

## Health systems responsiveness to the mental health needs of forcibly displaced persons

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In this chapter, we discuss health system responsiveness to the mental health needs of forcibly displaced persons. First, we discuss health system responsiveness as key health system characteristic, and introduce a conceptual framework guiding its assessment. We then present the use of a rapid appraisal methodology upon which the conceptual framework is based. Finally, we present findings of a case-study on mental health care among Syrian refugees residing in the Netherlands employing this methodology.

### **Mental health service provision for refugees**

It is now recognized that refugees have high levels of mental health needs due to the exposure to violence and traumatic events and ongoing exposure to daily stressors during and after the displacement.(Silove et al. 2017; Lindert et al. 2009) However, evidence suggests that utilization of mental health and psychosocial support (MHPSS) services by refugees and other forcibly displaced persons remains low.(Norredam et al. 2006) Some of the reasons for this low utilization include: low-levels of awareness of mental health and MHPSS services; different cultural perspectives of mental health and associated services; stigma around mental health including discrimination against refugees; linguistic barriers; costs of services; poor quality of services; and low trust in health services and service providers.(Bartolomei et al. 2016)

MHPSS is defined as any type of local or outside support that aims to protect or promote psychosocial well-being and/or prevent or treat mental disorders.(IASC 2007) MHPSS is a composite term that acknowledges the need for continuing and comprehensive care for people who are facing or have faced adversity. Consequently, MHPSS incorporates services for both prevention and treatment provided by multiple providers (specialists and non-specialists). MHPSS services should, overall, provide holistic care: i.e. through community programmes that offer psychosocial support to prevent the onset of mental disorders and to build resilience for persons with mild or moderate mental distress, and through health care platforms offering more targeted health system interventions for persons who are in need of more specialised support.(UNHCR 2013)

There are contrasting approaches to delivering MHPSS services for refugees in Europe. In Germany, for example, mental health services are commonly delivered by specialist mental health care providers such as psychiatrists and psychotherapists. This has caused bottlenecks in accessing care as the demand for services outstrips the supply, with waiting times typically over six months.(Aida 2018; Bajbouj M 2016) In addition, these specialists have limited training on the particular MHPSS needs, experiences and cultural perspectives of refugees; and limited funds for interpreters.(Bajbouj M 2016; Böttche M 2016; Priebe et al. 2016) It has been argued that this specialist care may not be required or appropriate for the majority of refugee mental health needs as they relate to more mild and moderate mental disorders that could be addressed through psychosocial support or low-intensity psychological interventions. Some NGOs in Germany have established psychosocial centres but these only reach around 4% of the estimated number of refugees who likely require MHPSS support.(BAfF 2015) A contrasting response has been the dependence on parallel systems of MHPSS care in countries such

as Greece and Italy which is predominantly provided by NGOs as well as church and community groups. This type of care has commonly focused more on psychosocial support rather than on more specialist mental health services. These services are essential in the absence of state-provided services. However, they are often short-term, fragmented and disjointed.(Lionis et al. 2018) Limited staff capacity, language and cultural barriers are also common, and trust of refugees in these services was reported to be low among refugees in camps in Greece.(Priebe et al. 2016; Satinsky E 2018; Ben Farhat et al. 2018) Regulation on the types of MHPSS services being provided and oversight of their quality and effectiveness is also very limited.(Priebe et al. 2016) Countries such as Sweden and the Netherlands have taken more balanced approaches through greater provision of MHPSS care at the primary care level, incorporating services provided by more regulated NGOs. However, these have limited coverage and access challenges remain.(Satinsky E 2018)

Health system responsiveness is understood as the way in which individuals are treated and the environment in which they are treated in, encompassing the individual's experience of contact and interaction with the health system. (Valentine 2003) Responsiveness is therefore not a measure of how the system responds to health but of how the system performs relative to non-health aspects, meeting or not meeting a population's expectations of how it should be treated by providers of prevention, care or services. (Darby et al. ; Valentine 2003; Papanicolas and Smith 2013) Health system responsiveness was conceptualized by the World Health Organization (WHO) as a composite measure to grasp both patient satisfaction with treatment but also the interaction of the patient with the health system(Valentine 2003), and was incorporated as measure in the WHO World Health Survey.(WHO 2018b) Eight domains related to responsiveness have been identified: (1) autonomy (involvement in decision on health care), (2) choice (of health care decisions), (3) communication (adequate communication from and with provider), (4) confidentiality (of records and personal information), (5) dignity (respectful treatment by provider), (6) quality of amenities (quality of health care surroundings/clinics), (7) prompt attention (no treatment delay) and (8) family and community support (building on family and community support in care and treatment).(Papanicolas and Smith 2013) Responsiveness is a complex construct: Its domains are not discrete entities, and overlap to some extent with the definition of other health system outcomes such as access, quality, coverage and safety. This has also been recognised by Mirzoev & Kane who argue that expectations of the health system by patients such as availability of services, health system resources which are available for treatment but also access and quality expectations shape patient's judgement of anticipated success or failure of service outcomes including the system's responsiveness.(Mirzoev and Kane 2017) Table 1 operationalises responsiveness domains according to the conventional definition of the WHO and indicates their relevance to intermediate health system outcomes such as access, coverage, quality and safety (defined further in Box 1).

