A COMPREHENSIVE APPROACH TO HEALTH LITERACY: VALIDATING THE ALL ASPECTS OF HEALTH LITERACY SCALE (AAHLS) IN A REPRESENTATIVE SAMPLE OF ARABIC-SPEAKING ADULT SYRIAN REFUGEES

By

Raafia Siddiqui, BSc (HONS)

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AUTHOR: Raafia Siddiqui, BSc Hons. (York University, 2014)

SUPERVISOR: Dr. K. Bruce Newbold

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ABSTRACT

The purpose of this study is to quantify current health literacy levels amongst a segment of the Syrian refugee population in Canada by translating and validating an existing comprehensive health literacy assessment tool, the All Aspects of Health Literacy Scale (AAHLS) into Arabic. This study (1) determined functional, communicative and critical health literacy levels amongst Syrian refugees. Functional and critical health literacy was comparatively low but respondents seemed able to effectively communicate with their providers and access supports to read and fill in health documents. Significant correlates of low health literacy were presence of long-term health conditions and place of origin (country versus refugee camp). This study also validated the AAHLS in Arabic-speaking Syrian refugees, with a Cronbach's alpha of 0.67 for the overall scale and 0.63 for health literacy items. The overall scale had high content validity. The feasibility of this instrument as a self-administered screening tool in clinical or community settings was demonstrated with a high response rate of 0.86.

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ABBREVIATIONS

AACC- Auntie Amal Community Centre

AAHLS – All Aspects of Health Literacy Scale

CIC- Citizenship and Immigration Canada

GAR- Government Assisted Refugees

HCP- Health Care Provider

LIFT- Low Income Families Together

NGO- non-governmental organization

UN- United Nations

UNHCR- United Nations High Commissioner for Refugees

UNICEF- United Nations Children's Fund

1.0 INTRODUCTION

1.1 Research Context

1.1.1 The Syrian Crisis and Canada's Response

Since 2011, a civil war in Syria has ravaged the entire country, displacing more than 11 million of its citizens. Around 4.8 million have sought asylum in surrounding countries such as Jordan, Turkey, Iraq and Lebanon, and more than 6.3 million remain displaced in Syria. Most neighbouring countries are themselves poor and can offer limited financial and infrastructural supports (Mercy Corps, 2017). Lebanon for example, hosts up to 1.5 million Syrian refugees (European Civil Protection and Humanitarian Aid Operations [ECHO], 2017). The population lives in devastating conditions with the majority (71%) living in overcrowded apartments with poor infrastructure, sanitation and high risk of damage. Another 12% live in informal settlements like makeshift tents and 17% live in non-residential buildings such as garages or worksites (Inter-Agency Coordination Lebanon 2016). The United Nations (UN) estimates that one in ten Syrians live in a refugee camp, one of the largest being Jordan's Za'atari refugee camp which houses 80,000 Syrians (Mercy Corps, 2017). Camps like Za'atari and Azraq in Jordan and the 22 camps in Turkey are jointly run by local governments and UNHCR, often with additional support from non-governmental organizations (NGO's). Over a million Syrians have fled to Europe to seek asylum, traversing the life-threatening waters of the Mediterranean. The response in Europe has been quite tempestuous, with countries like

Greece, Italy and Hungary, bearing most of the weight in settling asylum seekers (BBC News, 2016).

Janet Dench, executive Director of the Canadian Council for Refugees reminded Canada in 2015 of its long history of accepting refugees and its "moral obligation" to offer resettlement to Syrians. She said it represents "balancing out in a very minor way, because obviously we are never going to get anywhere close to the proportion of refugees that a country like Lebanon has, or Turkey" (Brean, 2015).

