Department of Human Services Southern Metropolitan Region

Understanding the client experience: Refugees accessing and utilising the health system in Australia

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Table of contents

1.	Background and aims3
1.1	Health care systems in developing countries4
2.	Experiences and views of refugees5
2.1	Overall satisfaction with the health care system in Australia5
2.2	Access to GPs and the conduct of clinical tests5
2.3	Logistical difficulties and cultural differences6
3.	Experiences and views of GPs treating refugees
3.1	Time constraints of GPs7
3.2	Language barriers and the use of interpreters7
3.3	Unfamiliarity of refugees with the health system and appointments system8
3.4	Recommendations by GPs8
4.	Experiences and views of non-Government organisations and researchers 8
4.1	Unfamiliarity of refugees with the health system and cultural differences9
4.2	Difficulties with cost, access to services and the use of interpreters
4.3	Workforce training and support services11
4.4	Settlement issues
4.5	Recommendations by non-Government organisations, health professionals and
acad	demics
5.	Summary12
6.	Limitations

1. Background and aims

Refugees are persons who have a well-founded fear of persecution due to their race, religion, nationality, political opinion or social grouping. Due to this fear, they are living outside their country of origin and are unable or unwilling to return, often surviving in perilous conditions.¹

Refugees are likely to have witnessed or experienced human rights abuses (e.g. murder of family members, torture) which may cause long-term physical and psychological trauma.² Refugees may have been forced to live in refugee camps for long periods (up to 20 years), where they lack sufficient medical care, safe drinking water, adequate food, shelter or sanitation, the chance at an education and freedom from violence and crime.² As such, under the leadership of the United Nations High Commissioner for Refugees (UNHCR), the office of the UNHCR seeks to protect refugees and assist them to restart their lives in a new, safe country.³

Australia accepts refugees in accordance with its international obligations under the UN Refugees Convention.⁴ Approximately 13,000 refugees are accepted into Australia each year, through the Commonwealth Humanitarian Program.⁴ Refugees require special assistance to adapt to living in a new country such as Australia. They are less likely to have family support and a secure financial base to alleviate settlement pressures, and this is often coupled with language difficulties.⁴ Refugees may have trouble navigating the new education, housing, social support and health systems in Australia. There is also a high likelihood of pre-existing health conditions and overall poor health status, due to inadequate or nonexistent health care in their country of origin.⁴ Thus, it is especially important that their physical and psychological problems do not go undiagnosed and hamper the settlement experience. Enabling refugees access to timely and quality medical care is crucial to their successful integration and settlement, as optimal health and wellbeing provides a stronger basis for them to adapt and thrive in their new country.

Despite the importance of refugees accessing appropriate medical care, this vulnerable population often require extra support due to the difficulties experienced accessing

¹ United Nations High Commissioner for Refugees. The 1951 Refugee Convention: questions and answers. 2007 Sept.

² Victorian Foundation for Survivors of Torture. Promoting refugee health. A guide for doctors and other health care providers caring for people from refugee backgrounds. 2007. Available from: http://www.foundationhouse.org.au/

³ United Nations High Commissioner for Refugees. [Homepage on the Internet] Available from: http://www.unhcr.org.au/

⁴ Victorian Department of Human Services. Refugee health and wellbeing action plan 2008-2010: current and future initiatives. 2008 Nov. Available from: http://www.dhs.vic.gov.au/multicultural/html/refugee_action.htm/

services. To improve health service planning, delivery and the formation of partnerships, it is paramount that the particular needs and opinions of refugees are taken into account. In particular, it is important for policy implementers in SMR to understand the refugee experience, given that 54% and 73% of refugees and entrants under the Special Humanitarian Program respectively settling in the eastern suburbs of Melbourne settle in SMR (2009).⁵ In the period 2005-2008, 33% of all refugees accepted in Victoria settled in SMR (2,981 people).⁴ Given these high levels of settlement, and the likelihood that these refugees will utilise health services within SMR, such services must undertake proactive planning to deal sensitively with refugees. A collation of research findings in the area of the refugee experience accessing health services will enable the consumer voice to be heard and acted upon. Therefore, this report seeks to review the literature in the area of refugees' ⁶ experiences accessing and utilising the health system in Australia, to inform the planning of health services to better cater for the needs of refugees in SMR.