Table 1: Responsiveness domains and linkage with other key health system characteristics

Responsiveness domains	Domain operationalization: Example items for measurement of responsiveness at the individual level	Links to intermediate health system outcomes
<u>1.Autonomy</u> : Involvement in decisions on care and services	<ul style="list-style-type: none"> <li>- Involvement in decisions about health care, treatment and services</li> <li>- Obtaining information about other possible types of services</li> </ul>	- Quality and safety
<u>2.Choice</u> : Choice of health care providers and services	<ul style="list-style-type: none"> <li>- Freedom to choose health care provider</li> <li>- Freedom to choose health care facility or service</li> </ul>	- Access
<u>3.Communication</u> : Clarity of communication	<ul style="list-style-type: none"> <li>- Service conducted in mother tongue of patient (or interpreter available)</li> <li>- Health care provider explains things clearly and listens carefully</li> <li>- Allowing patient time to ask questions about treatment and care</li> </ul>	- Quality
<u>4.Confidentiality</u> : Confidentiality of personal information	<ul style="list-style-type: none"> <li>- Personal information about medical history is kept confidential</li> <li>- Talks with doctors or nurses are done privately, and other people are not being able to overhear what is being said</li> </ul>	- Quality
<u>5.Dignity</u> : Respectful treatment and communication	<ul style="list-style-type: none"> <li>- Health care professionals treat patient with respect/talk to patients in a respectful manner</li> </ul>	- Quality
<u>6.Quality of basic amenities</u> : Surroundings	<ul style="list-style-type: none"> <li>- Cleanliness of facility where service is provided</li> <li>- Basic quality of waiting room and office where service is provided (space, seating, fresh air)</li> </ul>	- Quality, access (accommodation)
<u>7.Prompt attention</u> : Convenient travel and short waiting times	<ul style="list-style-type: none"> <li>- Travelling time to facility/service</li> <li>- Short waiting times for appointments and consultations</li> <li>- Getting fast care in emergencies</li> </ul>	- Access (availability, accessibility), quality and safety
<u>8.Access to family and community support</u> : Contact with family and maintenance of regular activities	<ul style="list-style-type: none"> <li>- Facility/service provider encourages interaction and collaboration with family/friends during course of mental health treatment</li> <li>- Facility/service provider encouraged to continue social and religious customs during treatment</li> </ul>	- Access (availability, accessibility)

\*Adapted from Papanicolas & Smith, 2013 (Papanicolas and Smith 2013)

## Box 1: Key health system characteristics: access, coverage, quality and safety

### Access and coverage:

We define access according to the framework of Pechansky and Thomas (1981)(Pechansky and Thomas 1981) which overlap in their definition with measures of coverage:

1. Availability – the volume (coverage) and type of existing services and whether this is adequate for the volume and needs of service users.
2. Accessibility – the relationship between the location of the services/supply and the location of the people in need of them. This should take into account transportation, travel time, distance, and cost.
3. Accommodation – the relationship between the organisation of resources (appointment systems, hours of operation, walk-in facilities) and the ability of service users to accommodate to these factors. User perceptions on the appropriateness of these factors should also be taken into account.
4. Affordability – the prices of services in relation to the income of service users. The user perception of the worth relative to total cost should also be taken into account.
5. Acceptability – the relationship of attitudes of service users about personal and practice characteristics of services to the actual characteristics of the existing services, as well as to provider attitudes about acceptable personal characteristics of service users.

### Quality

We conceive quality according to the Control Knobs framework(Roberts et al. 2008) which understands quality as:

- The scope of care (and quantity) which is provided to the patient (conceived as the amount of care necessary to achieve a desired treatment outcome).
- The clinical quality of the service provided to the patient (cleanliness of facility, but also skills and decision making of the provider, in addition to equipment and supplies; the use of an evidence-based intervention))

Service quality and acceptability of the service: convenience (e.g. travel time, waiting time, opening hours, etc.); and interpersonal relations (e.g. whether providers are polite, emotionally supportive and whether patients receive appropriate information and respect).

