

Population-Based Health Access Assessment for Syrian Refugees in Non-Camp Settings Throughout Jordan

With Sub-Investigation on Non-Communicable Disease Management

A Qualitative Cross-Sectional Cluster Survey

Contributing Organizations:

UNHCR, UNFPA, International Medical Corps - Jordan



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Acronyms

CBO – Community-Based Organization
IEC – Information, Education, and Communication (Materials)
IMC – International Medical Corps
INGO – International Non-Governmental Organization
MMU – Mobile Medical Unit
MoH – Ministry of Health
MoI – Ministry of the Interior
NCD – Non-Communicable Disease
OB/GYN – Obstetrics/Gynecology
UNHCR – United Nations' High Commissioner for Refugees

Introduction

Background

The Syrian conflict, now in its fourth year, has resulted in over 120,000 deaths, of which nearly 11,000 are women and children.¹ 2013 saw the number of people in need in Syria increase from 4 million to over 9 million, while the number of refugees registered with UNHCR in neighboring countries increased from around 550,000 to 2,300,000. By late Spring 2014, the number has risen to more than 2,775,00.²

Jordan continues to provide asylum for a large number of Syrians, despite the substantial strain on national systems and infrastructure. This pressure has become even more acute over the past two years, as the global financial crisis has had an impact on Jordan's economic situation and infrastructure for water, electricity, waste management, education, and healthcare.

As of late April 2014, between 200-800 Syrians were crossing into Jordan each day.³ Although the influx rate has dropped since a year ago, daily averages have risen steadily again in recent months. New arrivals now enter almost exclusively through the northeastern border—which requires a lengthy trek through harsh, desert terrain.

Over 593,000 Syrians are registered or awaiting registration in the Kingdom⁴. Based on current trends, UNHCR expects the numbers of Syrian refugees fleeing to Jordan to increase, with the potential risk of a larger, sudden influx. Push factors include generalized and targeted violence, in addition to a public service breakdown in most areas of Syria and increasing prices for fuel and food.

Aside from over 100,000 Syrians hosted in the Za'atari refugee camp, the vast majority of Syrians are known to be living among host communities, particularly in the governorates of Amman, Mafrqa, and Irbid—where their presence has strained access to many basic goods and services, including healthcare. Local hospitals have been challenged by the subsequent demand posed by the health needs—acute, chronic, and otherwise—of Syrian refugees.⁵

¹ March 2014 Monthly Forecast - Syria. Issue brief. Security Council Report, 28 Feb. 2014. Web. http://www.securitycouncilreport.org/monthly-forecast/2014-03/syria_5.php.

² "Persons of Concern - Jordan." *Syria Regional Refugee Response - Inter-Agency Portal*. UNHCR, 30 Apr. 2014. Web. <http://data.unhcr.org/syrianrefugees/regional.php>.

³ "External Statistical Report on Active Registered Syrians - 26 April 2014." *Syria Regional Refugee Response - Inter-Agency Portal*. UNHCR, 26 Apr. 2014. Web. <http://data.unhcr.org/syrianrefugees/country>.

⁴ "Persons of Concern - Jordan." *Syria Regional Refugee Response - Inter-Agency Portal*. UNHCR, 30 Apr. 2014. Web. <http://data.unhcr.org/syrianrefugees/country>.

⁵ 2014 Syria Regional Response Plan - Health. Rep. UNHCR. Web. 30 Apr. 2014.

The exact nature of these health access issues, however, went largely unexamined in the first years of the refugee crisis; heavy media coverage of Jordan's refugee camp(s) monopolized the attentions of the international community, relief actors, and donors, swaying allocation of funds and programming priorities. The camp setting also provided a consolidated refugee population, a far easier scenario for needs assessment, as well as program implementation. In recent months, Syrian refugees have increasingly settled directly in Jordanian cities and towns, and a significant proportion of those living in Za'atari refugee camp have begun to move out into communities in search of longer-term living arrangements. This trend has prompted renewed interest among health partners, including International Medical Corps (IMC), that seek to better understand the challenges facing non-camp refugees trying to access care, as well as the conditions, particularly non-communicable and chronic, that are most heavily impacting this underserved population.

Rationale and Objectives

The progressive urbanization of Jordan's Syrian refugee population (by late 2013, roughly 4/5 Syrian refugees in Jordan were living in non-camp settings) prompted IMC to focus attention on out-of-camp refugee health.⁶ However, disproportionately little information on the healthcare status of this population was available to inform new programming. In order to address these information gaps, IMC, with support from UNHCR and UNFPA, undertook the Population-Based Health Access Assessment for Non-Camp Syrian Refugees Throughout Jordan (heretofore referred to simply as the Health Access Assessment).

The field assessment sought to gather qualitative data pertaining to barriers to care, prevalent conditions, and secondary health factors impacting the health status of non-camp refugees. Pre-conflict statistics also indicated that non-communicable diseases have historically accounted for a significant portion of the disease burden among Syrians; a sub-investigation was added to the IMC Assessment to further explore refugees' management of these conditions under the current circumstances.⁷

OVERALL PROGRAM OBJECTIVES
<ul style="list-style-type: none"> To conduct a population-based qualitative assessment using focus groups and in-depth interviews with Syrian refugees living in a non-camp setting in Jordan, in order to better understand the current disease profile of the population, identify major barriers preventing them from accessing existing services, and determine any significant gaps in these services.
Activity Objectives:
<ul style="list-style-type: none"> By December 31st, 2013, the IMC assessment teams will have conducted 60 focus groups with Syrian refugees (aged 18 and up) residing in 30 (non-camp) cluster sites across Jordan.
<ul style="list-style-type: none"> By December 31st, 2013, the IMC assessment teams will have conducted 60 in-depth interviews with Syrian refugees residing in 30 (non-camp) cluster sites across Jordan and suffering from NCDs.
Output Objective:
<ul style="list-style-type: none"> By January 1st, 2014, the IMC assessment teams will use the initial findings from these focus groups and in-depth interviews to inform recommendations for IMC's MMU program, as well as other health/refugee relief organizations, in order to mitigate the barriers to care brought to light by assessment activities. By May 30th, 2014, a full analytical report of the assessment findings will be completed, for internal review and subsequent publication and dissemination.

⁶ United Nations' High Commissioner for Refugees, and International Relief and Development. *Syrian Refugees Living Outside of Camps in Jordan: Home Visit Data Findings*, 2013. <http://reliefweb.int/report/jordan/syrian-refugees-living-outside-camps-jordan>.

⁷ World Health Organization - NCD Country Profiles, Syrian Arab Republic. Tech. 2011. Web. Apr. 2014. http://www.who.int/nmh/countries/syr_en.pdf.

Timeline

The Health Access Assessment set out to address these critical data gaps in early November 2013. The assessment design was finalized by mid-month and activity logistics were arranged. IMC's data collection team received a one-day training on focus group facilitation and interview skills on November 24th, 2013. The assessment started the following week, with the team conducting the primary data collection from December 1st until December 12th, 2013.

Post-implementation activities (transcription, translation, analysis, and reporting) began immediately thereafter. Due to the large volume of notes, translation required approximately 1.5 months to complete (early February 2014). The subsequent data coding and analysis (described below) also took about 1.5 months (mid-March 2014). Initial results were presented at the UNHCR-hosted Syria Crisis Health Assessment Conference on March 20th, 2014.

Methods

Overall Study Concept

The concept for the IMC Health Access Assessment was initially conceived as a complement to a Johns Hopkins University/WHO/UNHCR study that would be exploring similar research questions among a comparable target population. The Johns Hopkins technical team planned to conduct an inter-sectoral, *quantitative* questionnaire (shelter, WASH, livelihoods, health, etc.) using cluster-sampling methods across Jordan. The IMC assessment was therefore designed to use comparable sampling methodology and collect *qualitative* data focused exclusively on health issues among the population of interest.

A special sub-investigation on the issue of refugees' management of non-communicable diseases, also emphasized in the JHU questionnaire, was added to further develop the evidence base on the subject. The Syria crisis has been among the first instances of a major humanitarian response for a country where the epidemiological transition is already well advanced and the burden of disease has largely shifted away from communicable disease (typical in most refugee crises) and towards chronic conditions as the primary source of morbidity and mortality.

The narratives gathered during the IMC assessment provide important insight on Syrian refugees' health-related experiences. Particularly combined with relevant quantitative findings, IMC's qualitative data helps paint a well-rounded, humanized picture of the current healthcare situation for refugees in Jordan.⁸

Principal Assessment Design

Research Question

The principal assessment set out to answer the following research question using focus group research techniques:

Which health conditions are most heavily impacting Syrian refugees currently residing in non-camp settings throughout Jordan, how does this population perceive its ability to manage these conditions, and what are considered the primary barriers preventing them from accessing the necessary health services?

⁸ The Johns Hopkins/WHO/UNHCR study has since been postponed till further notice.

Study Design and Implementation

The IMC Health Access Assessment followed a *qualitative, cross-sectional, partially-randomized, cluster* survey model.

IMC's data collection team, trained in focus group and interview facilitation, gathered from 60 focus group discussions narrative data pertaining to the research question above. Following a structured focus group topic guide (translated from English into Arabic, and then back-translated), each focus group discussion lasted between 45 minutes and 1.5 hours and was comprised of six to ten participants of the same gender. One female and one male focus group discussion was conducted per cluster site; 30 cluster sites across nine governorates in Jordan were weighted and then randomly selected for assessment. Data collection was completed over a two-week period - December 1st – December 12th, 2013 - with each of IMC's three research teams (two females, two males per team) visiting one cluster site per day.

Target Population

The target population for the IMC Health Access Assessment was all adult (18+) Syrian refugees residing in non-camp settings throughout Jordan. From this sampling frame, 600 participants were to be recruited from 30 randomly selected cluster sites proportionally distributed over nine governorates (details of sampling methodology in next section).

Sampling Methodology

Site Selection

The IMC Assessment used a multi-step sampling methodology in order to obtain a maximally representative sample. The site selection methodology was derived from UNHCR-provided data: Spatial Distribution of Urban Refugees Map (November 2013) – See Appendix 1.1. To account for differences in refugee population density, each UNHCR hexagonal zone was broken down into units of 100 persons and weighted accordingly. The data was then stratified by region, with the percentage of the country's total population of refugees determining the number of clusters that would be drawn from each region (North, Central, South – See Appendix 1.2). This double stratification was done in order to preserve the proportionality of the sample and to ensure that a diverse range of refugee situations was assessed.

The Excel Random Number Generator produced 30 cluster sites to be included in IMC's Assessment. Nine governorates across Jordan (of 12 total) were represented in the random sample (See Appendix 1.6). 10 alternate clusters were also determined in the event that any of the initial 30 should prove unviable (i.e. restricted physical access to site, insufficient availability of target population, authorization/security concerns, etc.). Ultimately, IMC teams were able to access all 30 primary cluster sites.

Participant Recruitment

Within each of the 30 randomly selected cluster sites, a landmark was identified – in most cases a mosque, but could have been anything from an intersection to a notable geographic feature, depending on the urbanization of the area. This location was used as a point of departure for the combination-method sampling used by the IMC research team:

Shopkeeper Methodology: the local shop owner *nearest* to the point of departure referred researchers to the *nearest known* location of interest, i.e. a heavily Syrian neighborhood.



