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Collecting longitudinal data among newly arriving asylum seekers and refugees in Germany:

Experiences from a pilot study at the onset of
the COVID-19 pandemic

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2 Introduction

The project NEXUS ("Natural experiment on contextual effects on health and health care among refugees") is a project of the Research Unit "Refugee migration to Germany: a magnifying glass for broader public health challenges" (PH-LENS) funded by the German Research Foundation (DFG). A major goal of NEXUS is to analyse the relationship between health inequalities and contextual factors of the place of residence, e.g., housing, neighbourhood, and regional deprivation among asylum seekers and refugees (ASR). To achieve this goal, a prospective cohort study, embedded in a natural experiment design, was planned with ASR arriving in Baden-Württemberg, Germany. The distribution of ASR *within* the federal state is based on a population key, which makes the dispersal of ASR among the 44 urban and rural counties in Baden-Württemberg quasi-random and as such an opportunity for a natural experiment. Within the framework of a natural experiment, contextual effects can be assessed while avoiding compositional bias by individual factors, so that causal mechanisms can be studied (Craig et al. 2017).

The original plan was to recruit participants into a prospective cohort (starting in spring 2020) at the state's registration centre with a bi-monthly follow-up over 12 months to realise a repeated measurement of contextual exposures, such as living and housing conditions. The rationale was to recruit participants early after arrival to the reception centre (within 7 – 14 days of arrival) to capture baseline health status and assess the influence of post-migration social determinants on the future short- to mid-term health trajectory. The standardised instruments used for data collection, health status and access to care had been translated into seven languages and adapted for the refugee context in a previous population-based cross-sectional study (Biddle et al. 2019). Further adaptations were made to the questionnaire to suit the longitudinal design and especially the repeated measurement of contextual exposures. On March 11, 2020 the WHO declared the outbreak of the SARS-CoV-2 virus as a global pandemic, hence the planned cohort could not be realised as field access was denied by the local authorities in charge. However, the instruments and data collection strategy could be tested in a pilot study with 19 survey participants at baseline who were recruited shortly after their arrival at the reception centre. The aim of this working paper is (i) to report preliminary descriptive results, and to provide insights into field notes and qualitative interviews of this pilot study. Additionally, the paper aims (ii) to discuss the feasibility of the applied data collection methods based on challenges and obstacles experienced during the pilot study to derive conclusions for potential modifications for future field work.

3 Methods

This study was designed as a prospective cohort study to exploit the relationship between health inequalities and the contextual factors of the place of residence.

3.1 Conduct of the study

Established instruments already adjusted for the target population of ASR from the RESPOND study (respond-study.org) were used (Biddle et al. 2019). COVID-19 specific instruments and related questions were added to the baseline (t0) and contextual questionnaires (see table 1 and 2). The questionnaires were translated and provided in seven languages: German, English, French, Farsi, Arabic, Turkish, and Russian. Multi-lingual interviewers were recruited with all languages except Turkish represented. Interviewers were trained before data collection. The training comprised of a short introduction to the project, information on recruitment of participants, a detailed look into the survey questions and interview practice. The t0 questionnaire was conducted as a personal computer assisted interview (CAPI). This method was chosen as a CAPI offers the possibility to better include people with reading or writing difficulties, as opposed to pen-and-pencil questionnaires.