### Safety

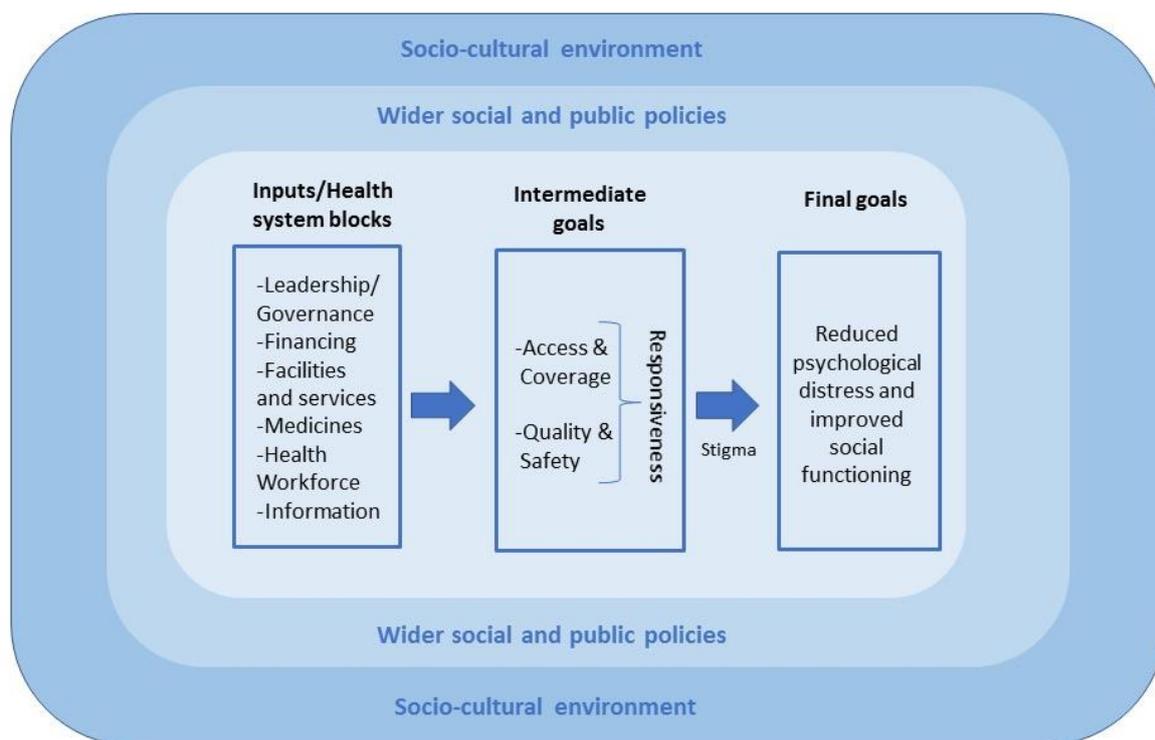
Safety is defined as the degree to which health care processes avoid, prevent and ameliorate adverse outcomes or injuries that stem from the processes of health care itself. (Kelley and Hurst 2006)

## **Conceptual framework on health systems responsiveness and pathways of care**

We have developed a conceptual framework for health system responsiveness to the mental health needs of refugees (see Figure 1) which is based on key health system's literature (WHO 2000b, 2007), and other health system responsiveness frameworks. (Mirzoev and Kane 2017) The conceptual framework conceives the health system according to the definition of the WHO (WHO 2007) and considers both state governed mental health services as well as non-state provision of mental health services as parts of the mental health system for refugees. Examples of non-state provision might be (a network of) non-governmental organizations (NGOs) funded by donors or United Nations agencies providing MHPSS services to refugees.

We conceive the health system as being influenced by the wider socio-economic and cultural environment of the country which in turn shapes social and public policies formulated by the government (as indicated by the two outer layers of Figure 1). Wider social and public policies are policies, legislation and social protection schemes influencing the health system. They reflect values, principles and objectives of a society, which can influence health outcomes but also broader societal outcomes such as employment. Public attitudes towards mental health, knowledge about mental health and resulting behaviour of individual people will determine stigma towards people with mental illness in a given society. (Evans-Lacko et al. 2012) Stigma consists of two components, namely discrimination (being treated unfairly) and prejudice (stigmatising attitudes), (Clement et al. 2013) which negatively influences help-seeking behaviour of the patient, (Vistorte et al. 2018) and leads to adverse treatment outcomes. (Hatzenbuehler et al. 2013) The importance of context has been recognized in other responsiveness frameworks as well. (Mirzoev and Kane 2017)

Figure 1: Conceptual framework for assessing the responsiveness of the mental health system for refugees with mental health needs



The health system inputs can be organised around the WHO building blocks (i.e. leadership/governance; financing; facilities and services; medicines, health workforce, information).(WHO 2007) These key health system inputs will vary according to country income group, overall disease burden, needs and priorities of the government to provide treatment for mental disorders.

As in other health system frameworks(WHO 2007), we conceptualize access, coverage, quality and safety as intermediate health system goals (described in box 1) which link health system inputs and the final health system goal such as improved health by ensuring adequate access to and coverage of effective health interventions, without compromising efforts to ensure provider quality and safety.(WHO 2000a)

In contrast to the conventional health system's framework of the WHO which understands responsiveness as final goal(WHO 2007) we conceptualize responsiveness as intermediate outcome. There is a debate whether responsiveness should be understood as intermediate or final outcome.(Kelley and Hurst 2006) For example, the Organisation for Economic Co-operation and Development conceptualizes access as a component of responsiveness, and due to its overlap with other health system goals (such as quality and safety) as intermediate outcome(Kelley and Hurst 2006). The Commonwealth Fund argues similarly and includes responsiveness in the definition of quality and access.(CommonwealthFund 2016) The WHO refers to responsiveness as respect for persons (health system and health provider's respect for dignity, autonomy and confidentiality) which can be understood as dimensions of quality of care, and client orientation (right to prompt attention to health needs, access to patient social support networks and choice of institutions providing care)(WHO 2007, 2000a; Papanicolas and Smith 2013) which include components of Penchansky and Thomas access definitions. Due to the overlap between several domains of responsiveness and key intermediate health system goals (as outlined in box 1) we argue that access as defined by Penchansky

and Thomas, coverage, quality and safety can be conceived as proxy responsiveness measures. Responsiveness as intermediate outcome may be especially important for mental health as patients may not seek or continue mental health services if the system is not responsive to their needs (e.g. by providing access to family and community support services, delivering services such as psychological therapies in the patient's mother tongue, and offering choice of health care providers and services). Those responsiveness domains are key for mental health and will determine if people with mental disorders seek or continue care. This is supported by evidence of the literature: an unresponsive system which does not provide prompt attention for mental health needs may lead to adverse mental health treatment outcomes and high unmet need at the population level.(Wang et al. 2007; Wang et al. 2004)