Randomized Door-to-Door Inquiry: once in the neighborhood indicated above, researchers spun a pen to select a random street and inquired at each house (sequentially) until they identified a Syrian household.



Snowball Methodology: the household identified through the door-to-door inquiry referred researchers to the *two nearest known* households of interest – Syrian households, preferably not of blood relation, (though this was not always possible given the size of Syrian extended families and their tendency to resettle in proximity). Repeated until the focus group quota was fulfilled.

Heads of household were given priority for focus group participation, though if unavailable or otherwise indisposed, another member of the household who met the terms of participation (see below) was invited to participate instead; no more than one participant was taken per household. Recruitment of focus groups participants took place in the mornings, or until target group size was achieved (usually completed in one to two hours). The focus groups – one male, one female group per site - were implemented immediately thereafter, as soon as all participants could convene in a communal area (i.e. community center, health facility, or private home, depending on availability).

Focus Group Terms of Participation

Once Syrian refugees were identified by the abovementioned sampling methods, they were selected for participation if they met the following criteria:

1. Of Syrian nationality, having fled the country because of the ongoing conflict (regardless of refugee registration status)
2. Currently residing in Jordan (residence *in* cluster not required, only physical presence on day of Assessment)
3. Over the age of 18
4. Mentally competent to understand the goals and activities of the Assessment

If these criteria were satisfied, IMC researchers explained the premise of the assessment, gave a verbal summary of activities, and gave potential participants an opportunity to ask questions. Oral consent was obtained when the individual fully understood the terms of participation and agreed to participate.

Each participant received a 5JD stipend to offset travel expenses to get to the focus group location. Refugees were informed of the compensation *after* verbal participation agreement/consent was obtained in order to avoid any possibility of financial coercion.

Focus Group Discussion Tools

See Appendix 1.4

Sub-Investigation – Non-Communicable Disease Management

The high prevalence of non-communicable diseases (NCDs) among the target population, in combination with a rather weak evidence base for NCD programming in humanitarian emergencies, prompted IMC to add the NCD Management sub-investigation to the principal Health Access Assessment. The population-based recruitment already being used for the main Assessment activities offered unique access to NCD patients; the qualitative interview model being implemented provided a easy segue into a second, more focused set of questions about NCD management.

Implementation

The in-depth interview, composed of 17 questions regarding condition status, treatment interruptions, regimen changes, barriers to care, and availability of services/resources, was designed to allow respondents to talk at length about their personal experiences. First, the respondent was asked to declare his/her main non-communicable condition, as well as any other lesser conditions (to demonstrate full range of health conditions, as well as co-occurrences), and then to answer subsequent interview questions based on the management of his/her *primary* condition (to avoid confounding data about the management of one condition with another). The full interview was conducted one-on-one with the patient and an IMC facilitator, lasting anywhere between 30 and 45 minutes.

Target Sub-Population

The NCD Management sub-investigation aimed to further understand the conditions, challenges, and care constraints faced by Syrians refugees currently living in Jordan and suffering from non-communicable disease(s). Since adults (18+) were eligible for the Health Access focus groups, and the in-depth interview respondents were selected from among focus group participants, the sub-investigation only looked at adult patients with one or more chronic disease diagnoses.

Interviewee Sub-Selection

Demographic surveys, administered at the beginning of each focus group discussion, provided the information necessary to establish a sub-sampling frame. The final question of the demographic questionnaire (See Appendix 1.3) asked participants whether they “suffer from a non-communicable condition that requires regular management.” The questionnaire purposefully did not define non-communicable condition in order to gauge understanding of the term among focus group participants and, more generally, the Syrian refugee population. When data collectors collected the questionnaires, they performed a rapid, response-quality check for the NCD question and set aside those questionnaires

that indicated a legitimate non-communicable condition (as defined by the WHO).⁹ One questionnaire was randomly selected from among those found to be eligible and the respondent was asked to stay after the conclusion of the focus group discussion. Should this initially selected respondent refuse, a second was drawn randomly, and so on, until a participant was successfully recruited. This selection process and subsequent interview was performed with 60 focus groups in 30 assessment sites; in several instances no NCD patients self-identified on the questionnaire and therefore no interview was performed.

In-Depth Interview Tools

See Appendix 1.5

Data Collection and Analysis

Data Collection

All data collected during the IMC Health Access Assessment and NCD Management sub-investigation was qualitative and recorded through detailed notes. Given the semi-emergent nature of the Assessment, it was decided that audio recording was not appropriate, owing to the excessive time necessary to transcribe, translate, review, and analyze the overwhelming amount of data that would be produced (100+ recorded hours). Instead, one of the two-person data collection team manually chronicled each focus group and interview session. He/she took notes with instructions to capture as many comments in as great detail (ideally including direct quotes) as possible. Group dynamics and non-verbal exchanges were also noted as indicators of range of attitudes among participants. All sessions were conducted and documented in Levantine Arabic by a research staff of native Arabic speakers.

Notes from all 60 focus groups were subsequently transcribed and translated professionally into English for the IMC's analytical team.

Data Analysis

The data analysis team worked with Atlas.ti, a computer-assisted qualitative data analysis software that offers advanced coding capabilities and analytic tools. Analysts used the program to facilitate the Constant Comparative Method of qualitative data analysis, in which codes are developed according to themes evoked by participants themselves.¹⁰ This approach allows respondents' ideas to drive the analysis and patterns emerge organically, rather than relying on researchers' preconceived notions.

Across 60 focus group transcripts, the Atlas.ti-supported analysis yielded 13 major code families (see Appendix 1.7), comprised of 167 distinct codes. The frequency with which these codes occurred was used as a measure of importance; the more frequently a specific idea (code) was mentioned, the more critical the issue was understood to be. The codes were also examined relationally, with the comparative frequency of a code essentially ranking an issue a priority over those less discussed. These code frequencies and rankings were further explored through five axes of analysis: Code Family, Gender, Governorate, Housing, Registration Status – each providing a different angle of insight.

⁹ "Non-communicable Diseases." *WHO Media Center - Fact Sheets*. World Health Organization, Mar. 2013. Web. <http://www.who.int/mediacentre/factsheets/fs355/en/>.

¹⁰ Chapter V in Glaser, B.G. & Strauss, A.L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New York: Aldine DeGruyter.

Challenges and Limitations

Limitations – Qualitative Assessment Study Design

Qualitative research offers myriad advantages – “humanized” data that represents attitudes as well as hard facts, respondents’ ideas expressed in their own words, access to often-valuable tangents that illuminate issues previously unknown to researchers, etc. However, it also comes with a number of inherent caveats that must be acknowledged from the outset. First, it is important to recognize that the frequencies and rankings produced through qualitative coding are *not* quantifiable data points and cannot be treated as such. Rather, the number of mentions, per code, can be used as an approximation of intensity of interest in a particular idea. When placed relationally to other codes, the number of mentions, comparatively, can create rankings that suggest priority issues. This can be extremely valuable insight for program development; to ensure that community priorities are reflected in services offered.

Secondly, group-based qualitative research often produces an abundance of extremely rich data because it captures exchanges between respondents and the diversity of their opinions. However, due to the often-anonymous nature of focus group participation (i.e. respondents’ names are not associated with their comments in the session’s notes), it is impossible to trace these opinions back to individuals. Thus, any analysis must be careful not to discuss opinions expressed in a focus group as either the exclusive consensus of the entire group nor that of a specific individual. For example, some of the IMC Health Access focus groups contained a mixture of registered and unregistered refugees (as revealed by the anonymous demographic questionnaire administered beforehand); if notes from a group with a higher proportion of unregistered refugees showed that they discussed discrimination more often than a group of only registered refugees, this can *suggest* that unregistered participants were experiencing more incidents of discrimination than their registered counterparts. However, since there is no way to tell if unregistered participants made these particular comments, the trend must be presented with a disclaimer. All reporting on qualitative data should pay similar attention to language so as to not misrepresent the opinions of individuals as general fact.

Challenges – Implementation

The most significant challenge presented itself at the data collection phase: interviewer bias. Because of the comparatively free flow and interactive nature of a focus group discussion (directed but not restricted by a focus group topic guide), there is more opportunity for the interviewer to unintentionally insert his/her personal opinions into the conversation through tone, leading questions, extraneous comments, etc., thus prejudicing participants’ responses. Training in proper interview techniques, like that which was completed by the IMC data collection team, can help minimize interviewer bias, though never entirely eliminate it.

As with any field study – qualitative, quantitative, or mixed method - selection bias also posed a challenge in the IMC Health Access Assessment. The sampling methodology outlined in the Methodology section attempted to systematically choose participants that would capture the situation and represent the position of the greater target population, thereby reducing the selection effect. Weighting by population density and subsequently stratifying by region during random cluster selection helped provide a more representative geographic distribution of assessment sites. However, with a highly mobile population like the Syrian refugees in Jordan, it is possible that the Nov-2013 data upon which the sites were selected was no longer accurate by Dec-2013. Because this base data was provided by UNHCR, it also reflected *registered* refugees only, thus biasing IMC’s Assessment towards this subset, albeit majority, of the refugee population and away from others. Whether there are distinctly different

settlement patterns between registered and unregistered refugees in Jordan is not yet sufficiently understood to determine to what extent this may have skewed IMC's data.

Convenience sampling methodologies – shopkeeper and snowball methods – were used to find and recruit the Assessment sample. Given the distribution of the refugee population within host communities, these methods offered the best balance between randomness and feasibility. That said, they also created several inevitable biases. Because shops and their keepers are usually located in more heavily populated areas, the first step in the identification of Assessment participants may have occasionally favored more urban refugees. The host community was also more likely to be aware of urban refugees, while refugees who had chosen to settle in rural and/or agricultural areas may have remained under the local “radar”. The second and final step in the recruitment process also introduced the possibility of participants with inextricably linked experiences. By asking Syrian refugees to indicate the next nearest Syrian household, the bias towards family relations was strong. The Assessment protocol specified that the IMC researcher team explicitly request non-family members, though there were instances in which family members were recruited despite this safeguard.

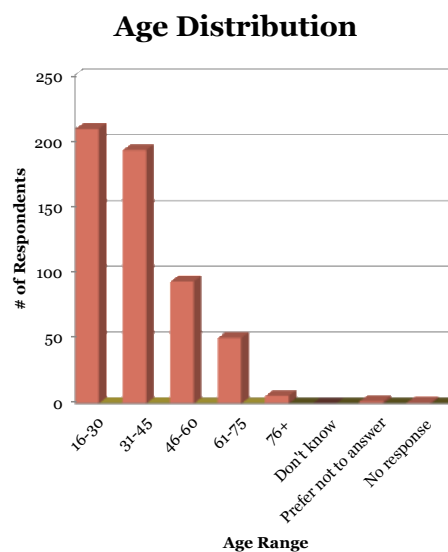
From a very practical perspective, the management of local partners became a challenge at certain sites. In the Assessment protocol, the role of local partners – NGOs, local associations and charities, and medical facilities – was limited to logistical support; they were meant to assist with notifying local authorities of IMC's visit, procuring meeting spaces for focus group discussions and interviews, and when necessary, advising on emergency referrals to local facilities. However, in several cases, well-intentioned but overly eager partners wanted to actively contribute in the recruitment of Assessment participants. They offered to gather participants for focus groups using previously established contacts from within the Syrian refugee community, most often beneficiaries from their organizations' own programs. This would, however, have created significant bias towards refugees already receiving services, health and otherwise, and further marginalized the higher-risk group not yet receiving services. Leaders of the IMC Health Access Assessment made every effort to avoid this form of recruitment and to adhere strictly to study protocol.