Although initially planned as a random sample, the recruitment and sampling process was adapted to a convenient sampling approach for the pilot phase due to COVID-19 restrictions. As all newly arriving ASR were quarantined for 14 days (regardless of SARS-CoV-2 infection status), the quarantine buildings were used as settings to approach eligible individuals for inclusion into the cohort. A few houses within the quarantine section of the centre accommodated ASR with presumed tuberculosis infection, which were also included for recruitment. All ASR speaking one of the seven study languages, being 18 years or older and staying in quarantine buildings of the initial reception centre for ASR in Baden-Württemberg, were eligible. Recruitment was based on a door-to-door approach, during which COVID-19 prevention policies were adhered to. After informing ASR verbally and in writing (by means of multi-lingual information sheets) about the study purpose and aim, the researchers invited eligible individuals to participate in the study. Those eligible and willing to participate could give their informed consent to (1) take part in the study; (2) take part in the follow-up study and be contacted via phone, email, WhatsApp or social media; (3) have their residence address enquired after transfer by contacting the authorities in charge; (4) be contacted by other PH-LENS research projects. Consent was received for each of the items, and individuals could decline completely, or consent to one or more aspects (e.g., take part in the study at baseline but decline follow-up; or agree to follow-up, but decline that researchers contact authorities to acquire their residence address after transfer). Of those who did not consent to participate, the reasons for non-participation, nationality, and gender were recorded.

Table 1: Survey instruments at baseline (t0)

Survey instruments at t0
General health status (EHIS © European Union & DEGS (“German Health Interview and Examination Survey for Adults”))
Mental health (PHQ2, GAD2, PC-PTSD5)
Disease-specific information (List of outpatient-sensitive diseases, adapted from Sundmacher et al. 2015)

Hospitalisation (Adapted from EHIS © European Union)
Health Behaviour DEGS (“German Health Interview and Examination Survey for Adults”)
Health-related quality of life (EUROHIS-QOL)
Utilisation of general practitioners and specialists (Adapted from EHIS © European Union)
Prescription drugs (Adapted from EHIS © European Union, Access to healthcare survey © European Patient Forum)
Non-utilisation of health care services (Adapted from EHIS © European Union)
Utilisation of emergency room (Adapted from EHIS © European Union, Access to healthcare survey © European Patient Forum)
General sociodemographic information
Mother tongue
Education
Information on family
Employment and income
Information on the asylum process
Subjective social status (Adapted MacArthur-Scale, capturing both pre- and post-migration subjective social status)
Setting specific questions:
<ul style="list-style-type: none"> • Agreement with pandemic control measures (COSMO-project (Betsch et al. 2020)) • Current housing situation (incl. internet access, sharing of living space) • Responsiveness of Health System regarding information, respectful treatment, privacy within the quarantine accommodation • Domestic violence

Table 2: Domains covered by the contextual questionnaire for bi-monthly follow-ups in a repeated measurements approach in a total of four follow-ups (tc 1-5)

Contextual questionnaire
Current housing situation
Information on the asylum process (incl. transfers, electronic health card...)
Geographical accessibility of services (healthcare services and e.g., supermarkets)
Employment and income
Current pandemic control measures implemented at the accommodation (adding a question on vaccination in the course of the study)

Participants in the follow-up study were contacted eight weeks after t0 and were invited to the contextual survey. The bi-monthly contextual surveys were conducted via telephone and comprised questions about the social and living environment, more specifically about the location, size, and quality of the current accommodation, but also about the spatial situation (e.g., sharing a room with strangers), cooking facilities, sanitary facilities or leisure opportunities, as well as about the personal situation (e.g., asylum status,

subjective social status in Germany) (see table 2). If participants could not be reached during the first attempt of contacting them, they were contacted three more times within ten days. Those who could not be reached were categorised as drop-out. Fieldnotes were taken throughout all survey rounds.

During data collection of contextual exposures, the research team decided to change the fifth contextual survey (tc5) into a qualitative semi-structured interview, given the small number of participants and their experiences captured in the fieldnotes. The purpose of the qualitative interview was to explore more in depth how the participants experience their accommodation situation and whether the contextual questionnaire covered all relevant dimensions of housing. The qualitative interview contained the following aspects:

- The impact of the accommodation on well-being and health
- Experiences in different types of accommodations (especially in RC/AC¹)
- Aspects of housing that are relevant to well-being and health from participants' perspectives
- Need for improvement of living conditions from participants' perspectives

The t1 survey followed 12 months after t0. Table 3 shows an overview of the instruments used and the domains covered in the t1 questionnaire.

