugees, including accommodation quality, is needed to support the planning of accommodation processes from a health perspective. In this context, qualitative research is also of great importance in providing insights to the significance of the 'living environment' from the perspective of refugees and in shedding light on the connections between the living environment and health in the unique context of collective accommodation facilities.

Primary care services are easily accessible from collective accommodation facilities by car, on foot or by public transport for most refugees. The average distance travelled by car was less than the ten minutes generally reported for the German population [43] for all included districts.

However, access to selected centres proved difficult, especially in rural areas. The question therefore arises as to whether it makes sense to accommodate refugees, who often do not have a car, in structurally underdeveloped regions. This study benefited from the Google Maps Distance Matrix API, which enabled the analysis of travel times by public transport. However, the analysis was limited to one practice and a single time of travel. Further analyses should aim to extend this to multiple primary care practices, other healthcare services and travel times at different points of the day.

This is the first population-based study in Germany that goes beyond individual diseases to map the health situation of refugees in collective accommodation facilities in a German federal state. In comparison to other population-based surveys of the general population, a high response rate was achieved. The approach shows that migration-sensitive health monitoring for refugees in initial reception and collective accommodation centres is possible in principle and can complement existing approaches to recruiting refugees via population registers. Refugees are not per se difficult to reach within the context of empirical surveys, although other approaches are necessary in addition to those usually used in Germany to date. The study was limited by the fact that it was restricted to one federal state and worked with a relatively small sample size. However, the instruments and the sampling method applied by the RESPOND survey have already been successfully repeated in Berlin [44]. Expanding the approach to other federal states and giving continuity to the described approaches can improve the empirical foundation of healthcare provision for refugees and close existing gaps in health monitoring.

Corresponding author

Louise Biddle

Section Health Equity Studies and Migration

Department of General Practice and Health Services Research

University Hospital Heidelberg

Im Neuenheimer Feld 130.3

69120 Heidelberg, Germany

E-mail: louise.biddle@med.uni-heidelberg.de**Please cite this publication as**

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Data protection and ethics

The study received ethical clearance from the Ethics Committee of the Medical Faculty of Heidelberg, Heidelberg University (S-516/2017). The study complied with the data protection regulations of the EU General Data Protection Regulation (GDPR) and the German Federal Data Protection Act (BDSG). Participants were informed verbally and in writing about the aims and contents of the study as well as about data protection.

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Conflicts of interest

The authors declared no conflicts of interest.

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Annex Table 1
Selected variables of the RESPOND
questionnaire, their source and categorisation
 Source: RESPOND Study 2018

Variable	Source	Categorisation
Sociodemographic data		
Age	DEGS	18–25, 26–30, 31–35, 36–40, ≥41 years old
Gender	DEGS	1= male 2= female
Nationality	DEGS	Region of origin according to UN Geoscheme
Educational status	EHIS	School and professional education
Months since arrival in Germany	–	0–6, 6–12, 13–15, 16–24, 24–36 months
Legal status	–	1= Asylum seeker 2= Refugee status awarded 3= Refugee status rejected/temporary suspension of deportation
Health insurance card	–	1= yes 0= no
Subjective social status in Germany	MacArthur Scale	1= low SSS 2= medium SSS 3= high SSS
Health status		
General health status	EHIS	1= moderate to very poor condition 0= good/very good condition
Chronic diseases	EHIS	1= present 0= not present
Health limitations	EHIS	1= severe limitations 0= moderate/no limitations
Pain	DEGS	1= severe/very severe pain 0= moderate to no pain
Depressive symptoms	Patient Health Questionnaire, 2-item version	1= PHQ-2 value ≥3 0= PHQ-2 value <3
Anxiety symptoms	Generalized Anxiety Disorder, 2-item Version	1= GAD-2 value ≥3 0= GAD-2 value <3
Use of health services		
Primary care visit	EHIS	1= Primary care visit <12 months 0= Primary care visit >12 months/never
Specialist visit	EHIS	1= Specialist visit <12 months 0= Specialist visit >12 months/never
Unmet need for primary care	EU-SILC	1= unmet needs 0= no unmet needs
Unmet need for specialist	EU-SILC	1= unmet needs 0= no unmet needs

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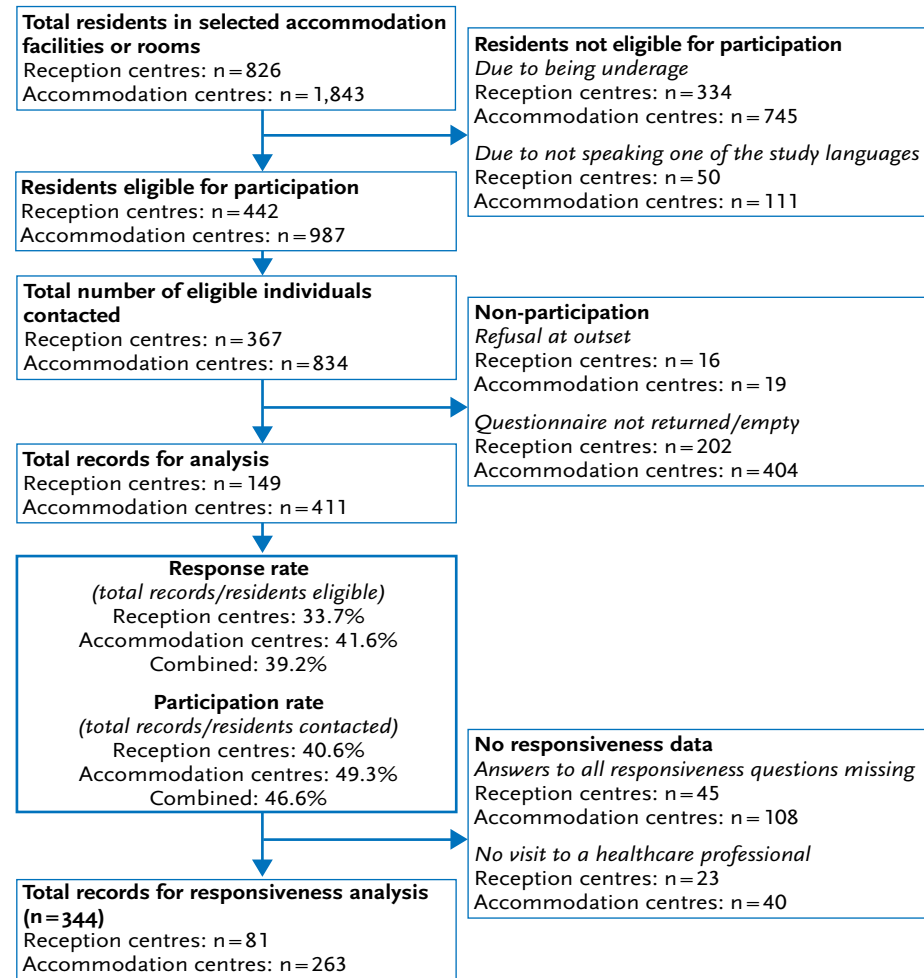
Annex Table 1 Continued
Selected variables of the RESPOND
questionnaire, their source and categorisation
 Source: RESPOND Study 2018

Variable	Source	Categorisation
Use of health services		
Prescription medicines	EHIS	1 = Medication was prescribed 0 = no medication was prescribed
Emergency room visit	EHIS	1 = Emergency room visit < 12 months 0 = Emergency room visit > 12 months
Health behaviour advice	DEGS	1 = Health behaviour advice 0 = no health behaviour advice
Quality of care		
Ambulatory care sensitive hospitalisations	EHIS	1 = Hospitalisation due to ASC 0 = no hospitalisation due to ASC
Medication abuse	SCID	1 = Medication abuse 0 = no medication abuse
Responsiveness: respectful treatment	WHS	1 = good/very good responsiveness 0 = moderate to very poor responsiveness
Responsiveness: Cleanliness	WHS	1 = good/very good responsiveness 0 = moderate to very poor responsiveness
Responsiveness: Confidentiality	WHS	1 = good/very good responsiveness 0 = moderate to very poor responsiveness
Responsiveness: Autonomy in decision-making	WHS	1 = good/very good responsiveness 0 = moderate to very poor responsiveness
Responsiveness: Communication	WHS	1 = good/very good responsiveness 0 = moderate to very poor responsiveness
Responsiveness: Choice of provider	WHS	1 = good/very good responsiveness 0 = moderate to very poor responsiveness
Responsiveness: Waiting time	WHS	1 = good/very good responsiveness 0 = moderate to very poor responsiveness
Distance of supply		
Perceived distance pharmacy	EPF Access to Healthcare	1 = close enough 0 = not close enough
Perceived distance General practitioner	EPF Access to Healthcare	1 = close enough 0 = not close enough
Perceived distance of specialist	EPF Access to Healthcare	1 = close enough 0 = not close enough
Perceived distance hospital	EPF Access to Healthcare	1 = close enough 0 = not close enough

EHIS = European Health Interview Survey, UN = United Nations, SSS = subjective social status, DEGS = German Health Interview and Examination Survey for Adults, PHQ-2 = Patient Health Questionnaire 2-item version, GAD-2 = General Anxiety Disorder 2-item version, EU-SILC = EU Statistics on Income and Living Conditions, SCID = Structured Clinical Interview for DSM-5, ASC = ambulatory-sensitive conditions, WHS = World Health Survey, EPF = European Patient's Forum

Annex Figure 1
Response rate calculated according
to AAPOR criteria

Source: RESPOND Study 2018



AAPOR = American Association for Public Opinion Research

Annex Table 2
Sociodemographic characteristics of the study
participants by type of accommodation