1.1 <u>Health care systems in developing countries</u>

Prior to exploring the views and experiences of refugees accessing the health system in Australia, it is important to give a general description of health care systems in developing countries, to inform the discussion. While not all the characteristics described below are common to all countries, some frequently occur.

Generally in developing countries, people access medical care through centralised hospitals and clinics.⁷ Specialists are accessed directly without the need for a GP referral.⁷ A patient may visit the same clinic but is often not seen by the same health professional.⁷ Patients may walk for many hours or days to access a health service, and then they sit and wait until they are seen; appointment systems are not often used.⁷ There is little regulation or control over the supply of pharmaceuticals, and they are used more widely than in Australia (e.g. the use of antibiotics for viral infections).⁷ Mental health services are limited and mental health issues are stigmatised.⁷ Instead, there is a focus on physical health concerns and acute care rather than health promotion and preventive care, due to a lack of funds.⁷ The past experiences of refugees using such health systems are highly likely to influence their views of the health system in Australia, and thus must be taken into account.

⁵ Adult Multicultural Education Services. IHSS Settlement Information, January – March 2009. Available from: http://www.ames.net.au/settlement/

⁶ In this report, only literature specific to 'refugees' (e.g. people who have been granted refugee status by a government) are included; the health care experiences of asylum seekers are beyond the scope of this review. ⁷ Victorian Foundation for Survivors of Torture. Towards a health strategy for refugees and asylum seekers in Victoria. 2004 Jul.

2. Experiences and views of refugees

Following a literature search, four Australian studies were identified in which refugees were asked to describe their experiences accessing the health system in Australia. Two studies had a smaller sample size (19 and 34 participants),⁸ ⁹ while two studies were larger (sample size 126 and 305 participants).¹⁰ ¹¹ The studies were conducted in the Australian cities of Melbourne, Sydney and Brisbane. From these four studies, a wide variety of findings emerged:

2.1 Overall satisfaction with the health care system in Australia

While a smaller study conducted in Sydney with 34 participants, reported that refugees had overall high levels of satisfaction with health services provided in Australia,⁸ a larger study conducted in Brisbane with 305 participants reported that refugees had an overall poor opinion of the health system in Australia.¹¹ These differing opinions may be due to the influence of using health facilities in different States, therefore from these two studies it is difficult to conclude the true beliefs of refugees.

2.2 Access to GPs and the conduct of clinical tests

There were a number of concerns expressed relating to GPs and the conduct of health assessments and clinical tests. For example, refugees found it difficult to understand why a GP referral is required to visit a specialist. This may be because in some refugee source countries, there is a shortage of GPs and people see a specialist directly.¹¹ In one study, refugees doubted the competency of GPs, when hospitals repeated a clinical test which had been previously carried out by a GP.¹¹

As reported in a study in western Melbourne, Sudanese refugees believed that initial health assessments were very important, however they wanted more detailed explanations about the process and the clinical tests conducted.⁸ In the same study, the refugees discussed how they found blood tests unfamiliar and thought they were used excessively. They were also concerned that their blood would be sold to a third party, as

⁸ Walker K. "I would rather they tell me." Sudanese refugees' experiences of health assessments: a pilot study. University of Melbourne, [unpub].

⁹ Sheikh-Mohammed M, MacIntyre CR, Wood NJ, Leask J, Isaacs D. Barriers to access to health care for newly resettled sub-Saharan refugees in Australia. MJA. 2006 Dec 4/18;185(11/12):594-7.

¹⁰ Neale A, Ngeow JYY, Skull SA, Biggs B-A. Health services utilisation and barriers for settlers from the Horn of Africa. Aust N Z J Public Health. 2007; 31(4): 333-5.