Results

Pre-Participation Individual Questionnaire (Basic Demographics)

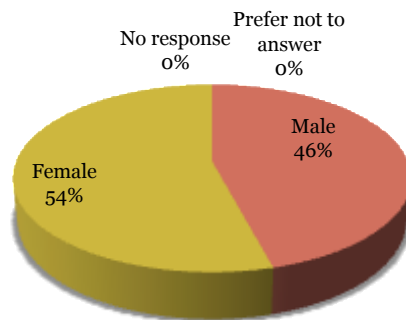
A simple percentage analysis of the pre-participation individual questionnaires (anonymous, identified only by cluster site number) offers an overview of the Assessment participants.

The largest participant age group was 16-30 years; subsequent age ranges accounted for progressively fewer participants. The oldest contingent – 76+ years – included just six participants.



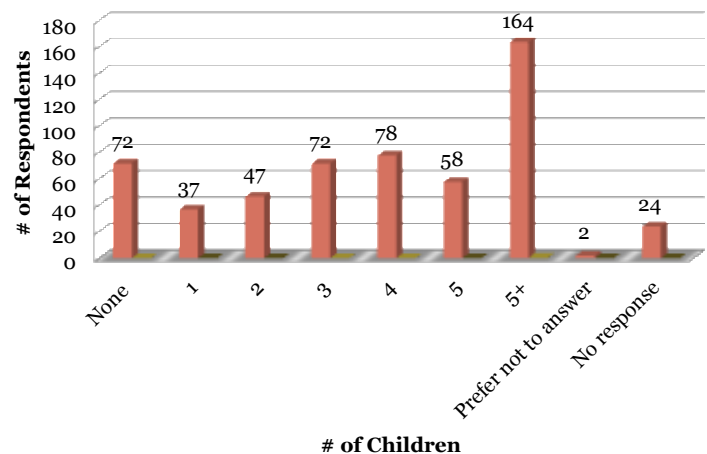
As dictated by study design, focus group participants were more or less half male (46%), half female (54%).

Gender Distribution

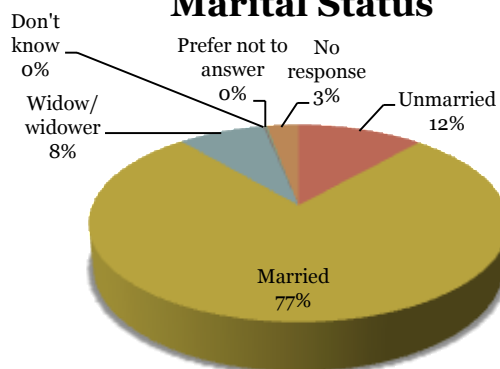


The most common response to the question regarding family size was, by a large margin, “5+ children”. The rest of the responses were distributed rather evenly between the other categories: “no children”, “1 child”, “2 children”, “3 children”, “4 children” and “5 children”.

of Children



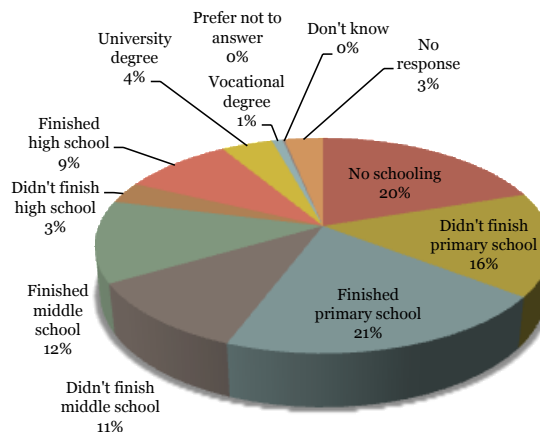
Marital Status



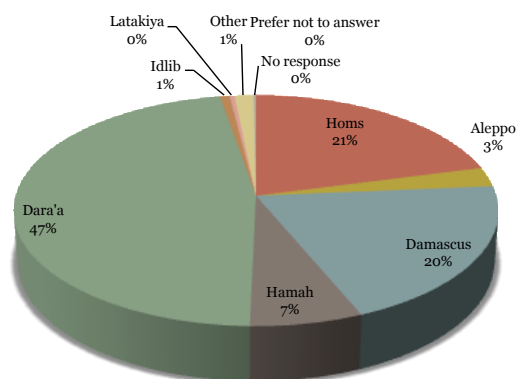
The large majority, 77%, of participants indicated that they were married, while approximately 12% reported being single. 8% were widows/widowers.

Responses to the question regarding education demonstrated limited schooling among refugee participants. 20% reported never having attended school, 16% did not finish primary school, and another 21% did not move on to middle school (NOTE: focus group facilitators assisted illiterate participants with the completion of their questionnaires). Only about 17% of participants had a high school education or higher.

Level of Education



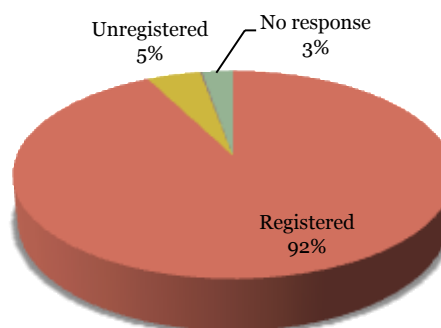
Hometowns



Dara'a accounted for the largest proportion of focus group participants, nearly 47%. The next largest participant group originated from Homs (21%), followed by Damascus (including Reef) at 20%. The remainder of participants had fled to Jordan from Idlib (1%), Aleppo (3%), and Hamah (7%). 1% was not comfortable answering questions about their home ties in Syria and declined to give their hometowns.

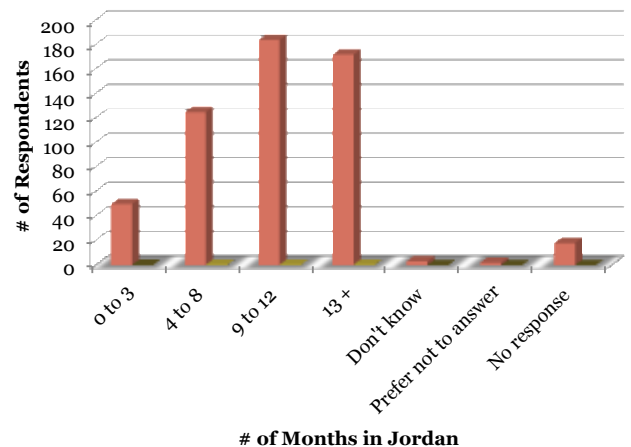
An overwhelming majority (92%) of focus group participants indicated that they were registered with the UN refugee agency, UNHCR. 5% said that they had not registered, while another 3% declined to respond to the question.

Registration Status

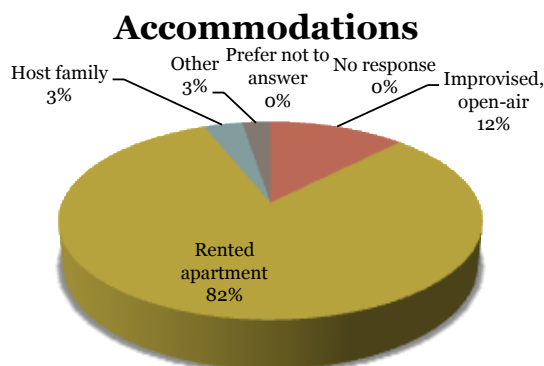


The bulk of Syrians who participated in the IMC Health Access focus groups were generally neither among the earliest to arrive in Jordan nor were they the most recent refugee arrivals. The Assessment captured mostly refugees who had been in Jordan between four months and more than one year. Some 50 respondents, however, had been in Jordan less than three months.

Length of Stay in Jordan



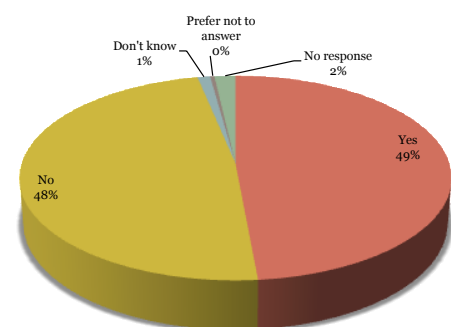
The accommodation question intended to gauge participants' living situations since their arrival in Jordan. 82% indicated that his/her household was currently living in a rented apartment. The next most frequent response was "improvised, open-air housing", which accounted for 12% of participants.



The rest of respondents reported living with host families or in other, unlisted circumstances. It is worth noting that the "other" option in the question was not necessarily used to indicate alternative housing but rather co-opted to express dire concerns about housing, the most common of which were prohibitively expensive rent and unsanitary living conditions.

When asked if they suffered from any non-communicable conditions that require regular management, nearly half (49%) of focus group participants responded in the affirmative and most also provided annotations on their conditions. 51 of the 269 participants who answered "yes" to this question were selected to participate in an in-depth interview about the management of their NCD conditions.

Self-Reported Non-Communicable Conditions



Analysis: Focus Group Discussions

Overall Observations

The most preliminary analysis – a review of the top-10 most frequent codes overall – demonstrated which issues surrounding healthcare access garnered the most discussion among focus group participants. The most frequently mentioned concern (by a large margin) was the lack of availability medication, a recurrent theme across multiple code families. However, it is worth mentioning that the opposite, the *availability* of medication (as a positive), was in fact #28 in the overall code ranking, suggesting that shortages may be widespread but are also dependent on other factors such as geographic location and the type of medication in question. Further research would have to be done in cooperation with the Jordanian Ministry of Health to determine which specific drugs are in shortest supply.

While the large refugee population is placing significant strain on Jordan's healthcare resources, the most frequently mentioned source of healthcare (consultations and medication) was nonetheless the Jordanian Ministry of Health (MoH). Refugees' usage of these Ministry facilities adheres to the healthcare scheme put in place by the Jordanian host government, which provides refugees (mostly) free services at these facilities. However, it seems that documentation requirements are still preventing a significant portion of refugees from accessing these MoH services. The two most mentioned barriers to care were administrative in nature: the residency requirement of the Ministry of the Interior-issued Security Card and the expiration and lengthy renewal process of the UNHCR-issued Refugee Registration Card, #1 and #2 respectively. The other most frequently mentioned barriers both pertained to limitations on physical access to facilities: distance to a medical facility and cost of transport to get there.

The service most often evoked as lacking/insufficient was for disabilities. The only positive aspect of the current healthcare situation to figure into the overall top-10 code ranking was availability of vaccinations for children.

Further Analyses – Code Families, Gender, Housing, and Registration Status

Disaggregating the data by critical variables provides different angles by which important thematic priorities, otherwise obscured in the overall frequency rankings, may emerge. A code family ranking analysis, in which comments within a specific code family are ranked by frequency of mention, offers insight into the comparative intensity of issues discussed; those more frequently mentioned than others can be considered of greater concern or priority to the focus group respondents and, if the Assessment's sample was indeed representative, to the wider refugee community residing in non-camp settings in Jordan.

Subsequently disaggregating the qualitative data by gender revealed that men and women experienced certain aspects of the healthcare system differently. Awareness of these discrepancies allows for more targeted interventions tailored to the challenges of each demographic.