Canada has been admitting between 4000 and 15,000 refugees a year since 1989, with some years showing even higher numbers (Schwartz, 2015). The country broke its own record in 2016 when it admitted a staggering 46,700 refugees. This is the highest number of refugees admitted into the country since the **Immigration Act** came into effect in 1978 (Puzic, 2017). The Act recognized the **1951 United Nations Convention Relating to the Status of Refugees**, which grants international rights to **Convention Refugees**, whom it defines as

> "person(s) unable or unwilling to return to their country of origin owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group (such as women or people of a particular sexual orientation), or political opinion" (UNHCR, 1967, p. 3)

As of January 29, 2017, 40,081 Syrian refugees have been resettled in Canada through its "#WelcomeRefugees" program (Citizenship and Immigration Canada [CIC], 2017). *National Post* contributor Joe O'Connor explains the impact the Syrian crisis had on the Canadian psyche, when "came that photograph of poor little Alan Kurdi, lying dead on a beach. Suddenly a peripheral issue for most Canadians catalyzed an election that produced a Liberal majority and, on Dec. 10 at Pearson International, a winning photo-op for the new prime minister" (2015, n.p.). The Liberal government accepted 25,000 Syrian refugees in 2015 and diverse sectors including settlement, health care, education, employment and several others mobilized to the mass arrival of Syrian refugees (Access Alliance, 2017, p.3; City of Hamilton, 2017; Wesley Urban Ministries, 2014).

They have generally arrived under one of three categories. The majority, around 20,000, were **Government-sponsored refugees (GAR's).** GAR's are persons identified as being vulnerable persons eligible for resettlement by UNHCR, who then refer them to the Canadian government. They are supported in their first year of arrival by the Government of Canada or the Province of Quebec under the *Resettlement Assistance Program*, through which they are given financial support for housing, health care and emergency dental care. They are also connected to necessary services and supported in finding temporary and permanent housing. For a period of time, the federal government even covered the cost of travel expenses and immigrant medical exam for Syrian GAR's (O'Neil, 2015). GAR's get their **permanent residence (PR)** card as soon as they arrive in Canada and are legally able to live, work and study in the country for the rest of their

lives. After three years, GAR's can apply to become Canadian citizens (Citizenship & Immigration Canada [CIC], 2017).

Another 14,000 arrived as **privately sponsored refugees**. In place of the government, an organization, referred to as a Sponsorship Agreement-Holder (SAH) or a group of individuals authorized by that organization (Constituent Groups or CG's) or assembled on their own (Group of Five or G5) assume responsibility for privately sponsored refugees during their first year of stay in Canada. It becomes the private sponsor's responsibility to find housing, food and clothing for the refugees. They connect them to a family doctor and to other service providers, help the children enroll in school and show them how to navigate local transportation, health care and banking systems (CIC, 2017).

Finally, some 4,000 Syrian refugees entered Canada under the blended visa stream. Like GAR's, these individuals are referred by the UNHCR but are jointly supported by the government and a private sponsor group for their first year in Canada, with each party contributing support for 6 months (CIC, 2017).

1.1.2 Syrian Refugee Health Care in Canada

Resettled refugees, refugee claimants, protected persons, victims of human trafficking and people detained by the Canada Border Services Agency (CBSA) receive their health care coverage through the *Interim Federal Health Program* (IFHP). This

program covers basic services comparable to that provided to Canadian citizens through provincial or territorial health insurance plans, including clinical or hospital in-patient and out-patient services from medical doctors, registered nurses and other licensed health professions, as well as laboratory, diagnostic and ambulance services and pre- and post-natal care. In addition, IFHP covers supplemental health services comparable to what individuals on social assistance would receive, including some visual and dental care, long-term or home care as well as services from allied health professionals such as physiotherapists and psychologists. Finally, the supplemental coverage plan also covers assistive devices and medical aids. In addition, the plan covers the immigrant medical exam (CIC, 2017). In 2012, the Canadian government made major cuts to the IFHP which left certain groups out of even basic coverage for life-saving medical treatment and had devastating impacts on refugees and other vulnerable groups. In 2016, the liberal government restored the IFHP to its original state (Medavie Blue Cross, 2016), in time for the arrival of the first wave of Syrian refugees.

Syrian refugees receive their IFHP certificates as soon as they land in Canada along with their permanent resident status and social insurance number (SIN). In Ontario, Quebec and some other provinces, they are immediately eligible for provincial insurance coverage. (Lifeline Syria, 2016).