Table 3: Survey instruments at 12-months follow-up (t1)

Survey instruments at t1
General health status (EHIS © European Union & DEGS (“German Health Interview and Examination Survey for Adults”))
Mental health (PHQ2, GAD2, PC-PTSD5)
Disease-specific information (List of outpatient-sensitive diseases, adapted from Sundmacher et al. 2015)
Hospitalisation (Adapted from EHIS © European Union)
Health Behaviour DEGS (“German Health Interview and Examination Survey for Adults”)
Health-related quality of life (EUROHIS-QOL)
Utilisation of general practitioners and specialists (Adapted from EHIS © European Union)
Prescription drugs (Adapted from EHIS © European Union, Access to healthcare survey © European Patient Forum)
Non-utilisation of health care services (Adapted from EHIS © European Union)
Utilisation of emergency room (Adapted from EHIS © European Union, Access to healthcare survey © European Patient Forum)
Family doctor (yes/no)
Health expenditures
Health promotion
Geographical accessibility of services
Responsiveness (WHO-Responsiveness)

¹ RC= reception centre, AC= accommodation centre

Education**Employment and income****Information on family****Information on the asylum process****Subjective social status (MacArthur-Scale)****Questions on COVID-19 vaccination**

3.2 Data analysis

Results from the baseline survey (t0) were evaluated descriptively using StataSE 17 and displayed in a table format. Results from tc1-4 and t1 were narratively summarised. The qualitative interviews conducted at tc5 were transcribed and the main issues related to the living context that influenced the participants' health and well-being were explored.

4 Results

From June to August 2020, 19 persons were recruited for the baseline survey. The response rate was 29.6 percent. Reasons for non-participation were primarily the availability of the study language (n=29), 12 persons were not encountered in their rooms, three people participated already in another study and one person was not interested to participate.

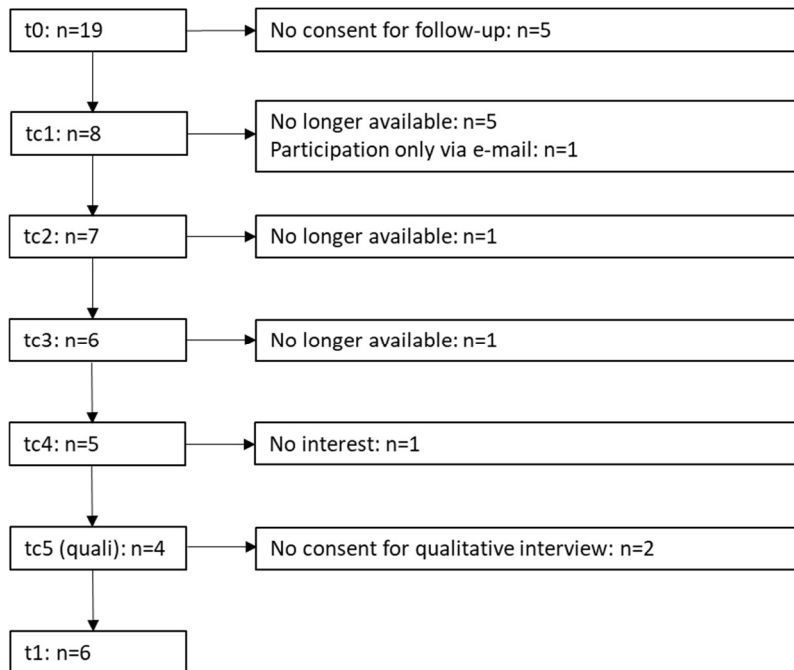
Five out of 19 participants did not agree to the follow-up study. Out of the 14 people who agreed to be contacted for the follow-up (tc1), eight individuals could be reached and participated at tc1. Tc2 included seven participants, tc3 six participants, and tc4 five participants. The main reason for drop-outs during the contextual surveys was the inability to reach the participants, other reasons of non-participation were either personal issues or no consent to the qualitative interview at tc5. Finally, six respondents (about 32% of the baseline sample) took part in the t1 follow-up survey after 12 months (see figure 1).

