Co-funded by the Health Programme of the European Union

EUR-HUMAN

Report Work package 2

Deliverable 2.1

Communication and liaison with stakeholders and refugees groups

Health needs, views on and experiences with healthcare of refugees and other newly arriving migrants throughout their journey in Europe.

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Description of WP2

Background and general objective of the EUR-HUMAN project

In 2015 the flow of migrants, and especially refugees, entering Europe considerably increased. The high numbers of refugees arriving at the Greek islands and Italy shores, and travelling from there through South – Eastern Europe towards countries of their destination in Northern-Europe, led to the introduction of the term *'international refugee crisis'*. Many European countries are since then developing policies and plans to better define their role in supporting refugees entering Europe.

The EUR-HUMAN project, running from January to December 2016, aims to identify, design, assess and implement measures and interventions to improve primary health care delivery for refugees and other migrants with a focus on vulnerable groups. The objective is to provide good and affordable comprehensive person-centred and integrated care for all ages and all ailments, taking into account the trans-cultural setting and the needs, wishes and expectations of the newly arriving refugees, and to ensure a service delivery equitable to that of the local population. Related to this, the aim of the EUR-HUMAN project is to develop guidance documents/recommendations and to pilot guidance, tools and training for the provision of integrated comprehensive person-centred primary care for refugees at the intervention sites in hotspots, transit centres and longer stay first reception centres.

Objective of WP2

Given the above described aim of the project, Work Package 2 (WP2) seeks to facilitate the sense of coherence and community engagement of all involved (migrants as well as volunteers, primary health care workers and social workers) and to assess with a democratic dialogue the views, wishes, beliefs and attitudes of refugees and other newly arriving migrants.

Interventions, tools and information material can only be appropriate if the needs of the groups at stake, as well as those of the other stakeholders (volunteers, health care workers) are known. In the past some studies have been performed on the health needs of refugees. These studies were performed among asylum seekers who had already reached their country of destination, or were staying in longer stay refugee centres, often outside of Europe (summarized in the systematic review of Hadgkiss (2014) and the WHO health evidence network synthesis report (WHO 2014). However, there is a lack of information on the health needs of refugees and other migrants "on – the – move", at the hotspots, transit centres and during their journey through Europe. In former years there has been substantial groups of refugees passing through Europe (e.g. the people from former Yugoslavia in the 90-ies), but neither at the present scale nor circumstances. The recent waves of migration into Europe presents new health challenges, alongside larger humanitarian issues. In the past, EU authorities have discussed the risk of communicable diseases in refugee centres in member states and the implications for national healthcare, but the scale of movements of people since the summer of 2015 has created unprecedented needs (Jonson 2015). Besides, the largest present group of migrants entering Europe are Syrian refugees, coming from a country with a high standard healthcare system (before the war) and in that way differs from former refugee groups from the Middle-East or Africa. (See figure 1)

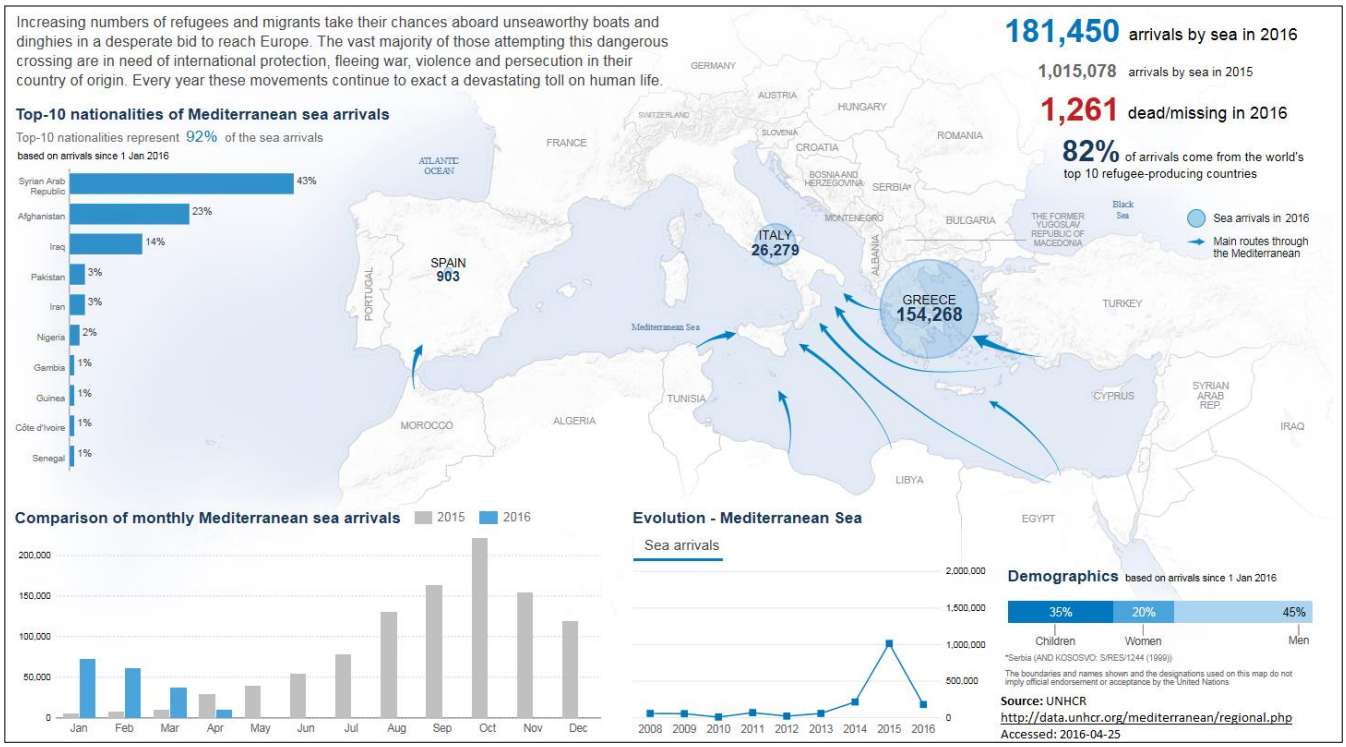


Figure 1. UNHCR: Refugees/Migrants Emergency Response – Mediterranean first months 2016 - 2015

For those reasons, we needed information on the current group of migrants, entering Europe in Greece or Italy, travelling from there (often at high speed) through Croatia, Slovenia, Hungary to Austria (the so called "Western Balkan route") or other countries of final destination in Northern Europe like the Netherlands. Since we wanted get insight into the whole journey, we added fieldwork in the Netherlands – which was not mentioned in the description of work (DOW), but the teams of ARQ and Radboudumc were able to add this work within their budget.

Therefore, the overall aim in WP2 is to gain insight in the health needs and social problems, as well as the experiences, expectations and barriers regarding accessing primary health care and social services, of refugees and other newly arriving migrants ***throughout their journey through Europe - from the hotspots via the transit centres to the first longer stay reception centres***.

The questions we wanted to be answered by our fieldwork were: what are the main health and social problems, as well as the experiences, expectations, wishes and barriers regarding accessing (primary) health care and social services of refugees and other newly arriving migrants throughout their journey through Europe - from the hotspots via the transit centres to the first longer – stay reception centres?

Overview of work in WP2

The Description of Work (p.67) mentions the following tasks in WP2:

Task 2.1: Participatory Learning and Action (PLA) was chosen as the appropriate research methodology, as it uses specific techniques that enable all people to be meaningfully engaged, despite language or educational differences. Local staff members from all intervention sites were trained in the application and ground rules of the PLA method, and were supported in their fieldwork by the Radboudumc team. Members of the local teams of all involved sites were present and very actively involved at this two day training which was attended by in total 16 participants.

Task 2.2: At the intervention sites, by purposive sampling, migrants of different age, gender, educational and geographical backgrounds were recruited to participate in the local stakeholder group. For this step, local research teams had to be sensitive to regulations and governance of the refugee centre, and arrange the necessary permissions to enter the centre and recruit refugees. Local health professionals working in the centre were involved to facilitate the recruitment.
The Radboudumc team developed a detailed instruction for the recruitment, and guidance for the fieldwork (see Appendix A2).

Task 2.3: PLA moderated sessions took place at all involved sites to generate data on views, experiences and expectations of the migrants as well as (in one instance) of other stakeholders regarding health and social needs, access and use of healthcare and social services. The Radboudumc team provided support during the fieldwork and a coding framework for the analysis of the local data.
The *Local teams* coded and analysed the local data resulting in a local report (see for coding and analysis in more detail the methodology section)

Task 2.4: Based on the local reports, the WP leader drafted the present report on the views, experiences and expectations regarding health and social needs and access and use of services of the refugees and other newly arriving migrants as well as of other stakeholders.

Milestones

Milestone 2.1 Local staff members were trained in PLA on February 6th – 7th, 2016.
Milestone 2.2 PLA moderated meetings between local staff and refugees took place between February 10th 2016 and March 30th 2016.
Local reports were all sent to the WP leader by March 30th, 2016.
Milestone 2.3 The synthesis report of aggregated data of all local sites was drafted in April 2016, circulated for comments between all partners and finalised on 26th of April 2016.

Deliverable 2.1

Report on views, experiences and expectations of refugees regarding their health and social needs and access and use of services.

Timeline

6-7 February 2016	Task 2.1 Training in PLA methods **(milestone 2.1)**	Radboudumc, UoC, UoD, UL, FFZG, MUW, AUSLTC, ARQ
1 January – 29 February 2016	Task 2.2 Preparation of the PLA dialogues with migrants	Radboudumc, UoL
15 February- 31 March 2016	Task 2.3 PLA dialogues with refugees at local sites **(milestone 2.2)**	Radboudumc, UoC, UoD, UL, FFZG, MUW, AUSLTC, ARQ
21 March – 31 March 2016	Preliminary summary report of deliverable 2.1 for WP4	Radboudumc
30. April 2016	Final summary report **(deliverable 2.1, milestone 2.3)**	Radboudumc

Methods

Design

We conducted a qualitative, comparative case study in hotspots, transit centres, intermediate - and longer- stay first reception centres in seven EU countries (Greece, Croatia, Slovenia, Hungary, Italy, Austria, and the Netherlands) using a Participatory Learning and Action (PLA) research methodology. The fieldwork ran from February 2016 until the end of March 2016.

Methods: Participatory, Learning & Action (PLA)

The PLA research methodology, based on the work of Robert Chambers (Chambers 1987), is a practical approach that enables diverse groups and individuals in a cooperative manner to share, enhance and analyse their knowledge, encouraging them to focus on issues that affect them (O'Reilly 2010).

A PLA 'mode of engagement' promotes reciprocity, mutual respect, co-operation and dialogue in research encounters within and across diverse stakeholder groups. PLA techniques are inclusive, user-friendly and democratic, generating and combining visual and verbal data. This encourages literate and non-literate stakeholders alike to participate. They are seen as 'local experts' who are uniquely knowledgeable about their own lives and conditions (O'Reilly 2016).

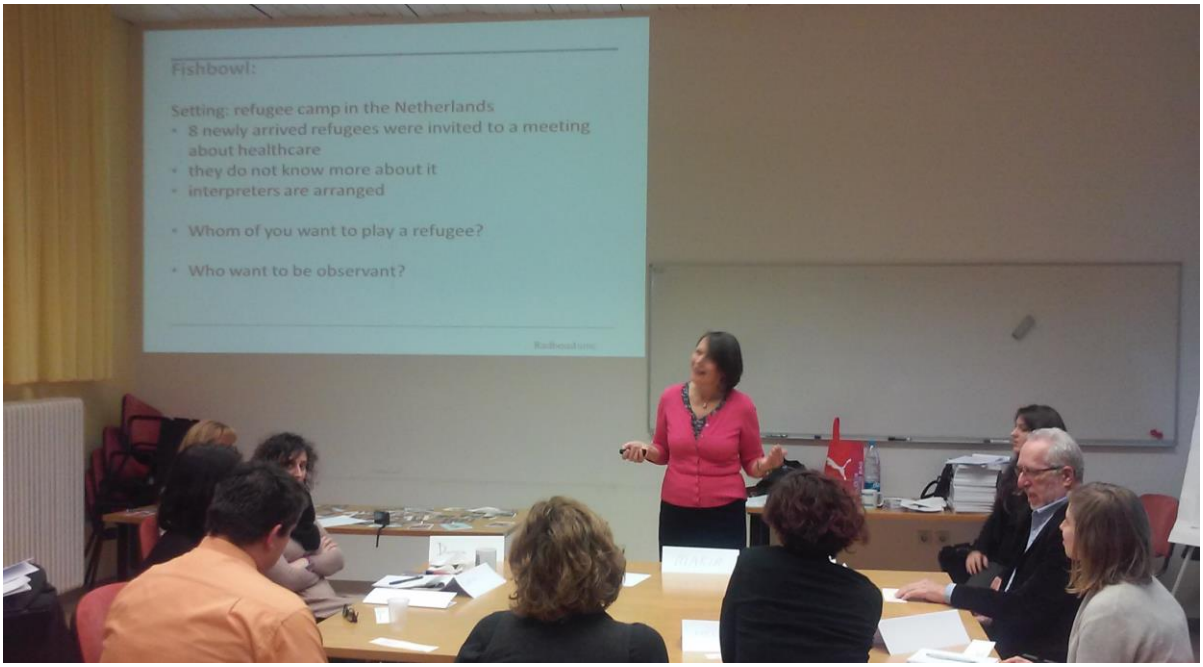
In our fieldwork we used the techniques of the flexible brainstorm and individual interview.

Several key factors may constitute insurmountable barriers to access and meaningful engagement with hard to-reach migrants (O'Reilly 2016). In this study, we had to take account of the following:

- The involved staff members of the local EUR -HUMAN teams' researchers had no familiarity with the languages or cultures of the migrant research participants - interpreters had to be found and used.
- Migrants (particularly at the hotspot and transit centres) were reluctant to participate in the PLA moderated meetings, mainly because of time pressure and other more urgent priorities.
- Migrants and especially refugees may feel uncomfortable in research, and distrustful to the intentions of researchers; our mode of engagement needed to reflect a very open and power-sharing approach from the outset (O'Reilly 2016).
- Among migrants, literacy abilities range from high to low; low literacy must be addressed sensitively.

PLA Training

Because of the above described importance of the "PLA- mode of engagement" and the need for mastery of PLA techniques, 16 staff members of local teams involved in the fieldwork were trained during a two-day course. The training took place on the 6th and 7th of February 2016 at the department of primary care of the University of Ljubljana. The training was specifically designed for this project and delivered by the staff members of Radboudumc, the work package leaders of this WP2, who are experienced in PLA research. For a detailed description of the training, see appendix A1.



PLA training in Ljubljana

Study setting

The fieldwork took place in 7 countries: Greece, Slovenia, Croatia, Italy, Hungary, Austria and the Netherlands. The local sites were chosen because they all reflect a part of the journey refugees make through Europe; they differ regarding how long and where newly arriving migrants stay (table 1).

1. The “hotspot centre” in Lesbos, Greece, where migrants enter Europe – this was before the so called "Turkey deal” came into effect. In the months the fieldwork was carried out, 60% of all migrants arriving in Greece entered via Lesbos.
2. The transit centres in countries where migrants want to pass as soon as possible on their way to final destinations - in our case Croatia and Slovenia.
3. Intermediate -stay first reception centre in Hungary, where after the closing of the borders by Hungary end of 2015, refugees are staying for some months.
4. “Long-term” refugee centre where refugees stay for a long period, to apply for asylum or because they cannot travel further, in our study Italy, Austria and the Netherlands.

Table 1. Overview of the sites

Country	Site (location)	Type
Greece	Moria, Lesvos	Hotspot
Slovenia	Šentilj	Transit
Croatia	Slavonski Brod	Transit
Hungary	Bicske	Intermediate
Italy	Villa Pepi and Villa Immacolata	Long-term
Austria	Vienna	Long-term
The Netherlands	Heumensoord (Nijmegen)	Long-term

Recruitment and Sampling

Our study population consisted of a) newly arriving refugees and other migrants, who were no longer than half a year at the implementation site and did not have permanent staying permits and b) healthcare workers and volunteers involved in the care for these refugees at the implementation sites. For convenience, all migrants or asylum seekers involved in the fieldwork will be referred to as refugees in the present report, although it is possible not all of them eventually will receive a legal refugee status.