Therefore we conceptualized responsiveness as precursor of improved mental health as a patient's initial perception of responsiveness, and subsequent interaction with the health system(Mirzoev and Kane 2017)may determine health seeking behaviour and treatment outcomes. Demand-side factors influence help-seeking as well and play a key role in the recovery from mental illness. People with mental disorders may not seek care for three reasons: (1) lack of knowledge about evidence-based treatments and the treatability of mental disorders, (2) lack of knowledge about where and how to access treatment, and (3) expectations of discrimination and prejudice against people with a mental disorder.(Henderson et al. 2013) The latter is important as experience of stigma at the individual or community level (in form of public attitudes and behaviour) or institutional level (reflected in legislation, funding, availability of services)(Corrigan et al. 2004) may prevent patients from accessing services; this is something which needs to be tackled so that the needs of people with mental health can be adequately responded to (e.g. through community anti-stigma campaigns, by educating providers on these sensitivities, and by advocating for mental health at the wider policy level). It is only then when improved population mental health will be achieved.(Hatzenbuehler et al. 2013)

The final goal in our conceptual framework is reduced psychological distress and improved social functioning at the level of the population which has been facilitated by a responsive health system. Reduced psychological distress can be operationalized by measures of improvement in symptoms of common mental disorders such as depression, anxiety and posttraumatic stress disorder, or reduced levels of stress, fear and helplessness. Improved social functioning can be conceived as an individual's ability to perform and fulfil normal social roles without disruption such as domestic responsibilities, interacting with other people, self-care and/or participating in community activities.(Hirschfeld et al. 2000)

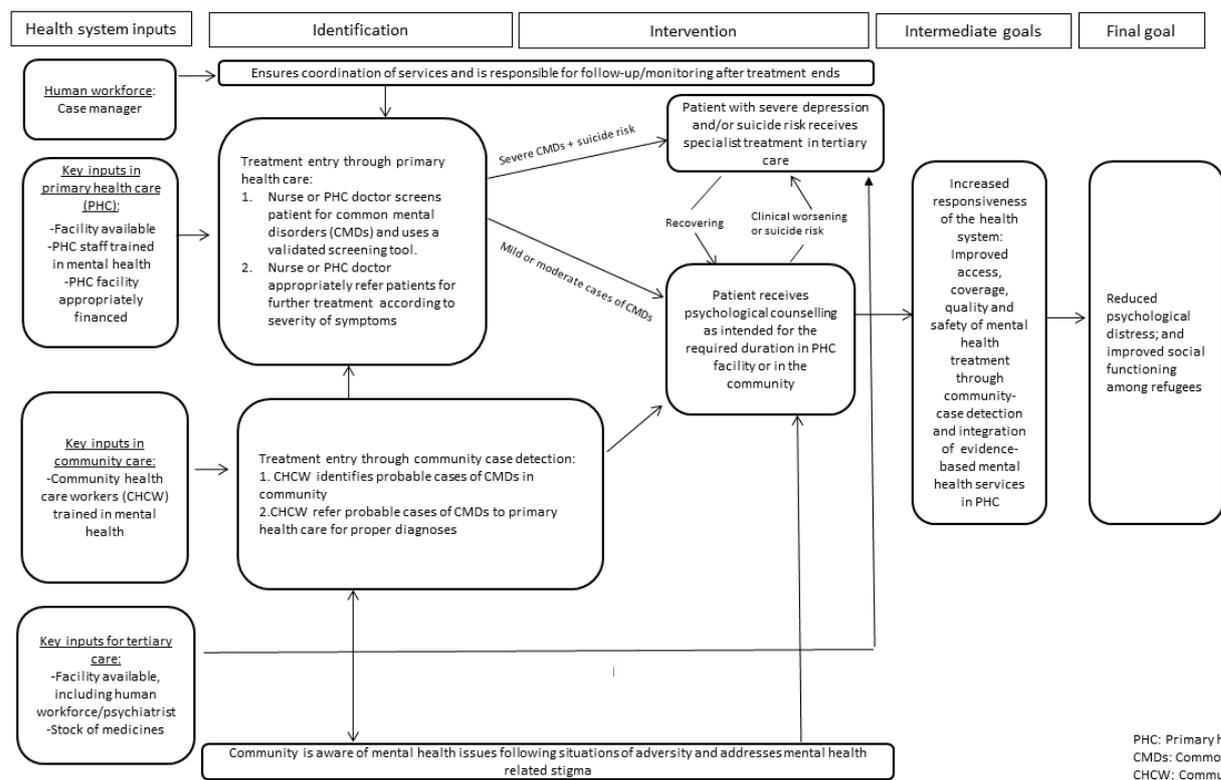
#### Pathways of care

The assessment of the responsiveness of the mental health system is guided by the conceptual framework and key intermediate outcomes. In addition, we also assess pathways of care, and how refugees in host countries navigate the mental health system. Our assessments of pathways of care is guided by the literature suggesting main components of a mental health care model,(Thornicroft and Tansella 2013, 2004) and the mhGAP intervention guide(WHO 2010b) suggesting evidence-based treatment steps for a person with common mental disorders (see Figure 2). Figure 2 indicates that the gateway into mental health care may be the community or primary health care. Case detection in the community, or screening in primary health care is key to identify probable cases of mental disorders and patients who might need help. Low intensity psychological interventions (such as brief psychological therapies delivered by a trained lay health care providers) may be offered first. In case of non-response or clinical worsening, patients may be referred to higher intensity treatment or tertiary care. Ideally, a case manager coordinates the care of the patient including any after care. The mhGAP intervention guide not only identifies essential treatment and services for people with mental