4.1 Baseline survey (t0)

The t0 questionnaire took one and a half to two hours including informing participants about the goals of the survey and informed consent. There were more men (n=15; 79%) in the sample than women (n=4; 21%), which fairly represents the sex distribution of incoming refugees in Germany. More than half of the sample was 18-25 years old and two people were over 41 years of age. Almost 58 percent (n=11) of the participants arrived in Germany between zero and ten days before recruitment, the other participants had been living in the reception centre for up to 14 months. These long periods of stay relate to participants with a chronic or severe illness who remain in the initial reception centre until treatment is completed. The sample comprised eight different nationalities: Albania (n=1), Afghanistan (n=1), The Gambia (n=4), Georgia (n=2), Nigeria (n=3), Syria (n=5), Togo (n=1), and Turkey (n=2). Three quarters of the participants were asylum seekers, i.e., in an ongoing asylum process, the other five participants had already received a protection status or were tolerated (i.e., their application is rejected, but their deportation is suspended). More than half of the sample

was single (n=11), the other participants were married (n=4), living in a partnership (n=3) or were divorced (n=1). About half of the participants (n=10) had completed high school, six had completed mandatory schooling and three indicated no schooling (see table 4).

Figure 1: Flow-chart of participation and drop outs



Regarding health outcomes almost 90 percent (n=17) reported very good, good or fair general health status and none of the participants reported any kind of severe pain in the last two weeks. Three participants stated to be severely limited by a health problem, the other 12 respondents reported no severe limitations due to a health problem. However, almost half of the participants (n=7) screened positive on the PHQ2, indicating a potential depression. On the screening tool for possible anxiety disorder GAD2, five participants screened positive (see table 4).

Table 4: Description of the sample at baseline

Sociodemographic Characteristics					
sex	n	(%)	residence status	n	(%)
male	15	(79)	asylum seeker (process ongoing)	14	(73.7)
female	4	(21)	asylum granted - 3 years	1	(5.3)
N (%)	19	(100)	subsidiary protection - 1 year	1	(5.3)
			permanent residence permit	1	(5.3)
age			toleration ('Duldung')	2	(10.5)
18-25	11	(57.9)	N (%)	19	(100)
31-35	5	(26.3)			
36-40	1	(5.3)	family status		
41+	2	(10.5)	Single	11	(57.9)
N (%)	19	(100)	Married	4	(21)
			Partnership	3	(15.8)
time since arrival			Divorced	1	(5.3)
0-5 days	4	(21.1)	N (%)	19	(100)
6-10 days	7	(36.8)			
2-3 months	3	(15.8)	highest level of education		
4-6 months	3	(15.8)	no education	3	(15.8)
7-14 months	2	(10.5)	mandatory schooling complete	6	(31.6)
N (%)	19	(100)	high school complete	10	(52.6)
			N (%)	19	(100)
nationality			Health Outcomes		
Albania	1	(5.3)	general health		
Afghanistan	1	(5.3)	very good-fair health	17	(89.5)
Gambia	4	(21)	bad/very bad health	2	(10.5)
Georgia	2	(10.5)	N (%)	19	(100)
Nigeria	3	(15.8)			
Syria	5	(26.3)	health disability		
Togo	1	(5.3)	not severely limited	12	(80)
Turkey	2	(10.5)	severely limited	3	(20)
N (%)	18	(100)	N (%)	15	(100)
Primary language			pain in the last two weeks		
Albanian	1	(5.3)	no severe pain	18	(100)
Arabic	4	(21.1)	N (%)	18	(100)
Dari	1	(5.3)			
Georgian	2	(10.5)	PHQ score		
Kurdish	1	(5.3)	No symptoms of depression	8	(53.3)
Mandinka	2	(10.5)	Symptoms of depression	7	(46.7)
Turkish	1	(5.3)	N (%)	15	(100)
Other	7	(36.8)			
N (%)	19	(100)	GAD score		
			no anxiety	12	(70.6)
			anxiety	5	(29.4)
			N (%)	17	(100)