PLA sessions with refugees

The participants were recruited at the local implementation sites, based on purposive sampling using a combination of network and snowball sampling strategies. The number of sessions and the number of participants included in the fieldwork depends on the type of centre at the local sites and were highly dependent of the time available for a certain group of migrants to stay, and to participate.

- At the hotspot/transit/intermediate sites it was only feasible to hold **1 session per group**, since the refugees are only there for a few hours. At these sites, more different groups were recruited.
- At sites where refugees stay longer it was sometimes feasible to hold **2-3 sessions per group**.

Per group approximately 5 persons took place. The groups were usually either male or female. In a few cases, mixed groups were used.

Because of these practical limitations, we could not achieve optimal diversity within participants at *every local site*, but instead sought diversity across sites. In this we succeeded: the participants were of different ages (≥18 years), educational attainment, countries of origin, with and without chronic health conditions, with good, bad or without any experiences with medical care in the centre. In a few instances minors were present during the sessions because they accompanied their parents.

PLA sessions with health care workers

In Croatia, the PLA sessions were conducted with healthcare workers. Participants worked in NGO's or were medical staff employed by the ministry of health. Per group approximately 5 persons took place. The groups were mixed female/male and with different ages.

Informed consent

All participants received a letter explaining the purpose and content of the research. The letter was available in English, Arab and Farsi (Appendix A3).

Every participant of the PLA sessions filled in an informed consent form (Appendix A4). The informed consent was user-friendly and specific for the refugee target group. Short sentences and clear language was used. The informed consent forms were available in English, Arab and Farsi. Since refugees are known to be reticence to sign any form, a short version of the consent form was designed. This short consent form has as little references to legal issues as possible. During the PLA meetings, considerable time was taken to explain, orally and personally, the consent procedure, the scope of the study and the confidentiality.

Data generation and analysis

Data were generated using PLA-style flexible brainstorm discussions and PLA-style interviews. This means that the encounter involved a PLA mode of engagement and the use of PLA techniques to encourage interactive data generation (O'Reilly 2016). Interviews were only used when there was a single participant involved/available.

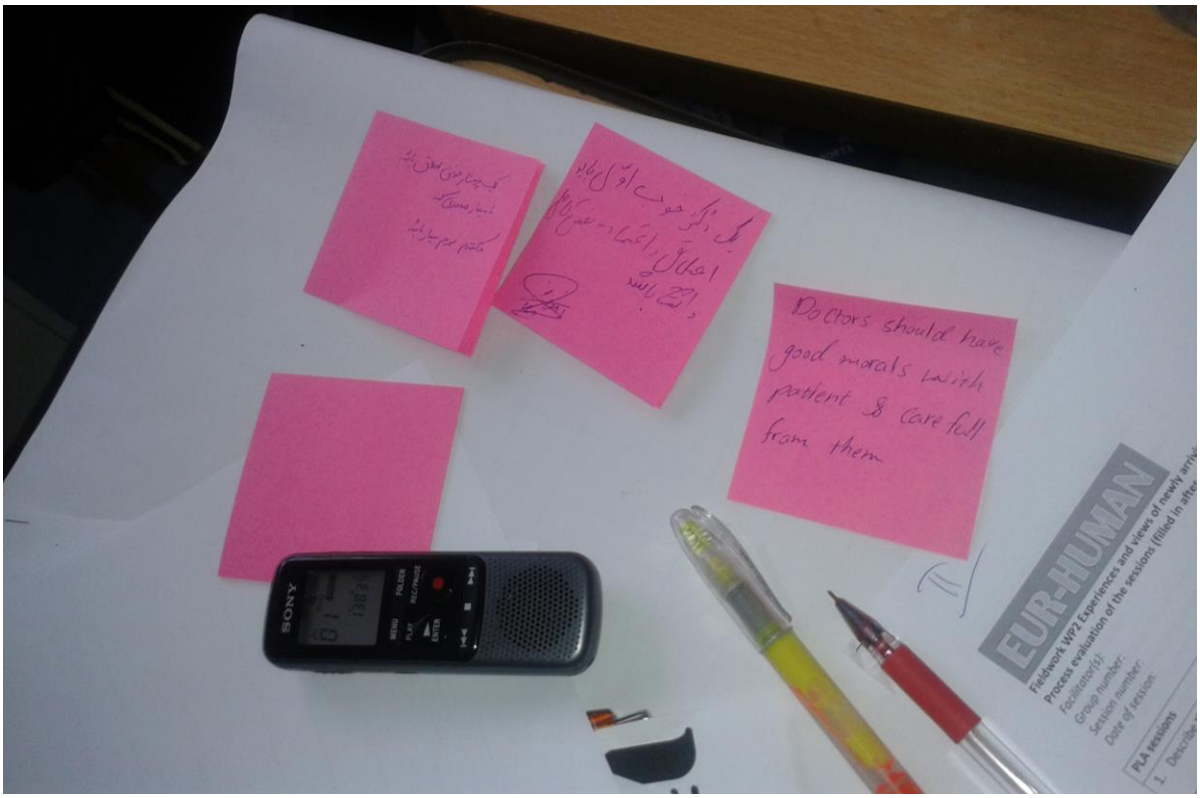
Data were generated on PLA charts that ensured that verbal and visual forms of data were recorded in a consistent manner across all stakeholder groups. All PLA charts were computerised after each data generation session in order to preserve the data. Verbal data were recorded on Post-It notes in point form or short phrases rather than in full verbatim quotes.

As by the nature of the flexible brainstorm and in-depth interviews, topics were brought up by the participants. In addition, to ensure that all relevant aspects of health needs were covered, facilitators could use the topic list that was developed by Radboudumc based on literature and the input of all EUR-HUMAN members (Appendix A6).

Most of the sessions were audio taped and transcribed. In a few sessions, refugees refused to participate if the sessions were audio taped. In those instances, extensive field notes were taken and worked up after the sessions.

All sites analysed their data themselves based on a fieldwork evaluation form and coding framework provided by Radboudumc (Appendix A7). At all sites, several researchers were involved who co-coded and independently analysed at least part of the data.

Radboudumc then completed thematic analysis of all local reports.



Fieldwork in Hungary

Ethical approval

Prior to the start of the fieldwork, all countries acquired ethical approval in accordance with the legal requirements in their country (table 2).

Table 2. Overview of ethical approval

Country	Approval	Ethic committee	Date/Filenumber
Greece	Approval	2nd health region of Piraeus and Aegean. Approval from the governor of 2nd health region	Protocol number: 7496, date 22-02-2016
Italy	No approval necessary	-	-
Slovenia	Approval	National Ethic Committee	24/3/2016
Croatia	Approval	University of Zagreb, Faculty of Humanities and social sciences, Department of Psychology	01March2016
Hungary	No approval necessary	-	-
Austria	Approval	Ethics committee of the Medical University of Vienna	Ethical approval EK Nr: 2181/2015
The Netherlands	No approval necessary	Research ethics committee of the Radboud University Nijmegen Medical Centre	**2016-2306**

Results

Settings

Greece

Site of the fieldwork

The fieldwork in Greece took place in the hotspot of Moria. The hotspot is located on Lesvos, a Greek island of Northeastern Aegean Sea. Refugees who survive the journey and succeed in crossing the maritime border between Turkey and Greece are obligated to reach the hotspot of Moria in order to be registered and to continue their journey. The police, First reception centre (KEPY), Ministry of Interior/Migration, Frontex and the ministry of Defence, are responsible for the management of the hotspot of Moria. There are several national and international NGOs which provide humanitarian support such as: Praxis, Metadrasi, IOM, Médecins Sans Frontières/Doctors Without Borders (MSF), Médecins du Monde (MDM), Danish Refugees Council and Better Days For Moria. The UNHCR is responsible for coordinating all NGOs activities.

Organisation of and entitlements to healthcare for refugees at the hotspot of Moria

There are several facilities on the site. Refugees with need of medical assistance are escorted usually to MDM facilities, which are next to the registration areas. The health care professionals consist of a multidisciplinary team (general practitioners, nurses, psychologists, social worker). The Greek healthcare system provides services to all the documented immigrants/ refugees and the asylum seekers. For all people with emergency needs free services are provided by the public health system regardless their status. Many times refugees/immigrants/asylum seekers are referred from the NGOs doctors to the hospital on the islands (i.e from Moria hotspot to the Mytilene hospital) or to other more specialized structures in the mainland. Due to the increasing number of population in Greece, the Greek parliament is expected to vote a law in May which provides health services to all these people. Health care providers usually come from different parts of Greece to take turns in providing support. The majority of the NGOs at the hotspots hand out hygienic supplies, clothes and food for all refugees/immigrants. The area for unaccompanied minors, which is managed by First Reception, hosts and provides food and some activities to children for maximum 15 days. Afterwards these children go to another public or private institution in Greece until the age of 18, then according to the law they will have the opportunity to apply for asylum or to travel to other European countries.

Between 500-600 persons were registered daily in the hotspot of Moria during the first months of 2016. The Syrian refugees left the hotspot almost immediately further to Western Europe. The rest of them stayed between 3 days to 1 week. The island of Lesbos, accepted around 60% (406,000) of all refugees and immigrants arriving in Greece in 2015.

A total of five PLA sessions were held with a total of 20 people. Four sessions included Afghan refugees and one session was done with Syrian refugees. Interpreters were used to overcome the language barrier (Dari, Arabic, Pashto).

Fieldwork in Moira, Greece

Croatia

Organisation of and entitlements to healthcare for refugees at the transit centres in Croatia

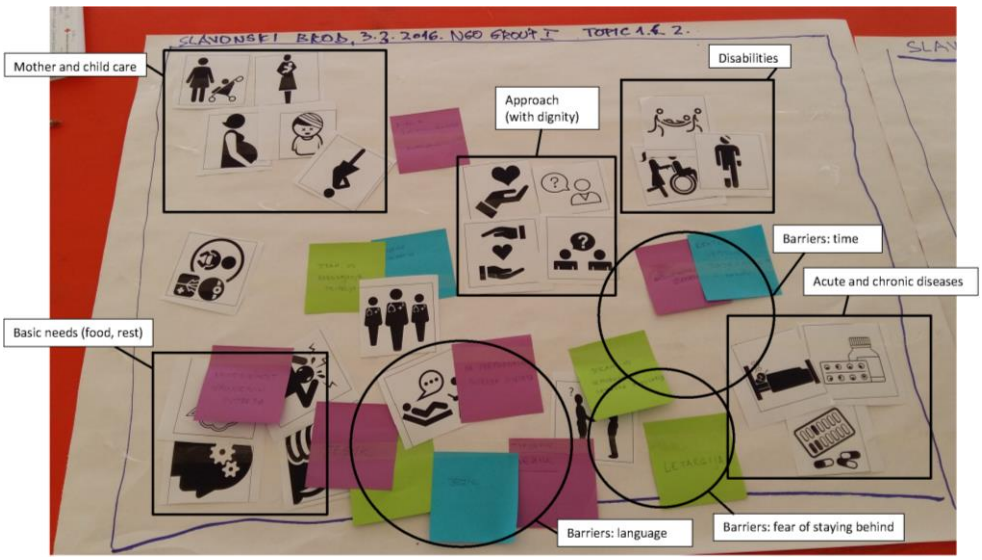
Governmental, international and civil society organizations offered their support to all arriving refugees and migrants during transit in Croatia. In the only transit centre in Croatia since 03 November 2015 (transit centre Slavonski Brod, also the site of the fieldwork), refugees and migrants were entitled to humanitarian assistance (hygienic supplies, clothes and food), as well as medical care. Refugees and migrants in need of medical assistance had access to the stationary ambulance working 24/7. The medical staff consisted of a team of nurses, who were located at the sight daily, and a medical doctor, who rotated every couple of days and came from different parts of Croatia. In addition, refugees and migrants had priority admission right to local hospital, in case of more serious medical conditions. In the Mother and baby centre, mothers with small children had access to paediatric care for children (offered by Magna) and advice regarding child care and breastfeeding. Several tents for longer-term accommodation were available.

Site of the fieldwork

The fieldwork in Croatia took place in the Winter Reception and Transit Centre near Slavonski Brod, a town in eastern part of Croatia. Refugees arrived to the centre by train from Šid, Serbia, and were transported to Dobova, Slovenia. The centre was managed by the operating headquarters of the Republic of Croatia Ministry of the Interior. Other governmental organizations were involved through the Ministry of Health and the Ministry of Social Policies and Youth. There were several national and international NGOs present at the site: ADRA (Slovakia & Croatia), Caritas, IOM, Jesuit refugee service, Magna, Samaritans, Save the Children, and Croatian Red Cross, who were coordinating NGO activities. Overall, there were about 200 volunteers and staff at the site. Up to 4 trains arrived daily, at 07,30 a.m., 15,00 p.m., 19,30 p.m. and 03,00 a.m., and the maximum number of refugees aboard one train was about 900. The map of the transit centre is shown below.

Slavonski Brod. Legend: 1 – the train station; 2 – registration; 3 – ambulance; 4 -distribution tent; 4 – Mother and baby centre; 5 – food distribution; long-term accommodation shaded

It was not possible to include refugees and migrants in the PLA exercise due to very quick transit of refugees through the centre where they remain. Instead, PLA sessions were held with experienced care providers who were asked about the topics related to refugee health. All stakeholder organisations at the transit centre were invited to participate including Croatian Red Cross, MAGNA, ADRA, IOM, UNHCR, UNICEF, Save the Children, Caritas and medical staff. A total of 5 sessions were held; 5 different groups had 1 PLA session. Two groups were with different NGO workers, 1 group with medical staff, 1 with Croatian Red Cross workers and 1 with interpreters.



Picture 1. Fieldwork chart from NGO group, Croatia

Slovenia

Organisation of and entitlements to healthcare for refugees at the transit centres

Health care in transit centres in Slovenia is organized by the nearest primary health centres. Zdravstveni dom Maribor - primary health centre Maribor – organizes health care at Šentilj centre on the daily basis . Zdravstveni dom Brežice (primary health centre Brežice) organizes health care at Dobova centre and Zdravstveni dom Logatec Health centre Logatec provides health care of refugees in centre for people, waiting for asylum in Logatec.

Through the Ministry of Health, commodity reserves were activated to provide medication, sanitary supplies, and medical devices. Furthermore, mobile trauma surgical facilities were put into use. Local health care workers cooperate with the Slovenian Red Cross, Caritas Slovenia, Civil Protection Services, Administration for Civil Protection and Disaster Relief, and foreign organisations and offices.

Site of the fieldwork

Fieldwork was carried out in a transit centre at the border crossing Šentilj. At approximately 12am every day in the first months of 2016 about 800 migrants arrived by train. The Austrian border control authorities let 200 refugees across the border every hour. 200 migrants were transported immediately to the border with Austria, while the remaining 600 migrants were settled in large, heated tents, where they got food, drinks and clothes. The last refugee left Slovenian border at 16 o'clock. Besides a health clinic, which was located away from the tents of migrants, there was a larger tent of Czech military doctors who were trained in surgical procedures.

The refugees were in the centre only for a short period of time (a few hours). Therefore the researchers carried out sessions/interviews with individual refugees or with small groups (max 3). In total 14 sessions/interviews were carried out with 19 refugees. An interpreter was present to overcome the language barrier.

Fieldwork site in Šentilj, Slovenia

Hungary

Organisation of and entitlements to healthcare for refugees in Hungary

The *official* procedure starts at the Hungarian border, supposing the crossing was not *illegal.* At this point, some of the available temporary centre will be assigned for the asylum-seeker. At the moment there are three, of which two in the Western part of Hungary (*Bicske, Vámosszabadi*) and one in South Hungary (*Kiskunhalas*). Refugees, who are registered in the centres, get a card certifying the legal stay in Hungary and a few days later a health-card will be issued. According to recent Hungarian regulations, asylum seekers could achieve two stages in the official process; ***protected*** (allowed to stay for 3 years in Hungary) and ***recognized refugee*** (without limitation). In the official procedure they have to prove the previous pursuit or life-threatening circumstances. Usually this process takes a few months. However, many refugees do not wait, but leave the centres and move forward towards Western Europe, often without informing authorities. Those who become recognized as a refugee, get some financial help to start their lives outside the centre.