In addition, local municipalities and communities have assembled coordinated responses to address the health needs of newly arrived Syrian refugees. In Toronto for

example, 32 different health care provider agencies work cohesively to ensure that Syrian refugees receive the care they need (Access Alliance, 2017). The major assumptions for refugees arriving in Ontario are that, they are generally in good health with the exception of specific health needs associated with having experienced trauma and-or difficult living conditions, that they will need support learning to navigate the Canadian health care system and major challenges will include language and cultural barriers to communication and delivery of health services (Ontario Ministry of Health and Long-term Care, 2015).

1.2 Background on Health Literacy

1.2.1 What is health literacy?

Health literacy is an evolving concept within the Canadian public health domain, defined as "the degree to which people are able to access, understand, evaluate and communicate information to engage with the demands of different health contexts in order to promote and maintain good health across the life-course." (Kwan, Frankish & Rootman, 2006). A health literate individual or organization employs a range of skills, including communication (reading, writing, listening, speaking), critical thinking, and interaction to advance their own health or that of their patients (Coleman et al., 2011). The Public Health Association of British Columbia has referred to health literacy as being "critical to the Canadian's capacity to manage their health" (2012, p.3). Understandably so, given that individuals with poor health literacy skills are 1.5 to 3 times more likely to

experience negative health outcomes (DeWalt et al., 2004). In addition, they are more likely to suffer from chronic diseases like diabetes or heart disease or suffer from an accident. Poor health literacy has also been linked to lower life expectancy, misuse of medication and misunderstanding of health information or instructions (ABC Life Literacy Canada, 2016).

The current levels of health literacy in Canada are alarming. According to the Public Health Agency of Canada, 60% of Canadian adults and 88% of seniors do not possess adequate health literacy skills. That means that they "cannot confidently and knowledgeably access, understand, evaluate and communicate information that is related to their health and the health of their loves ones. They cannot navigate the often-complex health care systems across this country nor can they decode health information that we all need to process in our daily lives" (ABC Life Literacy Canada, 2016, n.p.). ABC Life Literacy Canada explains how integral good health literacy is to basic health interactions like picking up a prescription. A person needs to be able to understand what is written on the package or label, what condition or symptoms it has been prescribed for and have the basic language skills to convey their questions or concerns. For someone with poor health literacy, these basic tasks become highly difficult. In addition, "once we add low literacy or language barriers into the mix, and then compound those with the stresses of being sick or worried, we quickly realize what a challenge navigating our health system can be" (2016, n.p.).

1.2.2 Theoretical Framework: The Nutbeam Model of Health Literacy

Nutbeam has developed a health literacy model which frames it as a critical outcome of health promotion and education activities. This model aligns well with the very broad definition of health literacy set by The World Health Organization (WHO),

"Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health" (Nutbeam, 1998, p.349).

"Health literacy means more than being able to read pamphlets and successfully make appointments. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment" (WHO, 2016, n.p).

Nutbeam argues that in order for the kind of health literacy described to be achieved, there needs to be a shift away from defining and addressing health literacy strictly in terms of reading or writing ability and adherence to prescribed treatments. In fact, Nutbeam notes that health education programs in general underwent a transformation in the 1980s as they began to shift away from basic modes of transmission of information to the masses (ex. using mass media, or ad campaigns) which only benefitted a select few individuals with the social and economic means to receive that

information and make the recommended lifestyle modifications, towards a system that acknowledged the role of social environments on individual behavioural decisions. These programs "focused on helping people to develop the personal and social skills required to make healthy behaviour choices" (Nutbeam 2000 p.260). This shift in the approach of health promotion programs demonstrates the need to move beyond interventions that focus on communication of information to those that address the social and environmental barriers to good health, particularly as it pertains to the context of marginalized countries or populations. This includes addressing public policy and other structural or social conditions which influence individual behaviours. A classic example would be anti-smoking campaigns which achieved their goals through a combination of public education through public ads, in addition to policies which limited access to smoking by making cigarettes more expensive or restricting their use.