¹¹ Brisbane Inner South Division of General Practice. The refugee consumer voice: how to ensure it makes a difference. Commonwealth Department of Health and Aged Care. 2001 Jun.

happens in Sudan.⁸ Refugees were also worried that if the doctors told them that the results of a clinical test were clear, that they were not telling the truth. This stemmed from experiences in the refugee camps, where doctors did not tell patients they had a disease because they knew they would not survive.⁸ Some refugees also believed that GPs were reluctant to use interpreters,¹¹ however they did report that GPs were their major health care provider.¹⁰

2.3 Logistical difficulties and cultural differences

Other issues raised related to logistical difficulties, lack of knowledge of the health system and cultural differences. In a study conducted in Sydney, refugee parents reported that they did not know where to seek medical help, how to access services or how to make complaints about health service providers.⁹ They also lacked a general understanding of health issues.⁹ Refugee parents found it difficult to coordinate appointments (e.g. Centrelink, English language classes) and hence often missed them.⁹ This may also be due to their unwillingness to take time off from work (often casual employment) to attend medical appointments.

Refugees emphasised that often they did not have all the information they needed to make decisions about their children's health care, nor did they have the money to pay for health services.⁹ Refugees expressed that their most common difficulty related to language and communication, and that they would appreciate translated information about the health system in Australia, so they are able to more easily access services.¹⁰ When Sudanese refugees in western Melbourne were asked about their views of health, they described that health was the absence of disease, and for good mental health in particular, the companionship of family and close friends was important.⁸

3. Experiences and views of GPs treating refugees

As well as papers documenting the actual experiences of refugees accessing the Australian health system, evidence has also been collated from GPs in Australia documenting their experiences treating refugees. Three studies were identified in which GPs and medical directors of Divisions of General Practice were asked about their experiences treating refugees and planning GP services.^{12 13 14} These studies were conducted in Adelaide,

¹² Johnson DR, Ziersch AM, Burgess T. I don't think general practice should be the front line: experiences of general practitioners working with refugees in South Australia. Aust N Z Health Policy. 2008 Aug 8;5(20). doi:10.1186/1743-8462-5-20.

Brisbane and Melbourne, and involved interviewing 15, 13 and 6 participants respectively.^{12 13 14} Key themes which emerged are outlined below:

3.1 <u>Time constraints of GPs</u>

It was consistently identified by GPs that treating refugees, including organising follow up, ordering investigations and coordinating referrals was time consuming work.^{12 14} GPs felt under resourced at an individual and structural level to provide effective care, due to cultural differences, the special health needs of refugees and the extra administrative work required.^{12 14} Therefore, GPs had difficulty accepting new refugee patients due to time constraints.¹⁴ GP practices also found it difficult to trace refugees to organise follow up if they did not have a case worker, adding to the difficulties.¹⁴

Among a sample of 12 GPs in Brisbane, most reported that they did not routinely use MBS item 714 (provided to perform an initial medical assessment of refugees within 12 months of arrival), because it was too time consuming and they were overwhelmed by the sheer number of MBS items and item changes.¹³ Another barrier mentioned was the lack of remuneration for the extended consultations which are required.¹² GPs also reported that when treating refugees, an additional burden related to dealing with their social and psychological problems- for example, housing issues and family reunions.¹⁴

3.2 Language barriers and the use of interpreters

There were a number of issues raised regarding working with interpreters. GPs reported that they were not able to find interpreters at short notice,¹³ and that working with onsite interpreters was much easier than working with telephone interpreters.¹³ However, they emphasised that all interpreters required training in health care communication.¹³ GPs found they were not able to provide detailed explanations when using an interpreter, and they found it difficult to deal with sensitive issues (e.g. mental health problems).¹² GPs also reported that the additional time needed to conduct consultations was a significant barrier to treating refugees.¹² In addition, there were communication challenges when contacting refugees by phone or letter to organise follow up appointments.¹²

¹³ South East Alliance of General Practice (Brisbane). Survey of GPs- refugee health care. [Homepage on the Internet] Available from: http://www.seagp.org.au/

¹⁴ Tiong A. Health needs of newly arrived African refugees from a primary health care perspective. Australian National University, [unpub].