Site of the fieldwork

The fieldwork was done in the temporary transit centre at *Bicske*, located 30 km from Budapest. The centre has 903 inhabitants on the capacity of 900 beds. Refugees were transported with buses, provided by the government, from the southern (Serbian) border of Hungary. Usually 2-3 busses arrive daily. The centre follows an "*open-policy*"; refugees can leave when they want. There is a high turnover of inhabitants. People, who are leaving, usually go to Western Europe, mainly towards Austria. There are also people in the centre, who are transported (deported) back from other countries (Switzerland, Sweden etc.). There are families (woman and children) whose men are already working in Hungary. The mean age of the populations staying actually in the centre is low, only a few people were seen above 50 years of age.

The available accommodations in the centre are rooms for 3-4 persons, with a communal kitchen and mainly communal lavatories. Families usually can stay together in one room. Persons who were registered in the centre get some *allowance*; it is cc. 25 EUR/week/persons, a little bit higher for children. In the nearby supermarkets (TESCO, LIDL) every required items could be purchased. There are 3 main *meals* served in the centre. A free *WiFi* is also provided in the centre. It is the most common way of communication between them and with the outside world. There are organized Hungarian language courses for inhabitants, for adults and children as well.

In total 6 sessions were held. Interpreters in Arabic and Farsi were available for translating during the sessions.

Fieldwork site Hungary

Italy

Organisation of and entitlements to healthcare for refugees in Italy

In Italy, there is a legislation allowing the access to healthcare for all, differentially regulated among the diverse legal statuses. All migrants can access the Italian healthcare, through the STP code (Straniero Temporaneamente Presente), which guarantees the access to healthcare for the period preceding the asylum request. After the application, they are registered in the national health system, and they are assigned to a general practitioner (GP).

Site of the fieldwork

The fieldwork was carried out in "Villa Pepi" and "Villa Immacolata". These are facilities in Tuscany where refugees and migrants are located after their arrival. In Villa Pepi there are about 135 people and in Villa Immacolata there are just 4 people. They are managed by Caritas Firenze, like many other facilities of this type in the area. Refugees and migrants stay in these facilities for long periods, between 12 and 18 months, waiting for the documents or the granting of international protection. In the meantime, do some activities such as Italian language courses and job orientation laboratories.
A total of four sessions were held: two different groups (one male and one female) had 2 sessions. Interpreters were used to overcome the language barrier (English, Italian, Urdu).

Austria

Organisation of and entitlements to healthcare for refugees in Austria

In Austria, as soon as it is clear that a refugee is permitted to the asylum procedure, he or she is insured in the common health insurance system and is entitled to receive health care exactly like Austrian citizens. The specific administrative procedures related to health insurance for refugees differ in each of the 9 federal states of Austria. Furthermore, an asylum seeker in Austria receives general basic supplies and a small allowance depending on the individual housing situation. The inclusion in the conventional Austrian health insurance system means that asylum seekers are strictly speaking able to consult any doctor and hospital with the same limitations an Austrian would face in the Austrian insurance system (e.g. regulations concerning cost coverage of drugs, health supplies, and procedures, and waiting time for procedures).

Site of the fieldwork

The centres were the fieldwork took place were in different districts of Vienna and housed 150 to 250 refugees, both single people and families. Either the city of Vienna or private individuals or companies own the buildings and NGOs manage them. People need to check in and check out of the houses in order not to lose the basic provisions. If they stay away more than three nights they lose their place in the house. The refugees stay in the houses until they are granted asylum. After that, they receive a minimal income and can stay anywhere. If food is provided in the house, refugees get an allowance of 40€ per month. If the refugees are responsible for their own meals, the allowance is higher.

In total 6 sessions were held. There was one male and one female group who had three sessions. All participants spoke English.

Fieldwork chart from Austria

The Netherlands

Organisation of and entitlements to healthcare for refugees in first arrival centres in the Netherlands

Migrants who want to apply for asylum have to await the result of their procedure in special asylum seekers centres. In those centres they receive lodging and food, a small weekly allowance as well as a medical insurance. This insurance covers all medical costs that are also covered by the basic health insurance of all Dutch inhabitants. At all asylum seekers centres general practitioners and primary care nurses provide primary care; in the Netherlands general practitioners act as gatekeeper to specialist medical services.

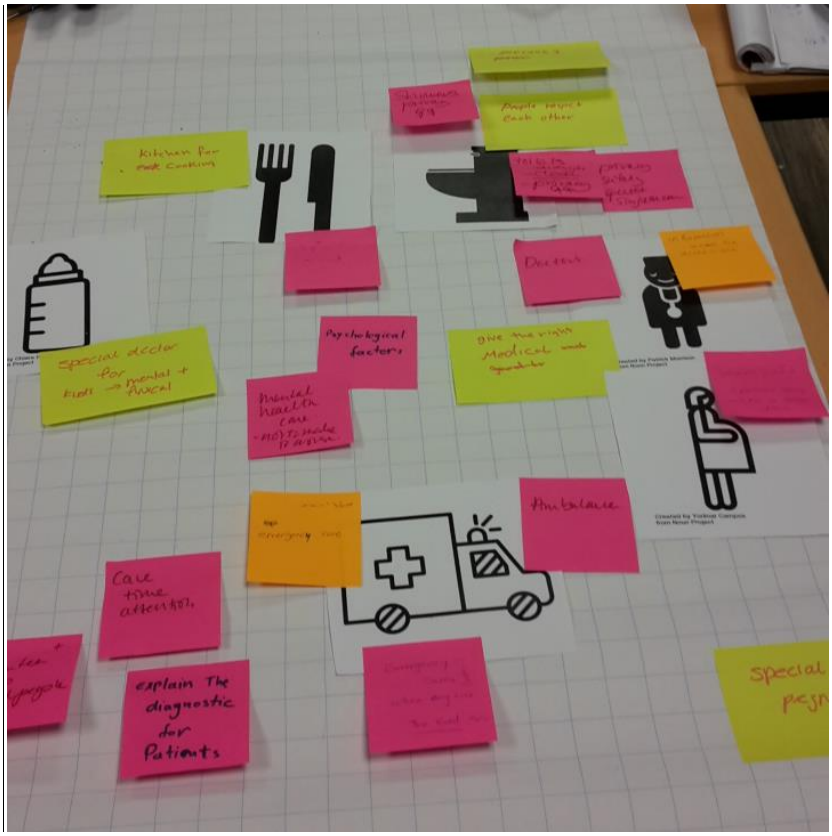
In 2015, the influx of asylum seekers in the Netherlands was larger than expected, and there was not enough room for them in the asylum seekers centres. Therefore, several temporary first reception centres were opened where the asylum seekers had to wait before they could enter the official asylum seekers procedure. In those emergency centres, the migrants were entitled to receive the same medical care as asylum seekers, covered by the same health insurance. However, they did not receive the weekly financial allowance.

One of those temporary first reception centres is Heumensoord, in Nijmegen. Whenever the refugees in Heumensoord need to see a doctor, they have to go to the doctor's post between 09.00 and 10.00 to get an appointment. First there will be an appointment with a nurse, and if necessary with a doctor. When there's need of a doctor after 10.00h, they have to call the "GCA praktijklijn", which is a countrywide phone number for refugees living in asylum seekers centres. A trained nurse or doctor on the phone decides whether and when an appointment is necessary.

Site of the fieldwork

All participants of the fieldwork in the Netherlands were staying at a temporary first – reception centre Heumensoord; with 3000 refugees living there awaiting their asylum procedures. Approximately 100 people per tent, divided in small "rooms" shared with 8 other refugees. Most of the refugees in this centre are still awaiting the start of their procedure, which takes a couple of months. As of may 2016 the centre will close, and refugees will be moved on to asylum centres elsewhere in the Netherlands.

In total 3 sessions were held. Two of them were located at the Radboud University medical centre, and the third was held at Heumensoord. All refugees were from Syria and spoke English. When things were unclear the refugees discussed in Arabic and one of the refugees functioned as a translator. As one participant did not feel comfortable about being audio-taped, extensive field notes were taken instead of making an audiotape.



Picture 2. Fieldwork chart from Heumensoord, the Netherlands

Participants

Figure 2 provides an overview of the fieldwork, the amount of sessions and participants.

A total of 98 refugees participated in a total of 43 sessions. Variation in gender, age, country of origin and educational attainment was reached throughout sites. Table 4 provides a summary of the characteristics of the participants. Two third of the participants were male or between 18 and 30 years old. 40% of the participants were refugees from Syria. The second largest group were Afghans (31%).

Table 4. Characteristics of refugees

Refugees		Total (98)
Gender	Male	65
	Female	33
Age	18-30	66
	31-40	21
	41-50	6
	51-60	3
	60+	2
Country of origin	Syria	39
	Afghanistan	30
	Iraq	12
	Pakistan	6
	Nigeria	4
	Somalia	2
	Gambia	1
	Ghana	1
	Iran	2
	Egypt	1

In addition to the sessions with refugees, in Croatia the PLA sessions were held with health care workers or volunteers in the transit centres. They had different roles in the centres: psychosocial support or counsellor (7), interpreters (5), cultural mediator, nurses (3), emergency unit worker, mobility tracking assistant, administrator, protection associate, organiser, coordinator for urgent interventions, infant and young child feeding consultant, assistant project field manager and a volunteer-distribution of clothing. Although not all of them are providing health care, for convenience they are referred to as health care workers in this report.

Most of the participants have worked 3-4 months (*N* = 11) and 5-6 months (*N* = 11) in transit centres (Opatovac and Slavonski Brod). Other participants had worked for 1-2 months (*N* = 2) or periodically (*N* = 1) in Croatian transit centres (see table 5).

Table 5. Characteristics of health care workers.

Health care workers		Total (25)
Gender	Male	9
	Female	16
Age	18-30	9
	31-40	11
	41-50	4
	51-60	1
Length of stay	1-2 months	2
	3-4 months	11
	5-6 months:	11
	periodically:	1

Figure 2. Overview of the fieldwork

	# of groups	# of sessions per group	Total # of sessions	Total amount of participants	Target groups	Country of origin	Setting	Language barrier	PLA method
Greece	5	1	5	20 (+5 minors)	Refugees	Syria, Afghanistan	Hotspot	Interpreter	Flexible brainstorm
Slovenia	14	1	14	19 (+ 3 minors)	Refugees	Syria, Iraq	Transit	Interpreter	Flexible brainstorm, individually or in pairs
Croatia	5	1	5	25	Health care workers	-	Transit	Interpreter	Flexible brainstorm
Hungary	6	1	6	32	Refugees	Syria, Afghanistan, Iraq, Iran, Pakistan, Egypt	Intermediate stay	Interpreter	Flexible brainstorm, fishbowl, direct ranking
Italy	2	2	4	11	Refugees	Pakistan, Gambia, Nigeria, Ghana, Somalia	Long-term	Interpreter	Flexible brainstorm
Austria	2	3	6	8	Refugees	Afghanistan, Iraq, Syria, Iran, Somalia	Long-term	English speaking participants	Flexible brainstorm
The Netherlands	3	1	3	8	Refugees	Syria	Long-term	English speaking participants	Interview Flexible brainstorm

Main health problems

This section discusses the main health care problems refugees face during their journey or during their stay in the centre. The results reflect the experiences of the participants themselves, their families, other refugees or health care workers.

Most often mentioned health problems were disabilities or injuries, mental health problems, pregnancy related issues, dental problems and chronic conditions.

Disabilities and injuries

The health care workers in Croatia mentioned that there are large numbers of people with physical disabilities, for whom the journey is especially difficult. At other fieldwork sites this feature was not specifically mentioned by the refugees. In general, the involved refugee participants rather spoke about their own problems than about health problems of other refugees.

> *"There are a lot of people with mobility impairments. Whether it is due to different amputations or physical disability, whether it is an older person who has difficulties moving through centre due to long transit."* **(Female, 30, psychosocial support, 3.5 months in the centre, transit, Croatia)**

These physical disabilities and injuries are often weapon or war related, caused by for instance landmines, suicide attacks or mob attacks. Other injuries are often a result from the journey such as burns, frostbites, broken bones, sprained ankles, pain in back and legs due to long walks, blisters, hypothermia and poor hygiene.

> *"Burns occur most often in their journey because they fall asleep by the fire, and frostbites are due to inadequate clothing, footwear and housing*."

And

> *"Blisters from long walking are very often, and in very poor condition; often the whole foot is affected*." **(Female, 30, psychosocial support, 3.5 months in the centre, transit, Croatia)**

> *"broken bones, wounds, that sort of injuries.."* **(Male, 50, Syria, long-term, NL)**

Mental health problems

At all implementation sites mental health problems were mentioned, although the participants told us that for many refugees it is not common to talk about mental health problems. At all sites refugees mentioned distress related to shocking events before or during their journey, depression, insomnia, fatigue, anxiety and uncertainty.

> *"I was so afraid during all this (the journey). I'm still very upset and sad. Even now when something happens, I lose my patience and I feel I have a sore throat. There are moments I lose my voice. I cannot talk and I hardly breathe."* **(Female, 33, Afghanistan, Hotspot, Greece)**

> *"I forget things, and I can't sleep."* **(Male, 21, Afghanistan, Transit, Hungary)**
> *"My life is stressful in the camp, I can't sleep well, I need some sleeping pill. The doctor give me pills."* **(Male, 35, Afghanistan, Transit, Hungary)**

> *"You are watching green window and I'm talking about the bad, a very dark window. I don't know the culture of this country. I don't know the language. Maybe I don't know what I'll get or what they give me. I miss my family and children and all of them. And*

my job and everything. Then I'm alone.[...] I'm thinking about another way." **(Female, 29, Somalia; Long-term, Austria)**

"Some people suffer from depression, or other kind of severe stress episodes. Persistent headache was quite common among migrants, even after a drug treatment." **(Male, 18-30, Pakistan Long-term, Italy)**

In Austria, participants repeatedly mentioned cases of suicide. There were both women and men in the centres who committed or attempted to commit suicide. One of the male participants even talked about attempting or planning his suicide. Sometimes the participants witnessed these attempts:

"Actually I saw it. He is one of my friends. I saw him just cutting his hand. And I told him what are you doing he said no I feel angry. And I said you feel angry why do you do that and I took the knife from his hand. And I started shouting on him: Just give it to me. And he refused to give it to me. I told him I am like your big brother, give it to me and he gave it to me and his hand was just from blood. And actually I found the other friend doing the same thing. (…) Just cutting his hand with the knife and I told him: Why do you do that. And he told I just feel stressed I am thinking. You thinking why do you do that to your body? And there is someone that has just tried to commit suicide." **(Male, 28, Afghanistan, Long-term, Austria)**

In Croatia, the health care workers saw a lot of disoriented people and people who had difficulties with their parenting capacity.

"*The biggest problems start with fatigue, and related to this fatigue is stress. When I look at the people, it seems to me that they do not even know where they are. They seem lost. … They don't know where their belongings are, where their children are."* **(Male, 55, interpreter, >5 months in the centre, transit, Croatia)**

Pregnancy related issues

Pregnant women in transit have almost no medical examinations, and are in fear that something might go wrong with the pregnancy: e.g.

"*There a lot of pregnant women. We often need to take them to the hospital to get an ultrasound check-up, because they are afraid that something is wrong with the child.*" **(Male, 36, medical technician, 3 months in the centre, transit)**

Medical staff emphasize that pregnant women are dehydrated, since they limit their water intake or are under pressure from the family to do so:

"They do not allow them to eat and drink… Their family doesn't let them, so they wouldn't have to use the toilet because they travel a long time." **(Female, 37, nurse, 2 months in the centre, transit)**

Because of this, pregnant women often need infusion (at the dispensary in the transit centre) and ultrasound examinations at the hospital.

Infectious diseases,

Common cold, flu and respiratory complaints

Because of bad weather conditions and the large number of people in small areas, many people have the flu, common cold or respiratory issues. It was a common problem at all sites.