Other vulnerability variables may significantly affect a refugee's ability to access healthcare, housing situation and registration status among them. Approximately 12% of respondents that participated in the IMC Health Access Assessment reported living in an improvised, open-air shelter (most usually a tent), compared to around 82% living in rented apartments. 5% of the Health Access Assessment respondents indicated on their surveys that they were not, at the time of the focus group, registered

with UNHCR. Though the Assessment's samples of refugees living in 1) open-air housing or 2) unregistered with UNHCR 3) or both, were quite small (but proportional national estimates) and may not provide a statistically valid comparison, a review of the code rankings nonetheless reveals thought-provoking discrepancies between the groups' healthcare-seeking experiences.

Administrative Issues in Accessing Care

The Administrative code family emerged as distinct from the Barriers to Care code family because of the range of document-related concerns that arose during focus group discussions. The residency requirement attached to the Jordanian Security Card topped the Administrative list as the most mentioned concern. Under Jordanian/UNHCR regulations, refugees can only access (free) healthcare services at the health facility indicated on their Security Card; focus group participants spent much time chronicling their displacements in Jordan, demonstrating that to return exclusively to the health facility where they originally registered for the Security Card was often impracticable (distance, cost, logistics, etc.). The second most frequently mentioned administrative issue was the expiration of the UNHCR Refugee Registration Card. A valid UNHCR card grants refugees access to a number of support services, notably free healthcare services (with limitations) at MoH facilities. However, the short period of validity, combined with time- and money-consuming renewal procedures that often took up to six months to complete left many focus group participants unable to access necessary care in the (lengthy) interim. Registration issues – lack of information regarding registration procedures, inability to access UNHCR offices to complete the registration process, or fear of registering (reprisals, relocation restrictions, deportation) - ranked a distance third on the Administrative most frequently mentioned list.

Gender and Administrative Issues

No remarkable differences to report.

Housing and Administrative Issues

Among the groups with a significant proportion of tent-dweller participants, the expiration of the UNHCR Refugee Registration Card was not mentioned at all, whereas among the fixed housing groups (refugees living in apartments, houses, etc.) this issue was ranked as the #1 administrative concern.¹¹ That expiration is not a relevant problem suggests that a greater proportion of refugees in tent housing may not be registered with UNHCR in the first place.

Registration Status and Administrative Issues

Where the issue of the expiration of the UNHCR Refugee Registration Card tops the general ranking in the Administrative code family, disaggregating the data by registration status reveals that the focus group comprised of a substantial proportion of self-declared unregistered refugees discussed *initial* registration with UNHCR most frequently.¹²

¹¹ A focus group was analyzed as an “improvised, open-air housing group” if 25%+ of participants indicated that they lived in this style accommodation. Four focus groups surpassed this threshold.

¹² A focus group was analyzed as an “unregistered group” if 25%+ of participants indicated that they had not registered with UNHCR. One focus group surpassed this threshold.

Barriers to Care

The top two Barriers to Care most mentioned in the Health Access Assessment focus groups were systematic issues with administrative documentation: #1 was the residency stipulation on the MoI Security Card that limits the cardholder to medical facilities where he/she originally registered. #2 was the rapid expiration of the UNHCR Refugee Registration Card and the lengthy and complex renewal procedure that, in the interim, leaves the refugee without access to free health coverage through the MoH. Issues of physical access were the next most frequently discussed: long distances to health facilities (#4), lacking means transportation (#6), and the cost of what little transportation is available (#3). Communication deficiencies also figured in the top-10, with #8 being comments expressing lack of or desire for more knowledge regarding healthcare services available and #9 confusion about the referral process.

“I took my daughter, whose body temperature was high, to the center, and there they found that my UNHCR document was expired. They refused to treat her unless I paid money, but I have no money, which led me to go back home without any treatment for my child.”

Gender and Barriers to Care

Administrative concerns (residency requirement of the Jordanian Security Card and expiration of the UNHCR Refugee Registration Card) were among the most mentioned barriers to care in both male and female focus groups. However, comments diverged remarkably on a number of other issues. Lack of knowledge, for example, ranked #4 on the women’s list of most-mentioned barriers to care, while it ranked only at #8 for men, suggesting that outreach and health education efforts may be reaching women less effectively. Gender issues, a code that covers any perceived obstacle to healthcare directly linked to gender (gender of healthcare provider, social restrictions on travel, traditional expectations of propriety, etc.), was the ninth most frequently mentioned barrier among female participants, but these concerns did not factor into the male top-10.

Housing and Barriers to Care

The Barriers to Care ranking from the focus groups that included a sizable tent-dwelling contingent differed considerably from those groups comprised exclusively of refugees living in fixed housing. Long distances to healthcare facilities was the most discussed barrier to care in groups where significant number of tent-dwellers participated, while it was only the fourth most mentioned barrier in fixed-housing groups. Also related to physical access to facilities, concern over inclement weather conditions ranked as the #5 most mentioned barrier to care; this concern did not register among the top-10 most-mentioned list in the fixed housing groups.

“I was pregnant and went to the Hospital, where nurses left me alone without care until 7pm, and when the doctor came, he said: ‘why did you not treat her?’ And the nurses said: ‘there are Jordanians before her!’”

The focus groups that included tent-dwellers spent much more time discussing previous incidents at healthcare facilities, incidents that they said were grave enough to deter them from seeking care there in the future. Discrimination based on nationality was the sixth most mentioned barrier to care among groups with tent-dweller participants, as compared to eighth in

fixed-housing groups. The same group described incidents of refusal to treat (#6), while these kinds of incidents were evoked comparatively less (#16) in fixed housing groups.

Lack of knowledge about health services ranked # 3 among groups with tent-dweller participants and barely made the top-10 most mentioned barriers to care among the other groups, suggesting a fundamental gap in outreach work to date.

Registration Status and Barriers to Care

The #1 barrier to care cited in the focus group with a sizable unregistered refugee representation was lack of knowledge about available health services, while lack of knowledge ranked last in the top-10 barriers most mentioned in primarily registered refugee focus groups. This finding mirrored that of the housing analysis, once again suggesting a relationship between tent-dwelling and unregistered refugee status.

Care-Seeking Decision-Making

Among the most mentioned motivators for seeking care (beyond medication, which was the #1 motivator), focus group participants cited deterioration of condition and medical emergency. This, in combination with other comments to similar effect, points to an overall trend of reactive care-seeking, with little to no preventative care being sought. Frustration with their lack healthcare options in Jordan pervaded the discussion (#1 most mentioned code in code family), indicating the relatively high level of control the population is accustomed to exercising over their own health. Different from many other humanitarian crises, these expectations could significantly impact how health actors develop their programs.

Gender and Care-Seeking

The major discrepancy between men's and women's comments regarding decisions to seek care was that men placed much more emphasis on cost as a factor in where they sought medical attention. This is consistent with men's overall focus on finances throughout focus group discussions.

Housing and Care-Seeking

No remarkable differences to report.

Registration Status and Care-Seeking

No remarkable differences to report.

Health Conditions

During focus group discussions, participants evoked personal health-related experiences - his/her own or that of a family or community member. The top-3 most frequently mentioned were as follows:

1. Disability (including both injury and disease)
2. Gynecological conditions
3. Chronic illnesses

Mental health cases ranked at #7. Communicable diseases were at #10, which, again, highlights the fact that the health response required for the Syria crisis is significantly different from other crises in which infectious disease control is often the most urgent priority.

Gender and Health Conditions

Knowing that disease and environmental factors do not affect the sexes in the same ways, it is expected that the medical conditions discussed in men's and women's focus groups would differ somewhat. OB/GYN cases were, predictably, one of these discrepancies; among women, OB/GYN was the most frequently mentioned type of case, while men talked more frequently about disability cases and chronic disease than they did about OB/GYN cases. Women and men were most vocal about services related to their respective most common ailments, with women adamant about the insufficiencies of OB/GYN services and men about the lack of physiotherapy and chronic disease treatment and follow-up.

Housing and Health Conditions

Communicable disease cases ranked at #3 in focus groups with tent-dwelling participants, whereas in the fixed-housing groups communicable disease cases were only the eighth most mentioned type of health condition. In the former group, water and sanitation concerns and weather conditions were also ranked much higher in the top-10 list of secondary health factors, a co-occurrence likely strongly correlated.

Registration Status and Health Conditions

No remarkable differences to report.

Perceptions of Facility Resources and Management

The common thread throughout much of this code family was overwhelming patient burden and its detrimental effect(s) on the healthcare experience. Among the top-10 most mentioned codes was the lack of facility capacity (general commentary), insufficient staff availability, and excessive wait times for consultations. Also frequently noted was the lack of Syrian medical professionals supporting refugee healthcare in Jordan, either formally in facilities or informally in the community (51 comments about the lack, only 12 mentions of any Syrian medical professionals at all). Focus group participants expressed preference for increasing Syrian staff, not only for the shared healthcare culture but also to help fill human resource gaps.

Gender and Perceptions of Facility Resources and Management

No remarkable differences to report.

Housing and Perceptions of Facility Resources and Management

No remarkable differences to report.

Registration Status and Perceptions of Facility Resources and Management

No remarkable difference to report.

Knowledge and Information Sources on Healthcare Services

While UNHCR was the #1 most mentioned source of information regarding health services, the second most frequently occurring code was still lack of knowledge. This code was applied any time a focus group participant commented on: 1) an instance when he/she did not have the necessary information he/she needed to seek timely and appropriate medical care; 2) mentioned in focus group discussion incorrect information about services available; 3) expressed a desire for more information but could not name a satisfactory source from which to obtain it. There is therefore much room to improve communications, whether through different media or different means, between health actors and the target population. That neighbors, friends, and family ranked #3, #4, and #5 respectively in the Knowledge and Information code family suggests a solid flow of information within Syrian refugee communities in Jordan, a network that, if put to better use, could help disseminate healthcare information more efficiently to more beneficiaries. Healthcare facilities should also be urged to redouble self-promotion efforts, as mentions of receiving information from a facility itself ranked only #8 in the code family's top-10.

Gender and Knowledge of Health Services/Sources of Information

The frequency with which women mentioned a perceived lack of knowledge and/or unsatisfied need for further information about healthcare services (#1) was much higher than men (#5). This suggests a serious discrepancy in knowledge, or, at the very least, in perceived empowerment to access information.

Housing and Knowledge of Health Services/Sources of Information

In fixed-housing groups UNHCR is the #1 most frequently mentioned source of information on healthcare services, while insufficient information (i.e. respondents were not able to name a single satisfactory source of information on healthcare services, etc.) was the #1 most mentioned response in groups with tent-dweller participant.

Registration Status and Knowledge of Health Services/Sources of Information

Groups comprised mostly of registered participants most frequently reported UNHCR as their primary source of information regarding healthcare services; in the focus group with a significant number of unregistered participants, on the other hand, the #1 most frequently cited source of information regarding healthcare was Jordanians from the local host community.