Source: RESPOND Study 2018

	GU (n = 411)		EA (n = 149)		Total (n = 560)	
	Number	%	Number	%	Number	%
Age group in years						
18–25 years	117	32.5	47	35.6	164	33.3
26–30 years	60	16.7	29	22.0	89	18.1
31–35 years	62	17.2	25	18.9	87	17.7
36–40 years	52	14.4	14	10.6	66	13.4
≥41 years	69	19.2	17	12.9	86	17.5
Total	360	100.0	132	100.0	492	100.0
Sex						
Male	115	31.3	43	31.2	158	31.3
Female	252	68.7	95	68.8	347	68.7
Total	367	100.0	138	100.0	505	100.0
Region of origin						
Eastern Europe	12	3.2	0	0.0	12	2.4
Southern Europe	6	1.6	12	9.2	18	3.6
West Asia	112	30.2	22	16.8	134	26.7
South Asia	119	32.1	9	6.9	128	25.5
West Africa	63	17.0	57	43.5	120	23.9
Central Africa	9	2.4	5	3.8	14	2.8
North Africa	2	0.5	1	0.8	3	0.6
Other nationalities	48	12.9	25	19.1	73	14.5
Total	371	100.0	131	100.0	502	100.0
Educational status						
Low	102	35.9	27	24.5	129	32.7
Medium	122	43.0	51	46.4	173	43.9
High	60	21.1	32	29.1	92	23.4
Total	284	100.0	110	100.0	394	100.0
Months since arrival in Germany						
0–6 months	53	15.5	94	81.0	147	32.0
6–12 months	39	11.4	17	14.7	56	12.2
13–15 months	95	27.7	4	3.4	99	21.6
16–24 months	130	37.9	0	0.0	130	28.3
24–36 months	26	7.6	1	0.9	27	5.9
Total	343	100.0	116	100.0	459	100.0

Continued on next page

Annex Table 2 Continued
Sociodemographic characteristics of the study
participants by type of accommodation

Source: RESPOND Study 2018

	GU (n = 411)		EA (n = 149)		Total (n = 560)	
	Number	%	Number	%	Number	%
Legal status						
Asylum seeker	177	54.3	104	82.5	281	62.2
Asylum approved	76	23.3	3	2.4	79	17.5
Refusal/temporary suspension of deportation	73	22.4	19	15.1	92	20.4
Total	326	100.0	126	100.0	452	100.0
Electronic Health Card						
No	123	35.2	94	87.0	217	47.5
Yes	226	64.8	14	13.0	240	52.5
Total	349	100.0	108	100.0	457	100.0
Subjective social status in Germany						
Low	200	69.9	77	72.6	277	70.7
Medium	57	19.9	13	12.3	70	17.9
High	29	10.1	16	15.1	45	11.5
Total	286	100.0	106	100.0	392	100.0

GU=regional accommodation centres,
 EA=federal reception centre

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Editors

Johanna Gutsche, Dr Birte Hintzpeter, Dr Franziska Prütz,
Dr Martina Rabenberg, Dr Alexander Rommel, Dr Livia Ryl,
Dr Anke-Christine Saß, Stefanie Seeling, Dr Thomas Ziese
Robert Koch Institute
Department of Epidemiology and Health Monitoring
Unit: Health Reporting
General-Pape-Str. 62–66
12101 Berlin, Germany
Phone: +49 (0)30-18 754-3400
E-mail: healthmonitoring@rki.de
www.rki.de/journalhealthmonitoring-en

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Rosa Jahn¹, Sven Rohleder^{1,2}, Markus Qreini¹,
Stella Erdmann³, Sukhvir Kaur¹, Frank Aluttis¹
Kayvan Bozorgmehr^{1,2}

¹ Section for Health Equity Studies and
Migration, Department of General Practice
and Health Services Research, University
Hospital Heidelberg, Heidelberg, Germany

² Department of Population Medicine and
Health Services Research, School of Public
Health, Bielefeld University, Bielefeld,
Germany

³ Institute of Medical Biometry and
Informatics (IMBI), University Hospital
Heidelberg, Heidelberg, Germany

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Health monitoring of refugees in reception centres for asylum seekers: Decentralized surveillance network for the analysis of routine medical data

Abstract

Refugees and asylum seekers living in reception centres tend to be not adequately included in population-based studies, routine medical data and official statistics. As part of the research project ‘Health and primary-care sentinel surveillance in reception- and accommodation-centres for asylum-seekers in Germany’ (PriCare), a health-monitoring approach was developed for the secondary use of routine medical data from on-site outpatient clinics in reception centres. To this end, a software application (Refugee Care Manager, RefCare©) for the digitisation and harmonisation of medical records was designed and implemented in reception centres in three German federal states. The approach of distributed computing in a surveillance network allows for the decentralised, harmonised analysis of the routine medical data stored in RefCare© in a manner that fully complies with data protection regulations and circumvents the need for centralised data storage. RefCare© provides an integrated surveillance feature that enables analyses of 64 indicators on population, morbidity, healthcare processes and quality of care to be undertaken across multiple facilities. This article describes the conceptual and practical approach and the technical procedures put in place to do so, and provides examples of the results that have been gained so far.

HEALTH MONITORING · SURVEILLANCE · MIGRATION · FORCED DISPLACEMENT · ASYLUM · DISTRIBUTED COMPUTING

1. Introduction

The federal health monitoring is tasked with compiling robust data on health, health risks, and healthcare provision for the population in Germany from a broad range of sources, and making this information available to decision-makers and the general public. However, asylum seekers and refugees are insufficiently included in health-related data collection in Germany and other European countries [1]. This shortcoming also applies to routine medical data,

defined as all personal data stemming from health and social services that are primarily collected for routine administrative purposes (cf. [4]). These data provide an essential basis with which to study morbidity and the utilisation of medical services [2–4].

In Germany, asylum seekers are not provided with statutory health insurance and commonly receive medical services on-site in the reception centres, with infrequent referrals to specialist outpatient medical practices. They thus receive healthcare largely outside of regular care provision

Info box

The forms of accommodation used to house asylum seekers at the state level can be divided into registration and reception centres. When asylum applicants are first registered, they tend to be placed in registration centres, which only provide for a short-term stay. In contrast, reception centres provide medium-term accommodation, and asylum applicants may remain in these facilities for up to 18 months. In fact, depending on their country of origin, some applicants remain in reception centres accommodation during the entire application process and until a decision has been made on whether to transfer them to a district-level facility.

These facilities can be further distinguished from the accommodation centres provided at the district level, which tend to vary in size and are a temporary measure. Depending on the outcome of an asylum application, applicants would then be transferred to private housing (see also the article [Monitoring the health and healthcare provision for refugees in collective accommodation centres](#) in this issue of the Journal of Health Monitoring). For the sake of simplicity, these institutions are all referred to here as 'reception centres' or 'facilities' unless a particular type of facility is being referred to.

structures and associated routine medical data sources. The centralisation of the asylum process over the last five years has increased the length of time that asylum applicants live in reception centres. Particularly individuals from 'safe countries of origin' may now remain in reception centres for the duration of their entire asylum process. Moreover, during the first 18 months of their stay in Germany, asylum seekers are only entitled to a limited range of medical care. The electronic health card, which facilitates access to healthcare in Germany and enables data on diagnoses and healthcare provision to be recorded digitally, is also not consistently made available [5]. Spatial, legal and administrative differences, therefore, mean that healthcare is provided to asylum applicants within structures that are inadequately linked to information sources such as routine data (e.g. data from health insurers) [6]. Some federal states provide asylum applicants with an electronic health card, and the healthcare they receive is therefore included in the routine data collected by health insurance providers [7]. However, as these data are only available on a quarterly basis and are primarily gathered for accounting purposes, they are unsuitable for both target-group specific monitoring, and the timely and ongoing surveillance of the health of and healthcare provided to asylum applicants in reception centres, in particular.

With this in mind the development of setting-specific systems for the standardised recording, regular analysis and communication of data about the health of and healthcare provided to asylum applicants in reception centres is an important means of raising awareness about the health needs of this population group ([Info box](#)).

Medical records from outpatient clinics in reception centres constitute an important data source on the health

of refugees, but timely monitoring across all facilities requires standardised and, preferably, electronic medical records. Due to the lack of national and regional guidelines on healthcare provision and medical records in reception centres, however, the situation is characterised by a high degree of fragmentation [8]. The on-site medical services use different electronic medical records, which are often unsuitable for the specific setting of reception centres, and some even rely on paper-based index card systems [9]. The lack of compatible or digital medical records not only has a negative impact on the quality of care caused by communication difficulties for health providers inside and outside of the facilities [10, 11]. It also means that routine medical data from clinics in reception centres are not readily available for analysis and health reporting [10, 12].

The project 'Health and primary-care sentinel surveillance in reception- and accommodation-centres for asylum-seekers in Germany' (PriCare, duration: 2016–2020), which was funded by the German Federal Ministry of Health, was established to improve the quality of medical records in reception centres and to set up a system that can be used to routinely monitor the health of and the healthcare provided to asylum seekers and refugees [9]. The project developed and implemented a tailored software (RefCare©) to digitise and harmonise medical records in reception centres. In addition, in cooperation with medical service providers, the project developed a means of performing regular, automated and real-time statistical analyses of the local routine data using pre-defined indicators. This article describes the conceptual and practical approach and the technical procedures that were put in place to do so, and provides examples of the results that have been gained so far.

2. Methodology

2.1 Software development and implementation

Reflecting the legal requirements for medical records as well as experiences gained from working with healthcare providers in reception centres for asylum seekers, we developed a prototype for the electronic medical records system RefCare©. The prototype provided the basic functions found in typical electronic medical records. Functionalities that were less relevant for care provision in reception centres, such as the accounting of medical services, were disregarded while others, such as vaccinations and multilingual communication, were added. The prototype underwent usability tests with eight doctors working in reception centres [9]. Usability issues raised by these tests were discussed with the software development team and addressed accordingly.

A pilot version was tested as of October 2017 in a clinic in a large reception centre in Bavaria. Feedback was systematically logged and recorded, before being checked for feasibility by the project and development team; ideas were then prioritised and built into the software wherever possible.

Additional test sites followed in 2018 in Bavaria and Hamburg, with the collection of feedback from users and iterative software development continuing as a long-term process that went beyond the initial pilot phase. During this period, the software and the implementation process were further adapted and tailored for use in reception centres (for details, see [9]). This process included that the software supported patient files to be sent between reception centres and healthcare providers for further treatment in a manner that complied with data protection regulations. In addition, a multilingual patient interface and, in March 2020, a module for recording the screening and testing for SARS-CoV-2, and treatment of patients with COVID-19, were also added (Figure 1). Interfaces with existing medical software systems are in the planning stages (as of January 2021).