> *"People usually come with airway inflammation, problems in the upper respiratory system. Classic: common cold, sore throat, breathing issues, difficulty swallowing, and most of them, almost 30-40% of our patients have this kind of complaints."* **(Male, 24, organiser, 5 months in the centre, transit, Croatia)**

> *"Like me I live in one room with 13 people (…) If one of us got the flu all the room will get the flu."* **(Male; long-term, Austria)**

Gastro enteritis and dehydration

At all sites people mentioned as frequent problem diarrhoea, viral gastroenteritis, vomiting and dehydration. The participants considered that this was caused by poor nutrition, and travelling in large groups, e.g.:

> "*Throwing up and diarrhoea are also due to travel, the food, always eating canned food, and travelling in large groups where all kind of viruses spread quickly*." **(Female, 30, psychosocial support, 3.5 months in the centre, transit, Croatia)**

> ***"****Like for the food one day in our camp they gave us rotten food. Like 30 people have diarrhoea an all of them."* ***(Male, 28, Afghanistan, Long-term, Austria)***
> ***"*** *(laughing) Diarrhoea"* ***(Male, 26, Iraq, Long-term, Austria)***

In Croatia several of the healthcare workers also stressed poor nutrition as a major health problem, mainly mentioning malnutrition:

> "*They must be sick, I mean, they must be starving for nutrition basics. And from that their conditions can only get worse. I'm wondering where they get vitamins or something. And still we are providing them with sardines. For hygienic or whatever the reasons*." **(Female, 26, assistant project field manager, 2 months in the centre, transit, Croatia)**

Other infections

At all sites various other infections were mentioned, especially scabies, lice and other skin infections, but also varicella in adults::

> *"There's a problem with all these people all together in a small area. It is dangerous to other people. For example somebody had a skin disease which was very contagious, then everybody had this skin disease. This has happened before."* **(Female, 40, Syria, long-term, NL)**

In the long-term centre in Italy as well as in the Netherlands, women had a lot of issues related to eyes irritations as well as urogenital infections:

> *"When we arrived, we have contracted an infection in practically low parts and we were taken to the doctor and the doctor gave us a cream to put under."* ***(Female, 22, Nigeria, long-term, Italy)***

> *"In my tent there was someone with a bacteria in his eye, and his eye was all red. Then the 9 other people in his room also had this infection."* **(Female, 30, Syria, long-term, NL)**

Dental problems

At the hotspot, transit as well as long-term centres, a lot of refugees mentioned dental problems and the lack of good care for such problems.

> *There's also a problem with dental problems. You need to have money on your insurance card, if there's no money left on the card the dentist doesn't do anything. Besides that, they don't repair teeth, they only take them out. I know several people who had 3 teeth removed at the same time."* **(Female, 25-30, Syria, long-term, NL)**

Chronic diseases

Although not frequently, some refugees mentioned problems related to having a chronic disease. As these problems were mainly related to the lack of continuity of care and lack of availability of the right medicines, they are discussed in more detail in the next section of this report.

Experiences, needs and barriers with health care

Experiences and barriers in general

Time pressure

In the hotspot and transit centres, the problem of time pressure and the related lack of trust and information were mentioned by refugees and health care workers as one of the biggest barriers to provide or receive care in such centres. For instance in Greece, the participants mentioned that they did not want to receive care but want to continue their journey as soon as possible.

> *"I do not want to go to the doctor now. The only thing I want is to leave the centre and to reach Germany. Then I will go to the doctor."* **(Female, 41, Afghanistan, hotspot, Greece)**

In Croatia, when refugees arrive at the centre, they usually have 3-4 hours before they are boarded back on the train to continue their journey. The time period of their stay in this transit centre is too short to provide all the necessary care and on top of that the refugees often refuse help because they are afraid of missing the train or being delayed, separated or left behind in the centre. They are often worried about borders closing.

The problems arising from such time pressure are: difficulty to identify a person's need, establish trust or provide the necessary information.

> *"The lack of time is crucial. A crucial point is that we don't have enough time to establish some kind of trust between us and the person we are talking to. They do not have a sense of when the train will depart or will it leave without them. That creates insecurity: should they go, should they even ask for help… "* **(Male, 32, consultant, 2.5 months in the centre, transit, Croatia)**

> *"I saw someone who probably had a broken ankle, who did not want to be held back, who wanted to get on the train as quickly as possible because he thought that he will get help at the next stop, but they're in pain obviously […] It's a complicated issue because there is help available here in Slavonski Brod, the medical staff will take you to the hospital, they'll help you here, but they're refusing help."* **(Male, 40, volunteer, 5 months in the centre, transit, Croatia)**

Time pressure is also closely related to family pressure. As people are generally concerned about missing the train or being retained, family members can exert pressure on each other not to seek medical help. Sometimes even in high-risk cases, which were seen in Croatia:

> *„I've noticed that parents often do not report chronic diseases of their children or some conditions that are really serious. For example, parents of a child with certain blood vessel malformations which were clearly visible did not want us to change the baby's clothes so we*

would not notice the problem and leave him for treatment. They insisted that the child is sent away to be treated in Germany." **(Female, 44, infant feeding consultant, 6 months in the centre, transit, Croatia)**

"*Sometimes if our doctors want to send the child in the hospital the refugees do not accept it. The baby was in a very bad condition and it had to take the therapy so we told the family that they cannot go. Then they sign a document for the release of the child.*" **(Female, 37, nurse, 2 months in the centre, transit, Croatia)**

„If a woman has some problems, especially if it's about some female issues, but the husband thinks it is not so important… We had a case like that, the husband insisted they continue the journey. "**(Female, 35, coordinator, 4 months in the centre, transit, Croatia)**

Lack of facilities

All refugees describe a lack of facilities during the journey and in the centre, mainly the amount and quality of food, water, toilets and showers. They mention that there are too few facilities for the number of people, especially at border crossings, and that the available facilities are not clean.

For instance, participants in the hotspot in Moira, Greece mentioned lack of dry clothes, accommodation, personal hygiene facilities, water and food, access to legal assistance, medicine and money for transportation. All participants emphasised that they needed a place to sleep. Due to the overcrowded situation in Moira, they often had to sleep outside.

Many refugees mentioned having wet clothes when arriving at the hotspot, due to trip with the boot or bad weather conditions, also some lost their shoes during the trip, forcing them to walk barefoot.

At the other sites similar needs were mentioned:

"It was just not enough water." **(Female, Syria, 32, transit, Slovenia)**

"*We don't have enough water for everybody. We told them that we are saving this for mothers and babies*." **(Female, 44, infant feeding consultant, 6 months in the centre, Transit, Croatia)**

"There were very bad conditions in the centre in Slovenia. People were sleeping outside, it was really cold. Everything (rubbish etc) was being burnt there, so there was a lot of smoke. It was not good for children who for instance have asthma. There was a lack of food, no soap, no clean water." **(Male, 50-55, Syria, long-term, NL)**

"Here in Heumensoord there is also a problem with facilities like toilets and showers. There are not enough toilets and they are not clean. It 'is especially a problem for women and children. With women having their menstruation. How can they change themselves? This is a risk for diseases. There is urine and stool retention – causing problems." **(Male, 50, Syria, long-term, NL)**

Most of the refugees come from countries where squatting lavatories are more common than lavatories with seats. It was mentioned several times that this causes problems in the centres. The toilets were unhygienic because most people did not know how to use them:

"..*And what is important for us: that we did not have this kind of toilets in our country. We are not used to this. And even people in the building where we live. They stand on this. They don't sit because..."* **(Male, 26, Iraq, long-term, Austria)**

***"..** It is not clean"* **(Male, 28, Afghanistan, long-term, Austria)**

Health needs, experiences and barriers in accessing healthcare

Health care resources and access

In the Netherlands, participants reflected on the available healthcare resources during the journey. The refugees illustrate that in every country and every border crossing the Red Cross was available for health care. Some stated that there was no trouble in finding a doctor. However, others did not agree and suggested the opposite with doctors being difficult to find, especially at busy border crossings.

"I didn't experience problems with doctor's along the road. The healthcare was really good, even better than what people are used to in their own countries." ***(Male, 55-65, Syria, Long-term, NL)***

"I don't agree. We need more doctors on the road. Some people lost their medication and need help. I know cases where people needed help and then they said in the next centre there will be a doctor. But then there was none. It's difficult when there are so many people in one spot to find out where the medical help is. Especially at the borders this is really important." **(Male, 25-35, Syria, Long-term, NL)**

In Hungary one of the participants also mentioned the insufficient number of health care providers during the journey.

"… but there were too many of us and not enough health care providers…" **(Male, Iraq, Transit, Hungary)**

In Austria, people who have applied for asylum and are assigned to stay in Vienna receive a health insurance e-card with which they can officially receive health care services. In many cases there is a long waiting period for the e-card. Even though – officially – they are already insured with having an ID card for asylum seekers, sometimes doctor practices do not accept patients who do not have an e-card. People who have e-cards sometimes face the fact these cards have not been activated and people do not receive much needed care until they take an additional administrative step.

***"**If you don't have an e-card, it is very hard to go to the doctor, you know, this and doctor (...) My family, you know, my aunt has diabetes and she meant, they sent us to very, very far diabetes clinic or something and because we didn't have any e-card they just said: „Sorry, we can...* **(Female, 20-25, Iran, Long-term, Austria)**

"..Sorry, we can't have you" **(Female, 30, Syria, Long-term, Austria**

Also in the Netherlands, the refugees in the temporary reception centres, experienced that the healthcare workers applied restrictions to their access to hospital care to which they were referred only in case of severe acute illness.

Continuity of care

Lack of continuity of care was mentioned as a big problem. This related to the lack of information on previous treatment (lack of personal health record), the difficulty to obtain chronic medication during the journey and the lack of knowledge among healthcare workers about care available in the "next" country. In transit centres time pressure added to these difficulties.

In the transit centre in Croatia for instance the healthcare workers noticed that the refugees were not appropriately treated or their treatment was interrupted as they passed from one country to another. This was due to the time pressures during their journey, and the fact that medical and psychosocial staff in the transit centre didn't have enough relevant information about the medical history of their patients or about the care already provided on the way to Croatia. In addition, they lacked information about the care that can be provided in the countries after Croatia, such as Austria, Germany or the Netherlands.

> *"They fell in the sea between Turkey and Greece but were not treated until Croatia so that's why they have serious respiratory problems."* **(Female, 26, coordinator of psychosocial support, 4 months in the centre, transit, Croatia)**

> *"They do not have a medical record that states which medicines they received for example in Greece."* **(Female, 26, mobility tracking assistant, 5 months in the centre, transit, Croatia)**

> *"For example, we have people in here who come with medical reports written in Greek. That's a big problem. First it's a medical report and then it's in Greek letters."* **(Male, 24, organiser/logistic, 5 months in the centre, transit, Croatia)**

> "*Now we send them from country to country to country but we don't really know what is in Germany. We are missing the information." (***Female, 44, infant feeding consultant, 6 months in the centre, transit, Croatia)**

> "*I think that in this situation of transit a coherent system of care from Greece to Austria or Germany would help them a lot.*" **(Female, 26, mobility tracking assistant, 5 months, transit, Croatia)**

When arriving in Hungary, refugees usually do not have medical records. The medical staffs of the centre give a small booklet recording the vaccination administered. For children who attend the local kindergartens and schools, the issue of vaccination is strictly controlled. Also in Italy, participants would appreciate a medical record that collects all data about their health status, vaccinations, treatments, etc. They would positively consider having this medical record always with them, even when travelling across different countries.

> *"It is good because, many people now, likewise me now, maybe most of them doesn't know their group type of blood. But you may be sick, totally sick, you can't utter any word, you can't say anything but through those written information the doctor can understand and treat you..."* **(Male, 24, Nigeria, Long-term, Italy)**

With regard to chronic disease management, there were often not enough medicines in the transit centres in Croatia to provide necessary care. On the other hand, medical staff also mentioned good examples of chronic disease management, such as preparing person specific drugs and instruction to use it.

The refugees in Heumensoord, Netherlands, find it difficult to make sure that they receive the right medical care, since they do not have their personal medical file. One of them explains that he feels

that doctors here don't believe their medical history and therefore treatment is different from what they're used to in their country of origin.

> *"The doctors in Syria have good education and are qualified. When a person has Diabetes Mellitus, doctors here don't believe this and want to do all the investigations all over again."* **(Male, 55-55, Syria, Long-term, NL)**

Many refugees mention that there is a need for some sort of medical health information system. While some argue that it is best to have something that they can take with them on paper of on their phone, others think it is better to have an electronic, digital version since they are a moving population.

> *"It would be good to have an electronic health record."* **(Male, 19, Afghanistan, Hotspot, Greece)**

> *"I think that this can help us very much because we are moving all the time."***(Male, 32, Afghanistan, Hotspot, Greece)**

Regardless how the information is kept, they want information about their treatments.

> *"… we did not get any documentation of the treatment we received…"* **(Male, 26, Syria, transit, Hungary)**

In Slovenia, one of the participants had made a picture of his injury, on his mobile phone and showed it to health care providers in order to create some sort of information continuity.

Information needs

Information needs arise at all sites. Refugees mention in the hotspot and transit centres that they would like information about regulations and procedures, as well as information about care that is provided in the next countries.

In the long-term centres in the Netherlands, Austria and Italy, refugees mention the need for information about how the health care system work in the country they arrived. For instance, how can they get a GP consultation, or what to do in case of an emergency. Moreover, information about payments and insurance is mentioned.

During the sessions, it became clear that some of the participants were illiterate. So, there is not only a need for more information, but also a need for information that can be understood by all refugees even those who cannot read or write. Information should be presented not only in the appropriate language but also by using visual materials, or orally explained.

Psychological support

A lot of refugees cope with mental health problems, resulting in a high need for psychological support. In most cases in the hotspot and transit centres it is enough if refugees can just talk about situation. In some cases and in the long-term centres there is more need for expert mental health care.

In the long-term centres, there was a high awareness of the need for psychological help for children. For instance the children from Syria are traumatised from what they had to go through during the war and the subsequent flight to Europe. For many refugees it was clear that in particular children need psychiatric care:

"But this not just for a man or a woman, a child need that so much. (…) Because they see everything having in the world in our country (…) My child see the father die, his father, my husband his die, Selua and Ibrahim see .. oh my father die. They see him on the earth and … very bad. And now in the night they sleep and wake up and cry and „oooh I need my father" **(Female, 30, Syria, Long-term, Austria)**
" They all have crisis." **(Female, 20-25, Iran, Long-term, Austria)**
" … I need, I need" .. they need help. Every child, not just my child, because they see everything in the way for here or in the country." **(Female, 30, Syria, Long-term, Austria)**

"There are 2-3 cases which concern children who need psychological help. From the GCA there's no psychological help. These are children who arrived here with only one parent and left the rest of their family. These children need special treatment. One child is always crying for its mother. We need to accept that they're here and need help." **(Male, 50, Syria, Long-term, NL)**

In order to provide mental health care, health care workers need to be trained appropriately. Health care workers in Croatia mention this need for training in psychological support for the volunteers and other staff: *"To be able to provide psychological support, training is needed. It should include assessment of vulnerable groups and first psychological aid. They need examples what to do in specific cases; when to discuss some issues and when not, what to say, advise… Interpreters also need this training."* **(Female, 35, psychosocial support, 4 months in the centre, transit, Croatia)**

Even if there is proper psychological support or care available, there is often a cultural barrier in accessing such care. Many refugees mention that it is not common in their culture to go to psychologist or are afraid of being stigmatized:

"Maybe it can be different, if I go to psychologist now, the Somali people who lives there saw me, they will say „Ooooh [Name]., she is crazy". (…) Because of the culture. We don't have this… **(Female, 29, Somalia; long-term, Austria)**

"In Pakistan, it is quite rare going to a psychologist. We don't believe in such thing. The people who have severe mental disorders are usually shipped off to mental hospitals." **(Male, 18-30, Pakistan, Long-term, Italy)**

<u>Mother- and child-care</u>
A lot of pregnancy related needs were mentioned, such as ultrasound examination, care for newly born children, and better nutrition for woman who are pregnant or breastfeeding, more privacy and places to rest.

In Austria, several of the participants (both male and female) were concerned about the fact that many women in the camp were getting pregnant. They thought it ill-advised in the situation that they were in. The discussions in this context mostly turned to the topic of availability of contraception.