The Nutbeam model suggests that desired health and social outcomes, such as increased quality of life, functional independence, equity, reduced morbidity, mortality or disability, health promotion activities centered on education, can be improved by focusing social mobilization and advocacy work on improving modifiable social determinants of health such as healthy lifestyle behaviours, use of health services and the quality of environments individuals live and work in. The means of modifying these social determinants of health is through health promotion activities and program which address one's social action and influence, public policy and organizational practice and individual and population health literacy (2000, p. 262).

Nutbeam's model of health literacy divides it into three categories:

- **Basic/functional health literacy**: *"sufficient basic skills in reading and writing to be able to function effectively in everyday situations"* (p.263).
- **Communicative/interactive literacy:** *"more interactive cognitive and literacy skills which together with social skills can be used to actively participate in everyday activities to extract information and derive meaning from different forms of communication and to apply new information to changing circumstances"* (p.264).
- **Critical literacy:** *"more advanced cognitive skills which together with social skills, can be applied to critically analyze information and use this information to exert greater control over life events and situations"* (p. 264).

1.2.3 Health Literacy through an Empowerment Lens

The Public Health Association of British Columbia (2012) has cited health literacy as a social determinant of health that is closely tied to other social determinants including literacy, education and income. A recent study by the Canadian Council on Learning (CCL) found a significant gap in the average health literacy levels of immigrants and non-immigrants in Canada. They found the average health literacy scores to be even lower for immigrants with poor English or French language proficiency. Furthermore, immigrant women were found to have lower scores than men (Murray et al.,

2008). These findings demonstrate the intersections of various factors such as status, gender and language proficiency in determining health literacy outcomes and underscore the need for a more thorough examination of health literacy levels in marginalized groups.

The Nutbeam model of health literacy suggests that health literacy is dependent on not just individual intelligence, but one's social location and self-confidence and well as access to social supports. By this definition, it can be understood why marginalized groups may experience greater difficulty in achieving adequate or high literacy levels. However, it also suggests that an improvement in an individual's functional, critical and communicative health literacy can lead to greater personal empowerment and autonomy (Nutbeam, 2000). Critical health literacy in particular, is a powerful measure of an individual's ability to derive information from different forms of communication and to critically analyze that information, using it to exert greater control over their lives. Thus, critical health literacy and health literacy overall can be key components to the empowerment of marginalized groups (McKeary & Newbold, 2010; Nutbeam, 2000).

Given the substantial link between health literacy and health outcomes, there is an imperative to include health literacy assessment and promotion tools as a part of primary care practice, especially for vulnerable populations. The large number of Syrian arrivals requires support in their navigation and use of the Canadian health care system. For clinicians and other service providers to fully meet their health needs, culturally

appropriate measures to assess and promote comprehensive health literacy in this patient population are needed.

1.2.4 *A comprehensive measure for comprehensive health literacy: the All Aspects of Health Literacy Scale (AAHLS)*

A major issue with previous assessments of health literacy amongst immigrants is that tools were administered in English or French, which may not have truly reflected the health literacy of newcomers who struggle in these languages. Another limitation is that most tools only measure functional health literacy and not critical or communicative or critical health literacy.

The All Aspects of Health Literacy Scale (AAHLS) is a 14-item self-report scale which measures individual reading and writing skills as well as access to support networks, communicative as well as critical health literacy. This scale was developed by Chinn and McCarthy (2012) as a quick and effective clinical measure of health literacy in London, UK. The tool was piloted in a sample of 146 English and Sylheti speaking adults in Tower Hamlets, London. An oral Sylheti version was used for 35 Bengali participants (the largest ethnic minority in the region). The 14 items on the scale loaded on 4 factors related to skills in reading or understanding health documents (functional literacy questions or FQ 1-4), communicating with health professionals (communicative literacy questions or CommQ 1-3), managing health information (critical literacy questions or

CritQ 1-4) and the capacity to take civic or community action for one's health (empowerment questions or Emp 1-3).