3.3 <u>Unfamiliarity of refugees with the health system and appointments system</u>

A consistent theme reported by GPs in all studies was the unfamiliarity of refugees with the appointments system in Australia and negotiating appointment times. GPs reported that refugees regularly missed appointments, arrived late or in some circumstances, arrived two hours later and still wanted to be seen.^{12 13 14} In addition, whole refugee families occasionally presented for a single consultation.¹⁴ GPs identified that unfamiliarity with public transport, lack of knowledge of how to access services and illiteracy may contribute to the number of missed appointments.^{13 14}

GPs reported that refugees were unfamiliar with the Australian health system, and lacked understanding of health problems.^{12 13 14} This meant that GPs had to spend time explaining how the health system worked- e.g. connections with other agencies, referrals to specialists and prescriptions.¹²

3.4 Recommendations by GPs

When asked to provide recommendations, GPs suggested that it would be best for voluntary organisations and community health workers to play a greater advocacy role and assist refugees to navigate the health system.¹² GPs also emphasised the importance of the refugee health nurse program in coordinating refugee health care.¹⁴ A group of private practice GPs in Adelaide voiced the strong opinion that they should not be the front line for refugee health care; instead initial care should be provided via a specialist refugee health service.¹² To assist care, GPs would like refugees to arrive for appointments on time and to book separate appointments for each family member.¹³

4. Experiences and views of non-Government organisations and researchers

As well as papers published describing the views of refugees themselves and the opinions of GPs who regularly treat refugees, much information has also been published by nongovernment organisations (e.g. Foundation House, Refugee Council of Australia), academics and other health professionals who study refugee health care. Findings from these sources are outlined below:

4.1 <u>Unfamiliarity of refugees with the health system and cultural differences</u>

The most common issue discussed by these reports related to the unfamiliarity of refugees with the Australian health system, including their confusion over the differences between public and private health services.¹⁵ Refugees often lack knowledge of the services available and when to use them. For example, calling an ambulance when someone is ill and not once they have died, as is the practice in some countries.

Refugees are likely to hold different beliefs relating to the causes of and treatment for illness (e.g. mental illness, disability), the role of health providers and expectations of the health system.¹⁶ Refugees are generally not familiar with the concept of preventive health care (e.g. dental health practices) and illness prevention services (e.g. screening programs).⁷ ¹⁷ Refugees often have a reduced inclination to play an assertive role in their health care and may delay seeking help, especially for mental health concerns.⁷ In addition, refugees are generally not knowledgeable of the principles relating to informed consent and confidentiality, and often need reassurance about the latter.^{7 18}

An area of particular concern relates to refugees' limited awareness of the central role of GPs in providing health care in Australia, and the importance of developing a relationship with a GP.⁷ Instead of presenting to a GP in the early stages of illness, refugees are more likely to use hospital emergency departments for general medical issues,⁷ as they are used to only seeking medical help when a problem is acute.¹⁷ In the same way, refugees are not likely to take their children to a GP to check general development; instead only when they are ill.¹⁷ These practices may be a legacy of their time spent in refugee camps, where health infrastructure was limited or nonexistent.

Refugees are unfamiliar with the role of GPs in referring to specialists, and may view GP involvement in this process as a delay to diagnosis and treatment.⁷ This may be because in some developing countries, there are more specialists than GPs. Refugees are generally not able to navigate the health referral processes without assistance,¹⁹ and they view

¹⁵ Correa-Velez I, Gifford SM, Bice SJ. Australian health policy on access to medical care for refugees and asylum seekers. Aust N Z Health Policy. 2005 Oct 9;2(23). doi:10.1186/1743-8462-2-23

¹⁶ Murray SB, Skull SA. Hurdles to health: immigrant and refugee health care in Australia. Aust Health Rev. 2005 Feb; 29(1):25-9.