Perceptions of Patient-Provider Relations

The most noteworthy feature of the Patient-Provider Relations code family was the divided opinion that manifested in the #1 and #2 most mentioned comments; *negative* healthcare staff attitudes topped the list, and *positive* healthcare staff attitude ranked immediately thereafter. The raw number of mentions of negative healthcare staff attitude is nearly double (67) the positive comments (34), indicating that a significant proportion of healthcare staff members' attitudes are so poor that they risk adversely impacting care-seeking behaviors among their refugees patients. Many focus group respondents perceived this poor treatment by healthcare staff as prejudice against Syrian refugees and spent a good deal of time discussing the discrimination they felt played an important and highly detrimental role in their healthcare experiences in Jordan (ranked #3 in the code family). However, the fact that a

substantial minority of focus group respondents painted a far more favorable image of healthcare staff suggests that discriminatory attitudes seem to be at the individual rather than systematic level.

Gender and Perceptions of Patient-Provider Relations

Overall, women's perception of patient-provider relations leaned much more heavily towards the negative than men's did. Disrespect from healthcare providers, for example, ranked #4 among female focus groups, whereas it appeared at #7 of the men's list of comments regarding patient-provider relations. With regard to health staff attitude, men were much more split on the issue, while women much more consistently discontent with their treatment by health facility staff.

Housing and Perceptions of Patient-Provider Relations

No remarkable differences to report.

Registration Status and Perceptions of Patient-Provider Relations

Unfortunately, the only discussion of provider-patient relations in the focus group with a substantial number of unregistered refugees pertained to incidents of refusal to treat, when a refugee seeking care was turned away from a facility without being seen by a medical professional and, often, without being given any explanation.

Overall Perceptions of Health Status

When respondents were asked to categorize their level of satisfaction with both availability of services and access to those services, dissatisfaction dominated both. However, there was a significant minority that expressed appreciation for the status quo. This split opinion implies that availability of and access to healthcare services is far from uniform; other axes of analysis will help determine which factors (geography, gender, housing, registration status) are contributing to the inequity.

Gender and Overall Perceptions of Health Status

No remarkable differences to report.

Housing and Overall Perceptions of Health Status

No remarkable differences to report.

Registration Status and Overall Perceptions of Health Status

No remarkable differences to report.

Perceived Positive Aspects of Healthcare Services

Access to childhood vaccinations was the overwhelmingly most mentioned positive aspect of the current healthcare situation for refugees in Jordan. The second most mentioned was, in fact, positive attitude among healthcare providers, surprising considering that *negative* attitude among healthcare providers topped the list in the Provider-Patient Relations code family. The variation in patient

experiences suggests that poor attitude towards Syrians should not be characterized as a system-wide prejudice but rather a matter of individual bias or mood.

Gender and Perceived Positive Aspects of Healthcare Services

No remarkable differences to report.

Housing and Perceived Positive Aspects of Healthcare Services

No remarkable differences to report.

Registration Status and Perceived Positive Aspects of Healthcare Services

No remarkable differences to report.

Perceptions of Quality of Care

As previously mentioned, Syrian refugees are coming to Jordan from a relatively advanced healthcare system that, before the conflict, provided decent quality care at very low cost to the patient.¹³ With these standards in mind, it is not necessarily surprising that eight of the top-10 codes in the Quality of Care code family were negative. Insufficient physical resources such as (once again) lack of drug availability (#1) and medical equipment (#3) ranked high on the list of grievances. The shortage of specialists, a *human* resources issue, was also oft discussed in focus groups, ranking as the second most frequent comment pertaining to quality of care. Some respondents raised questions about the competencies of their non-specialized providers, citing lack of physical exam (#5), dubious drug regimen changes (#6), and suspected misdiagnoses (#7). Whether these perceptions are couched in truth or not, the perception alone can be enough to weaken trust in the health system and deter care-seeking in the future. The lack of follow-up, ranked at #9, certainly doesn't help change these perceptions and may actually further erode the relationship between refugee patient and host national facilities if they believe that no one is concerned about their well-being in the long-term.

“Once I had a swelling in the leg and at the same time I had nephritis; the doctor said to me that I have to choose only one of the two medical conditions to be treated. She said she would only treat one condition of the two! I chose the nephritis; she examined me, tested my blood, and then prescribed me a medicine. The prescription was stamped by the UNHCR office, but every time when I go to get the medication, they say that there is no medication.”

Gender and Perceived Quality of Care

The gender disaggregation brought to light the fact that female focus group participants were more positive about drug availability than their male counterparts. While the lack of medication availability

¹³ *Health Systems Profile - Syria*. Rep. Regional Health Systems Observatory. Web.
<http://gis.emro.who.int/HealthSystemObservatory/PDF/Syria/Health%20system%20organization.pdf>

was, overall, among the most discussed healthcare concerns, this finding suggests that the shortages may be affecting certain medications more than others, specifically those for conditions more prevalent among male Syrian refugees.

Housing and Perceived Quality of Care

No remarkable differences to report.

Registration Status and Perceived Quality of Care

No remarkable differences to report.

Secondary Health Factors

The Secondary Health Factors code family encompasses a variety of issues; essentially anything that focus group participants discussed that indirectly affected their health or their ability to access healthcare. Comments demonstrated that many refugees, even in focus groups where the majority of participants had been in Jordan for a year or more, are still struggling to fulfill even the most basic needs for their families (#2). Respondents often linked this lack of basic necessities with unstable financial status, which ranked #1 in this code family and resurfaced at the top of other lists as well; poor finances were frequently mentioned as a barrier to care because there was no money to pay for transport to the health facility, or for a full round of medication, or for a private clinic where the necessary service was available. Employment restrictions on refugees logically ranked #4, the perpetuating reason of this poor financial status.

Gender and Secondary Health Factors

Women's comments in focus group discussions regarding secondary health factors differed from men's comments on the same subject in that they placed much more emphasis on day-to-day survival. The second most mentioned secondary health factor for women was, for example, environmental hazards (given the timing of the Assessment immediately before a major winter storm, this was likely a reference to life-threateningly low temperatures sweeping the region), which ranked at #5 among men's comments. Basic water and sanitation (unsafe drinking water and communicable disease being two another major and immediate threat to survival) was the seventh most frequently mentioned health factor, where it only barely made the men's list of top-10 most mentioned. Men's comments were much more focused on longer-term financial concerns.

Housing and Secondary Health Factors

A comparison of rankings in this category hints at a considerably lower standard of living in tent communities. Basic necessities topped the list of secondary health factors evoked in focus groups including tent-dwellers, whereas the same needs were only ranked at #5 in fixed housing groups. Water and sanitation ranked #3 in focus groups that included tent-dwellers, as compared to #6 in the fixed housing groups. These distinct gaps suggest that those living in tents are still struggling to simply survive from day to day, while many of those in fixed accommodations have graduated to longer-term health concerns.

Registration Status and Secondary Health Factors

The focus group with a sizable unregistered contingent demonstrated serious concern over the lack of even the most basic necessities, (#1), while basic necessities fall much lower in the ranking of secondary health factors in groups of mostly registered participants.

Perceived Service Availability

The majority of service availability comments were offered during focus group discussions without prompting, reflecting the services that participants had used in the past or had needed but were unable to access. The focus group topic guide did, however, explicitly ask about several services, notably OB/GYN, pediatric, and disability. The perceived lack of OB/GYN services (#1) and pediatric services (#3) were among the top-3 frequently mentioned codes in the code family. While the high number of mentions maybe be attributed to the specific references in the topic guide, the opinions on this issue are nonetheless clear. Both services, OB/GYN and pediatrics, are perceived to be unavailable, or, at the very least, insufficient to respond to the needs felt by participating refugees. Mention of other services for disability, chronic disease, dental, mental health, nutrition, etc. followed a similar trend towards unavailability, with the notable and consistent exception of childhood vaccination.

Gender and Perceived Service Availability

The frequency with which men mentioned the lack of specialists made this their #1 most talked-about service gap. This insistence on specialized physicians was not as strong in the female focus groups, where the lack of specialists ranked only as the fourth most frequent comment on service availability/unavailability. Men also mentioned the lack of chronic disease services (including follow-up) comparatively more often than women, which is consistent with the heavier chronic disease burden among male participants that had been described during focus groups.

Housing and Perceived Service Availability

No remarkable differences to report.

Registration Status and Perceived Service Availability

The disaggregation by registration status reveals a potential exception to the otherwise overwhelmingly positive feedback on vaccination availability. The lack of vaccine services was the third most frequent comment on service availability in the focus group with a significant number of unregistered participants, while groups consisting mostly of registered respondents did not raise this issue frequently enough for it to make the top-10 list.

Healthcare Usage Trends

When asked where they had sought care in the past, the most common response from focus group participants was that they had visited an MoH clinic facility (#1), which is the way the refugee healthcare scheme is meant to work. The second most frequent response was private clinics, not at all far behind MoH usage. When asked to elaborate, many respondents indicated that they went to private clinics because either the treatment they needed was not available at MoH clinics or they had been turned away from said clinics for lack of proper documentation. A few also expressed a preference for private clinics for the perceived superior quality of medical care. Those who reported seeking “care” from the

pharmacy directly, which was the third most frequent healthcare usage response, were in danger of receiving incomplete or incorrect counsel and/or treatment. Other related comments suggest that many of these refugees ended up at the pharmacy because MoH had on previous occasions run out of their medication and sent the patient to the pharmacy to purchase the drug; in subsequent visits, disillusioned patients skipped the clinic and went straight to the pharmacy. Others, when given the choice between paying for transportation to a consultation but receiving no drugs and drugs with no consultation, were forced to choose the latter all too often.

Gender and Healthcare Usage

While men indicated MoH facilities as their most frequently utilized source of care (#1), women indicated private clinics (#1). Women's use of pharmacy (without medical consultation) was also more frequently mentioned, demonstrating that female participants were more likely to go outside the prescribed system for refugee healthcare, whether by choice or by force of circumstance.

Housing and Healthcare Usage

It is important to note that the only mention of "no formal health services accessed" was made in a focus group session including a significant proportion of tent dwellers. In this same group, feedback about their previous healthcare experiences was therefore not available.

Registration Status and Healthcare Usage

Largely registered groups most frequently referenced MoH facilities as their primary source of care. Considering that MoH facilities are set up to accommodate these *registered* refugees, it isn't surprising that in the group with a high proportion of unregistered refugee respondents, there was no mention at all of MoH usage. Instead, this group's comments indicated pharmacies (without medical consultation) as their most-utilized source of care.

Governorate Analysis

As has been demonstrated through the tremendous range of responses given in the Health Access Assessment focus groups, refugee healthcare is not reaching all Syrian populations in Jordan equally; a top-3 ranking comparison across Governorates showed that geography is a least one factor significantly impacting access, though in very diverse ways. Knowing exactly which barriers to care are most frequently mentioned where helps health actors to adjust their activities depending on the location of the intervention, or visa versa.

Lack of medication availability was a nearly ubiquitous presence in the Governorates' top-3 most mentioned barriers to care, missing only from Madaba. Beyond that, however, focus groups in a number of locations evoked barriers to care that were semi-unique to their Governorates. For example, only in Zarqa Governorate did far distance to healthcare facilities, lack of transportation, and prohibitively high transportation costs all appear in the top-3 most mentioned barriers to care list; this confluence of frequently mentioned codes suggests that the issue of physical access in Zarqa is more dire than in other places. Similarly, only in Madaba did lack of trust in health facilities rank in the top-3 most mentioned barriers to care. Ajloun and Mafraq were the only two Governorates where insufficient facility capacity factored into the top-3 barriers list; only in these same Governorates, with the addition of Amman, was discrimination included among the top-3 most mentioned barriers to care.