4.2 Contextual Survey

The collection of quantitative contextual data (tc1-4) via CATI (computer assisted telephone interview) required on average 25 minutes (min: 7 minutes; Max: 50 minutes). The final qualitative interview (tc5) lasted about 40 minutes. The following issues impacted participants' health and well-being and emerged from the contextual surveys and the fieldnotes taken by the researchers. Firstly, from the participants' perspectives, the main driver for their general health and well-being or feeling comfortable in the accommodation was not primarily the characteristics of the accommodation but rather their personal circumstances which in most cases were related to the asylum process, such as uncertainty about the legal situation (e.g., not being able to work or study), long process to access healthcare in case of chronic illnesses, and lack of information to navigate the health and asylum system which caused a kind of helplessness and made it very difficult for the asylum seekers to understand their rights (see box1).

Box 1: Quotes on topics of “healthcare access” and “navigating the system” mentioned by participants

Healthcare access

“The appointments they give me are always too far in time.... But what can I do...” (P1)

Navigating the system

“We rely on other people [refugees/asylum seekers] experiences and knowledge to know how to navigate the system around asylum; people who have been here for longer. I prefer if the government informs me about the laws. Of course, I would believe the government and trust it more than random people who share their experiences.” (P1)

“I think that the [sickness] and my situation was stressing me, and I didn't want to keep pushing for a separate accommodation... so I gave in and accepted my reality (...) Just recently, I got to know that it was her responsibility to find a room for me and isolate me without me approaching her [the accommodation manager]” (P3)

Waiting was highlighted by almost all participants; the seemingly endless wait on a response of the Federal Office for Migration and Refugees (BAMF) to the asylum procedure for example was mentioned throughout all five contextual surveys by one participant, which made him “hopeless and depressive” (P5). Additionally, another participant mentioned the following at tc5:

“When I receive my resident permit my situation should be better... right now I am working on adjusting a lot of things... There are still many projects I want to accomplish... I am in a waiting state right now to be honest.” (P2)

Overall, social support measured in the number of people participants could count on if they had a “serious personal problem” differed between zero and three persons as well as across different survey rounds. E.g., one participant indicated three persons at tc1, zero at tc2, one at tc3, and three at tc4.

“The problem is that the people that I trust [friends he met in previous accommodations] to keep my valuables with are now far away from where I live. This became the norm since I moved to Germany.”
(P2)

Often doctors and teachers were mentioned as social support:

“The best thing that happened to me here in Germany was the medical doctors in Heidelberg. (...) I am very grateful to having dealt with them. And the managers at school and the teachers.” (P3)

The issue of privacy was highlighted by all the participants regardless of whether they had come to Germany alone or accompanied. Room sharing prohibited participants from having their personal space. Issues highlighted by many participants included not being able to have time alone to recharge and reflect, suffering from very loud and noisy roommates and housemates, encountering unclean shared areas (mainly bathrooms and kitchen), and enduring social clashes.

“I really got tired of cleaning and cleaning and cleaning. This [the cleanliness] affects my habits in using the toilet. I do not enter the kitchen because it is very dirty. And this [referring to the lack of hygiene] increases the confrontations [with housemates] ... and I do not like having problems with others... It [the hygiene issue] is psychologically tiring.” (P2)

“The place drained me on all levels psychologically and physically. The difficulties stemmed from the people we shared our living space with...” (P1)

Moreover, the lack of places to store valuable belongings and as a result thereof getting things stolen was perceived as a problem in shared accommodation centres.