"And above the pregnant: You know some families are getting pregnant here because there is no protection. I mean the condom. And people in the office are always joking: Why in this situation they are having a baby. They still don't know if

they stay here or not. They still want to have a baby. And this was the problem that woman had in the AKH." ***(Male, 25, Iran, Long-term, Austria)***

In some of the centre, condoms are only given to families, while in other centre condoms are freely available for everybody:

" *Like yes I mean of the protection. Families want to have some privacy so if they give them."* ***(Male, 25, Iran, Long-term, Austria)***
*"Actually in our camp they give them condoms. (…) Yeah this is no shame from it. They give condom to families for protection in our camp."***(Male, 28, Afghanistan, Long-term, Austria)**
"But not in our building. There is no condom. And that is why they are pregnant." ***(Male, 25, Iran, Long-term, Austria)***

Regarding children, there was a high need for children to have space and toys suitable for them, thus to be able to act childlike:

".. There's no place to play that is suitable for them. And there are no toys" .. "They don't have psychological problems yet, but these children will have problems in the future. Right now they are still on a trip/journey. We need to make sure that they are able to play now." **(Male, 50-55, Syria, Long-term, NL)**

<u>Other needs related to health</u>

The needs as described above are frequently mentioned and at many sites. There are also a lot of needs or preferences mentioned incidentally or regard a specific group:

- Care for people with disabilities : lack of sanitary facilities suitable for them

- Information and facilities for reproductive health, such as sanitary napkins and contraception

- In the long-term centres, it was mentioned that there is a need for speeding up the asylum process. Uncertainty brings a lot of stress in the centres.
-
- Physical activities in the centres where refugees stay for a longer period. When physical activities are organized in the centres, the organizers often only think of men as participants, for instance when soccer games for young men are organized. The female participants complained that there is nothing organized for women.
  "There are too less activities, people get bored. Also there are too many different groups in a small area which gives friction." **(Male, 50-55, Syria, Long-term, NL)**

- Leisure activities can help with distraction.
  "We don't have these possibilities. We are eating and sleeping in the camp. That's what i always.. I have talked to the manager of the building. I said: these people need a little bit rest but not too much rest because they need to go visit some parties/parks. Go for creations." **(Male, 28, Afghanistan, Long-term, Austria)**

Good experiences with accessing healthcare

At all sites, refugees mentioned good experiences with the care they received. For instance a participant in Hungary referred back to his time in Greece:

> *"The Greek centre was the best, when we arrived, we got complete health examination (X-ray, blood examination, dermatological examination). They organised Greek language lessons."* **(Male, 24, Pakistan, Transit, Hungary)**

Other participants also mentioned that they were satisfied with how they were approached and with the health care, for instance they appreciated the childcare.

> *"He (her son) went to great doctor. They treated him very good. They were very professional. And very kind and helpful. Perfect. They were very kind."* **(Female, 35, Syria, Transit, Slovenia)**

In Croatia, the medical staff is satisfied with overall quality and extent of services offered to migrants and refugees such as enough staff, medicines, supplies, emergency vehicle, migrant priority admission to the hospital. Since in Croatia no refugees participated in the fieldwork, we do not know if they would agree.

Many refugees mention that the care they received is better than they are used to in their own country:

> "*I think the medical treatment is much better here, than at home."* **(Male, 30, Iraq, transit, Hungary)**

> *"Yes. What is good here in Austria in the hospitals: Whenever I go to doctors they only take blood and they will not give you any medicine until they find out what is the reason. That is good I think. Because in the society in Iran we lived, whenever we went to doctor to prescribe to give me this medicine."* **(Male, 25, Iran, Long-term, Austria)**

Barriers in accessing healthcare

Organizational barriers

Organisational barriers included increasing uncertainty about the rules of procedures in the centres and lack of clarity about how the healthcare systems work in the country they arrived. For instance, participants in Greece mentioned the lack of information about processes; they thought that it needed to be available the moment they arrive at the country. The rapidly changing political situation and regulations added to the lack of clarity, even for the healthcare workers

> *"A month ago we could tell the people that they will arrive to their destination as soon as they came in Croatia. However, now with the changes in regulations in the last 3 weeks nobody is sure anymore. They ask me "now that I crossed to Croatia, will they let me pass into Slovenia". There is a fear that they will not make it to their final destination. Lately they're not sure because they started to deport migrants from Slovenia and Austria."* **(Male, 55, interpreter, 6 months in the centre, transit, Croatia)**

Many of the organizational problems are due to inadequate information about the functioning, organization and location of the health services.

"There is no dentist here. I don't know how to travel to Budapest and how to find the dentist." **(Male, 28, Iraq, transit, Hungary)**

In Italy refugees mentioned that it was difficult for everyone to navigate within the labyrinth of times, locations and modalities to access medical clinics. This forces them to make use of the emergency department for treatment of acute care or injuries instead of GP care.

In Austria, refugees seem to lack exact information about the health system and what the health insurance actually covers. The lack of information results in people being surprised by bills they receive subsequently. Repeatedly participants talked about the anxiety people have when they are not able to settle the bill for a health care service they utilised, as for instance the transport by an ambulance:

"Another one, she was really sick and then the responsible people they called ambulance and she didn't have insurance number or the e-card and then she went to the hospital they check everything and they give her medicine and… After five month, she gets the bill, six hundred Euro, you have to pay it. And she just gets 10 Euro per week. No food, because they give her the food three times a day but no money. (..) She's crying all the time. She doesn't have six hundred Euros and what then, she don't know what to do it. And this is causing madness or sickness or doing something herself maybe, it can happen." **(Female, 25, Iran, Long-term, Austria)**

<u>Discrimination of country of origin</u>

At the hotspot in Moira, Greece, some of the Afghan participants mentioned that they were discriminated due to their origin, even if their country has been involved in war for 40 years and that they faced closed borders, while the Syrian people had better support (e.g. financial) from some international NGO's. They wished for equal behaviour in all European countries.

"Our voice is being heard by nobody (authorities and population they get in touch) due to our country of origin." **(Male, 59, Afghanistan, Hotspot, Greece)**

<u>Financial barriers</u>

Financial barriers in the hotspots and transit centres were primarily linked to the lack of money and resources necessary to satisfy basic needs.

"The horrible part in this story with the baby is that the mother received the baby food in Greece but she couldn't buy any more. I don't know how long she stayed or how long she travelled from Greece to Croatia, but she had only little food left and was saving it, so she gave her baby infant formula for 3 or 4 times and for the rest she was feeding her with water and sugar. The baby was 3 months old and extremely underweight." **(Female, 44, infant feeding consultant, 6 months in the centre, transit, Croatia)**

"… we had to pay for lots of investigations, it's very expensive." **(Male, 26 Syrian, transit, Hungary)**

In the intermediate and long-term centres refugees describe the lack of financial resources for proper care or problems with insurance or administration. For instance in the Netherlands, refugees describe the following financial problem; in the temporary reception centres, until they enter the asylum seekers procedure, they don't receive pocket money. Since some of the refugees do not have any money, they are not able to pay for medication that is not covered for by the insurance, or for

instance get physiotherapy or regular dental care. The insecurity about the duration of the asylum procedure makes the financial situation more difficult.

> *"We shared our money for someone I know to make sure he could buy the medication he needed, we see that this is happening a lot."* **(Male, 50, Syria, Long-term, NL)**

> *"A lot of people have spent their money already. They expected to be in the centre for maybe 3 months and then they are able to earn money/have a house etc. Nobody expected that it would take this long and now you don't have any idea about how long it will take. We also need to save some money as we are uncertain about how long we'll stay here."* **(Male, 50, Syria, Long-term, NL)**

Experiences, preferences and barriers in contacts with healthcare providers

Importance of trust and positive, compassionate attitude

Most important for all refugees is the way they were approached by health care workers. They want to be approached with respect, a smile or kind word, so they have the feeling of being accepted and can build trust with the health care provider. These issues were also mentioned by the health care workers.

> *" A doctor should be humane and open minded."* **(Male, 38, Iraq, Transit, Hungary)**

> *"We are here to meet their basic needs; needs for food, water, clothing and a sense of security. But all this does not reach them if you do not offer a kind word. In our mother and baby area we always try to smile, play with the child, and try to provide the feeling of being accepted and that these children have a future."* **(Female, 44, infant feeding consultant, >5 months in the centre, transit, Croatia)**

In Austria, refugees made both positive and negative observations about the competencies of health care workers. On the one hand, they experienced compassion, equity and active involvement in the treatment. On the other hand, participants described discrimination, misinformation, carelessness, as well as intentional adherence to speaking only German.

> *"They take care of the people no matter where they are from. What the colour of the skin is. They take care of the health. That is really good."* **(Male, 25, Iran, Long-term, Austria)**

> *"Ah yes we are the same. The language barriers. For example some of the refugees they are not saying all of them are same but some of them they are using their local language. And then Me I know English I can tell my problem and … she wouldn't listen to me. I don't want to say her name but I met a female doctor and then she is using her language. Deutsch. And it was my first time I came here. Now I can understand Deutsch but I can't reply. But at that time I was really shocked. I said please, please doctor I can't understand Deutsch. I know English can you tell me. And she is talking she continued her explanation. And I was really serious… "* ***(Female , 29, Somalia, Long-term, Austria)***

At the other sites, refugees also mention both good and bad experiences with how they were approached and treated.

> *"I went to the doctor now due to my leg injury. Doctors behaved me very well."* **(Male, 19, Afghanistan, Hotspot, Greece)**

Cultural differences: general

Many of the cultural differences are related to male and female relationships. These were mentioned at all sites by both refugees and health care workers, sometimes as a barrier to good care for instance when women do not want to speak to a male doctor.

> *"It is the religion. Women in our country, they don't want to talk about anything, about life. Women can better talk with women doctor."* **(Male, 29, Syria, transit, Slovenia)**

> *"Women do not want to talk about their needs in public. She will not say that she needs sanitary pads or that she's in labour, she will not ask for underwear or publicly say that she has problems with painful breasts. Maybe she will tell it to a female interpreter. If the condition is severe maybe she will tell it to her husband so he can tell it to the interpreter indirectly."* **(Female, 44, infant feeding consultant, 6 months in the centre, transit, Croatia)**

> *"Women often refuse to go to the gynaecologist because they want to be examined only by a female gynaecologist which is difficult to ensure here."* **(Female, 30, coordinator of psychosocial support, 3.5 months in the centre, transit, Croatia)**

> *"If the nurse is female, sometimes men will not let them to administer the injections."* **(Female, 37, nurse, 2 months in the centre, transit, Croatia)**

In Austria, Cultural barriers became particularly apparent in connection with the need for – often male – refugees to translate in situations where it was not culturally appropriate for them to be present:

> *"Because I told the doctor and the person who was helping her to get birth. I told her we are Moslem and there should be some curtain and I could stay with them. But if there is nothing I will not go inside. And she was sitting there: we need you because they don't understand English nor Deutsch. So whenever I was just trying to take your baby out I should tell them what to do. I said: ok I will be there in the room but there should be a cover. And I will stand behind that or sit there and just be there. And that was a new experience for me."* **(Male, 25, Iran, Long-term, Austria)**

In Austria, the female participants preferred female doctors and if possible, they should be from the same geographical/ cultural background.

Other issues were experienced by healthcare workers as cultural differences

> *"We give them clean clothes here, they change their clothes but in the middle of the night or day they all walk around without socks. They are barefoot in shoes. We tell them all the time that they have to wear socks but they're all barefoot here. I think their climate is milder so they probably don't wear socks."* **(Female, 37, nurse, 2 months in the centre, transit, Croatia)**

> "*In the beginning, blankets were distributed in the Opatovac transit refugee centre and everybody was given a blanket. In the meantime we realized that a lot of blankets were thrown away. Than some interpreter who was better informed about that culture told that they take whatever is given to them and if they don't need it they will get rid of it later, rather than refuse to take what is offered to them.*" **(Female, 26, mobility tracking assistant, 5 months, transit, Croatia)**

Cultural differences in healthcare

In the long term centre in Heumensoord, Netherlands, it became clear that the expectation about good care differs from what they are used in their own countries. The health care systems of the Netherlands and Syria differ a lot. In the Netherlands, unlike in Syria, you have no direct access to hospital care: it is the general practitioner who decides if specialist care is necessary and who has to refer the patient to the hospital. In Syria it is possible to go to a specialist directly in an outpatient department or get medication without prescription at the pharmacy. On top of that Dutch doctors are, compared to others quite reluctant in prescribing antibiotics and other medication. Several refugees experience difficulties in dealing with this difference and don't really trust the general doctors with a wait and see policy and prescription of only paracetamol.

> *" We also need specialist doctors, not general doctors. Special care for pregnant women and children. This is important."* **(Female, 25-35, Syria, Long-term, NL**)

> *"I think the medical system in the Netherlands is great, I've seen the Radboud hospital. But in Heumensoord I feel like we're "rats of the laboratory". The people who work at the GCA have no experience with refugees, Syrian people or people from the Middle East. And they have no experience with our cultures."* **(Male, 50, Syria, Long-term, NL)**

> *" I have an example of a child with asthma. The parents know their child has asthma. Normally in Syria this child with an asthma attack will be admitted in a hospital immediately. Here she goes to the doctor and it takes 3 days before they send her to the hospital. She was admitted for 4 days."* **(Male, 55-55, Syria, Long-term, NL)**

Similar issues were also mentioned in the transit centres in Slovenia and Hungary:

> "*We have had better treatment in real medical institutions (buildings) than in tents. We got a specialist there."* **(Female, Syria, 32, transit, Slovenia)**

> *"There are no specialist doctors in the centre, for example gynaecologist. I have to go to another town and I have to pay if I need gynaecologist. "* **(Female, 27, Afghanistan, transit, Hungary)**

Language Barriers

Language barriers were mentioned at all sites both by health care workers and refugees. Problems arise when doctors or other health care workers and refugees do not speak the same language. In some situations health care workers speak English but refugees not. In other situations it is the other way around. In some instances, interpreters are available but this often results into trust issues, especially when it is about mental health problems.

> *"Health workers didn't have interpreter in Serbia and Macedonia. They are speaking a little bit Arabic, but not so much. So this was a problem. Because the doctor couldn't understand. This was a big problem."* **(Female, 32, Syria, transit, Slovenia)**

> *"It is also related to the lack of interpreters who are able to… You know that psychological or psychosocial support should be conducted in a very careful way in order not to increase the psychological stress. So the lack of experience in the interpreter to conduct the clinical interview… It is not a very good idea to have an interpreter between the counsellor and the person. It is better to have the interpreter who can himself provide psychosocial support."* **(Male, 26, psychosocial counsellor, 3 months in the centre, transit, Croatia)**

"There are not enough interpreters at the doctors during the journey, I can't speak languages, so I try to communication with body language." Who speaks languages try to help." **(Male, 24, Pakistan, transit, Hungary)**

"Usually there is no interpreter, we try to communicate with our arms and legs. If there is somebody, who speaks in English, he/she try to interpret." **(Male, 35, Afghanistan, transit, Hungary)**

"There were not enough interpreters at the doctors during the journey; we had problems with the language and understanding each other…" **(Male, 28, Syrian, Transit, Hungary)**

"They are very good [the doctors]. But a special problem we suffered from was that not all of them spoke English. We needed interpreters to talk to them. Not all of them, let's say 70% do not speak English. Only German. Sometimes the nurse came and translated between us." **(Male, 44, Iraq, Long-term, Austria)**

In the Netherlands, when having an appointment with a nurse/doctor there is an interpreter available through the telephone. One of the refugees suggests that it would be better to let the refugees translate themselves. They also suggest a female interpreter for women and that there should be more interpreters available in the centre, not only for medical care.

"I'm a paediatrician and speak good English. Let me help, because these people trust me. .. I'm able to translate and know the taboos. I think I can solve a lot of problems, but I'm just not allowed." **(Male, 50, Syria, Long-term, NL)**

In Italy, the main issue concerning the access to the national healthcare is the language barrier. In fact, all participants were assigned to a general practitioner, with whom they were unable to communicate. Because of this, participants mentioned they preferred to be assigned to a GP with good English communication skills (or other communal languages), or the attendance of a interpreter during their visit.