disorders but also suggests to follow principles of care (e.g. being respectful, ensuring provider's communication is sensitive to culture, age; and urges to protect human rights) which addresses domains of responsiveness. Therefore, we conceive a responsive mental health system as a service structure which facilitates treatment entry, offers evidence-based treatments according to MhGAP and ensures that key domains of responsiveness (Table 1) are adhered to during treatment delivery.

A proposed pathway of care is presented in Figure 2.

Figure 2: Suggested pathway of care



### The rapid appraisal methodology to investigate health system responsiveness

Rapid appraisal methodology employs multiple evaluation techniques to quickly but systematically collect data on a distinct health topic (McNall and Foster-Fishman 2007). By using diverse but interlinked methods (such as interviews, focus groups, mini surveys, community discussions or secondary data analysis), it seeks to produce coherent data. Different information sources are validated by triangulation of data. (USAID 2010) It is highly action-oriented, and iterative: data can be analysed while other data are being collected, and preliminary findings are used to guide decisions about additional data collection until theoretical saturation is achieved. (McNall and Foster-Fishman 2007) Rapid appraisals are relatively quick, systematic and cost-effective (USAID 2010), and draw on the perspectives of multiple stakeholders (e.g. patients, health care providers, key informants such as policy makers and NGO workers). (Kumar 1993) They allow taking a patient-centred approach (Balabanova et al. 2009) assessing how the patient navigates through the health system (which can be used to understand health systems' bottlenecks and inefficiencies). Rapid appraisals have been widely used for different purposes: for example to assess health systems performance for maternal and child health (Anker et al. 1993), for chronic conditions such as diabetes and hypertension, (Balabanova et al. 2009; Riso-Gill et al. 2015) for alcohol and substance use in conflict-affected settings, (UNHCR and WHO 2008) and for MHPSS in emergencies. (WHO/UNHCR 2012) The latter rapid appraisal suggests topics that ought to be addressed in MHPSS; however, it did not consider an assessment of health system responsiveness as such and did not provide a theoretical framework guiding its assessment. For this reason, the MHPSS rapid appraisal presented in this

chapter specifically focusing on the health system responsiveness to the mental health needs of forcibly displaced persons presents a valuable new perspective.

Our rapid appraisal is based upon a conceptual framework (Figure 1), and has been developed for the STRENGTHS (Syrian Refugees Mental Health Care Systems) study which explores the health system responsiveness towards the mental health needs of Syrian refugees in Jordan, Lebanon, Turkey, Egypt, Germany, the Netherlands, Sweden, Egypt, and Switzerland. The STRENGTHS study explicitly focuses on Syrian refugees as Syrians make up the largest refugee population group in the countries under study. One important aspect of the rapid appraisal is to investigate how Syrian refugees enter the mental health system in these countries, and how they navigate it (Figure 2). We predominantly employ three methods in the rapid appraisal. First, desk-based reviews are employed to elicit information on country-specific health system inputs and intermediate health system goals (access, coverage, quality and safety) as suggested by our conceptual framework; second, analyses of existing country-specific qualitative data (where available); and third, collection of primary qualitative data obtained through semi-structured interviews to understand pathways of care for Syrian refugees in host countries. Desk-based reviews were conducted to obtain a better understanding of the structure and components of the different health systems Syrian refugees seek care in. A data extraction sheet has been specifically developed for this purpose, extracting information on health system inputs (described in the first part of this chapter) and processes related to investing these. The review included peer-reviewed literature (quantitative and qualitative studies, primary and secondary sources) and grey literature (e.g. documents from international and local NGOs) were included. Validity of the collected information was ensured by using multiple methods and data sources (i.e. triangulating government reports with other research studies), and by seeking expert opinion on major themes and discrepancy in the collected information collected from different sources. In the STRENGTHS study, the desk-based review was complemented by existing qualitative data from partner countries (which were collected as formative work to support the adaptation of a scalable MHPSS interventions developed by WHO for use in low- and middle-income countries and conflict-affected settings).

A core part of our methodology relies on new primary qualitative data collected via semi-structured interviews and focus group discussions to obtain information on intermediate health system goals and other domains of responsiveness. The sampling approach needs to be adapted to local circumstances and should include purposive (including convenience) sampling to select a diverse range of respondents on the basis of their characteristics, roles or experiences; and snowball sampling, asking respondents to nominate other people they know. This is important to ensure a mix of respondents (e.g. providers from different tiers of the health system and from diverse specialties) are interviewed, covering a range of perspectives. Respondents should include key informants (with detailed knowledge of how the system(s) for mental health work, such as from government, health system/service managers, donor agencies, NGO, academia); MHPSS providers (such as nurses, social workers, peer support workers, psychologists, or psychiatrists); Syrian refugees receiving MHPSS services/care (recruited from primary health care facilities, community psychosocial support centres); and family members of Syrian refugees receiving MHPSS services/care.