“I had my money stolen twice in the same place where I live now... I do not file a case... for what? To tell them an unknown person stole my money!!! I do not think they offer help at this level! I don't think...”
(P2)

Three out of the six participants completing the pilot study mentioned that they stayed with family members (parents, siblings, or grown-up children), who are residents of Germany, even though those participants were assigned to live in shared accommodation centres.

Another aspect that was mentioned by two single male participants as a stressor was living in a remote location. Participants indicated that supermarkets were difficult to reach, e.g., only by public transport.

The associated proximity or distance to schools and doctors was also addressed. One Participant (P4) was now staying in a different city than his doctors and the hospital he used to visit for treatment.

“Because my, my doctors also all for my health all stay in [city1] and [city1] hospital.” (P4)

Moreover, some participants, when living in a remote area, expressed struggles to have social interactions beyond the asylum setting.

“It was difficult on all levels. They put us in an isolated place. We had houses around us, but it was as if they were haunted... no social life... nobody to be seen to mingle with.” (P1)

Some participants were able to attend German courses online, which was beneficial in remote locations. However, participants had to use mobile data or public Wi-Fi hotspots, as few accommodations provided Wi-Fi. When asked about the COVID-19 vaccinations, participants indicated that they were offered vaccinations on a voluntary basis at certain dates in the accommodations.

4.3 Follow-up survey (t1)

Originally, it was planned to run t1 as CAPI like at baseline survey, i.e. face-to-face, however the researchers decided for reasons of practicality to conduct it by telephone (CATI). Overall, 57 percent of participants dropped out. All six participants who could still be reached at tc4 participated in the final t1 survey round. The survey lasted about 60 minutes (+/- 20 min.). Participants were already familiar with many questions through the different survey rounds; however, one participant did not follow the response pattern and instead provided detailed explanations for his answers, which made it difficult to ensure the quality of the collected data. There were nine participants who initially agreed to have their residence address enquired after transfer by contacting the authorities in charge to contact them for follow-up at t1. Of these, five people either dropped out after t0 or after tc1. However, we did not contact this group of participants again for t1, as it would have required the involvement of authorities, which would not have been an efficient resource use for the pilot study.

5 Discussion

This pilot survey gave insights on collecting longitudinal data among newly arriving asylum seekers and refugees in Germany. The study, which was actually planned as a large prospective cohort study, was only conducted as a pilot study due to limited access to the field during pandemic times. However, it offered the opportunity to test the partially redesigned questionnaires and the CAPI survey method in this setting. The results obtained allow for a discussion on the feasibility of the questionnaires in a large cohort as well as on the recruitment and acceptability of the participants.

5.1 Feasibility

The initial baseline questionnaire deployed as CAPI took up to two hours. Additional time is required for the recruitment with the door-to-door approach. Therefore, the feasibility of implementing the t0 questionnaire in a larger cohort for potential scale-up needs to be considered. Shortening the baseline questionnaire might improve feasibility and minimise participant drop-out. In case of scaling up the study, the mode of data collection could be reconsidered regarding the available resources and the added value of a CAPI compared to a pen and paper questionnaire.

The contextual surveys had not been pilot-tested before, but our experiences were generally positive, in the sense that the questions were easy to understand, the survey was of an appropriate duration, and the participants became familiar with the questions after the first or second survey round. Moreover, the participants seemed to gain more trust in the researchers over time. However, the reachability of participants turned out to be a big challenge. Even though the research team set up a WhatsApp business and Instagram account (that worked well for the ones using it) changing phone numbers of participants could not be tracked as we would have actually hoped to do. This meant that some participants dropped out because they could not be contacted and were possibly no longer in Germany, e.g., due to deportation. Another very time-consuming part of the contextual surveys was the organisation of the telephone interviews including repeated attempts to reach participants, making appointments, and documenting the process. The feasibility of these surveys in a large cohort would require an even more structured planning and, possibly, an adaptation of the recruitment plan. At the same time, a reduction in contact attempts could also lead to a higher drop-out rate.