1.3 Study Purpose and Objectives

The purpose of this study is to quantify current health literacy levels amongst a segment of the Syrian refugee population in Canada by translating and validating an existing comprehensive health literacy assessment tool. Currently, the most reliable scale to have been validated in Arabic speaking populations is the Short Version of the Test for Functional Health Literacy in Adults (S-TOFHLA), which only measures functional health literacy (Al-Jumaili et al., 2015). The current study will translate the AAHLS into Arabic and validate it in Arabic-speaking Syrian refugees. The feasibility of the translated AAHLS as a self-administered tool in clinical or community settings will also be assessed. Lastly, correlates of poor health literacy amongst Syrian refugees will be identified, aiding the development of targeted health literacy promotion measures for this population.

This study aims to (1) determine comprehensive health literacy levels amongst Syrian refugees and identify correlates (2) validate an existing instrument which can assess functional, communicative and critical health literacy and can be used for screening for low health literacy in Arabic-speaking populations and (3) assess the feasibility of this instrument as a self-administered screening tool. It is hypothesized that the overall health literacy of Syrian refugees will be comparable to that of other

newcomer groups and that correlates of low health literacy will include government-assisted status and educational achievement.

This paper has introduced the study population, the theoretical framework around health literacy which has informed the research process as well as the study objectives in the first introductory chapter. Chapter 2 describes the methodology for participant recruitment, translation of the AAHLS into Arabic and data analysis. Chapter 3 is the results section and it details the findings on health literacy scores overall and in the sub-scale areas, identifying significant correlates. Chapter 4 discusses the significance of the findings and places them within the context of relevant literature. This section adopts a health systems approach to health literacy which views health literacy not as an individual skill or competency but rather a responsibility of health providers and systems. It draws from the findings of the study to recommend best practices health care providers can adopt to accommodate this specific population and suggestions to improve communication and understanding of health documents in medical settings. Chapter 5 is the conclusion chapter which determines whether the study met its objectives, the limitations to the research approach and assessment tool, as well as suggestions for future research.

2.0 METHODOLOGY

2.1 Participants

This study conducted a cross-sectional assay of health literacy levels in Syrian refugees, most of whom came to Canada within the last year through the Canadian government's Syrian refugee resettlement program. A total of 76 individuals participated in this study. Eligibility criteria included being an adult refugee who identifies Syria as their country of origin (not necessarily the country where the refugee claim was made). Exclusion criteria included those under the age of 18, those who were unable to speak and understand Arabic or were physically or mentally incapable of providing consent and understanding the scope and requirements of this study. Individuals who were unable to read or write Arabic were supported by a bilingual research assistant while completing the survey.

2.2 Measure/Variables

All Aspects of Health Literacy Scale (AAHLS). This scale was developed by Chinn and McCarthy (2012) as a quick and effective clinical measure of health literacy in London, UK. The tool was piloted in a sample of 146 English and Sylheti speaking adults in Tower Hamlets, London. An oral Sylheti version was used for 35 Bengali participants (the largest ethnic minority in the region). The 14 items on the scale loaded on 4 factors

related to skills in reading or understanding health documents (functional literacy questions or FQ 1-4), communicating with health professionals (communicative literacy questions or CommQ 1-3), managing health information (critical literacy questions or CritQ 1-4) and the capacity to take civic or community action for one's health (empowerment questions or Emp 1-3). The overall test was found to have considerable internal reliability (Cronbach's alpha=0.74) (Chinn & McCarthy, 2013). The present study is the first to test this tool in Canada and in a language other than English or Sylheti.

A short demographic questionnaire was also administered which asked participants their age, time in Canada, sponsorship status (government assisted versus privately sponsored) and education level. Health-related variables were obtained by asking participants to rate their own health status and report whether they had any long-term health conditions.