2.2 Distributed computing network

RefCare© enables medical records to be digitised in a standardised manner, and, therefore, provides for cross-facility harmonisation of locally-stored routine data in participating facilities. In order to perform a cross-institutional analysis of this routine data, and comply with data protection regulations, a procedure was developed that enables decentralised analyses to be conducted without the need to disclose personal information to third parties (i.e. outside of the facilities themselves). This procedure is known as ‘networked distributed computing with the result of an anonymised indicator’. In the following, it is simply referred to as the ‘hive approach’ due to the large number of decentralised yet coordinated analytical processes involved (Figure 2). The hive approach to health monitoring follows five steps.

Administrative features	Patient medical records
Patient administration Task lists and daily lists Saving external documents User administration Administration of external doctors Facility and outpatient clinic data	Recording a patient contact (patient histories, findings, clinical findings, diagnoses, therapy etc.), contact history Medication plan, vaccination status Writing and saving doctors' letters COVID-19 documentation Printing forms (e.g. prescriptions) Tool for multilingual communication
Surveillance	Transfer of medical records
On-site triggering of surveillance and data export through the click of a button Review and export of anonymised results for meta-analysis and reporting	Encrypted transfer of patient records between participating institutions Transfer of patient records to/from other facilities on request or in anticipation of patient transfer

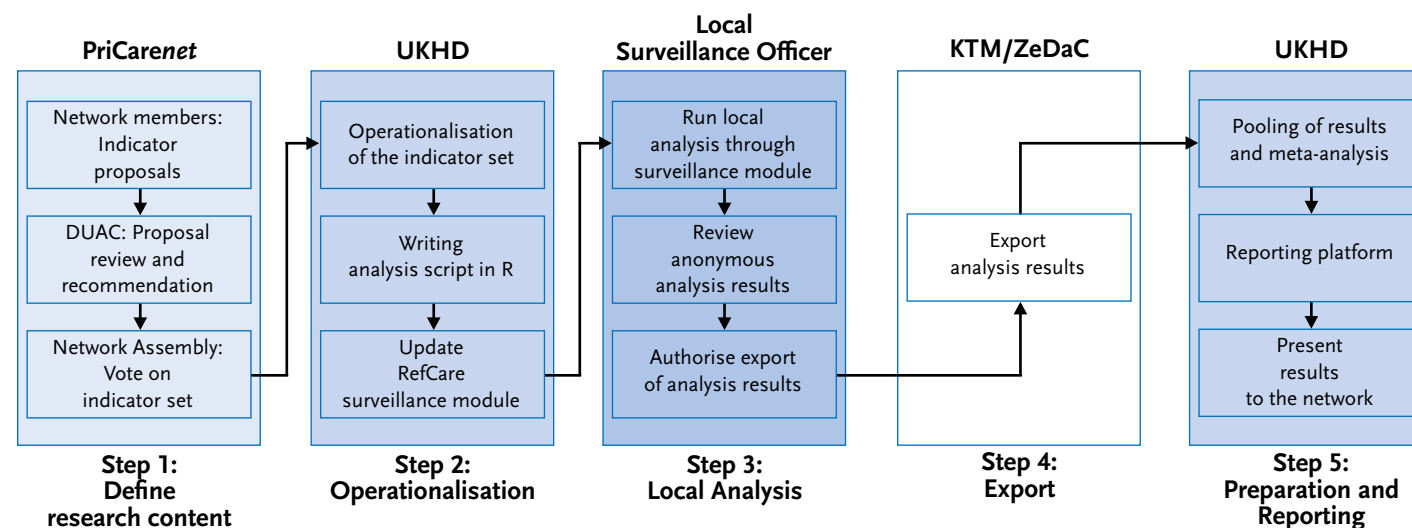
Figure 1

Current overview of the functions available in RefCare© (as of October 2020)

Source: PriCare network, Heidelberg University Hospital

Figure 2
The hive approach: flow chart of distributed
computing used by the PriCarenet network

Source: PriCarenet network,
Heidelberg University Hospital



DUAC = Data Use and Access Committee, KTM = cryptography and transfer module, UKHD = Heidelberg University Hospital, ZeDaC = Central Data Exchange Container

Step 1: Building consensus on surveillance indicators within the PriCarenet research network

The PriCarenet research network consists of representatives from facilities that use RefCare®, the authorities involved, and academic partner institutions. The network jointly develops and adapts the indicator set used in the routine health surveillance. Each member of the network can submit and provide arguments in favour of proposals for new indicators. The scientific basis, feasibility and ethics of the proposals are then assessed by the elected Data Use and Access Committee (DUAC). The committee subsequently provides a recommendation and the indicators are presented to the network's members at the network's general assembly, which is its decision-making body. Finally, members vote on whether to include the indicator in the set; only representatives from the clinics are entitled to vote. The aim of the DUAC is not to secure access to the data 'from the

outside', but to select and coordinate indicators and scientific research questions for analysis at the local level.

The current health and healthcare indicator set, which has been approved by the PriCarenet network, consists of 64 indicators from the fields of population, morbidity, quality of care, healthcare process and syndromic surveillance (Table 1).

Step 2: Operationalisation of health and healthcare indicators

Once an indicator has been approved by the research network, it is operationalised by the project team at Heidelberg University Hospital. Operationalisation is based on the data fields available in RefCare®, particularly diagnosis (International Statistical Classification of Diseases and Related Health Problems, 10th revision, German Modification, ICD-10-GM), reason for seeking medical advice

Table 1
The current health and care indicator set (n = 64)

Source: PriCarenet network,
Heidelberg University Hospital

Indicator
Population
Total population
Patients
Morbidity
Multimorbidity
Disabilities, by diagnosis
Diseases of the skin and subcutaneous tissue, by diagnosis
External causes of morbidity and mortality, by diagnosis
Consequences of external causes
Frequent outpatient diagnoses in accordance with ICD-10-GM
Diseases of the digestive system, by diagnosis
Diseases of the blood-forming organs, by diagnosis
Certain infectious and parasitic diseases
Notifiable infectious diseases
Infectious agents that are resistant to certain antibiotics or chemotherapy
Diseases of the circulatory system, by diagnosis
Hypertension
Body Mass Index
Hypercholesterolemia
Endocrine, nutritional and metabolic diseases, by diagnosis
Diabetes mellitus
Diseases of the musculoskeletal system and connective tissue, by diagnosis
Neoplasms, by diagnosis
Diseases of the nervous system, by diagnosis
Diseases of the ears and mastoid process, by diagnosis
Diseases of the eyes and adnexa, by diagnosis
Certain conditions originating in the perinatal period by diagnosis
Events related to pregnancy, childbirth and the puerperium
Frequency of pregnancies
Mental disorders and behavioural problems, by diagnosis
Therapy with psychotherapeutic medication
Prescription benzodiazepines
Diseases of the respiratory system, by diagnosis
Diseases of the genitourinary tract, by diagnosis

ICD-10-GM = International Statistical Classification of Diseases and Related Health Problems, 10th revision, German Modification,
DPT = combination vaccine against diphtheria, pertussis and tetanus, STIKO = Standing Committee on Vaccination

Indicator
Quality of care
Prescriptions of antibiotics among adults
Ambulatory care sensitive hospitalisations among adults
Ambulatory care sensitive hospitalisations among children
DPT vaccination in children <1 year
DPT vaccination in children 1–5 years
Documentation of vaccination history
Primary immunisation against diphtheria, tetanus, polio started
Basic immunisation against diphtheria, tetanus, polio completed
Frequency of internally performed STIKO vaccinations
Frequency of externally performed STIKO vaccinations
Patients diagnosed as HIV positive undergoing therapy
Consultations where there was a language barrier
Approved reimbursement requests
Diabetes mellitus treatment
Metabolic complications in diabetes mellitus
Healthcare processes
Total number of patient visits
Average number of visits per patient
Healthcare services utilisation per inhabitant
Ten most common reasons for seeking medical advice
Referrals to outpatient, specialist medical facilities
Referral to in-patient facilities
Factors that affect health and lead to healthcare utilisation
Potentially health-endangering incidents (critical incidents)
Syndromic surveillance
Acute respiratory infection
Chronic cough
Fever and rash
Meningitis/encephalitis
Gastroenteritis
Bloody diarrhoea
Skin parasitosis
Fever and bleeding
Acute jaundice

Data on healthcare provision to refugees and asylum seekers in reception centres is essential for individual healthcare and needs-based care planning.

(International Classification of Primary Care, ICPC), prescriptions (Anatomical Therapeutic Chemical Classification System, ATC), vital parameters (e.g. heart and respiratory rate, fever, blood pressure), medical referral forms, and personal data (e.g. age, sex, country of origin). If necessary, software updates can be used to provide new fields, responding to challenges such as the COVID-19 pandemic. To comply with the principle of data minimization, only patient data required for the immediate care provision can be recorded.

Based on the indicator operationalisation, an analysis script is then produced in the programming language 'R'. The script is internally validated by a second team member, using methods such as independent programming, in order to review the plausibility of its results. The script is then made available to the clinics for decentralised, automated analysis via a RefCare© software update [13].

Step 3: Local analysis of routine medical data using the surveillance module

In principle, the analysis of the local routine medical data is conducted by the care providers on a voluntary basis. The analysis script can be executed locally through the integrated RefCare© surveillance module by a simple click on a button (Figure 1). The script begins by anonymising the data set before calculating the results (for details about the technical process see [7]). Access to the surveillance module is only granted to authorised surveillance officers in the clinic itself. Surveillance officers are selected by the responsible staff in the facilities and they are provided with training on how to use the module. They are also given written supporting information and brief instructions. In order to

ensure that the analyses are standardised, and to provide for conclusive meta-analyses, analyses are carried out for cross-facility reporting for precise monthly periods up to the last day of each month. However, facilities can also conduct additional analyses for user-defined periods for their own purposes.

Once the analyses have been completed, the results are immediately available locally. The results are saved in Excel files containing anonymised (i.e. aggregated) figures, such as absolute and relative frequencies or prevalence. Surveillance officers are also provided with an introduction and written instructions to reading and interpreting the output in Excel. This ensures that the healthcare providers have the skills needed to view the results on-site and to assess their plausibility.