"For them, the big problem is the language, when they go to the doctor, they can not explain the problem." **(Male, 18-30, Pakistan, long-term, Italy)**

"The doctor did not speak English, did not understand, then at some point spoke in Italian and gave us a sheet to be signed and goodbye." **(Female, 23,Ghana, long-term, Italy)**

"They have communication problems, often when they go to the hospital, often they just they say yes, without really understanding what the doctor said." **(Female, 22, Nigeria, long-term, Italy)**

A female participant in Austria explained that the interpreters who worked in their centre were not capable and not instructed to accompany them to medical facilities. In order to deal with the language barrier and the lack of interpreters, they came up with two solutions. First, those who could speak English or German were asked to accompany others who don't speak these languages (by both their own family members and strangers). Secondly, doctors who speak the mother tongue are

deliberately sought out either by the refugees on their own initiative or with the support of the administration of the centre. This is also preferable for many, as they don't trust the "unofficial" interpreters, who are their fellow housemates. All the Austrian participants were Anglophone and all of them got used to accompanying others to the hospital or to the doctor. They all talked about extreme experiences and difficulties in coping with the enormous responsibilities, as well as the feeling of being overstrained and treated unfairly.

Bridging linguistic and cultural barriers

Overcoming these barriers is mentioned as the main need, both by refugees and health care workers. Multilingual health care providers can help overcoming the language barrier assuring that health care meets the needs of refugees.

> *"We need more experts who are native Arabic speakers, like we have a Syrian psychological counsellor. We also had paediatricians who lived and worked in the EU but come from these countries and are fluent in these languages and this greatly facilitated access to people and information, and sped up the healing process and also providing psychosocial support."* **(Male, 24, organiser, 5 months in the centre, transit, Croatia)**

> *"We need psychological first aid training for interpreters or Arabic training for the psychological support staff because they have a lot of social workers and psychological supporters but none of them speak the language."* **(Male, 40, volunteer - distribution of clothing, 5 months in the centre, transit, Croatia)**

In some instances, it was mentioned as a solution to involve refugees / migrants as mediators. However, this might not be preferable, especially in the hotspots and transits, as it puts enormous pressure and responsibility on the refugees who are translating and can result in trust issues.

Discussion

Main findings

The main health problems mentioned by our participants were related to the flight reasons (shooting war) and the journey the refugees had to undertake. During the journey and in the centres they faced unhealthy living conditions which caused or aggravated injuries, disabilities, mental health problems as well as common infectious diseases. Furthermore, many women worried about the development of pregnancies. Above that, the refugees mentioned health problems related to the lack of access to adequate healthcare: badly treated wounds, dental problems and a lack of continuity of care for chronic diseases and injuries.

The accounts of refugees and healthcare workers revealed important barriers in accessing healthcare related to the specific setting: At the hotspots and transit centres, the enormous time pressure is the main barrier. Due to this, refugees are reluctant to seek help for existing problems. Out of the same reason, health care workers have difficulty to assess the health care needs of the refugees and to build the necessary trust to address those needs, especially if they concern mental health. Participants at the hotspots also mentioned limited available health care facilities and health professionals. However, this problem was apparently not recognised by all participants.

Within the consultations with doctors and nurses, for all refugees the most important feature was trust and the feeling they were accepted and respected. The main obstacles mentioned at all sites

were linguistic or cultural differences. A lack of professional interpreters was mentioned, as was the disadvantages of working with interpreters who were strangers to the refugees concerned and therefore not trusted by them. Cultural differences related mainly to gender issues and to the medical culture in the different countries of origin of the refugees, e.g. the role of primary care in these countries.

Discussion under the light of existing knowledge

Most studies on health problems of refugees are conducted among refugees in long-stay refugee centres or refugees settled in the community (UNHCR 2015a, UNHCR 2015b, Bradby 2015, Hadgkiss 2014, Goosen 2014, Fazel 2005). Comparable to our findings, these studies also indicate the high prevalence of mental health problems. Above that, they mention different health problems that are related to a longer period of residence, such as the high prevalence of diabetes among settled refugees (Pykkonen 2010, Angyamang 2011) and problems related to pregnancy outcomes and reproductive health). Besides, there are health problems among settled refugees that are related to their country of origin, for example the higher prevalence of infectious diseases as tuberculosis, hepatitis B and C, endemic in many countries of origin of refugees.

Our findings on journey-related health problems mentioned by the refugees in our study (e.g. lower limb injuries, common respiratory infections) are supported by the analysis of 3500 consultations by an MSF medical team in Croatia during the last 3 months of 2015 (Escobio et al 2015) , and in the rapid assessment of the ECDC in 2015 (ECDC2015). As in our study, the main groups of refugees seen by teams of MSF were Syrians, Afghan, and Iraqis. The MSF report also mentioned a need for psychosocial services, which correlates with our findings, even though the extreme mobility of the people they treated did not allow a proper assessment of those needs (Escobio et al 2015).

Organisational barriers as well as financial barriers, as reported by our study participants in long-term centres, have been mentioned before (e.g. Hadgkiss 2014, WHO 2015).
The importance of bridging linguistic and cultural differences is well known, as is the importance of trusted interpreters and the disadvantages of family members acting as interpreters (e.g. Flores 2005, van den Muijsenbergh 2013) has been confirmed, which supports calls for (training in) cultural sensitive healthcare (Seeleman 2014)

The suggestion of participants to provide them with a personal medical record is in line with the IOM initiative of such a passport (IOM). However, previous experiments already made negative aspects apparent: for instance, undocumented migrant women were provided with a paper person-held medical record; however, the women in this group were reluctant to use this form of medical record fearing that family members or stranger would get access to confidential information (Schoevers 2011)

A new and very important finding of our study is that time pressure is the most difficult barrier in accessing healthcare at hotspots or transit centres. Especially this finding is relevant for the development of suitable assessment tools. The importance of trust in doctor-patient relationship and of continuity of care has been well documented before (Baker et al 2003), and Primary Care is well placed to provide this trustful, person centred relationship over time (Wonca 2001, WONCA 2015). The challenge in context of health care for refugees is to develop a system that provides a continuity

of care in the various health care contexts with different health care professionals the refugees interact with on their journey by taking into account the known barriers and new findings.

Strength and limitations of the fieldwork

The strength of this fieldwork was that we managed to involve so many, different, refugees during their journey in so many countries over the same period of time. We are not aware of any other study documenting the experiences of migrants undertaken in the difficult circumstances at the hot spots and the transit centres. Our approach enabled us to get a snap shot of the health needs and experiences with healthcare of refugees in their chain of travel through Europe during the first 3 months of 2016.

This approach clearly has its limitations as well: in many places it was not possible to speak at length with the refugees, due to time constraints. Furthermore, not at all fieldwork sites it was feasible to work with interpreters, which led to a high number of English-speaking refugees involved as participants.

Conclusive implications for the development of interventions in EUR-HUMAN

As described in the introduction, the aim of the EUR-HUMAN project is to develop guidance documents/recommendations and to pilot guidance, tools and training for the provision of integrated comprehensive person centred primary care for refugees at the intervention site in hotspots, transit centres and longer stay first reception centres. This study, combined with the results of the review of the literature in WP3, was carried out to provide input for these guidance, tools and training.

From our results we can draw the following conclusions relevant for the choice and development of guidance, tools and training.

1. Because of the time pressure and the large amount of refugees in hotspots and transit centres, it is recommended to use instruments for rapid assessment for both physical and mental health problems in order to identify the population with urgent conditions.
2. Short interventions aiming at identifying as well as treating (acute) mental health problems are needed
3. Considering the variety of stakeholders working together at these sites (volunteers of different NGOs, doctors, nurses, social workers from different background as well as local healthcare providers) it is important to streamlining the health care processes. Actions to improve health care in centres should also target volunteers.
4. Specific attention in guidance of professionals as well as in health promotion materials is needed for (the prevention of) common infections, healthy food, wound care including burning wounds and blisters, pregnancy care , providing care and medication for chronic diseases.
5. At all sites, information on procedures and on the organisation of healthcare should be provided. As many refugees are illiterate, information should not only be provided in writing but should also contain a lot of visual material and be explained orally.
6. To ensure continuity of care across different countries and sites, a person held medical record (like the IOM medical passport) would be very helpful. An electronic based passport would have many advantages above a paper based passport, keeping in mind the wet and crowded travel

circumstances which threaten the confidentiality of medical data that are carried on paper. Considering the fact that many refugees own smart-phones, there is a potential possibility of developing suitable apps for health related purposes.

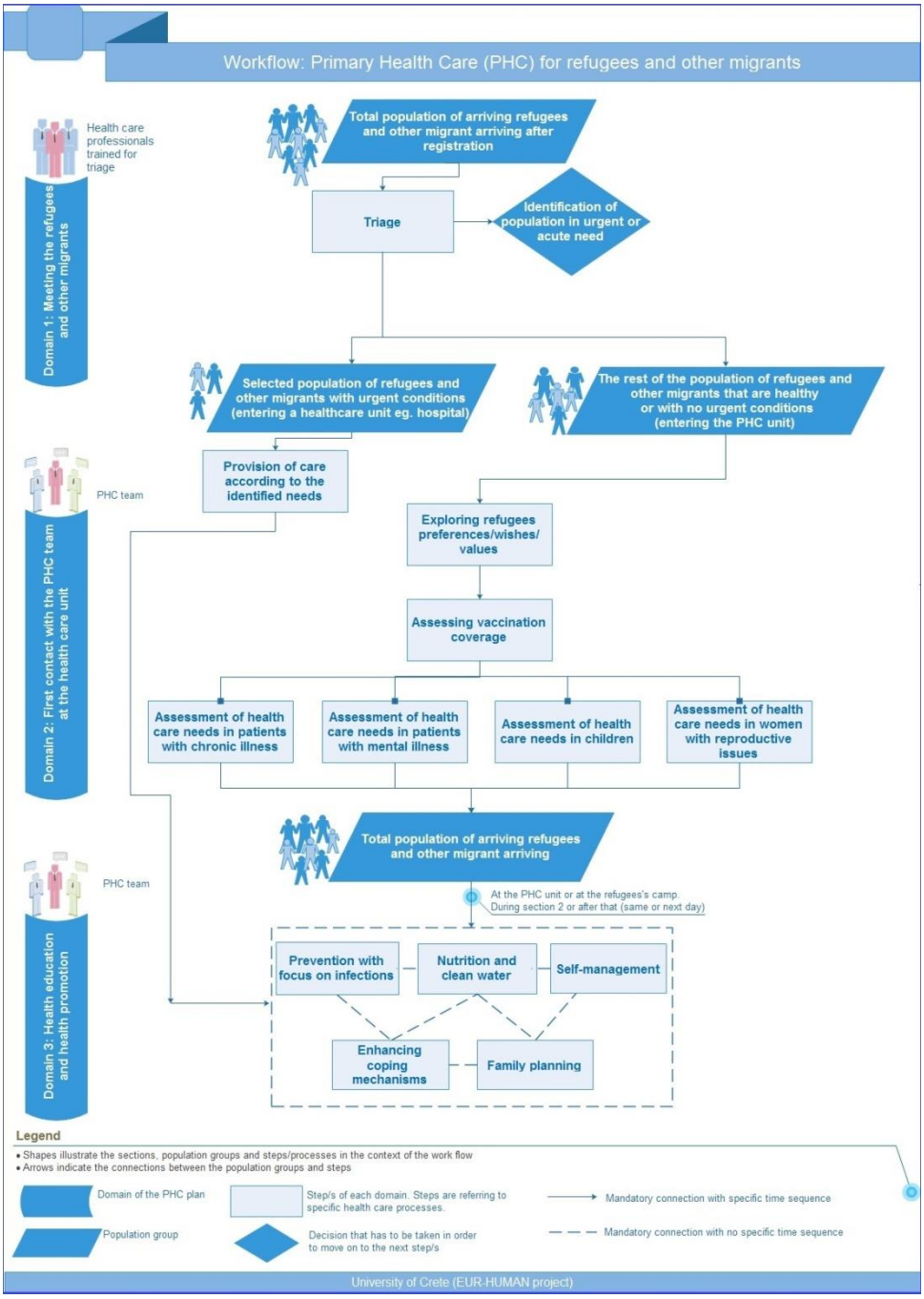
7. An important element of training for professionals should consist of training in culture sensitive and diversity responsive healthcare, including working with interpreters.

Implications and recommendations for the upcoming WPs

The ultimate aim of EUR-HUMAN is to implement interventions to improve primary health care delivery for refugees and other migrants with a focus on vulnerable groups. The objective is to provide good and affordable comprehensive person-centred and integrated care for all ages and all ailments, taking into account the trans-cultural setting and the needs, wishes and expectations of the newly arriving refugees, and to ensure a service delivery equitable to that for the local population.

An impression of the nature of services PHC will have to provide for refugees is been described in the following diagram of workflow (Figure 3)

Figure 3. Operational plan; workflow of Primary Health Care for Refugees and other migrants



The results of this fieldwork have important implications for the development as well as for the implementation of these interventions, and thus for the next work packages in EUR-HUMAN.
We will describe these implications for each of the following work packages.

Work package 4

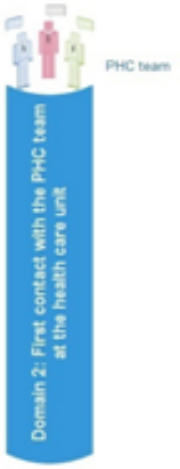
Task 4.1.
In this WP an expert consensus meeting is being organized in June 2016 in Athens in order to reach consensus on the content of good and affordable comprehensive person-centred and integrated PHC for refugees and other newly arriving migrants in different settings.
This meeting will be guided by specific questions for the experts, related to the above mentioned operational plan of workflow. From our results the following questions arise:

1. What consequences does the nature of the site (hotspot, transit centre, long stay centre) have for the operational plan regarding availability and access of PHC services, given the time pressure refugees face in hotspots and transit centres and the huge numbers of refugees entering and leaving these places within a very short timeframe ?
2. It might be possible that the workflow will differ, depending on the site (see figure 4)
3. How should we prioritize services and interventions, given the brief encounter and the large numbers?
4. What are the most essential actions always to be taken?
5. What should be the composition of a local PHC team, at the different sites and how could volunteers be involved ensuring good quality of care? Considering the variety of stakeholders working together at these sites (volunteers of different NGOs, doctors, nurses, social workers from different background as well as local healthcare providers) it is important to streamlining the health care processes. Actions to improve health care in centres should also target volunteers.
6. What health promotion issues need to be addressed?
7. How could the continuity of care across sites and countries be guaranteed? What are the pro- and con's of the IOM patient held record ("Medical passport")? What possibilities do mobile phones offer in terms of apps that could be useful, or to transport personal medical data?

Task 4.2.
Based on the consensus on the operational plan, a package will be developed of the most relevant guidance, tools, training and health promotion materials, information and best practices to assess and address the health needs of refugees and newly arrived migrants, especially in transit countries and hot spots of first arrival. Regarding the development of the package our results lead to the following recommendations. The package should contain at least:

- Instruments for rapid assessment for both physical and mental health problems in order to identify the population with urgent conditions, and that can be used also by lay people / volunteers
- Training in cultural competences and on communication with low literate people and across language barriers
- Guidance on information to the refugees about procedures, about the healthcare etc
- Examples of health promotion materials for (the prevention of) common infections, healthy food, wound care including burning wounds and blisters, pregnancy care , providing care and medication for chronic diseases.
- Guidance and tools for the continuity of care

Figure 4. Workflow depending on type of intervention site

Overarching issues across sites			
• Interpreters • Cultural competent healthcare workers • Information provision about (asylum) procedures, health care services • Trust building between providers and refugees			
	Hotspots	**Transit/intermediate**	**Long-term facilities**
	TRIAGE • rapid assessment infections ... • rapid assessment acute illnesses • rapid assessment acute mental health problems	• … • …	• screening for tuberculosis… • screening for mental health problems
	• assessment vaccination coverage • brief intervention for mental support, suited for volunteers • ……	• … • …	• plan vaccination coverage to standards of country of destination… • referral to specializes mental health care treatment • …..
	• … • …	• … • … •	• … • …

Work package 5:

Wp 5 will develop a protocol for early identification of highly traumatized refugees, including tools and procedures for rapid assessment of mental health needs and psychosocial status that can be easily implemented in real settings, and to facilitate early and appropriate interventions and services leading to shorter period of recovery from adverse life experiences and exposure to trauma.