Certain exceptions were also valuable to note; lack of knowledge regarding health services was, for example, among the top-3 most mentioned barriers to care everywhere *except* Irbid, Ma'aan, Mafraq, and Zarqa. This information could help direct outreach and education activities towards the areas most in need and not expend resources on those places that maybe have already been reached.

Analysis: In-Depth Interviews on Non-Communicable Disease Management

The sub-investigation on refugees' management of non-communicable disease engaged a total of 51 individuals (25 female, 26 male) through in-depth one-on-one interviews. Patients were asked to speak in detail about their experiences controlling their NCD conditions under the adverse circumstances of active conflict and displacement (See Appendix 1.5).

Disease Management Pre-Departure from Syria

Non-Communicable Conditions

Of the 51 interviewees, a majority (26) declared hypertension as his/her primary condition (about which he/she would answer the remainder of the interview questions). The next most common condition (18) was diabetes, followed by cardiovascular disease (13). Note that six patients who had been diagnosed with both hypertension and diabetes answered the interview questions for both conditions, insisting that the two were inextricably linked and part of a single disease management experience.

Duration of Treatment

The majority of individuals with NCDs who participated in the in-depth disease management interview had been diagnosed and started treatment relatively recently (24/51 diagnosed within past 2-5 years). The next most common timeline was diagnosis dating back 6-10 years (9/51 diagnosed within past 6-10 years). A number of long-term chronic disease patients, those who had been undergoing treatment for 20 years or more, were also interviewed (6/51 diagnosed 20+ years ago), with one interviewee a lifelong (congenital) patient. The most recent diagnosis was less than one month ago (1).

Treatment

When interviewees were asked about the status of their treatment before their departure from Syria, nearly all (49/51) responded that they were receiving a consistent drug regimen on a regular basis. This provided a baseline against which questions about current status of disease management could be weighed; this stable baseline only makes more obvious the dramatic deterioration that most respondents have experienced since their departure from Syria.

Frequency of Follow-Up

Interviewees reported frequent and regular follow-up consultations for their chronic condition before their departure from Syria. The most common response was monthly check-ups (16/51), followed by once every two months, and then, twice per month.

Barriers to Care

The vast majority of interviewees declared that they faced no barriers to care while in Syria. Hearing their comments on the myriad healthcare challenges they currently face as refugees, however, begs the

question as to whether their depiction of health access in Syria has been filtered through nostalgia. That said, several interviewees did mention finances (primarily with regard to private clinic fees and transportation expenses) as a constraint in the management of their condition in Syria. A few others mentioned that physical access to facilities was occasionally limited, preventing them from attending all of their follow-up consultations or obtaining their medication refills on time; a number of these comments referred to distance from health facilities and/or limited means and funds for transportation as the barriers, but also growing insecurity as the conflict intensified.

Status of Disease Management

Given the high percentage of interviewees who reported receiving regular treatment before their departure from Syria, it's not surprising that 41/51 considered their condition to be completely controlled during that period. Only six respondents indicated that, before leaving Syria, their conditions were not controlled.

Disease Management as a refugee in Jordan

Effect of Conflict on Condition

Beyond the structured evaluation of interviewees' disease management, participants shared often-lengthy personal narratives that contained important, if somewhat less quantifiable, insights about the effect of the conflict on their health conditions. The most frequent remark was about the addition of psychological burden to existing physical ailments; the psychological distress (incurred due to any combination of war-related trauma, such as loss of family members, loss of home, upheaval of community, violence, torture, etc.) made it more difficult to maintain the personal composure needed to adhere to a strict health regimen, many interviewees said. The rapid deterioration of the family framework as people were displaced internally or fled to beyond Syria's borders also had a destabilizing effect on their disease management, according to a number of interviewees. Without the consistency and support provided by family, they found it much more difficult to adhere to their disease management plan.

Comparative Status of Disease Management

When interviewees were asked to compare the current status of their chronic condition with its status pre-departure, 34 stated that their condition had worsened since leaving Syria. Eleven reported that their disease management status had remained about the same as in Syria during their time in Jordan. Only three said that their condition had actually improved since their arrival.

Drug Regimen Adherence

Medication is one of the first elements of disease management to be disrupted by conflict. The breakdown of the supply chain infrastructure can cause severe shortages, which, when coupled with restricted access to medical facilities, can prevent patients from securing the appropriate medications. Instability might also render impracticable a regular medication and/or monitoring schedule. Interviewees cited these reasons for interruptions to their drug regimens in the period immediately before their departure from Syria, during their flight from the country, and until their arrival in Jordan. The majority indicated, nonetheless, that they had been able to avoid any major interruptions (26/51). 11/51, on the other hand, reported total medication cessation (stoppage of longer than two months).

Another 10 interviewees reported having gone through a brief period of either partial or full drug cessation (temporary stop of two months or less).

Difference(s) in Treatment

The majority of interviewees – 36 out of 51 – had not experienced any substantive changes in their prescribed treatment since their arrival in Jordan (“total reprise”); some had endured an interruption during the turmoil and returned to the regimen, while others had managed to adhere continuously to their regimen. Of these 36 total reprise cases, 22 noted, however, that they were receiving an alternative but equivalent drug brand. Although there were no explicit complaints of compromised drug efficacy, a number of interviewees were skeptical about the changes and expressed preference for their old medication, citing familiarity more than anything else. In order to prevent this skepticism from escalating and eventually negatively impacting drug regimen adherence, education should be of utmost priority for chronic patients.

Among those whose drug regimens had been amended by a healthcare provider since being in Jordan were eight individuals with dosage adjustments. Another four had received new prescriptions entirely, either for a newly developed conditions or a drastically altered pre-existing one.

While a medical professional supervised the majority of treatment changes, there were four reports of refugees adjusting (usually reducing) their own drug consumption, according to the severity of their symptoms, their need to prolong a course of medication, or some combination thereof.

Adverse circumstances have forced medication changes on a number of interviewees. Six individuals said that they no longer took their prescribed medication due to their prohibitively high cost. Another five people maintained that their medications were not available anywhere in Jordan, even at a price, due to stock shortages at the pharmacies.

Source of Medications

For a number of interviewees, the source of care and source of medication differed. MoH facilities, for example, were cited as the most frequently utilized source of *care*, while pharmacies were the most frequently utilized source for *medications* among participating interviewees. This discrepancy indicates that at MoH clinics and hospitals, where most of the medications were prescribed, not all were readily accessible to refugee patients. Interviewees recounted the reasons given by facility personnel – most often that they didn’t have the drug in stock – but several speculated that they were restricting distribution to refugees to conserve stocks for Jordanian patients. Follow-up key informant interviews with healthcare management would be required to further elucidate the underlying cause(s) of the shortages.

That cost was cited as the #1 barrier to care is consistent with the report that many NCD patients are purchasing their medications from pharmacies. Considering the financial hardship reported by many refugees during focus group discussions, a healthcare situation in which finances determine a chronic patient’s ability to effectively manage his/her condition is unsustainable, especially for those who will require long-term and/or expensive medications.

Cost Comparison: Syria vs. Jordan

Only four interviewees confirmed that they were receiving their medications from the MoH at no cost to themselves. When asked about the price of medication purchased at the pharmacy, 31 interviewees

answered that their drugs were more expensive in Jordan than in Syria. Two individuals specified that their prescriptions were 100% more expensive in Jordan than in Syria; three said that their prescriptions were up to 200% more expensive in Jordan than in Syria.

Primary Source of Care

Interviewees reported seeking care for their NCD conditions at a variety of facilities, the most common of which was MoH clinics (20/51). However, quite a few interviewees (10) responded that hospitals (directly, without referral – i.e. emergency) served as their primary source of care in Jordan. This suggests that some NCD patients, rather than managing their conditions, are waiting for them to escalate to become medical emergencies before seeking care. The Barriers to Care section (below) sheds light on some of the reasons that many chronic disease sufferers are not accessing regular care through the MoH. Though health NGOs and local charities were not cited as a major source of care – four and three respectively - it seems that they are picking up at least a few outliers.

Barriers to Care

The interviews with NCD patients revealed that administrative issues did seem to not restrict access to care nearly to the extent that they did in the general focus group, where the Jordanian Security Card residency requirement and the expiration of the UNHCR card topped the Barriers list. As a result of their conditions, many interviewees had been navigating healthcare systems for an extended period and discussed some of the more complex aspects of seeking care (documentation, referrals, etc.) with a certain level of familiarity. Unfortunately, no level of familiarity seemed to be able to change some fundamental supply issues. The #1 most common barrier mentioned by NCD patients was cost of medication, closely followed by availability of medication at #2. The two issues are inextricably linked, as patients are forced to purchase their own drugs (often at high cost) in the event of stock-outs in MoH facilities. Some of these stock-outs, interviewees mentioned, extended even to the pharmacy level. Since Syria's disease profile closely resembles that of Jordan, most relevant medications would normally have been stocked. However, interview participants, particularly those with highly prevalent conditions (diabetes, hypertension, etc.), reported that pharmacies did not have enough supply to cover the needs of the current patient load, which has drastically increased since the outbreak of the civil war in Syria and subsequent arrival of massive numbers of Syrian refugee in Jordan. NCD patient participants also indicated human resources as a major barrier to care, as care for those with advanced and/or complex conditions must be highly specialized. The lack of specialists was the third most mentioned concern in this section of the interview.

Frequency of Follow-Up

In the general focus groups, follow-up was more or less absent from their healthcare experience; nearly all care-seeking behaviors were reactive and oriented towards short-term solutions. Many of the NCD patients interviewed, however, demonstrated an appreciation for the importance of regular consultation; 18 of the 51 interviewees reported one medical visit per month, and another seven reported even more frequent visits, with one patient describing as much as weekly visits. That said, the #2 most common response was “never”, meaning that these interviewees had never attended a regularly scheduled follow-up consultation in Jordan.

Regardless of the exact frequency of their respective follow-ups, the large majority of interviewed respondents reported attending consultations comparatively less frequently in Jordan than in Syria.

Quality of Care

Using medical history checks and physical exams as indicators for the quality of care offered in healthcare facilities in Jordan, the results, according to NCD patients were much more positive than perceived by general focus group participants. Only nine interview respondents of 51 reported incidents of no medical history taken and/or no physical exam performed. It is difficult to determine why exactly NCD patients seem to be receiving, or at least perceiving, better quality care in Jordan; it's possible that their extended contact with health systems may have made them more effective advocates for their own needs.

Self-Monitoring

While drug regimen adherence and follow-up consultations are critical components of NCD management, self-monitoring is often what successfully brings and keeps a condition under control. It is also the most often neglected, particularly in healthcare cultures like Syria's that place such strong emphasis on medication. Of the 51 interviewees, 30 reported performing some kind of self-monitoring: eight used at-home testing, six cited close observation of changes in symptoms, and five regulated exacerbating activities (diet, excessive physical exertion, stress, etc.). Another eleven answered yes, they did engage in self-monitoring, but provided only vague descriptions of these activities. Seven explicitly reported no self-monitoring at all, while 12 mentioned only *facility* follow-up (even after self-monitoring was further defined), suggesting a lack of basic familiarity with the concept of home/self-monitoring.

When asked about the frequency of these activities, the response rate overall was low and the most commonly mentioned frequency was "irregularly", highlighting a pervasive de-emphasis on self-monitoring in NCD management among Syrian refugees in Jordan.