¹⁷ Refugee Council of Australia. Australia's refugee and humanitarian program: community views on current challenges and future directions. 2008 Feb.

¹⁸ Harris M, Zwar N. Refugee health. Aust Fam Physician. 2005 Oct; 34(10):825-9.

¹⁹ Refugee Council of Australia. Australia's refugee and humanitarian program: community views on current challenges and future directions. 2009 Jan.

follow-up care through multiple specialists as a complex and stressful experience.⁷ In this way, refugees often require intensive support to manage these referrals.²⁰

Likewise, refugees are not familiar with the central role of the appointments system which operates in Australia for administrative and funding reasons, and may prefer to turn up and wait rather than make an appointment.^{7 17} Refugees also are generally unaware of the need to make separate appointments for each child. They are not familiar with the process of arranging and keeping appointments, and often need reminder calls as they may not be able to record details of an appointment due to illiteracy. Illiteracy (in their own language and English) makes refugees extremely vulnerable to exploitation. Similarly, refugees may not comply with prescription instructions due to illiteracy or communication difficulties with the GP or pharmacist, and thus may use medicines inappropriately.⁷ In some instances, refugees are prescribed medication without knowing what or who it is for.¹⁹ When GPs do not prescribe pharmaceuticals, refugees may become frustrated as drugs are more readily supplied in developing countries.⁷

4.2 Difficulties with cost, access to services and the use of interpreters

A widely reported barrier related to the cost of and difficulty accessing health services by refugees.¹⁶ Refugees are generally unable to afford the cost of specialist health services,¹⁵ and a lack of bulk billing GPs and specialists in rural areas makes access difficult.^{15 17 20} In addition, refugees may not be aware of their rights, including their right to access bulk billed services and an interpreter free of charge.¹⁶

At the same time, reimbursement for GPs is inadequate for the additional time spent treating refugees, providing follow up and coordinating care.²⁰ This may cause some GPs to refuse to treat refugees at all,¹⁷ and cause extra burden on willing GPs and hospital emergency departments.

Communication difficulties were a consistent theme.¹⁶ Language barriers may cause miscommunication, misdiagnosis and cause follow up to be problematic.²⁰ As reported by the Refugee Council of Australia, the refusal or failure of GPs and specialists to use interpreters (even free telephone interpreter services) during consultations is a systematic problem.^{17 19 20} These problems are exacerbated in rural areas.¹⁵ Refugees living in rural and regional areas face particular difficulties in accessing health services. If they lack

²⁰ Finney Lamb C, Smith M. Problems refugees face when accessing health services. NSW Public Health Bulletin. 2002 Jul 1;13(7):161-2.

private transport, then dependence on public transport or the kindness of others (e.g. family, friends) to provide transport to medical appointments is not a long term solution.

4.3 <u>Workforce training and support services</u>

The mainstream health workforce in Australia generally have a low level of awareness of refugee health issues, and generally do not receive the training and support they need to treat refugees.¹⁶ Many cases were reported during consultations to the Refugee Council of Australia, of GPs lacking basic understanding of refugee health issues and failing to employ culturally appropriate practices.¹⁷ It is reported that volunteers and refugee case workers spend a significant proportion of their time assisting refugees to make medical appointments and accompanying them to appointments.¹⁷

4.4 <u>Settlement issues</u>

Even when medical appointments are made, refugees still experience difficulties attending. For example, refugees who work in casual and low paying jobs may be afraid to take time off work to attend medical appointments due to the loss of income or threat of dismissal.¹⁶ They may also be more likely to work in hazardous occupations, further endangering their health.¹⁶ Lack of private transport to attend medical appointments may mean appointments are missed due to infrequent public transport services in outer suburban areas where refugees usually settle. Due to previous traumatic experiences including torture, afflicted by or under the supervision of government authorities and medical staff, refugees may avoid using government health services altogether.^{16 18 20}