Wp5 drafted an excellent report describing procedures of rapid assessment of mental health needs within the model of stepped care, overall supportive response to refugees in need of psychological support, specific focused short-term interventions and procedures for successful referral, including interventions targeting children and training and expertise needed for proposed procedures.

Regarding the development of the protocol and training our results lead to the following recommendations;

- Interventions aiming at identifying as well as treating (acute) mental health problems are needed, differentiating between hotspots , transit centres and longer stay centres; this will mean cultural sensitive instruments for Mental health and psychosocial support (MHPSS) in a stepped care model starting at the first sites where refugees enter Europe and stay for a very brief period - assuring continuity of care during their journey - until they finally reach their country of destination where long term care can start. These will include assessment and screening tools, and guidance for support and for referral in acute and chronic problems.
- Especially at the hotspots and transit centres there should be interventions that can be used by lay-people/volunteers.
- There should be guidance on how to work with confidentiality and with language barriers, given the nature of the different sites.

Work package 6:

Wp 6 will guide the choice and implementation of interventions to improve primary health care delivery for refugees, at different sites.

Regarding the choice of sites and interventions as well as the implementation, our results lead to the following recommendations:

- Hot spots and transit centres ask for interventions that are little time consuming, and possible to implement by different healthcare workers and volunteers for a large group of refugees.
- Training in cultural competences and especially communication skills is urgent at all sites.
- Providing information to refugees on procedures, on the organisation of healthcare and health promotion materials is also urgently needed. This information should not only be provided in writing but should also contain a lot of visual material and be explained orally.

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List of abbreviations

ADRA = Adventist Development and Relief Agency

DOW = Description Of Work

ECDC = Centre for Disease Prevention and Control

GCA = Gezondheidscentrum Asielzoekers (Asylum Seekers Health Centre)

GP = general practitioner

IOM = International Organization for Migration

MAGNA = Medical and Nutrition Global Aid

MDM = Médecins du Monde

MSF = Médecins Sans Frontières

NGO = non-governmental organization

PLA = Participatory Learning and Action

STP = Straniero Temporaneamente Presente

UNHCR = United Nations High Commissioner for Refugees

UNICEF = United Nations Children's Fund

WHO = World Health Organization

Appendix

A1. PLA Training Material

A2. Recruitment and fieldwork guide

A3. Informed consent (English)

A4. Participation Letter (English)

A5. Approval Letter of the Ethical board

A6. Topic List

A7. Fieldwork evaluation template

A1. PLA Training Material
Invitation and agenda

PLA Training Meeting, February 6th–7th 2016 Ljubljana, Slovenia

Meeting Venue: University of Ljubljana, Faculty of Medicine,

Department of Family Medicine, Poljanski nasip 58, Ljubljana

VENUE address:

University of Ljubljana, Faculty of Medicine,

Department of Family Medicine

Poljanski nasip 58

1000 Ljubljana, Slovenia

Tel.: +386 1 43 86 915;

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Tessa van Loenen tel: + 31617260636

Co-funded by
the Health Programme
of the European Union

PLA – TRAINING

February 6 – 7 Medical Faculty Ljubljana

AGENDA

Moderators: Maria van den Muijsenbergh

Tessa van Loenen

SATURDAY February 6th

14.00 hours	Welcome and introductions
14.30 – 15.30	Ground rules and PLA basics (fishbowl exercise)
15.30 – 15.45	Coffee / tea break
15.45 – 17.15	PLA technique 1. Flexible brainstorm (exercise in 1-2 groups)
17.15 – 17.30	Questions
17.30	End of the meeting
19.00	Dinner. Location will be announced during meeting

SUNDAY February 7th

9.00 hours	Start of the meeting
9.15 – 10.15	PLA technique 2. Direct ranking (exercise in 1-2 groups)
10.15 – 10.30	Coffee break
10.30 – 11.30	Information about the fieldwork in EUR-HUMAN
	= stakeholders to be involved / contacted
	= local sites and target Refugee groups
	= recruitment
	= PLA moderated sessions / topic list / how to address mental health issues
	= coding and report
11.30 – 12.00	Questions and discussion
12.00 – 12.30	PLA technique 3. Speed evaluation
12.30	Closing of the meeting

Training Manual

PLA – TRAINING

February 6 – 7 Medical Faculty Ljubljana

Manual

Facilitators: Maria van den Muijsenbergh
Tessa van Loenen

Preparations:

- Make PPTs on PLA and on guidance fieldwork
- copy texts ground rules
- ask Danica for beamer, flipover, coffee/tea /2 rooms / possibility to arrange chairs into circles and at what time we can access the room
- ask Sanne to observe and take notes
- take with us:
    - 4 piles of stickies (M)
    - cards for the icebreaker (M)
    - pictures from internet on healthcare workers and settings (M+T)
    - markers (6x) (M+T)
    - Dutch stroopwafels (Schiphol)
    - present for Danica (Schiphol)
    - nametags (M+T)
    - tape and glue for the walls (M)
    - paperclips 8 different colours (M)

SATURDAY February 6th

13.00	preparing the room arranging chairs, making signs to the room, having coffee / tea and dutch sweet available testing beamer get all materials in place etc name tags	M&T
13.45 -14.00	Welcome in a PLA mode: addressing each participant individual, small talk, offering coffee etc	M &T
14.00 – 14.45	Interactive Ice breaker exercise for introductions • choose a card that illustrates one positive aspect of refugees • 5 minutes to choose and think • Then each participant including T&M 2 minutes to tell their name, affiliation , function/ role in EUR-HUMAN and why they choose that card	M
14.45 – 15.00	General introduction to PLA • short explanation why we took so much time for introductions • introduction to PLA PPT presentation • how we will run the training: we will pretend they are a group of refugees with different background; roles will be distributed (T). We are going to be dividing the group in 2 for some of the exercises • explaining role Sanne (taking notes and observe)	
15.00 – 15.30	Ground rules and PLA basics (fishbowl exercise) • M&T researchers leading a meeting of refugees, not taking enough time, pressing, supposing they can read etc • 8 participants with roles of refugees insight the bowl – the other participants observing	
15.30 – 15.45	Coffee / tea break • distribute roles • put a lot of stickies on the tables as well as pictures on different healthcare workers and settings (pictograms etc)	
15.45 – 16.15	Discussion about observations, ground rules and basic elements of PLA PTT on ground rules and basic attitude of PLA facilitators	
16.15 – 17.15	PLA technique 1. Flexible brainstorm (exercise in 1-2 groups) • short presentation 5 minutes PPt • 2 groups of 8-9 refugees and M&T facilitating. Subject of meeting: refugees have been asked by NGO to come with suggestions how they should arrange (mental) healthcare for the refugees. • Every-one gets pile of stickies, marked personally.	

- Write down your own solutions answers to the question 1 solution per stickie (individually) ;
- if you can not write, choose any pictures or materials and explain what it means
- We will have a flip-over chart sheet on table; ask one participant to draw a circle and a line in the middle. Ask who wants to be the first and explain first sticky. Then discuss and ask if some-one else has something related to this first stickie/ or something completely different. Start looking for themes and make pile, moving stickies around etc. We should end up with various themes.
- Encourage explanations, discussion, grouping, be flexible. Ask if they can identify themes, what does this chart mean, are there gaps now it is all on the board?
- Time keeping. Make sure every-one gets to say something.
- Re-order during discussion. Alarm clock running (perhaps someone has app otherwise alarm clock online

17.15 – 17.30 Plenary Questions T and S taking notes

17.30 End of the meeting

- tape both flipovers to keep
- look at flexible brainstorm and choose 5 often mentioned suggestions and put them with a symbol on a commentary chart
- put the commentary card to the wall
- prepare flipover for evaluation tomorrow
- ask Sanne for debriefing of notes and observations
- discuss necessary adaptations/ improvements for the next day
- close off (ask Danica)
- reorder and clean room - ready for tomorrow

19.00 Dinner at……

SUNDAY February 7th

8.45 prepare last things and presentation

- paperclips on the tables
- flip over on the table
- markers on the table

9.00 hours Start of the meeting

- welcome all participants with coffee
- ask if everybody can stay until the end or planes need to be caught

9.15 – 10.00 PLA technique 2. Direct ranking (exercise in 1-2 groups)

- Mini presentation explaining direct ranking following the commentary chart
- Now every team has to choose one solution. Each individual has equal voting power.
- Go through the commentary charts briefly
- Every-one gets equal nr. of paperclips (calculate). Facilitator asks who wants to start the process of casting votes. Does any-one feel strongly

about one of the three interventions? How many of their paperclips and why. Who goes next same process. Make sure every-one casts votes and gets a change to speak. Every-one casts all his/her votes. Some-one (of the team counts) and writes next to solution. Then we make chart with thermometer.

- Solutions from high to low with spacing (visual).

10.00 – 10.15 Plenary comparing results, questions on the technique

10.15 – 10.30 Coffee break – attach flipover for evaluation to the wall

10.30 – 11.30 Information about the fieldwork in EUR-HUMAN

= local team
= stakeholders to be involved / contacted
= local sites and target Refugee groups
= recruitment
= PLA moderated sessions
= support UoL and RUMC
= coding and report

11.30 – 12.00 Questions and discussion

12.00 – 12.30 PLA technique 3. Speed evaluation

- Have a flip chart ready with at least 8 categories.
- Questions: our own (5) plus ask them if they see any other categories for the evaluation and add on chart

1. Comments on PLA as a research method
2. The used materials
3. Facilitation
4. Actual results
5. Did we meet your expectations

- On stickies on pre-prepared chart : start with first category until no more comments then move on.
- Facilitators move around chart and ask for clarifications, here and there again inviting participants to speak
- Interactive discussion on these key issues

12.30 Closing of the meeting – thanking Danica - cleaning up

Presentation

PLA Training Ljubljana

EUR-HUMAN

Dr. Maria van den Muijsenbergh
Tessa van Loenen, MSc
Prof.Chris Dowrick
Dr. Nadja van Ginneken

February 6 – 7, 2016

Radboudumc

Dobrodošli Üdvözöljük

ترحيب

Herzlich Willkommen dobrodošli

استقبا Καλώς ήλθατε

benvenuto خوش آمدید

Welcome Welkom

Program oversight

- SATURDAY February 6th
- 14.00 – 17.30 Introductions and PLA training
- 19.00 Dinner at Restavracija Most (own costs)
- SUNDAY February 7th

9.00 hours Start of the meeting
9.15 – 9.45 PLA technique 2
9.45 – 12.30 Information/ discussion fieldwork
12.30 Closing of the meeting

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Program today

14.00 – 14.45 Ice breaker exercise for introductions
14.45 – 15.30 PLA basics (fishbowl exercise)
15.30 – 15.45 Coffee / tea break
15.45 – 16.15 Ground rules – PLA mode of engagement
16.15 – 17.15 PLA technique 1. Flexible brainstorm
(exercise in 2 groups)
17.15 – 17.30 Questions
17.30 End of the first part of the meeting

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Icebreaker

Choose a card that tells
something about your self

tell us
- your name
- role in EUR-HUMAN
- why you chose the card

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General introduction to PLA

What is it?
Why do we use it in EUR-HUMAN
How are we going to train it?

Acknowledgments to Mary O'Reilly- De Brún & Tomas de Brún
RESTORE

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What is Participatory Learning and Action

"A growing family of approaches and methods to enable ***local people to share, enhance and analyse their knowledge of life and conditions***, and to plan, act and monitor and evaluate"

Chambers 1997

Qualitative research method

Participatory Action Research

Community based participatory research

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In PLA

- Stakeholders are considered to have expert knowledge of their own lives and experiences
  - ✓ **PLA** enables all stakeholders to **participate**, **learn** and **act** in a co-operative and democratic manner to achieve agreed goals
  - ✓ All voices and perspectives count – *culture-sensitive* with mutual respect and equal participation

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In PLA

- Emphasis on *dialogues*
  to identify problems
  and to create workable solutions
- Stakeholders are involved as much as possible from start to finish

Chambers, 1994; O'Reilly-de Brún and de Brún, 2010

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PLA mode of engagement

- Creates a safe and positive space for stakeholders from different backgrounds to work in partnership together
- promotes reciprocity and mutual respect
- cultural sensitive – gender issues, language, topics
- facilitator "follows" the group
- much attention to atmosphere and attitude

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PLA researcher – facilitator Essentials

Pay attention to

- Attitude
  - building trust and partnership
- Materials
  - choose and prepare the appropriate materials
- Methods
  - identify most appropriate PLA –technique
  - secure data (and analyse – report)

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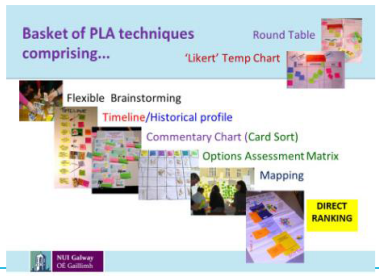

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Why PLA in EUR- HUMAN

- interventions work best as developed with all stakeholders
- as researcher we miss the emic view = the refugees life and context (and experiences healthcare workers in the field)
- refugees on the move are very vulnerable
- questionnaires not feasible because of linguistic and cultural diversity

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How will we train this today?

- Learn by experience:
  you will be part of PLA moderated sessions
- You all get roles as refugees or as observants
- Sanne will observe and take notes about process

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Fishbowl:
the importance of the PLA mode of engagement

- Inner circle participants to a research meeting
- Outer circle critical observants
- Tessa and Maria facilitate the meeting

Questions:
- How did you feel as participant to the meeting?
- What did you see as an observant happening
  - was trust built?
  - did all participants felt included and engaged?

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Fishbowl:

Setting: refugee camp in the Netherlands
- 8 newly arrived refugees were invited to a meeting about healthcare
- they do not know more about it
- interpreters are arranged
- Whom of you want to play a refugee?
- Who want to be observant?

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Key attitude for the PLA mode of engagement

- be relaxed: do not rush!
- build report and trust
  - take time for introductions
  - explain the goal of the meeting
  - explain confidentiality
  - ask consent for audiotaping / Photo's
  - give plenty room for questions
- be respectful and aware of diversity
  - illiteracy / language barrier? – use lots of pictures
  - cultural sensitive pictures
  - always *asks* who wants to do something

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Key features for facilitation in PLA

- Be well prepared (materials, setting, topic)
- Be flexible: go with the flow of the group
  - they are the experts
  - ensure everyone has an equal voice
- Listen and learn
- Embrace mistakes: they lead to unforeseen insights
- It is 90% attitude -10% technique

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Flexible Brainstorm

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Flexible brainstorm

Aim

- To elicit participant perspectives, knowledge & expertise, generating a record of data in a flexible moveable format that can be used to achieve various results.
- In a fast, creative, democratic, way

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Flexible brainstorm

- Generates ideas
- Creates informal atmosphere
- Fluid flexible method
- Good learning tool - participants educate each other
- Strong visual aid
- No pressure to speak
- Empowers and includes all participants

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Flexible brainstorm procedure 1

- Welcome and introduction in PLA mode of engagement – explanation of goal and method
- Facilitator invites participant to draw circle on flipchart sheet on table
- Facilitator invites to discuss the question at stake
- Each participant writes down / chooses a picture each important issue – 1 at 1 sticky
- Each participant in turn is asked to put a sticky / picture on the chart with circle on the table
- Who has something similar? something different?

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Flexible brainstorm procedure 2

- Until all issues are on the flipchart
- Facilitator opens up to new themes all the time etc.
- Participant arrange issues in themes
- Iterative process: go back to new issues / rearranging
- Until no new issues arise and every one is satisfied about the arrangement in themes

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Flexible brainstorm

Result

- Perspectives / idea's
- Shared understanding
- Shows the wealth of knowledge/expertise there is within the group
- Opportunity to fill in gaps
- Flows on to our next step: selection / development of interventions

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Let's do a flexible brainstorm

2 groups : 1 Tessa, 1 Maria

You all are refugees in a camp

Interpreters available

Topic of meeting – question at stake:

"What health care do you need now, in this camp?"