The conduct of t1 as CATI instead of CAPI seemed to be beneficial and feasible as half of the participants did not live in the assigned accommodations but with family or friends and thus would have been hard to reach in person. Moving out autonomously of the assigned shared accommodation centres shows the agency of individuals to circumvent adverse conditions, and could be seen as a strategy of individuals to improve their privacy and quality of life in view of the adverse conditions of accommodation centres. However, participants were only comfortable to share this information after repeated contacts (of the same researcher), when trust in researchers was built. This interpersonal level should not be underestimated in data collection; hence, we suggest to aim for a continuity of interviewers for each participant in case of a scale-up. Another advantage of a CATI compared to a CAPI is its resource-saving implementation. Visiting each participant in person is expected to be very costly and time-consuming and thus, depending on time, personnel and financial resources, challenging to implement. At the same time, seeing and experiencing the accommodation and its surroundings as a researcher and the personal contact to participants gets lost when conducting a CATI. Additional pictures of the accommodations sent to the researchers, for example using a photovoice methodology (Budig et al. 2018), by participants could complement telephone-based interviews to get some further insights. Nevertheless, this information should only be required if it represents significant added value for the research goals.

5.2 Recruitment and acceptability

The response rate of 29.6 percent was within the common practice of population-based surveys, such as the German Micro census (Mikrozensus im Wandel 1989). Effective strategies to improve the response rate in health surveys among refugee populations, such as language concordance across all languages, would be beneficial for a scale up. Challenges in the pilot study were the time-consuming recruitment of participants and conduct of t0 as well as organising follow-up surveys (tc1-tc5) and the management of multilingual interviewers. Further factors affecting the response rate were the availability of a phone (e.g., for contextual survey) and, presumably,

participants' trust in the interviewers as well as the prospects of a successful asylum claim as people whose asylum claim was rejected appeared to be less likely to participate in the follow-up. The exceptional situation of the COVID-19 pandemic and quarantine may also have affected the response rate, as the situation in the early phases of the pandemic was still relatively new at the time of data collection, and the affected individuals may have been facing more serious or personal issues and therefore did not have the capacity to participate in a survey.

The drop-out rate of 57 percent is not unusual in the ASR context as asylum claims may be rejected and thus people leaving the country, but tends to be on the upper end. Similar results could be observed in a study investigating tuberculosis screening coverage in migrants, where there was a drop-out rate of 79 percent of people at 1-year follow up (Bwire et al. 2001). However, other studies investigating asylum seekers children and adolescents report of rates between 19 - 39% (Jensen et al. 2014; Jakobsen et al. 2017; Müller et al. 2019), and a study with Syrian refugees migrating to Norway found an attrition rate of 24 percent.

The research team observed that privacy was already difficult to maintain during the baseline interviews, since many participants had to share rooms. During the telephone surveys (i.e., contextual survey and follow-up), especially in accommodation centres, private space was not always available for participants during phone interviews which may rather be an argument in favour of pen-and-pencil approaches.

Finally, a rather content related point for discussion is the different answers across the survey rounds regarding the number of people participants can count on if they had a serious personal problem. This might be due to transfer into different accommodations, which can disrupt social support networks, but could equally indicate constraints in the reliability of the instrument. The same happened to the subjective social status (measured by the MacArthur scale) where some answers were contradictive across survey rounds and field notes indicated difficulties in understanding and/or answering the question. Further research and capturing more aspects of social support networks or even social capital may generate more evidence on this topic.

5.3 Conclusion

This pilot study gave useful insights for attempts to scale-up health surveys combined with a longitudinal, and repeated measurement of exposure, within a larger cohort. The drop-out rate was acceptable in the light of the challenges of the pandemic, but not surprising in such a highly mobile population, where legal aspects such as deportations also play a role. In order to achieve lower drop-out rates in future cohort studies, sufficient (financial) resources are necessary to be able to afford the high requirements, i.e., multilingual personnel and time-consuming organisation and coordination in the data collection process.

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