Data obtained from existing country-specific qualitative data were analysed using both deductive and inductive analysis. Deductive analysis involved coding units of data according to key inputs, processes and outcomes specified in the conceptual framework. Inductive analysis (seeking to elicit new themes or unexpected findings) was done through assigning new codes (outside of our conceptual framework) and further refining and categorising these.

## **Case study: The Netherlands**

We present here some initial findings of a rapid appraisal we conducted in the Netherlands on the responsiveness of the health system to the mental health needs of Syrian refugees. The study was conducted as part of the STRENGTHS study. Data sources were obtained from a desk-based review and transcripts from existing country-specific qualitative data collected by STRENGTHS partners to inform the development and implementation of a trial evaluating a low-intensity psychological intervention for Syrian refugees. We did not collect primary qualitative data ourselves and did not use a topic guide which included specific questions on responsiveness. Therefore, we used access, coverage, quality and safety as proxy responsiveness measures as justified above. Qualitative data were from semi-structured interviews with key informants such as psychiatrists, general practitioners, nurses, and counsellors (n=10) and MHPSS providers (psychiatrists, family doctors, nurses and counsellors) (n=11), and semi-structured interviews (n=10) and focus group discussions (n=4) with Syrian refugees not using MHPSS services. Data were collected between May and August 2017. Ethics clearance for these interviews was obtained by the Ethics Review Committee of the VU University Medical Center, Amsterdam. The following sections present a summary of key findings.

### Wider health system environment and policies

From April 2011 to June 2017, 33,897 Syrians sought asylum in the Netherlands which represents 3.5% of the total Syrian Asylum Applications in Europe.(UNHCR 2017) In 2016, 27,971 Syrian nationals were given a residence permit (61.3% male; 38.7% female; 36.1% below 18 years of age).(CBS 2017) Refugees whose temporary permit expires after five years can receive a permanent permit if protection is still required and if refugees have successfully completed the Dutch integration exam.(Government of the Netherlands 2017b)

### Mental health system inputs

*Leadership and governance:* The Netherlands has a mental health policy and plan(WHO 2011a) which is considered fully implemented.(WHO 2014) Dedicated mental health legislation exists and legal provisions for mental health are covered by other laws such as the Health Insurance Act.(Kroneman et al. 2016)

*Financing and expenditure:* In 2014, the Dutch Government spent 10.7% of its gross domestic product on health.(The World Bank 2017) Of the total expenditure on health, 10.7% was used for mental health in 2011, of which 59.2% was spent on mental health hospitals.(WHO 2011b, a) The Dutch mental health system is financed by the following sources: the social support act and youth act (via the city councils), health insurance act (via health insurers), justice (in criminal cases), and the long-term care act (Wlz) (via care offices).(GGZ Nederland 2018a) Basic health insurance including mental healthcare is mandatory for all citizens.(Kroneman et al. 2016) Insurance covers basic psychological support offered by a psychological wellbeing practitioner (nurse, community worker or psychologist) located at the general practitioner's (GPs) practices. Specialized mental health care is only covered when a diagnosis complies with the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition. Asylum seekers are insured collectively under the Asylum Seekers Healthcare Scheme and are entitled to nearly all health care, including mental health, provided under the standard package and the Wlz.(Government of the Netherlands 2017a) Once refugees receive refugee status and are settled into a municipality, they are required to start paying a monthly insurance premium and a deductible of up to €385 per year out of pocket for most health care except general practitioner consultations and care

for children under the age of 18 years.(Kroneman et al. 2016) Interpreters are covered by the insurance for refugees residing in asylum seeker centers, however, this is not the case for refugees who obtained a residence permit.

*Facilities and services:* In 2011, there were 1.19 mental health outpatient facilities, 260.1 day-treatment facilities, and 0.12 community residential facilities per 100,000 population available in the Netherlands.(WHO 2011b, a) Mild to moderate mental disorders are treated in basic ambulatory care settings (e.g. primary mental health care offered by a psychological wellbeing practitioner).(Mossialos et al. 2016) More severe and complicated cases are referred by GPs to specialist mental care providers and/or institutions, also called 'GGZ-instellingen' [Mental Health Care institutions] which provide care for all people of all ages.(Mossialos et al. 2016; GGZ Nederland 2018b)

*Mental health workforce:* The Netherlands has a high number of psychiatrists (20.2 per 100,000 population) and psychologists (90.76 per 100,000 population) but a low number of nurses working in mental health (2.87 per 100,000 population).(WHO 2014) Larger GP practices are generally supported by a psychological wellbeing practitioner/mental health care worker (called POH-GGZ in Dutch; usually a nurse, community health worker or a psychologist working at a GP facility) or social-psychiatric nurse, who are able to diagnose, offer basic treatment, and make referrals in consultation with the GPs.

*Information and research:* Sources collecting information on mental health care at the national level do not disaggregate data for refugees. NGOs involved in livelihood and provision of social support for asylum seekers and refugees do not consistently publish data on their activities on their websites (except for the Dutch Council for Refugees).

### Intermediate health system goals and responsiveness

#### *Care pathways:*

The following care pathways were obtained from interviews with key stakeholders: Adult asylum seekers receive a medical screening at the GP practice that is linked to the asylum centre they are residing in. However, this medical screening may not always include psychological questions. Early detection and referral can also be conducted by case managers, Dutch Council for Refugees volunteers, Community Health Services and other NGO volunteers. Self-referral is also possible. Asylum seekers are assigned to a GP practice at the asylum centre linked to their community, while refugees in the community can choose their own GP.