Introduction is performed in PLA mode

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Flexible brainstorm: Data management

- put date, place, name of meeting on flipchart
- take a picture of the chart (and if possible of process)
- tie all stickie's / pictures down and safe as original data
- gather all consent forms and keep
- transcribe audiotape verbatim
- analyse as qualitative data (coding etc)
- ideally: discuss analysis with participants

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Program

- SUNDAY February 7th

9.00 hours	Start of the meeting
9.15 – 10.15	Information and discussion about the fieldwork
10.15 – 10.30	Coffee break
10.30 – 11.20	Information and discussion about the fieldwork
11.20 – 11.30	how to address mental health topics and acute anxiety
11.30 – 12.00	Questions and discussion
12.00 – 12.30	PLA technique 2. Speed evaluation
12.30	Closing of the meeting

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Direct Ranking

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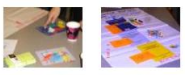
Direct Ranking is a **democratic, inclusive decision-making tool**



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Aim

- To give each stakeholder **'equal voice'** – levels the playing field
- And **equal voting power** (number of votes)
- **Respecting stakeholder expertise**
- **through a visual/tranparent voting procedure**

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Procedure

- Interventions are placed around the chart on table
- Commentary charts on wall
- Each stakeholder gets an equal number of votes (paperclips, buttons etc.)
- Identify top (most suitable)/bottom (least suitable) of chart and draw line in middle (a participant) and write the topic of the ranking
- Globally discussion on the intervention that should be at the top and bottom
- Any participant starts placing first votes and clarifies why. Facilitator 'moves through' participants inviting them to cast votes and explain
- When all votes are cast, one participant counts and writes the number of votes
- Interventions are placed on the line : top one first, then bottom-one and the ones in the middle

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Speed evaluation

to gain insight in the opinions / experiences of the participants on process and content regarding

- time and venue of the meeting
- facilitation
- the way we used materials
- comments on PLA as a research method in general
- comments on PLA as method in Eur human
- the information on the fieldwork
- the discussion on the fieldwork
- did we meet your expectations
- do you feel confident to start the fieldwork
- ? other issues

- Method
  - 1 item on 1 sticky place on the flipchart

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End of the meeting

Hvala zbogom Grazie addio

Ευχαριστίες αντίο

Thank you Good bye

Hvala zbogom

DANKE SCHÖN AUF WIEDERSEHEN

Hartelijk bedankt en tot ziens

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A2. Recruitment and fieldwork guide

Goal

At the intervention sites refugees will be recruited to participate in the local stakeholder group. These groups will participate in PLA moderated sessions in order to generate data on *views*, *experiences* and *expectations* of the refugees regarding their health and social needs, access and use of healthcare and social services.

The number of sessions with each refugee group depends on the sites:

- At the hotspot/transit sites it is only feasible to hold **1 session per group**, since the refugees are only there for a few hours. At these hotspot sites, more groups of refugees will be recruited (approximately 4 groups).
- At sites where refugees stay longer it might be feasible to hold **3 sessions per group**.

Recruitment instruction

Participant groups

- At Hotspot/transit sites 4 groups of approximately 5 persons (1 session per group)
    - 2 groups of female asylum seeker
    - 2 groups of male asylum seekers
- At sites where refugees stay longer 2 groups of approximately 5 persons (3 sessions per group)
    - One group of female asylum seeker
    - One group of male asylum seeker

- Within these groups recruit participants of:
    - Different ages (≥18 years)
    - Different educational attainment
    - Different countries of origin
    - with and without chronic health conditions
    - Preferable with good and without any or with bad experiences with medical care in the camp
    - No staying permits

Location of recruitment

- Participants for the stakeholder group will be recruited within the refugee centre
- Be aware of regulations and governance in the refugee centre and arrange necessary permissions

How to approach the participants

- Purposive sampling; make use of contacts within the centre, e.g. doctors, but make sure also participants are included who do not have contacted a medical service.
- Letter for the participants explaining the purpose and the content of the research. *(example letter in English available)*
- In addition oral explanation; make explicitly clear :
    - that all information is confidential, will not be shared with authorities or doctors
    - that participation will not help them to get a staying permit or whatever other benefits in the camp, but that it intends to help future refugees
    - that they will receive a gift at the end of the sessions

Fieldwork instruction

Ethical approval

In preparation of the fieldwork make sure ethical approval is acquired in accordance with the legal requirements in your country. We provide you with an example letter for you Ethics Committee.

Informed consent

It is very important to obtain an informed consent form of every participant. We have designed a user-friendly format for an informed consent (English and Arab) which you can use as an example. There is also a short consent form available in English and Arab.

We need a digital copy of all the signed consent forms.

For refugees, there might be some reticence to participate. Explain the consent process to participants but don't overwhelm participants with too much information. Take time to explain, orally and personally, the scope of the study and emphasize the confidentiality. Make sure that the informed consent has simple and short sentences and as little as possible references to legal issues.

Language barrier

One of the main problems in this type of research is the language barrier. Within the refugee centre several languages will be spoken. The most common languages probably will be English or Arabic. Either a staff member speaking these languages or a professional interpreter should be available to tackle possible language problems.

Another way to tackle language problems is the use of visual material. Visual materials are information tools that assist a training session by showing the information in picture images.

Location of sessions

- Choose the location for the sessions carefully.
- Make sure the location is safe and discrete.
- Easy to reach
- Provide something to drink and eat

Audiotape

All sessions will be audiotaped and transcribed ad verbatim. Explain that no-one will be identified by name on the tape. The information recorded is confidential, and no one else except the research group will have access to the tapes. You have to store the audiotapes yourself for at least 5 years. A **copy of the transcripts** of the audiotapes should be RADBOUDUMC

Fieldwork reports

We provide a *process evaluation* form with questions about the recruitment and fieldwork processes. Please fill these out.

Coding and Local PLA reports

All the data will be coded and analysed by the local settings. We will provide you with a coding framework.

A3. Participation Letter (English)

Information letter for participation in **EUR-HUMAN**

Co-funded by
the Health Programme
of the European Union

Place....Date...

Dear Sir/Madam,

I am [your name], working for the [university/research center]. We want to improve the medical care for refugees like you. For us, it is very important to know what you think about the care that refugees receive, what health problems you or other refugees have, and what care you need.

Therefore, we organize meetings with a group of refugees to talk about their experiences and needs. There is a group for men and a group for women. Each group is led by an experienced interviewer. The meetings will take 2 hours. There will be interpreters to translate for those who cannot speak English. Participants can choose themselves what they want to say and what not. They can leave the meeting at any time they want.

The meetings will be audio taped and later written down in documents. In these documents there will be no names of participants - they are anonymous. The information recorded is confidential, and no one else except the research group will have access to the information.

The results will be used to make training for healthcare workers and information for refugees, and so to improve the healthcare for refugees.

I want to invite you for this meeting because I believe that your views and experiences can teach us more about the care of newly arriving refugees. Your participation in this research is entirely voluntary.

The meeting will take place in [location] on [date]. No one else but the people who take part in the discussion and the interviewer will be present during this meeting.

If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact any of the following: [contact information]

Thank you in advance.

Kind regards,
[your name]

On behalf of:
[Research Group]

This research has been reviewed and approved by [your ethic committee], which is a committee whose task it is to make sure that research participants are protected from harm.
This letter is part of the project '717319 / EUR-HUMAN' which has received funding from the European Union's Health Programme (2014-2020) The content of this letter can not be considered to reflect the views of the European Commission and/or the Consumers, Health, Agriculture and Food Executive Agency or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains."

A4. Informed consent (English)

Co-funded by
the Health Programme
of the European Union

Consent form participation EUR-HUMAN

Participant consent

PLEASE tick every box

- I have read the information, or it has been read to me. I have asked all questions about the project that I want. All my questions have been answered to my satisfaction.
- I consent voluntarily to participate in the group session about healthcare in the EUR-HUMAN study.
- I consent that the group discussions are audio taped.
- I consent that the audiotapes are being transcribed into written documents. No names of participants are written in these documents (it is anonymous). The tapes and transcripts are stored at a safe location.
- What participants say can be used as anonymous quotations in the reports on the EUR-HUMAN project.

Name of Participant_____

Signature of Participant _____

Date _____

Staff member / person taking consent

- I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands the purpose and scope of the study.
- I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability.
- I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Name of person taking the consent_____

Signature of person taking the consent_____

Date _____
Day/month/year

This letter is part of the project '717319 / EUR-HUMAN' which has received funding from the European Union's Health Programme (2014-2020)
The content of this letter can not be considered to reflect the views of the European Commission and/or the Consumers, Health, Agriculture and Food Executive Agency or any other body of the European Union. The European Commission and the Agency do not accept any responsibility for use that may be made of the information it contains."

A5. Approval Letter of the Dutch Ethical board

Loenen, Tessa van

Van: Cruysen, Yvonne van der namens Postbus Commissie Mensgebonden Onderzoek
Verzonden: maandag 8 februari 2016 9:40
Aan: Loenen, Tessa van
Onderwerp: 2016-2306

Opvolgingsmarkering: Opvolgen
Markeringsstatus: Voltooid

Titel: European Refugees - Human Movement and Advisory Network
Dossiernummer: 2016-2306

Dear mrs van Loenen,

On behalf of the research ethics committee of the Radboud University Nijmegen Medical Centre I hereby let you know that the abovementioned study doesn't fall within the remit of the Medical Research Involving Human Subjects Act (WMO). Therefore, the study can be carried out (in the Netherlands) without an approval by an accredited research ethics committee and without explicit informed consent of the participants.

Best regards,
Drs. R.B. Keus, Chairman

Research Ethics Committee
Radboud University Nijmegen Medical Centre

Concernstaf Kwaliteit en Veiligheid
Commissie Mensgebonden Onderzoek
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A6. Topic List

EUR-HUMAN Radboudumc university medical center

TOPIC LIST fieldwork WP2

Topic list for PLA moderated sessions with refugees and other migrants, to get insight into their views and experiences on health problems, healthcare needs and needs for social care / mental support.

The topic list consist of 2 parts: **Topic #1** and **Topic #2**

Single sessions:
For the single sessions you can use the questions of **topic #1** of the topic list. The emphasis should be on question 2 and 3. But question 1 is a good starting point for the discussion.
If after a few sessions you have the idea that you have heard 'everything' on topic #1, you can choose to start a group with **topic#2.** Try to have at least one group where **topic #2** is discussed.

Multiple sessions:
If a group has multiple sessions, start the 1th sessions with **topic #1.** The emphasis should be on question 2 and 3. But question 1 is a good starting point of the discussion.
In the 2nd and 3th session you can use **topic #2.**

Sessions with NGO's and other stakeholders:
You can use the same topics.

Important remarks for the sessions:

- Guidance has been circulated separately on how to facilitate the discussion, and how to achieve a PLA 'mode of engagement', as well as practical issues as collecting informed consent, audiotaping , data storage etc.
- Very important during each session is attention for ground rules, atmosphere, safety, giving every participant equal opportunity to speak, noting discomfort or anxiety as well as limitations in reading and/or speaking the communal language (as will be discussed during the training).
- Know exactly what you can offer them in terms of acute access to care, to social support, in reward, etc. Make sure you have some contacts with local healthcare / social / psychological workers in case there is an acute need for help.
- Very sensitive topics (like sexual abuse) often can be better addressed by asking if anyone has heard of such a thing, instead of if anyone has experienced this.

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Topiclist

Note: These are the topics we think are relevant to address – however there has to be room for topics the refugees themselves come up with!

Topics #1

1.What are the main health problems you have experienced so far in your life - at home or during your journey to Europe?

If participants do not mention the following conditions themselves, then please ask if they know people with these conditions:

- *Chronic diseases*
- *Other diseases (focus on communicable diseases)*
- *Mental disorders*
- *Childhood diseases*
- *Pregnancy related issues*
- *Disabilities / Injuries*

2. What experiences do you have with healthcare during your journey / in this centre? What barriers did you encounter if you wanted to see a doctor or if you needed medication?

If participants do not mention any experiences or barriers, you can help them with the following topics

- *administrative and financial hurdles?*
- *language?*
- *cultural/religious barriers?*
- *lack of facilities?*
- *lack of continuous health care*

3. What care would you appreciate for the health problems mentioned before these problems?

To help participants think about all issues, it could be helpful to specify after an introductory broad question (e.g. what healthcare facilities do refugees like you need?)
what is needed in relation with:

- *Acute illness (infections and others)*
- *Injuries*
- *Chronic diseases management and medications' provision*
- *Illness in Children*
- *mother and child care (pregnancy care, delivery and problems with newborns)*
- *Do you want a medical first aid kit for during your journey? If so, what should be in it?*
- *Stress, anxiety: other mental disorder?*
    - *Example questions: we know you all have suffered a lot. And we know many people feel very stressed, or have to think a lot. Sometimes they cannot sleep at all, or are very frightened. Or the cry the whole day. Or just are numb and sad. Or very easily irritated and angry. Do you recognize this? What do these people need, right now on their journey, and when they have reached their final destination?*
- *Sexual and gender based violence : this topic should be addressed only if there is a really confidential atmosphere in the group, and as last questions*

- *Example questions: we know very bad things happen with women in the war, or during the flight. If you have ever heard of such an awful thing, what do you think these women would need? With whom should they speak about this? And the same kind of questions related to torture.*

Related to the kind of services they need, it is important to get information on the following questions:

- What do you need to access care
- How do you get information on access – what kind of information would you want?
- How would you want to deal with language barrier?
- Preference for predictable and coordinated visiting schedule of clinics?
- Where do they find support when they do not feel well mentally? Where do they go to?
- If people have severe mental health problems: do they have access to mental health care facilities? Can they find the way? Would they go there if they had complaints?

Topics #2

1. Health information system

- *Do you want the doctors elsewhere to know your medical history?*
  - *How could this be achieved?*
- *Do you posses any paper or electronic personal health records?*
  - *Medical cards or booklets containing medical history*
  - *Vaccinations booklet*
- *What do you think of a personal health record (show the IOM example)*

2. Competencies of healthcare workers and previous experiences in healthcare

- *What are your preferences and expectations in relation to the care services?*
  - *Sufficient patient-doctor time*
  - *Active involvement in the decision of the therapeutic scheme*
  - *Physicians showing understanding and compassion*
- *What was your experience with the healthcare services in your country?*
  - *First point of contact in case of a health problem*
  - *Accessibility of healthcare services (eg. geographical barriers, insurance policy, private or public healthcare services etc)*
  - *Continuity of healthcare (eg. general practitioner, family physician or other physician)*
  - *Health information sources (eg. healthcare professionals, family, friends, media etc)*

A7. Fieldwork evaluation template

EUR-HUMAN

Fieldwork process evaluation report for WP2
Please complete this form as soon as possible after the last PLA moderated meeting

Evaluation of the preparation, sampling and recruitment
Country:
Staff member:
Date:

Ethical approval procedure	
1. Did you apply for ethical approval? *If not, please explain why not.*	
2. Where did you apply for ethical approval? *Please mention the name and level of the committee (e.g. University, national committee..)*	
3. Did you get ethical approval? *If not, please explain why not?* *if so, can you provide the number of the approval letter*	
4. Where were the any critical assessment points with regard to this study?	

Recruitment	
1. What type of implementation site did you use? (e.g. hotspots, transit camps, long-term camps)	
2. Can you give a description of the implementation site? (e.g. where the site is , how many refugees there are, how long refugees are in these sites..)	
3. Which bodies (professional or authorities) did you involve to support the recruitment?	
4. How did you approach the participants? P lease mention sampling procedure e.g. sampling by convenience, snowball etc.	
5. How many refugees in total were invited to participate in this study?	
6. How many groups of refugees were you able to form?	

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Fieldwork (overall)	
1. Who were the local staff members involved in the fieldwork? (Students, health care workers,..?)	
2. How many local staff members were facilitating the sessions?	
3. How did you deal with the language barrier? (e.g. bilingual researcher, interpreter)	
4. What was the general feedback from the local staff members on their contact with the refugees?	
5. What problems/difficulties were reported by the local staff member involved in the fieldwork?	
6. In total, how many sessions took place at you site? and how many sessions per group?	

Other	
1. Are there any other issues which you came across during the fieldwork which you think are important for us to know?	