Step 4: Encrypted export of the results

The surveillance officers then export the data for the defined surveillance periods from the facility to Heidelberg University Hospital. Exporting the results, too, is voluntary, and occurs independently of the local data analysis. The results are exported via a cryptography transfer module (Figure 2) integrated into RefCare©. This module enables the results to be sent as a data package to the Central Data Exchange Container (ZeDaC), together with details of the addressee (Heidelberg University Hospital) and the sender, before being stored in encrypted form. The PriCare project team at Heidelberg University Hospital can then automatically download the data packages stored on the ZeDaC system and transfer them to an internal surveillance server. Once data packages have been retrieved from ZeDaC they are deleted from the system.

Step 5: Preparation and meta-analysis of facility-specific results

In this step, the anonymised indicator results stored on the surveillance server in Heidelberg undergo automatic graphical processing using R and JavaScript, and are then displayed on a dynamic reporting platform. In this manner, both the results of the facility-specific and cross-facility meta-analyses are made available on the reporting platform. Each facility has its own login details which they can use to view their own analysis results, as well as anonymised data points from other facilities for benchmarking purposes. In addition to automated reporting via the reporting platform, further meta-analyses can be carried out across institutions and are published in regular surveillance reports without providing the names of specific facilities. In order to promote the translation of the analysis results and their utilization for care provision, the results and their possible implications are discussed at the assembly of the research network PriCarenet. This also ensures that the plausibility of the results is assessed regularly and that the indicators can be expanded and supplemented. If needed, facility-specific results can also be made available to the authorities responsible for the reception centres and to higher-level political decision-makers, either through direct access to the reporting platform, or through the healthcare provider. Cross-facility data are published by the network without reference to individual facilities and can thus inform political decision-making processes.

Data protection regulations

Data protection poses a major challenge to regular health monitoring across institutions, especially in the fragmented

and heterogeneous structures found in care provision settings at reception centres for asylum seekers. At the same time, the workload faced by medical staff at the facilities, language issues, and the vulnerability of asylum applicants, means that it is practically impossible to obtain informed consent for research using routine medical data from each patient. However, these challenges can be overcome with the hive approach as it enables researchers to protect the sensitive, personal data of a highly vulnerable population while still conducting cross-institutional health monitoring at regular intervals. Furthermore, this approach also enables medical service providers to evaluate their routine medical data automatically and anonymously and to do so in their own facilities without the need to disclose personal data to third parties. Finally, the approach yields indicators that do not enable any conclusions to be made about specific individuals, and, therefore, the indicator results can be passed on to third parties while still complying with data protection regulations.

The hive approach has a fundamental advantage over traditional surveillance that relies on centralised databases and analyses in remote research facilities: it requires no central storage of personal data. As the results from the various clinics are available in the same format (because they are produced by a standardised script) they can nonetheless be summarised through meta-analysis and comparisons can be made between facilities. The PriCarenet network provides an essential foundation for adherence to data protection regulations, and, therefore, for the use of distributed computing/the hive approach. It ensures that facilities have a say in the analysis of their data and the contents of the routine surveillance. Moreover, the local

Data are not yet systematically available for healthcare planning, research and reporting.

analysis of routine data through the surveillance module as well as the decision to export data are both voluntary. As the script used to analyse a facility's data is run on-site, analyses can therefore be justified by a health provider's legitimate interest in undertaking in-house research for healthcare planning and quality assurance. Depending on the type of healthcare setting and the way in which data protection responsibilities are organised, the legal basis for this type of data analysis is provided by data protection laws at the state or federal level (e.g. §27 Paragraph 1 of the Federal Data Protection Act). Since the analyses are conducted for in-house research with the aim of improving healthcare provision, and because the approach respects data minimisation and guarantees patient anonymity, there is no need to seek prior consent from the patients.

2.3 Examples of statistical analyses

The following provides examples of facility-specific and cross-facility analyses that can be carried out automatically at regular intervals as part of the PriCare project. These examples illustrate the potential of the approach for monitoring the health of asylum seekers and refugees. The results are an excerpt of the information that can be routinely accessed via the reporting platform. The following describes both a facility-specific analysis from a sample facility for the period between 1 May 2018 and 31 August 2020 as well as a cross-facility analysis of a morbidity indicator using data from eleven facilities from the period beginning with the implementation of RefCare© until 31 October 2018. The facilities are grouped by level and include registration centres (level 1) and reception centres (level 2) at

the state level as well as accommodation centres at the district level (level 3) (see also the article [Monitoring the health and healthcare provision for refugees in collective accommodation centres](#) in this issue of the Journal of Health Monitoring). Since the length of time spent in these facilities, the spectrum of morbidity, and the countries of origin differ in each facility, they are grouped by accommodation type for ease of comparability. [Annex Table 1](#) depicts the operationalisation of the morbidity indicators included in the analysis.

Facility-specific analyses

These analyses include information on patient numbers and the number of times that patients have attended the clinic. They also provide an overview of the most common countries of origin in absolute patient numbers per month, in addition to stating a monthly prevalence for the morbidity indicator 'mental and behavioural disorders' (ICD-10 diagnoses: Foo–F99) stratified by age and sex. Furthermore, morbidity profiles are generated for individual facilities using 29 morbidity indicators. This enables a period prevalence to be calculated for each indicator and each institution. When calculating prevalences, the total number of cases for each indicator serves as the numerator, with the total number of people acting as the denominator. In principle, the total number of people living in the facilities could also be used as the denominator. However, these statistics are not recorded directly in RefCare©, and, instead, are collected through a separate survey undertaken in each of the facilities participating in the network on the 15th of each month, stratified by age group and sex. As different facilities achieve different levels of completeness, the total number of people treated has proven a more reliable denominator.

A lack of routine medical data and differences between medical records currently preclude health monitoring across multiple regions.

Cross-facility analyses

The weighted, pooled prevalence and the 95% confidence interval for the morbidity indicator 'mental and behavioural disorders' are provided here, stratified by age and sex. The estimator is calculated using a meta-analysis via a random effects model, in which variance between facilities is accounted for as a random variable. The facility-specific and the pooled estimators are depicted using a forest plot, stratified by age (children up to 18 years, adults aged 18 or above) and sex (female, male).

3. Results

Since the beginning of the project and the implementation of RefCare© in a pilot facility, the software has been implemented in 29 institutions in Baden-Württemberg, Bavaria and Hamburg. Due to facility closures and changes in service provider, as of 2 October 2020, the software is currently used by 24 facilities in these federal states.

The PriCare project successfully developed and implemented the infrastructure required for distributed computing, the PriCaret research network itself, the indicator set, the analysis script and the surveillance module. Each of the 24 facilities can perform automated analyses and utilise the results for on-site planning and reporting purposes. The results particularly enable service providers to meet their sometimes contractually agreed reporting obligations with the authorities and thus directly facilitate their work and improve communication. Sharing facility-specific and cross-facility results within the research network has proven fruitful and contributes to more robust interpretations of the results, enables the indicator set to be adapted,

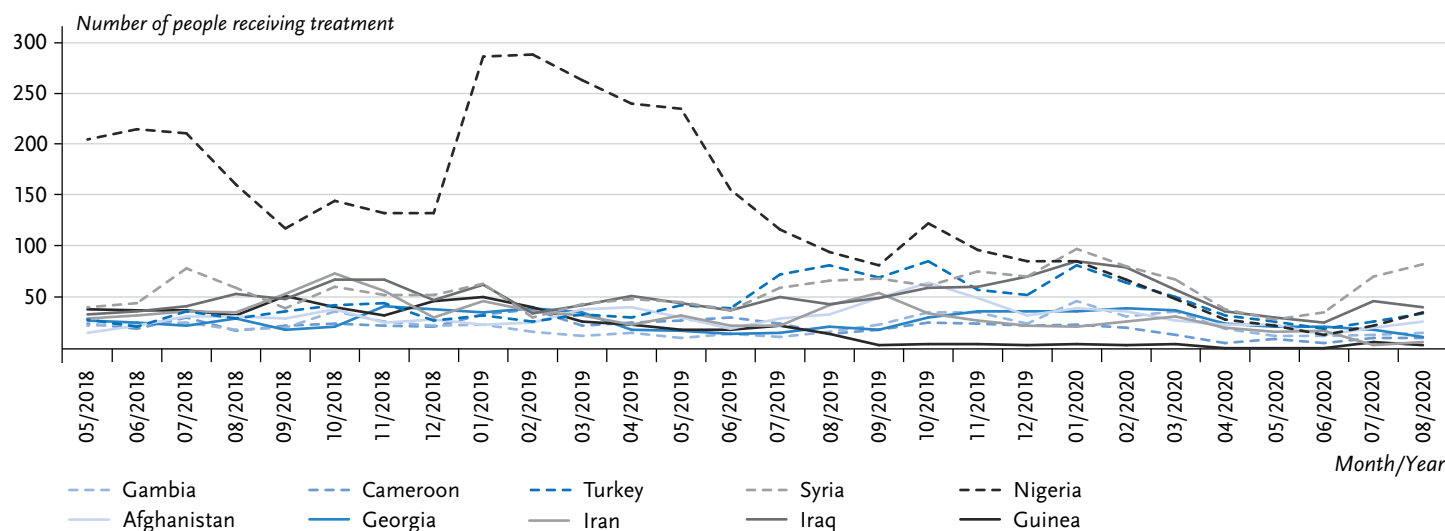
and encourages people to share good practices in the provision of medical care in reception centres.

3.1 Example results from one facility

A total of 11,579 patients were recorded in RefCare© in the facility in question between May 2018 and August 2020. The patients comprised 9,853 adults (85.1%), of whom 3,980 (40.4%) were female, 5,870 (59.6%) were male, and 3 (0.03%) were missing information on sex. 1,726 were children and adolescents (14.9%), of whom 791 (45.8%) were female, 928 (53.8%) were male, and 7 (0.4%) were missing information on sex. Overall, a total of 38,171 patient contacts were recorded. The mean number of contacts per patient was 3.5 for adults; 2.3 for children; 3.9 for female patients; and 2.9 for male patients. The ten most frequent countries of origin among all patients in the observation period per month are shown in [Figure 3](#).