4.5 <u>Recommendations by non-Government organisations, health professionals and</u> <u>academics</u>

Comprehensive educational programs for refugees explaining the health system in Australia, including the preventive health approach, may be of benefit to familiarise refugees with the health system of a developed country.¹⁷ An increased number of CALD health workers in the mainstream health system may improve the cultural responsiveness of health providers, thereby improving service delivery to refugees.¹⁶

5. Summary

Taking into account the viewpoints of refugees themselves, their treating GPs, non-Government organisations and academics, three key topics were brought up repeatedly by all three groups. These were:

- <u>Communication barriers and difficulties arranging interpreters</u>: Refugees are likely to arrive with poor English skills and are largely dependent on interpreters, at least during the initial settlement period. This makes navigating the health and other systems difficult and stressful. This is especially so when a patient has difficulty communicating with a doctor, pharmacist or allied health professional, during a consultation, a visit to hospital or during follow up. Treating refugees usually requires extended consultations- sometimes up to double the time of a standard consultation.</u> GPs have a busy workload and are unlikely to be able to provide all the follow-up care and case coordination necessary, and they are not adequately renumerated for their time.
- Lack of knowledge by refugees of the Australian health system: Refugees lacked knowledge and experience navigating a health system in a developed country. There are stark differences between the health systems in a developed versus a developing country. Refugees need time and assistance to adjust to a medical system which is based around appointments, referrals to specialists in different locations and often multiple clinical tests. Refugees need greater assistance during their orientation period, which may be achieved through greater dissemination of translated information about the health system, the services available and how to access them.
- Logistical and settlement issues leading to missed appointments: Finally, until refugees are familiar with their surroundings, some may require one-on-one assistance to arrange appointments and organise transport arrangements. These difficulties are further exacerbated if the refugee is illiterate. Refugees may feel pressured to stay at work or at English language classes rather than attend appointments (e.g. medical, Centrelink). In addition, they may avoid using health care services because they cannot afford to pay, or because of previous traumatic experiences in their country or birth or transit.

6. Limitations

There are several limitations of this review which must be acknowledged.

The generally small sample sizes of the studies may limit the accuracy and generalisability of their findings. For example, the three studies exploring the views of GPs ranged in size from 6-15 participants.^{12 13 14} Two papers investigating the opinions of refugees were also small (19 and 34 participants),⁸⁹ however two were much larger (126 and 305 participants).^{10 11} It is likely that studies with larger sample sizes would enable a wider variety of views to be expressed. The studies were conducted in the four capital cities of Melbourne, Sydney, Brisbane and Adelaide, in different populations including Sudanese refugees and refugees from the Horn of Africa. It is highly likely that refugees from different countries would have different expectations and hence experiences of the health system in Australia, depending on their previous experiences and exposure to trauma and persecution. In addition, their experiences are likely to differ according to their settlement location in Australia, as health service delivery differs between states (e.g. provision [or not] of specialised refugee health clinics). The collation of findings from these mostly small studies from different Australian cities, with varying cultural backgrounds of refugees, is likely to mean that a wide variety of experiences are reported. However, despite these differences, consistent themes emerged from these mainly qualitative studies, hence it must be assumed that there are common views and experiences shared by all.

It must be noted that refugees are likely to be completely dependent on the public health system, due to their dependence on Centrelink benefits or a low income, and this is likely to influence their perceptions of treatment and access. Use of the public health system may involve long waiting times for treatment in public hospitals for emergency care or elective surgery, dental care and community health services. Again, the largely exclusive use of the public health system by refugees is likely to affect their experiences, and must be taken into consideration when considering the outcomes of this report.

A further limitation relates to the range of resources used- not all were peer reviewed articles- for example, an unpublished report by the Brisbane South East Alliance of General Practice.¹³ This may have reduced the quality of the evidence collated.