Disease Management Support

Even under the best of circumstances, NCD management is challenging and requires a great deal of support, particularly for older patients who may be dealing with declining mental status and limited mobility in addition to their primary condition. Active conflict and/or emergency displacement situations dramatically increase the need for assistance. Sadly, a large proportion of interviewees – 19 of the 51 – indicated that they had no consistent source of support at all. Children and spouses were the next most frequently mentioned, with 13 and 12 mentions respectively. Other interviewees spoke of friends, siblings, neighbors, or in-laws who helped them to manage their conditions during and after their flight from Syria.

While disease management support must be tailored to the unique details of an individual's case, interviewees' responses highlighted several particularly common (and effective) forms of support: the #1 most mentioned form of support was accompaniment, primarily to and from doctor's appointments and pharmacies for prescription refills (17). Assistance adhering to drug schedules was the second most frequent response (5), and help with self-monitoring the third (4).

Knowledge of and Access to Emergency Services

Of course the goal of NCD management is to avoid flare-ups that require emergency care. But the reality is that, especially in the refugee context, these kinds of health crises will happen occasionally, and NCD patients have to be prepared. Nearly every interviewee was able to describe basic emergency protocols that would land him/her in a health facility equipped to provide the appropriate assistance. Hospital ERs

topped the list as the most frequently mentioned emergency point of care (24). Health centers and private clinics were also mentioned as emergency options, with eleven and five responses respectively. The “correct” answer would depend on the specifics of the case, but the fact that essentially everyone interviewed could articulate some kind of emergency plan on the spot can be viewed as encouraging for this component of health education/outreach.

Education about NCDs

Interviewees were unfortunately far less knowledgeable about other aspects of disease management, most notably about the conditions themselves. A huge majority – 36 interviewees out of 51 – reported having had no education whatsoever about their condition during their time in Jordan. Only eight individuals had received counseling from their healthcare providers (materials or sensitization session), and the remaining respondents cited family/friends and independent research as their primary sources of information regarding their condition.

The detrimental effects of this sizable education gap were evident over the course of the interviews as NCD patients spoke about their conditions. 18 of the 51 interviewed patients made comments that demonstrated a serious lack of knowledge about their condition. Whether he/she offered incorrect information about the causes, symptoms, or treatment of the disease, or explicitly admitted to a lack of knowledge on the subject, the takeaway message is the same. Health education has fallen to the wayside in the management of NCDs among refugees in Jordan, an oversight that no one can afford to leave uncorrected. Uncontrolled NCDs are not only dangerous for patients but also extremely taxing on a national healthcare system, as critical patient load and emergency costs rise steeply in coming years.¹⁴

Conclusion and Recommendations

The IMC Health Access Assessment intentionally took a very broad view of health access in order to capture the full range of issues perceived by participants as impacting their healthcare experience in Jordan. The qualitative data produced and presented here is very much a reflection of that. Though the questions posed to Assessment participants were all health-focused, the answers received revealed issues in many different sectors (health, WASH, shelter, nutrition, livelihoods) and attitudes derived from many different sources (history, culture, education). Which of these revelations are the most significant and require the most urgent attention depends on each relief organization/agency’s mandate.

That said, a number of these themes stand out as particularly crosscutting, referenced consistently and emphatically by Assessment participants of diverse backgrounds in Syria and disparate experiences as refugees in Jordan. This ubiquity suggests that these themes warrant further investigation and/or intervention.

¹⁴ Demaio A, Jamieson J, Horn R, de Courten M, Tellier S. Non-Communicable Diseases in Emergencies: A Call to Action. PLOS Currents Disasters. 2013 Sep 6. Edition 1. doi: 10.1371/currents.dis.53e08b951d59ff913ab8b9bb51c4d0de.

International Medical Corps' recommendations for priority actions are provided below:

1. Assessment participants perceived the two major refugee registration processes - the MoI-issued Security Card and the UNHCR Refugee Registration Card – to be the most significant barriers currently restricting their access to healthcare services. This widespread expression of concern suggests that a re-evaluation of the current processes is necessary, with the goal of simplifying and accelerating administrative procedures wherever possible. Implementing these kinds of changes within large-scale, bureaucratic systems, however, requires a great deal of coordinated planning and, therefore, time. In the meantime, INGOs and CBOs working with non-camp Syrian refugee populations, particularly those organizations with strong case management programs already in place, may consider expanding their administrative support services. With outreach staff available to clarify complicated procedures and assist refugees with the practical details of renewing their UNHCR registration, relocating the MoI Security Card, or accessing healthcare under their existing administrative status, the number of Syrian refugees missing out on MoH health services because of documentation issues could be significantly reduced until more permanent solutions can be put in place.
2. Qualitative data from the Health Access Assessment provides a strong evidence base for a Mobile Medical Unit (MMU) program (which IMC in fact ran from December 2013 until mid-April 2014 and expects to resume in coming months). Long distances to health centers, compounded by limited transportation options and prohibitively high transport fees, were among the most discussed barriers to care among participating refugees. Lack of medication availability was the single most mentioned issue overall. MMUs counter both of these concerns by bringing healthcare services – including *sufficient amounts* of the *correct* medications – *directly to* vulnerable refugee populations with particularly restricted access to healthcare services. It is important to note, however, that this kind of program is an effective stopgap for the short term only, to address the most acute access concerns until longer-term, sustainable solutions can be found.
3. Participant responses regarding access to information on health services revealed a gap in communication; many refugees either didn't know where to obtain information about services or demonstrated misunderstanding of the information they had received. In order disseminate information more widely and more effectively, health organizations, as well as partners from other related sectors, should consider reviewing their Information, Education, and Communication (IEC) materials. The illiteracy rate among Syrian refugees (Assessment sample showed around 20%), particularly among women, indicates limiting complex and/or lengthy written explanations and using pictures and symbols wherever possible. Direct verbal communication between beneficiaries and outreach workers would be the gold standard, i.e. Community Health Worker programs, MoH clinic outreach teams, etc. The fact that Assessment participants rarely mentioned the clinics themselves as a reliable and available source of information suggests that there is significant room for these facilities to improve their self-promotion activities.
4. This Assessment solicited feedback regarding the availability of healthcare services, with a particular focus on disability, OB/GYN, and pediatrics; Assessment participants generally perceived all three of these service areas to be seriously lacking. Considering the number of war-related injuries coming out of Syria, the high proportion of women fleeing the country, and the elevated wartime fertility rates (approx. 30% of Assessment respondents reported having five or more children), these service areas are of critical importance to the refugee population in Jordan and must be given top priority.¹⁵

¹⁵ *Health and Nutrition Quarterly (Iraq, Jordan, and Lebanon) - January - March 2014*. Issue brief. Inter-Agency Regional Response for Syrian Refugees, Apr. 2014. Web. <file:///Users/nmorencybrassard/Downloads/InteragencyRegionalSyrianrefugeesHealthreport2014Q1.pdf>

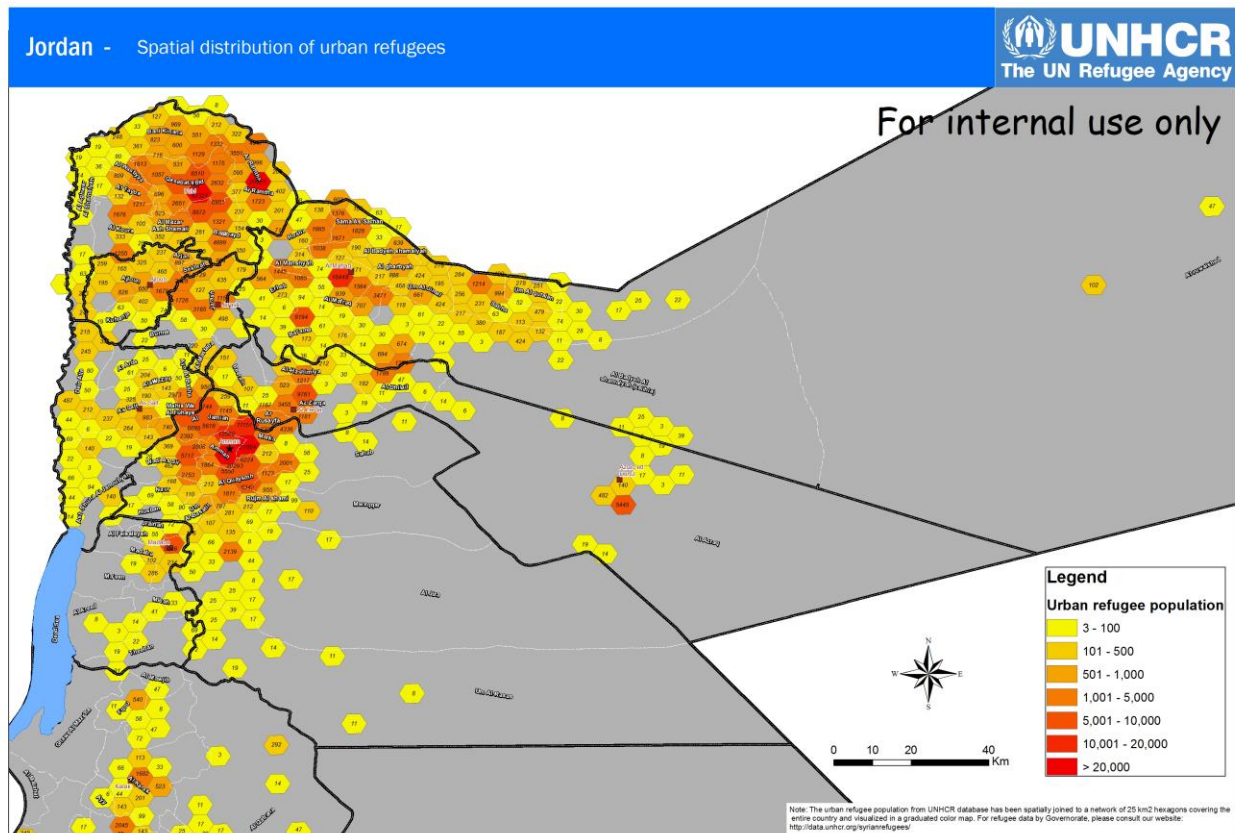
This priority should, insofar as possible, be reflected in the Jordanian Ministry of Health's distribution of healthcare resources, as well as in the programming choices of supporting health partners.

5. In light of the significant healthcare information gaps revealed during the Assessment, all health actors would be strongly encouraged to revamp the health education components of their programs. This should of course include disease management counseling for those with NCDs, as well as clear care instructions for acute conditions. However, health programs should also work to find new and creative ways to disseminate to a wider audience important health messages about healthy lifestyles and responsible care-seeking. Disease *prevention* is the health sector's most promising strategy to mitigate the increasing burden on the healthcare system as the Syria refugee crisis drags into a protracted emergency.

This report will be distributed widely among humanitarian and relief actors in Jordan with the hope that each organization will glean from it the data and/or recommendations most relevant to its sector of interest and use this information to inform future programming for non-camp Syrian refugees in Jordan.