The morbidity profile of this facility shows a predominantly primary care typical spectrum ([Figure 4](#)). Among adult patients, the morbidities with the highest prevalence are respiratory diseases (ICD-10: J00–J99) (female: 19.8%, male: 28.4%), musculoskeletal disorders (ICD-10: M00–M99) such as back pain (female: 14.3%, male: 19.8%), infectious diseases (ICD-10: A00–B99) (female: 14.0%, male: 21.1%), and diseases of the digestive system (ICD-10: K00–K99) (female: 14.3%, male: 16.2%). With a prevalence of 21.7%, conditions concerning pregnancy, childbirth and the postnatal period (ICD-10: O00–O99) are of particular relevance for female adult patients. Among children, diseases of the respiratory tract (female: 36.3%, male: 41.5%) are most prominent, with infectious diseases also

Figure 3
The ten most common countries of origin for people who received treatment over the entire period (absolute monthly patient numbers, n = 11,579)
 Source: PriCaret network, Heidelberg University Hospital



Digitisation of routine medical data is essential for the systematic health monitoring of refugees.

a common condition among this group (female: 17.4%, male: 17.1%). While infectious diseases overall occur frequently, notifiable infectious diseases are comparatively rare among adults (female: 2.4%, male: 5.0%) and children (female: 0.5%, male: 1.3%).

Beyond the primary care spectrum, the data demonstrate that healthcare needs also extend to mental disorders (ICD-10: F00–F99) as well as consequences of external causes (ICD-10: S00–T98). Mental and behavioural disorders were diagnosed in 15.1% of men and 8.8% of women over the entire period. However, mental illnesses were also identified among girls (5.6%) and boys (6.5%). The morbidity indicator ‘consequences of external causes’ includes injuries, burns and other conditions resulting from external causes such as accidents, assaults or operations of war. Men are particularly frequently affected, with a prevalence of 12.7%.

In principle, monthly analyses of absolute case numbers and prevalences for all morbidity indicators are available

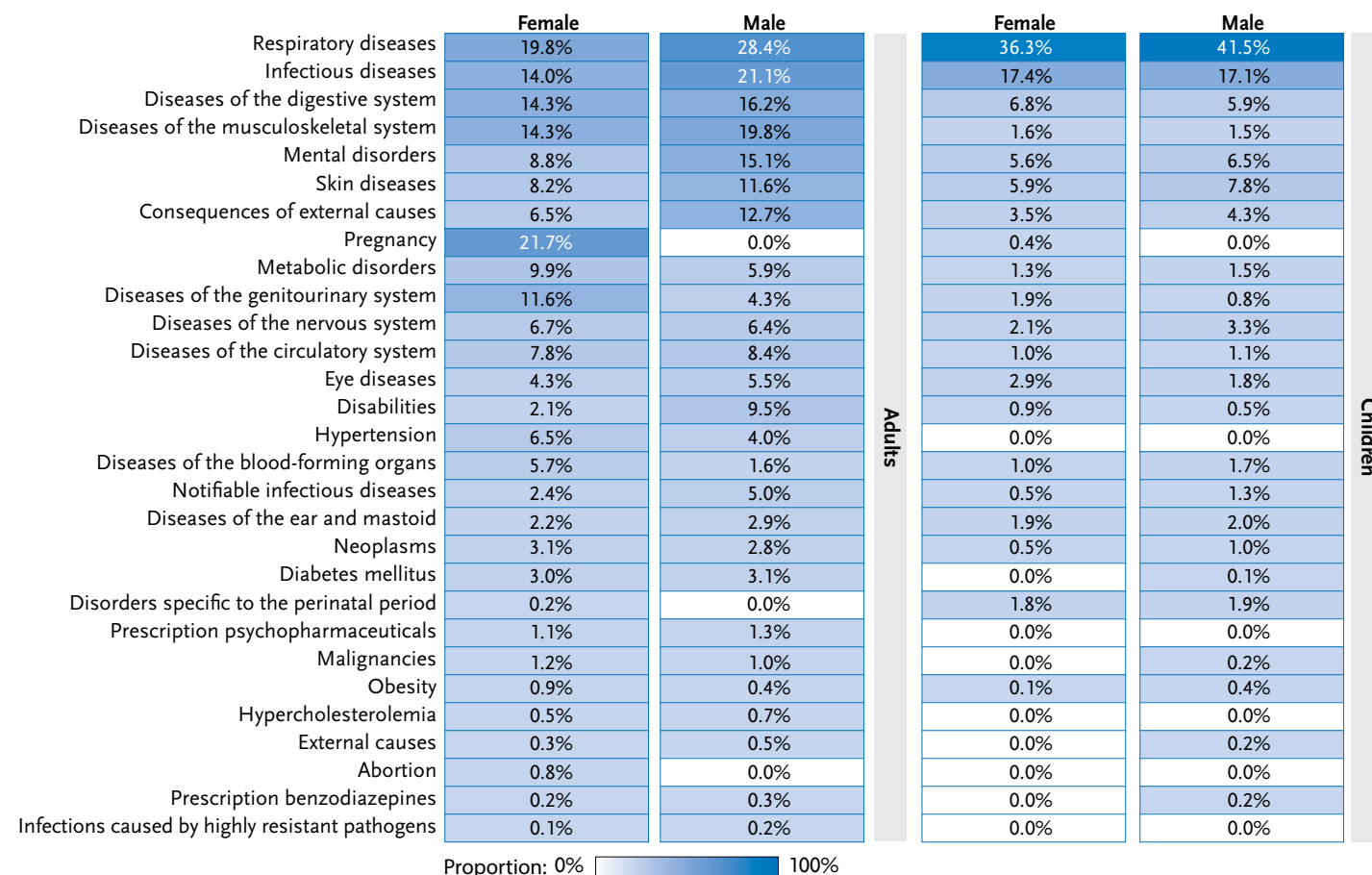
locally at the facility level. As an example, [Figure 5](#) shows the monthly prevalence (based on the total number of people who received treatment) for ‘mental and behavioural disorders’ by sex and age over time. It demonstrates a particularly notable increase in prevalence from 8.2% in April 2020 to 15.1% in May 2020, which is mainly due to a doubling of the prevalence from 10.1% to 20.9% among male patients ([Figure 5](#)). In order to determine whether this increase can be explained by a fluctuation in the number of people living in the facility, a further analysis was conducted using this figure as the denominator. This analysis also identified the same pattern over time ([Annex Figure 1](#) and [Annex Figure 2](#)).

3.2 Examples of results from a cross-facility analysis

Cross-facility analyses, particularly of morbidity indicators, can be conducted at regular intervals and the results are

Figure 4
Morbidity profile of the sample facility depicting the prevalence of morbidity indicators by age and sex (as a percentage of people treated¹), (adults: n=3,980 female, n=5,870 male; children: n=791 female, n=928 male)²
 Source: PriCaret network, Heidelberg University Hospital

Networks and distributed computing enable timely and data-protection compliant health monitoring to be undertaken in reception centres.



¹ For operationalisation, see [Annex Table 1](#)

² Prevalences are colour-coded: blue stands for higher prevalences and light blue to white for lower prevalences (see colour scale). In principle, it is also possible to create a morbidity profile that includes multiple institutions.

made available to the participating facilities for benchmarking purposes via the reporting platform. As an example, [figure 6](#) shows the pooled prevalence of the morbidity indicator 'mental and behavioural disorders' for the period ranging from the introduction of RefCare© until November 2018 for eleven facilities ([Figure 6](#)). The meta-analysis

found an 8.6% pooled prevalence of mental illnesses. Mental illnesses are mainly diagnosed among adults (women: 8.0%, men: 10.9%); the prevalence is 3.6% among girls and 4.0% among boys. Overall, the analysis reveals vast differences in the prevalence of mental illnesses between facilities.

Figure 5
Prevalence of the indicator 'mental and behavioural disorders' (ICD-10: F00–F99), by sex (above) and age (below) for a sample facility (as a percentage of patients, n=4,771 female, n=6,798 male, n=9,853 adults, n=1,726 children)