Syrian refugees have similar care pathways as the Dutch nationals. The GP can make an initial mental health diagnosis, and if needed, treats or refers to secondary care. GPs are responsible for treating people with milder forms of mental illness.(Rijksoverheid 2018) A POH-GGZ worker/psychological wellbeing practitioner (often available at larger GP practices) may also support a patient, but the GP retains ultimate responsibility for the patient.(Rijksoverheid 2018) People suffering from severe and complex mental disorders are generally admitted to mental health care institutions, either ambulatory or residential.(Rijksoverheid 2018)

#### *Availability and accommodation:*

Findings about the scope of services and workforce that are available were mixed. According to some providers interviewed for this study, there are sufficient resources to provide care for refugees; the scope of services to respond to the needs of refugee children was also seen as appropriate. However,

a few other interviewees raised concerns about service availability especially in rural areas and highlighted the lack of culturally appropriate MHPSS care. Training in cultural competence was recommended for all mental health providers. Some interviewees raised availability and accommodation concerns: a MHPSS provider complained that the POH-GGZ worker (a well-being practitioner supporting the GP at their practice) works for one day a week only. This was confirmed by another provider who indicated that it is sometimes difficult to have the right amount of care/services available due to fluctuating numbers of asylum seekers arriving in the Netherlands leading to difficulties in planning. A refugee added further that the Dutch Council for refugees was only open one day a week (for two hours) which was not considered to be sufficient.

*(Geographic) Accessibility:*

Providers and key informants commented that travel costs, time, and logistics of accessing MHPSS services may be a barrier for Syrian refugees. This was also confirmed by the literature.(Van Berkum et al. 2016) A provider reported that refugees generally receive social benefits but may have limited financial means. Moving accommodation (which some refugees have to undergo regularly) may lead to drop-out during treatment. Several providers were concerned about the accessibility of mental health services for Syrians residing in rural areas specifically, where less (culturally appropriate) services are available. In a focus group, Syrian refugees discussed that women may not be allowed to travel or attend appointments without their husbands. This suggests that physical access to services may be particularly problematic for women especially in rural areas. Geographic barriers may be less relevant for asylum seekers, as key informants explained that primary health services for this group are available at the asylum centres.

*Affordability:*

Several barriers to affordability of MHPSS were raised by study participants. Key informants were concerned that Syrian refugees may experience barriers in seeking MHPSS due to the need to pay the health insurance deductible out of pocket.(Van Berkum et al. 2016) This deductible applies to settled refugees only, not to asylum seekers.. 'Health insurance' may be a foreign concept to Syrian refugees: and some providers felt that this concept is difficult to explain to a refugee, especially the deductible component. Another key informant highlighted that while refugees on social welfare can get the greater part of their deductible costs refunded, the reimbursement process is complicated. Financial barriers were also raised with regards to professional interpreter services. These services are covered for asylum seekers (Asylum Seekers Healthcare Scheme), however, the health insurance of settled refugees does not cover interpreter services.

*Acceptability:*

A commonly mentioned barrier among respondents was related to the acceptability of services. Language was mentioned as a key obstacle for Syrian refugees in seeking support and receiving appropriate MHPSS care in the Netherlands. Both Syrian refugees and health care providers who were interviewed experienced communication problems. Refugees found it difficult to clearly express their mental health needs to providers in a foreign language or through an interpreter. Similarly, providers perceived it challenging to fully comprehend their patients' psychological complaints, even if interpreters were present. Interviewees suggested to have "interpreters who are being reimbursed and ideally of Syrian Arabic origin", and to employ primary and specialist care providers who understand mental health issues of Syrians refugees and have some knowledge of the Syrian culture. Employing Syrian mental health providers was considered a good option, however, according to interviewees their qualifications are usually not recognised in the Netherlands.

Key informants added that stigma may be an important reason why Syrian refugees refuse, or delay mental health care. Syrian refugees interviewed for this study expressed a fear of being labelled as

'crazy'. While seeking professional support for mental health issues is becoming socially more acceptable amongst Syrians, particularly for the young and the more educated, most Syrians prefer to keep these issues to themselves or within their families. A few Syrians indicated a concern that their psychological complaints may be reported in their 'file' and that this may negatively affect their citizenship status, child custody, and/or work opportunities.

#### *Quality and safety:*

Long waiting times in mental health care was the most frequently mentioned quality-related concern. Waiting times were regarded as particularly problematic for larger specialist intercultural services like i-psy (I-psy is a country-wide institution specialized in transcultural mental health care providing treatment to patients from different cultural backgrounds). According to a provider, smaller culturally sensitive centres have shorter waiting times but are less well-known to refugees. Key informants explained that providers commonly refer refugees with mental health needs to i-psy as its facilities as they employ providers from different cultural backgrounds and staff with a range of language abilities.

Another concern raised by study participants was related to continuity of care. The fact that many refugees are forced to move between different locations before being more permanently settled in a community was perceived as challenging. A key informant added that it may be difficult to find a new culturally appropriate provider for a Syrian patient who moved into a new area and that it may take time to build up trust.