Appendix: Assessment Tools and Statistics

1.1 Sampling Data



1.2 Regional Lines Used in Data Stratification

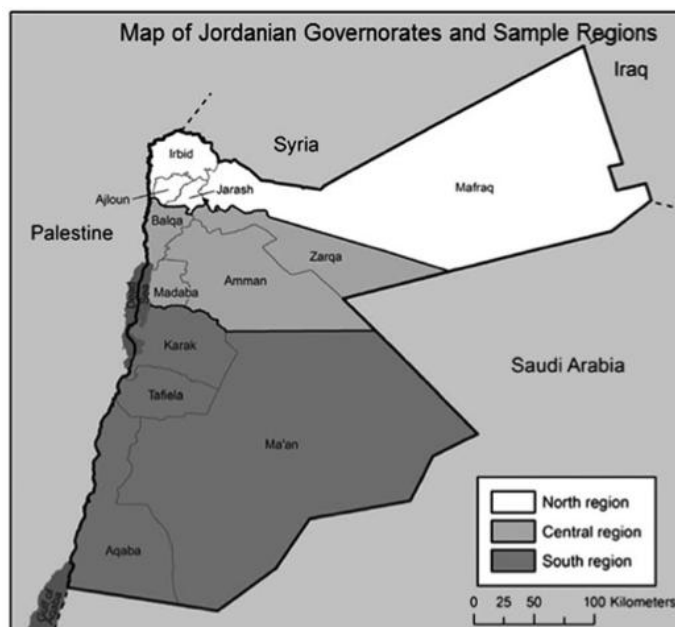


Figure 2. Map of Jordanian governorates and sample regions

1.3 Principal Assessment: Pre-Participation Questionnaire (Basic Demographics)

First of all, thank you for taking the time to talk to us today. As you know, we are trying to understand more about the health issues affecting displaced Syrians living in Jordan, the health services currently available to you, and obstacles that you face trying to access care. We do this with the hope that we can revamp existing programs and/or create new programs to better respond to your health needs.

Before we start with the group discussion, it would be very helpful to us if you could tell us a little bit about yourself. Please take a few minutes to answer the questions below by circling the response option that best applies to you:

- 1) What sex are you?
 - a. Male
 - b. Female
 - c. Prefer not to answer

- 2) How old are you?
 - a. 16 -30 years old
 - b. 31 - 45 years old
 - c. 46 - 60 years old
 - d. 61- 75 years old
 - e. 76 + years old
 - f. Don't know
 - g. Prefer not to answer

- 3) What is your current nationality? You can put more than one answer if that's how you identify.
 - a. Syrian
 - b. Palestinian
 - c. Jordanian
 - d. Lebanese
 - e. Other (Specify_____)

- 4) Where in Syria is your family from (pre-conflict)?
 - a. Homs
 - b. Aleppo
 - c. Damascus
 - d. Hamah
 - e. Dara'a
 - f. Idlib
 - g. Latakia
 - h. Other (Specify_____)
 - i. Prefer not to answer

5) Which of the following best describes your education level?

- a. None
- a. Some primary school
- b. All primary school
- c. Some secondary school
- d. All secondary school
- e. University
- f. Professional degree
- g. Don't know
- h. Prefer not to answer

6) Which of the following most accurately describes your marital status?

- a. Unmarried
- b. Married
- c. Widow/widower
- d. Don't know
- e. Prefer not to answer

7) How many children do you have?

- a. None
- b. 1
- c. 2
- d. 3
- e. 4
- f. 5
- g. 5+
- h. Prefer not to answer

8) How many months have you been in Jordan?

- a. 0 – 3
- b. 4 – 8
- c. 9 -12
- d. 13 or more
- e. Don't know
- f. Prefer not to answer

9) Are you currently registered with UNHCR? Please note that this information will be not be shared outside of our organization, will be used only to inform this project, and will in no way affect your status in Jordan.

- a. Yes, I am registered with UNHCR
- b. No, I am not registered with UNHCR
- c. Don't know
- d. Prefer not to answer

- a. OPTIONAL: If your response was **b. I am not registered with UNHCR**, please explain further why you have chosen not to register or have not been able to register. Share as much or as little as you feel comfortable. As stated above, this information will be not be shared outside of our organization, will be used only to inform this project, and will in no way affect your status in Jordan.

10) Which of these people currently members of your household? When I say household, I mean people living in the same accommodations with you right now. You can circle as many as apply.

- ~~a. Your partner~~
- ~~b. One or more of your children~~
- ~~c. One or more members of your extended family~~
- ~~d. One or more close family friends/neighbors~~
- ~~e. Other (Specify _____)~~
- ~~f. Don't know~~
- ~~g. Prefer not to answer~~

(Question discarded in demographic analysis: multiple-response format caused confusion, and thus inconsistent answers, among respondents)

11) In what governorate do you currently live?

- h. Mafrq Governorate
- i. Amman Governorate
- j. Irbid Governorate
- k. Zarqa Governorate
- l. Balqa Governorate
- m. Jarash Governorate
- n. Aljun Governorate
- o. Karak Governorate
- p. Madaba Governorate
- q. Ma'an Governorate
- r. Tafilah Governorate
- s. Aqaba Governorate
- t. Don't know
- u. Prefer not to answer

12) How would you describe your current accommodations?

- v. In an improvised shelter in an open-air refugee encampment
- w. In an rented apartment in an urban area
- x. In a host family's home (urban or rural)
- y. Other (Specify _____)

14) Do you suffer from a non-communicable condition that requires regular management?

- a. Yes
- b. No
- c. Don't know
- d. Prefer not to answer

OPTIONAL: Please provide a bit more information about your condition: diagnosis, how long you've been ill, what medications you require, how often you received medical attention in Syria, if you are receiving comparable care here in Jordan, etc. Share as much or as little as you feel comfortable. Any information you provide will be used only within our organization with the express purpose of improving healthcare services available to refugees like yourself.

1.4 Principal Assessment: Focus Group Topic Guide

- 1. Opening Question:** Please tell us your first name, how long you've been here in Jordan, and where in Syria you're from.
- 2. Introductory Question:** Now we would like to talk about your health and access to care during your time in Jordan. From your own experiences, as well as those of friends and family who are here with you, can you tell me what you would consider the most prominent health concerns in the refugee community?
- 3. Key Question:** Tell me about how you have obtained information about the health services available to help you address these health concerns. Do you feel like you have, or could easily find out, all the information you need to keep your family healthy?
- 4. Transition:** Many refugees choose to visit Jordanian Ministry of Health clinics and hospitals, some opt for NGO services, and others use private facilities. When you or your family has needed medical attention, where did you go?
- 5. Follow-up:** What about within your community? Are there community consultation or treatment options – Syrian doctors, nurses, or other medical professionals living in Jordan – that people use either in addition to or instead of facility-based care?
- 6. Key Question:** Particular groups of people often need more specialized medical care. Can you tell me a bit about the availability of services for women during their pregnancy and childbirth, and if women in your community are using them?
- 7. Follow-up:** What about their children? In your opinion, is early childhood care, including routine vaccinations, accessible to the refugee community, and are most parents taking advantage of it for their children?
- 8. Follow-up:** Many people arrived in Jordan with handicaps such physical disabilities or mental disorders. In your community, what kind of healthcare options do people who suffer from these kinds of handicaps have, and do you feel like these options are responding appropriately to their needs?
- 9. Key Question:** On these occasions when you or a family member have sought medical attention - whether for an acute illness, a chronic condition, or special circumstances such as pregnancy - what was it that prompted you to seek care? (i.e. a concerning symptoms, long duration of illness, need for medication, etc.).
- 10. Transition:** What about *where* you sought care...can you tell me about what made you choose one healthcare facility instead of another?
- 11. Key Question:** While you were at this healthcare facility, what did you think were the most positive parts of the experience? What were the most frustrating?
- 12. Transition:** Do you think you would return to the same facility next time you need medical assistance? What would make you decide to look for care elsewhere?

13. Key Question: So you've told me a bit about your experiences with healthcare services. Now, can you tell me if there has been an occasion on which you or your family needed medical care but were NOT able to access the services you needed? In your opinion, what were the main reasons that you weren't able to get help?

14. Follow-up: Can you describe some other major obstacles that refugees in your community have experienced when trying to access health services?

15. Ending Question: Suppose that the head of UNHCR were to come to _____ tomorrow, and he wanted to know which health services needed to be improved and how. What suggestions would you offer him?

1.5 NCD Management Sub-Investigation: In-Depth Interview Topic Guide

Pre-Departure from Syria:

1. What non-communicable conditions have you been diagnosed with?

Primary condition:

Condition 2:

2. When did you start treatment for this condition?
 - a. Were you taking this treatment regularly back in Syria?
 - b. ~~What did the treatment consist of? (If interviewee comfortable sharing, medications and dosages)~~
~~*If not able to remember, can prompt to see if they have meds with them?~~
(Medications data discarded post-interview as incomparable, and thus irrelevant to the study).
3. How often did you have check-ups for this condition back in Syria?
4. What do you feel was your biggest challenge managing your condition pre-conflict?
5. Overall, would you have considered your condition “under control” pre-conflict? (By “under control”, I mean you no longer suffered from major symptoms.)

Refugee in Jordan:

6. Would you consider your condition “under control” right now?
 - a. If not, how has the war made managing your condition more difficult?
7. Has your treatment for your condition been interrupted during the conflict?
 - a. If so, for what length of time?
8. Since you have arrived in Jordan, have you continued this treatment?
 - a. If not, have you stopped entirely or is your treatment now intermittent?
 - b. If yes, where have you received this treatment?

9. Are you taking the same drugs that you were in Syria? Same dosage?
 - a. If so, where are you able to find these medications?
10. How does their cost compare to in Syria?
11. If your old drugs are not available/too expensive, have you switched to other drugs? Stopped all together?
 - a. Follow-up: who told you what changes to make to your treatment regimen?
12. How often, in Jordan, have you seen a medical professional for this condition?
 - a. If this is less often than you saw your doctor in Syria, why the change in frequency?
13. When you have gone to the doctor's for a different ailment here in Jordan, did your doctor or nurse address this condition? When I say "address", I mean does he/she talk to you about it, ask you about your other medications, examine you?
14. How do you monitor the state of your condition?
 - a. Where and how regularly do you do so?
15. Is there someone in particular who assists you with the management of your condition, a friend or a family member?
 - a. If so, how do they help you?
16. If your health status worsens dramatically all of a sudden, do you know where to go for help?
17. Where have you received education about your condition?

1.6 Cluster Sites – Activities by Governorate

Governorate	Clusters Per Governorate	# Focus Groups	# Interviews
Irbid	9	18	16
Ajloun	2	4	4
Jarash	1	2	2
Mafrq	3	6	7
Zarqa	3	6	4
Madaba	1	2	1
Ma'an	2	4	2
Balqa	4	8	7
Amman	5	10	8
Totals:	30	60	51

1.7 Focus Group Data Analysis: Code Families

Focus Group Data Analysis: Code Families	
Administrative Issues in Accessing Care	Perceived Positive Aspects of Healthcare Services
Barriers to Care	Perceptions of Patient-Provider Relations
Care-Seeking Decision-Making	Perceptions of Quality of Care
Health Conditions	Secondary Health Factors
Perceptions of Facility and Resource Management	Perceived Service Availability
Knowledge and Information Sources on Healthcare Services	Healthcare Usage
Overall Perceptions of Healthcare Status	

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UNHCR
United Nations High Commissioner for Refugees
Haut Commissariat des Nations Unies pour les réfugiés