Source: PriCaret network,
Heidelberg University Hospital

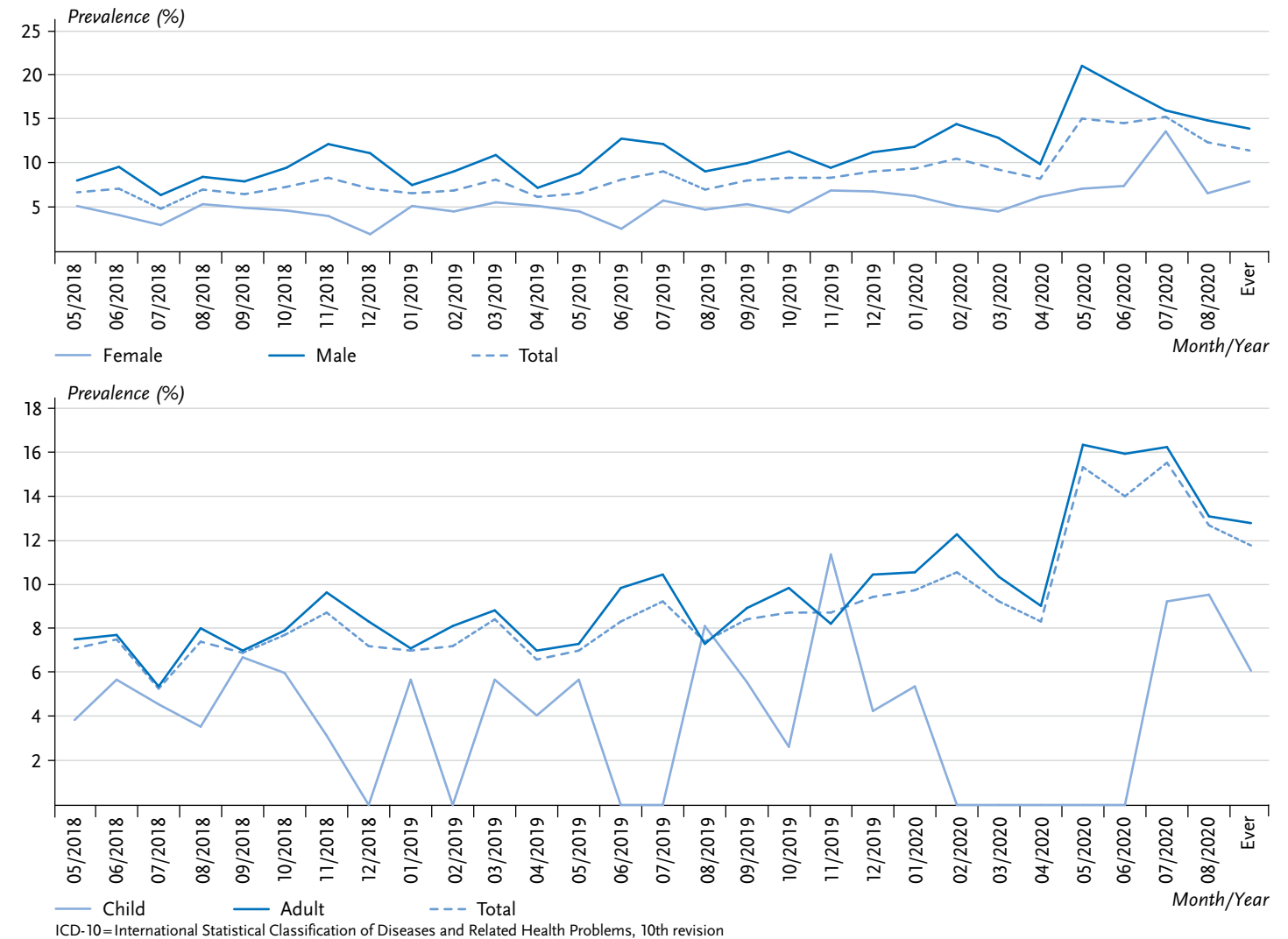
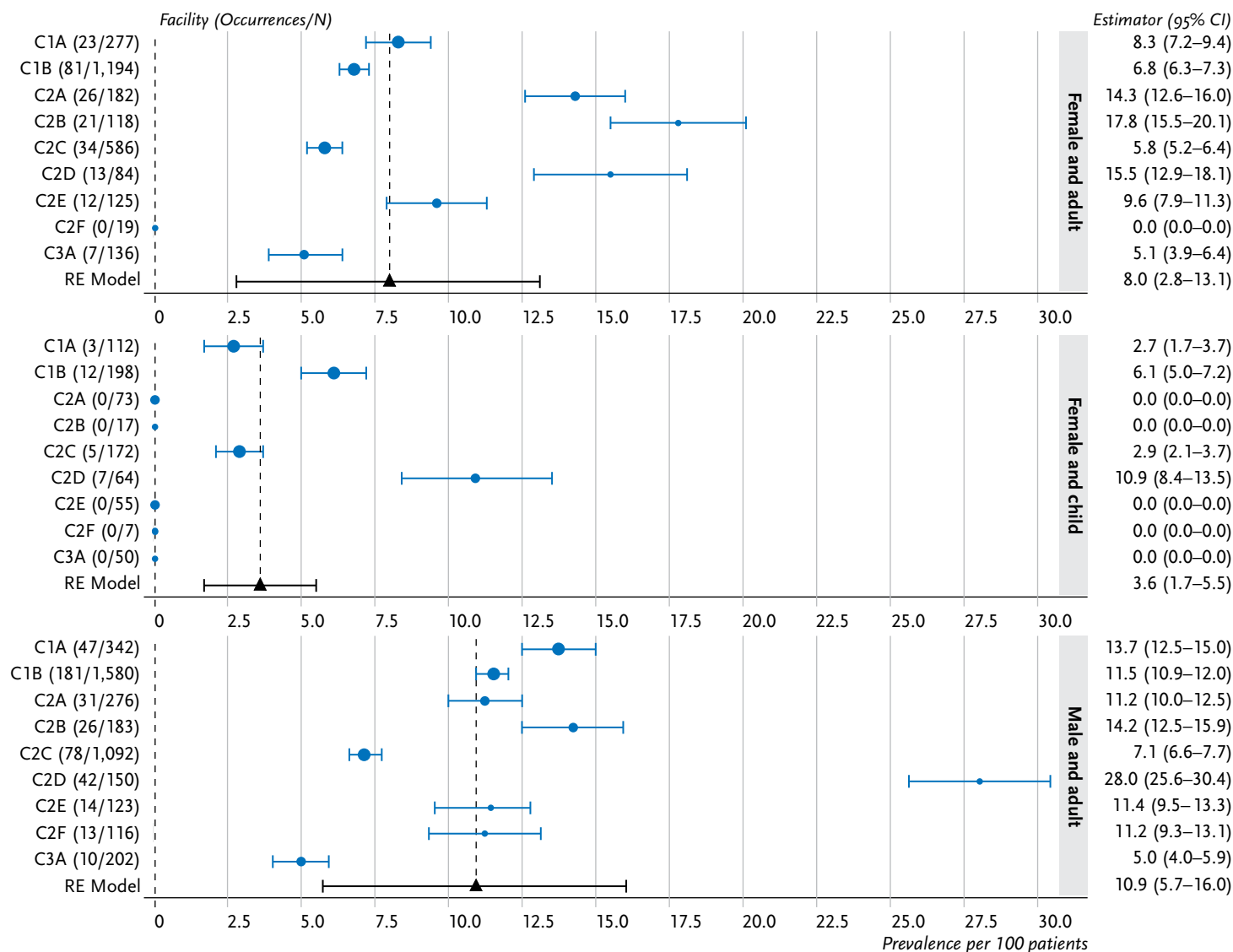


Figure 6
Mental and behavioural disorders
(ICD-10: F00–F99) (as a percentage of the
individuals who received treatment,
adults: n=2,721 female, n=4,064 male,
children: n=748 female, n=872 male)
 Source: PriCaret network,
 Heidelberg University Hospital

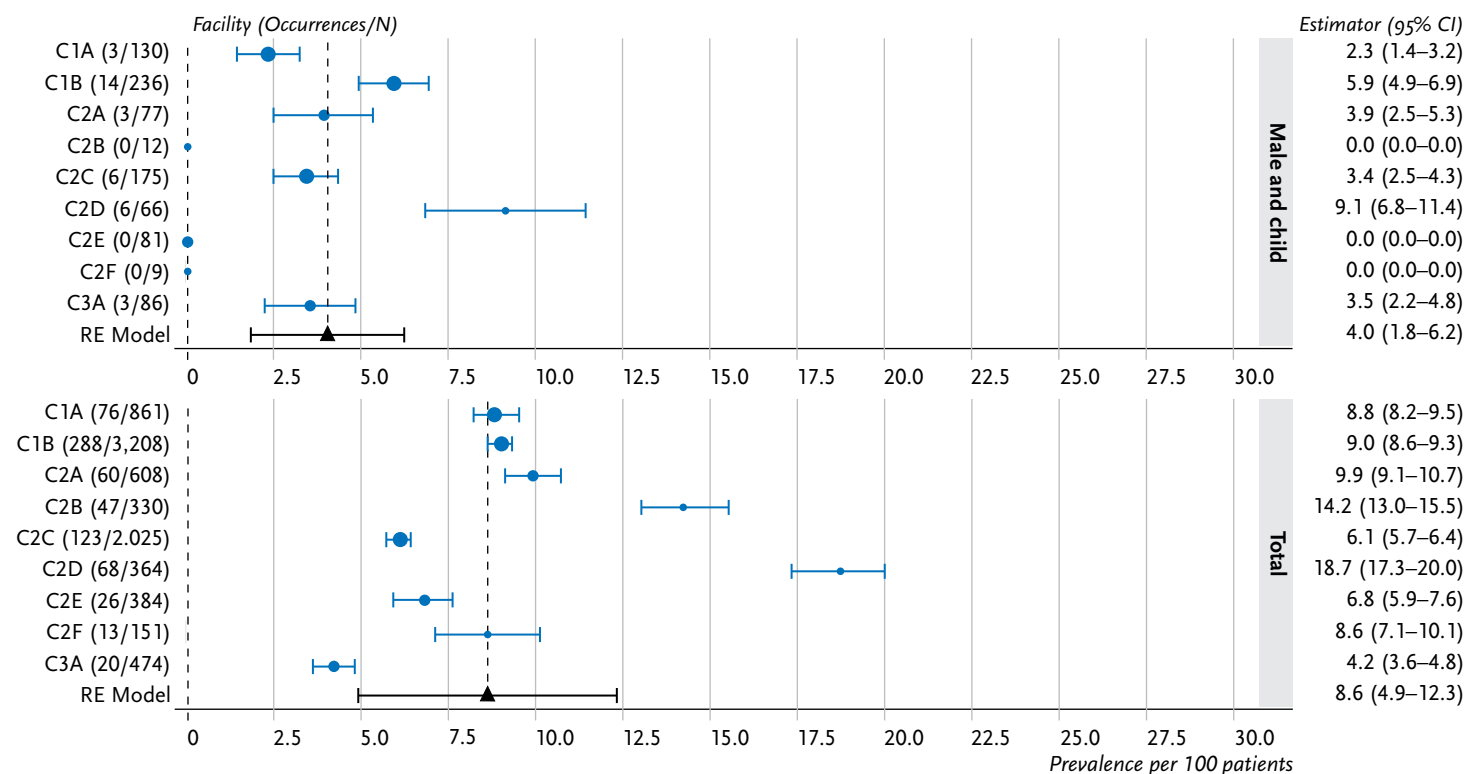
In addition to primary medical conditions, asylum seekers in reception centres often require treatment due to mental illnesses and consequences of external causes, such as accidents, assault, or operations of war.