The findings from the qualitative work also suggest that Syrians who do seek support may not always receive appropriate treatment. Interviewees mentioned that Syrian refugees commonly express their psychological needs in terms of physical complaints (e.g. headache, fatigue). Healthcare workers, according to several interviewees may be insufficiently trained to recognise that in some cases, mental health symptoms may underlie somatic conditions.

#### Discussion on mental health system responsiveness in the context of forced migration

The initial findings from our rapid appraisal indicate mixed results in relation to the responsiveness of the mental health system to the mental health needs of Syrian refugees in the Netherlands. Our rapid appraisal shows that the Netherlands have a high number of mental health professionals per population resulting in an adequate service coverage for the general population; this situation is similar to other Western European countries.(WHO 2018a) While mental health services may be available for Syrian refugees in urban areas, there seems to be scope to increase coverage of effective services in both urban and rural areas for this specific population group. Effective services are evidence-based treatments recommended for the treatment of mental disorders which have been tailored to the cultural needs of refugees and take account of different thoughts, schemas, beliefs or norms on mental health and mental illness(Dinos 2015).

Acceptability of services and language seem to be key barriers for Syrian refugees hindering help-seeking. It becomes evident that not only providers in primary health care and the community need to be culturally trained but that also services need to be adapted to the specific needs of this population group to facilitate service use. Interpreters may be indispensable during psychological treatment, however, for effective treatment delivery, the cultural background of interpreters themselves needs to be considered. To increase service uptake of culturally appropriate interventions, mental health stigma experienced by Syrian refugees needs to be addressed. Recommendations

include policy makers and health care workers in the community advocating for mental health awareness and providing educational activities to increase demand of mental health services.

While formal care pathways are in place, not all Syrian refugees may be benefiting from this service structure. Specifically, there is a need to improve early detection of psychological problems. This could be achieved by two means: firstly, by training case workers and social workers in mental health (who may interact with refugees on a frequent basis) so that different manifestations of mental health symptoms and acute worsening can be easily recognized in the community. Secondly, by strengthening the gatekeeping function of primary health care, by providing more GP practices with a mental health care worker or social-psychiatric nurse who are culturally competent in working with Syrian refugees. We see that integration of mental health services into primary health may not necessarily provide greater access to care and may fail short for refugees or patients who come from a different cultural background. Syrian refugees may not access primary health care in the Netherlands or any other European host country because of barriers related to language and culture,(Bartolomei et al. 2016) and the complexity of the health system which refugees fail to navigate.(Langlois et al. 2016) The initial assessment of pathways of care suggests that a collaborative model of care in which lay health care providers/social workers work together with trained mental health professionals may facilitate treatment entry. For example, a low-intensity psychological intervention (e.g. a brief counselling intervention delivered by trained lay health care providers) could be made available in centers like i-psy in which a large proportion of Syrian refugees seek help. There is evidence to suggest that choosing lay health care providers such as peer-refugees trained in the intervention itself may be more acceptable to refugees and contribute to reducing the waiting times and the high workload of mental health specialists in these centers.(Patel et al. 2018; van Ginneken et al. 2013) Integration of such an intervention into the public health care system of the Netherlands would require financial resources, possibly through health insurance. Insurance companies, however, may be unwilling to cover services provided to people who show signs of psychological distress only (as this is considered prevention) and by health workers who are not professionally registered. This means that this intervention may need to be funded by alternative sources such as (inter)national donors or local municipalities. The cost-effectiveness and financial sustainability of such an intervention will therefore be critical.

The responsiveness of the health system in the Netherlands towards the mental health needs of Syrian refugees may be similar to other Western European countries(WHO 2010a) where utilization of mental health services remains low among refugees despite availability of services in the community.(Priebe et al. 2013) Quality of services in European countries are usually high as providers are accredited and have undergone years of training. However, there are reports that refugees may not respond well to these treatments because of mistrust in the provider and unfamiliarity with psychological treatments.(Mangrio and Sjogren Forss 2017; Bartolomei et al. 2016) There also seems to be a need to strengthen collaboration and co-ordination between different services in European host countries to increase service use.(Priebe et al. 2016) Community outreach by social workers may be necessary to identify refugees in need of mental health services so that case workers can link refugees with culturally appropriate services in the community or primary health care.(Priebe et al. 2012) It is the case worker who can provide information about services and the health system, and link the patient with the treatment provider. For European host countries it remains important to overcome poor utilization of services among refugees as those may be a sign of stigma and discrimination(Bartolomei et al. 2016), and may lead to further isolation and exclusion reinforcing mental ill health.(Langlois et al. 2016)

## Conclusion

In this chapter, we discussed health system responsiveness to the mental health needs of forcibly displaced persons. We have presented a conceptual health system's framework, which guided our rapid appraisal applied to Syrian refugees residing in the Netherlands. Our conceptual framework conceives responsiveness as intermediate outcome and suggests that access, coverage, quality and safety may well act as proxy responsiveness measures if primary data cannot be collected. It thereby allows an initial assessment of the responsiveness of the health system by also taking pathways of care into account. Our rapid appraisal methodology is different to current rapid appraisals in MHPSS among conflict-affected populations as it specifically seeks to assess the responsiveness of the health system which is critical for service uptake and planning further investments in the health system. The development and implementation of evidence-based interventions may benefit from conducting a rapid appraisal on responsiveness as it can generate important insights into the functioning of a mental health system before a new intervention is scaled-up.

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