Total (I^2 : 94.56, τ : 3.93), Male und child (I^2 : NA, τ : 2.17), Male und adult (I^2 : 92.31, τ : 5.26), Female und child (I^2 : NA, τ : 1.71, Female und adult (I^2 : NA, τ : 5.02)
 C1=Registration centres, C2=Dispersal accommodation at federal-state level and dependencies, C3=Accommodation facilities at the district level,
 A, B, C, D, E, F=Facility designation, 95% CI=95% confidence interval, Observation periods: C1A=08/2018–10/2018, C1B=05/2018–10/2018,
 C2A=06/2018–10/2018, C2B=08/2018–10/2018, C2C=10/2017–10/2018, C2D=04/2018–10/2018, C2E=04/2018–10/2018, C2F=07/2018–10/2018,
 C3A=12/2017–10/2018, I^2 =measure of heterogeneity, NA=not specified due to the small number of cells in the substrata, τ =Tau-square statistics

Continued on next page

Figure 6 Continued
Mental and behavioural disorders
(ICD-10: F00–F99) (as a percentage of the
individuals who received treatment,
adults: n=2,721 female, n=4,064 male,
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 Source: PriCaret network,
 Heidelberg University Hospital



Total (I^2 : 94.56, τ : 3.93), Male and child (I^2 : NA, τ : 2.17), Male and adult (I^2 : 92.31, τ : 5.26), Female and child (I^2 : NA, τ : 1.71, Female and adult (I^2 : NA, τ : 5.02)
 C1=Registration centres, C2=Dispersal accommodation at federal-state level and dependencies, C3=Accommodation facilities at the district level,
 A, B, C, D, E, F=Facility designation, 95% CI=95% confidence interval, Observation periods: C1A=08/2018–10/2018, C1B=05/2018–10/2018,
 C2A=06/2018–10/2018, C2B=08/2018–10/2018, C2C=10/2017–10/2018, C2D=04/2018–10/2018, C2E=04/2018–10/2018, C2F=07/2018–10/2018,
 C3A=12/2017–10/2018, I^2 =measure of heterogeneity, NA=not specified due to the small number of cells in the substrata, τ =Tau-square statistics

4. Discussion

The PriCare project demonstrates that automated and timely health monitoring in reception centres for asylum seekers that is feasible and respects data protection regulations can be achieved through the innovative approach of networked distributed computing (the ‘hive approach’). For the first time, healthcare providers in reception centres for asylum

seekers can work with an electronic medical records system that is tailored to their specific setting and provides for structured recording and analysis of morbidity, healthcare utilisation and other healthcare indicators. The facilities can now regularly analyse their routine medical data on-site without the need for specialist knowledge about statistical methods, compare their results with other facilities, and thus base healthcare planning on a solid data foundation.

Consolidating and integrating decentralised analyses into data collection and evaluation structures would close existing data gaps.

This approach also generates a body of data that can be used to aid political decision-makers and to support needs-based healthcare provision. However, if this is to be successful, the results not only need to be communicated in an appropriate manner, there also needs to be a willingness among politicians to consider data on healthcare needs in their decisions about healthcare provision in reception centres.

The results presented here demonstrate that the patients receiving care in the sample facilities exhibit a largely primary care-typical morbidity profile. At the same time, the results also highlight particular needs in terms of mental illness and consequences of external causes. Regarding mental health needs, the results underscore a high degree of heterogeneity between facilities, which may be due to the type of facility, the range of care available, and a facility's particular demographic. The results also suggest that demographic aspects such as country of origin and the prevalence of individual diseases change dynamically, which underscores the need for continuous health monitoring.

This need is also clear from the noticeable decline over time in the indicator 'mental and behavioural disorders'. Between April and May 2020, the respective facility was placed in quarantine for 16 days due to confirmed SARS-CoV-2 infections and all leisure and social support programmes were consequently cancelled. The decline remains stable even after fluctuations in the total number of occupants are taken into account, which means that changes in the total number of people living in the facility do not suffice as an explanation. However, nor does this descriptive analysis of the data demonstrate any clear association between what was happening in the facility during this period and an increased prevalence of mental illness. Instead, this increase

could be due to random fluctuations over time or differences in coding practice resulting from personnel changes. Still, the results clearly illustrate the usefulness of health monitoring in this context: the descriptive time trend reveals a need for specific in-depth analyses that apply more complex procedures. This would involve examining possible associations in individual facilities and across facilities between, for example, measures put in place to contain the pandemic and the prevalence of psychological stress. Similar studies could be undertaken on the other morbidity and healthcare indicators, such as for vaccinations against influenza viruses and seasonal changes in the prevalence of respiratory infections.

In principle, this approach faces the typical limitations associated with the use of routine medical data [14]. These include issues of completeness, missing data, objectivity, reliability and, consequently, the validity of the content of the coded and documented data [14]. Since the monthly query of numbers of inhabitants has not proven practicable everywhere, the total number of patients (the outpatient population) has typically been used as the denominator. In periods with lower population flows, the figures for the total number of patients and inhabitants are closer to each other than during periods with greater levels of fluctuation. In the future, the higher discrepancy in the denominators during periods with a higher level of fluctuation could be accounted for with adjustment factors; however, these have yet to be developed empirically. In addition, heterogeneous coding behaviour leads to variance between and within facilities. Although this can be accounted for partially by using statistical methods, such as random effects models for the meta-analyses, the results are still not comparable to those

gained from standardised primary studies such as health monitoring surveys.

Other challenges arise with the internal validation of diagnoses, especially when it comes to differentiating between suspected and confirmed diagnoses, as these differences are not always recorded. In addition, the spectrum of medical services provided and the function of the respective facilities have an impact on the range of diagnoses that will be recorded. It is fair to assume that illnesses that require specialised diagnostics will go underreported, not least because of the restricted entitlement to treatment set out in the Asylum Seekers Benefits Act. This becomes especially clear through comparisons between the prevalence of mental illnesses reported here and the prevalence identified using survey-based approaches (see also the article [Monitoring the health and healthcare provision for refugees in collective accommodation centres](#) in this issue of the Journal of Health Monitoring). Moreover, the morbidity profile in protective facilities housing asylum seekers with special needs can be expected to differ from that found in registration centres, where people remain for a very short period of time. Therefore, additional information about the context and the facility itself are important in order to adequately conduct and interpret cross-facility meta-analyses. In the PriCare project, the research network fulfils this purpose by providing a forum for the context-specific interpretation of the results.

However, the hive approach offers a resource-saving approach to ongoing, timely and comprehensive health monitoring without the added burden of data collection. To compensate for the limitations associated with the secondary use of routine medical data, the routine health monitor-

ing could be supplemented with survey-based approaches undertaken at longer intervals (e.g. every three to five years) (see also the article [Monitoring the health and healthcare provision for refugees in collective accommodation centres](#) in this issue of the Journal of Health Monitoring).

In comparison to other efforts to utilise routine medical data from refugee camps in Europe to analyse health and healthcare parameters, too, the hive approach has significant advantages. For example, routine medical data from reception centres in Denmark and the Netherlands have been used in research. However, these analyses are based on centrally-stored routine medical data, and do not provide for regular analyses; as such, they are selective and guided by the interests of individual researchers [15, 16]. Therefore, these approaches are only partly suitable for timely, data protection-compliant health monitoring. Other approaches are based on the introduction of e-health systems, such as the system operated by the UN Relief and Works Agency (UNRWA), which is responsible for refugees from Syria, Lebanon, the West Bank and the Gaza Strip [17]. Research has also been undertaken using electronic patient files, such as those from the International Organization for Migration as part of the e-PHR project [18] and the electronic files held in Germany on asylum applicants [9]. However, these web-based applications for recording routine medical data use central ('cloud-based') data storage and are therefore associated with the risks and challenges of maintaining and protecting a database with sensitive personal data from a vulnerable population group (see also [9]). Distributed computing avoids these problems, while still enabling health monitoring to be conducted using individual-level data.

As technology development, methods, processes and the structures required for the PriCare project were funded by the Federal Ministry of Health, the next challenge is consolidating these structures and ensuring that they remain in place in the long term. Bilateral, non-commercial utilisation and licensing agreements have been concluded with most facilities within the network, and this should enable the project to continue for the time being. However, optimal long-term use of the infrastructure and procedures established by the PriCare project would require their expansion to all accommodation facilities in all federal states and, above all, the development of sustainable health reporting. This would enable the health of and the healthcare provided to refugees to be monitored in all accommodation facilities throughout the country and would, therefore, permanently close existing data gaps.

The hive approach can also be used in areas of health services research beyond the healthcare provision in reception centres for asylum seekers. The federal health system, with its fragmented healthcare provision and data landscape, poses similar challenges to those described above when using routine medical data for health monitoring and research. The application of distributed computing, therefore, could be an important tool for the Medical Informatics Initiative [17] as well as for prompt analysis and reporting of notifiable diseases. The limitations faced by conventional approaches such as the use of centralised databases or federal reporting systems could thus be avoided. The hive approach also avoids time lags of reports of notifiable diseases filed with district-level public health services reaching the federal level. The COVID-19 pandemic has shown that reporting lags of just a few days can

be of great importance for supra-regional health monitoring, evidence-based political decision-making and the broader public. However, distributed computing requires a standardised or an at least interoperable database structure across participating institutions that enables standardised scripts to be run on-site. This produces comparable, anonymised results that can then be made available for meta-analysis.

In cases like the implementation of the hive approach in reception centres for asylum seekers, where routine medical data are analysed for all patients without obtaining written consent, additional issues need to be addressed in order to guarantee data-protection compliance. In particular, a decision-making body is required to ensure that medical service providers have a say regarding the indicators used in the analyses of the local routine data. Distributed computing could be implemented in other areas of health with great potential once these foundations have been put in place.

In addition to the results from the statistical analysis, developing the infrastructure needed to implement the 'hive approach' in the heterogeneous settings of reception centres has led to positive side-effects. The implementation of standardised medical records that comply with data-protection regulations when transferring patient records between facilities, and provides customised outpatient administrative functions, contributes towards reducing the workload for its users and improving healthcare provision. Furthermore, the project encourages facilities to consider legal, administrative and organisational aspects relating to the protection of medical records in the often precarious and fragmented settings of care provision,

and to clarify where data protection responsibilities lie within their facilities.

Finally, in addition to developing the indicators used for health monitoring, the PriCarenet research network has also proven an important forum for sharing experiences between the participating institutions. This encourages members to discuss experiences, challenges and best practices. The interpretation of the results from health monitoring as well as discussion within the research network about possible implications for healthcare provision and planning also contribute to the further improvement of healthcare provision in reception centres for asylum seekers.

Corresponding author

Prof Dr Kayvan Bozorgmehr
Department of Population Medicine and Health Services Research,
School of Public Health, Bielefeld University, Bielefeld, Germany
P.O. Box 10 01 31
33501 Bielefeld, Germany
E-mail: kayvan.bozorgmehr@uni-bielefeld.de

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Data protection and ethics

This study complied with the data protection regulations set out in the EU General Data Protection Regulation (GDPR) and the Federal Data Protection Act (BDSG).

A comprehensive approach to data protection was developed jointly with the technology and method platform for networked medical research (TMF) e.V. [19]. It was approved by TMF's data protection group in February 2018. As the GDPR came into force afterwards, the approach was completely revised and sent for approval to the TMF; renewed approval was granted in September 2020.

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Conflicts of interest

Rosa Jahn, Kayvan Bozorgmehr and Frank Aluttis are registered at University Hospital Heidelberg as inventors of RefCare© in line with the Employee Invention Act (ArbnErfG). Rosa Jahn, Kayvan Bozorgmehr and Frank Aluttis state that they have no financial conflicts of interest. Sven Rohleder, Stella Erdmann, Sukhvir Kaur and Markus Qreini state that they have no conflicts of interest.

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Annex Table 1
Overview of the operationalisation
of the indicators
 Source: Own table

Indicator	Operationalisation (ICD-10 codes)
Disabilities	H54, R47, H90–H91, H80–H82, Q71–Q73, M20–M21, Z89, G82, F06–F07, I68, P91, F7, F1
Diseases of the skin and subcutaneous tissue	L00–L99
External causes of morbidity and mortality by diagnosis	V01–Y84
Consequences of external causes of morbidity and mortality	S00–T98
Digestive system diseases	K00–K99
Diseases of the blood and the blood-forming organs	D50–D90
Infectious and parasitic diseases	A00–B99
Notifiable infectious diseases	B30.0, B30.1, A05.1, A23.0, A23.1, A23.3, A23.8, A23.9, A04.5, A92.0, A00, A81.0, A97, A36, A98.4, A04.4, B67, A04.3, A75.0, A84.1, A95, A07.1, A41.3, A49.2, G00.0, J09, J14, J20.1, P23.6, A98.5, B15, B16, B17.1, B18.2, B19, B16.0, B16.1, B17.0, B17.2, B17.8, B20–B24, D59.3, M31.1, J09, J10, J11, A37, A07.2, A96.2, A68.0, A48.1, A48.2, A30, A27, A32, P37.2, B50–B54, A98.3, B05, A39, A41.0, A49.0, G00.3, P36.2, A22, B26.8, B26.9, A08.1, A70, A01.1, A01.2, A01.3, A01.4, A20, A80, A78, A08.0, P35.0, B06.8, B06.9, A0, A03, A50, A53, A82, Z20.3, P37.1, B75, A15–A19, P37.0, O98.0, A21, A01.0, A92.0, A92.4, A96, A98.0, A98.1, A99, B02, P35.8, A04.6
Infectious agents that are resistant to certain antibiotics or chemotherapy drugs	U80–U85
Circulatory system diseases	I00–I99
Hypertension	I10–I15 (or vital parameters: blood pressure > 140/90 mmHg)
Body Mass Index (BMI)	E65–E68
Hypercholesterolemia	E78
Endocrine and Metabolic Diseases	E00–E9
Diabetes mellitus	E10–E14
Diseases of the musculoskeletal system and connective tissue	M00–M99
Neoplasms by diagnosis	C00–D48
Malignant neoplasms	C00–C97
Nervous system diseases	G00–G99
Diseases of the ear and mastoid process	H60–H99
Diseases of the eyes and appendages	H00–H59
Disorders originating in the perinatal period	P00–P96

ATC=Anatomical-Therapeutic-Chemical Classification System for Medicinal Products,
 ICD-10=International Statistical Classification of Diseases and Related Health Problems, 10th revision

Continued on next page

Annex Table 1 Continued
Overview of the operationalisation
of the indicators

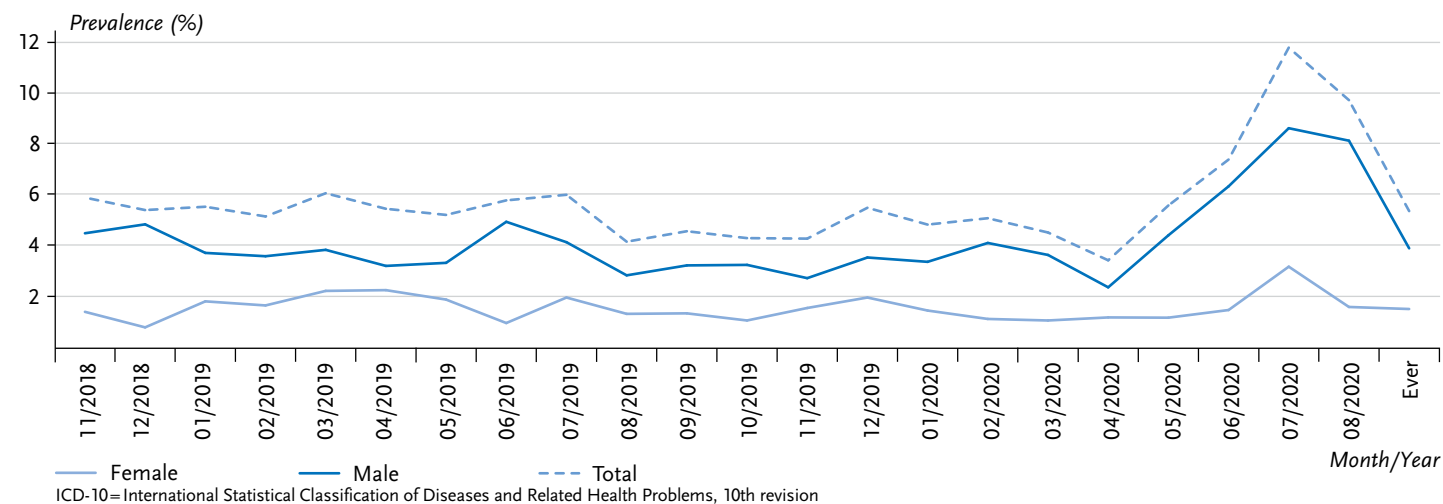
Source: Own table

Indicator	Operationalisation (ICD-10 codes)
Events related to pregnancy, childbirth and the puerperium	O00–O99
Abortion	O00–O08
Mental and behavioural disorders	F00–F99
Therapy with psychotherapeutic medication	ATC codes: N05 (antipsychotics, anxiolytics), N06A, N06B, N06C (antidepressants, psychostimulants, herbal psychotropic drugs), N07BB (drug for alcohol addiction treatment)
Prescription benzodiazepines	ATC codes: N05BA (anxiolytics) or N05CD (hypnotics)
Respiratory system diseases	J00–J99
Diseases of the genitourinary system	N00–N99

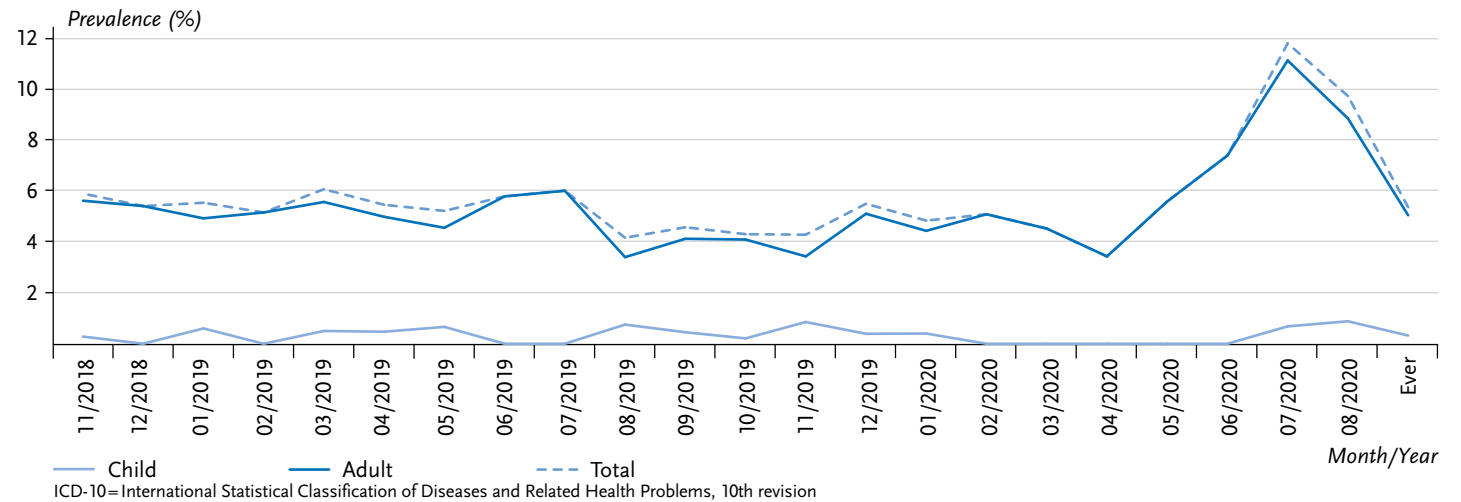
ATC=Anatomical-Therapeutic-Chemical Classification System for Medicinal Products,
 ICD-10=International Statistical Classification of Diseases and Related Health Problems, 10th revision

Annex Figure 1
Prevalence of the indicator ‘mental and
behavioural disorders’ (ICD-10: F00–F99,
as a percentage of residents)
for a sample facility

Source: PriCaret network,
 Heidelberg University Hospital



Annex Figure 2
Prevalence of the indicator 'mental and behavioural disorders' (ICD-10: F00–F99, as a percentage of residents) for a sample facility
 Source: PriCarenet network, Heidelberg University Hospital



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Editors

Johanna Gutsche, Dr Birte Hintzpeter, Dr Franziska Prütz,
Dr Martina Rabenberg, Dr Alexander Rommel, Dr Livia Ryl,
Dr Anke-Christine Saß, Stefanie Seeling, Dr Thomas Ziese
Robert Koch Institute
Department of Epidemiology and Health Monitoring
Unit: Health Reporting
General-Pape-Str. 62–66
12101 Berlin, Germany
Phone: +49 (0)30-18 754-3400
E-mail: healthmonitoring@rki.de
www.rki.de/journalhealthmonitoring-en

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