2.3 Community-Based Participatory Research Approach

This study was conducted in partnership with Auntie Amal Community Centre (AACC), a Toronto-based community organization that has serviced over 100 refugee families in Toronto and the Greater Toronto Area (GTA) over the past year. AACC has supported newcomers by connecting them to services and helping them navigate local systems of housing, education and employment. I, the primary researcher, have been volunteering with AACC since May 2016, as a means of grassroots engagement with the

refugee community. As I supported recently arrived Syrians and other newcomers to find and furnish a home, locate doctor's offices or legal aid and connect with community supports and programs, I learned a great deal about the barriers and challenges of navigating the Canadian settlement system. I learned about the financial, cultural, linguistic and physical barriers faced by refugees as they navigate this system, as well as their pre-migration experiences and finally, their hopes and fears for a new future in Canada. This experience was critical in helping me expand my research lens to consider the full context in which my study participants' health needs and literacy levels are placed. In addition, as a Canadian-born, university-educated and English-speaking "researcher", I recognized the power imbalance between myself and my research participants, who are newcomers to Canada and may not have the same level of familiarity with the English language or Canadian culture as I do. By volunteering with this group, taking the time to understand their culture and their viewpoints while also giving them the opportunity to learn about me and my intentions, I hoped to foster meaningful relationships with my potential study participants and bridge the divide between us. My intentions were to be able to enter participants' home or personal space as someone who they trust and whose study they can agree or decline to participate in without feeling any pressure or coercion.

A research assistant who understands Syrian dialectic and linguistic nuances was hired to translate the English version of the AAHLS into Arabic. In addition, the well-established connections of the RA with Syrian refugees aided participant recruitment, as

the RA was able to utilize her bilingual abilities to facilitate communication between myself and the research participants, to obtain verbal or written consent, and provide translation when needed. This arrangement was mutually beneficial for all parties involved, as it provided the RA with formal research experience, minimized the level of undue stress, discomfort or difficulty experienced by research participants, and eased the participant recruitment and engagement processes for myself.

I also collaborated with Low Income Families Together (LIFT), a human rights and education resource centre which facilitates sustainable development projects around food security and climate change resilience for youth, newcomers and the un/underemployed residents of St. Jamestown in Toronto. As a volunteer with LIFT, I have been facilitating a women's dance class since 2015 through which I have connected with several refugees. Eligible participants who attend these classes were invited to take part in the study, as were Syrian refugees who attend LIFT's other programs and events.

2.4 Procedure

Eligible participants were recruited over the phone by the research assistant through a registry kept by AACC. In addition, a research flyer was kept at 250 Wellesley Street, LIFT's main service location, for Syrian refugees who access LIFT's services. Some participants were engaged directly through the dance class and a drop-in document translation service offered by LIFT volunteers for Arabic speakers. Finally, the

researchers attended several community events with AACC. If an eligible individual agreed to participate, the research assistant set up an appointment with them to fill out a short survey and demographic questionnaire in their home, at the community event or over the phone. Consent was obtained over the phone or in writing by the main investigator, with the research assistant providing translation as needed. Altogether, data collection took place between December 2016 and February 2017.

The AAHLS was translated into Arabic as per the principles of good practice for translation and cultural adaptation for patient-reported outcome (PRO) measures cited by Wild and colleagues (2005), as well as guidelines for the translation, adaptation and validation of instruments or scales for use in cross-cultural health care research cited by D Sousa & Rojjanasrirat (2011). The forward translation was done by the RA, who is a certified translator and a Syrian refugee herself and thoroughly understands the cultural and linguistic nuances of the region. The new Arabic version was then blindly back-translated to English by a health care professional who speaks both English and Arabic and has knowledge of health terminology and content area of the instrument. Any discrepancies identified were rectified by the medical professional and primary researcher to yield a final Arabic version of the AAHLS. The equivalence of the Arabic version of the AAHLS was tested using a small pre-pilot with a bilingual subsample of 5 Syrian refugees. Any existing discrepancies were evaluated by a panel of three native Arabic speakers to yield a final version of the Arabic AAHLS. For a detailed account of the back-translation methodology, see table 1.

Table 1:

Back-translation Methodology adapted from D Sousa & Rojjanasrirat (2011).

Back-translation Best Practices	Methods Used	Result
Forward translation or one-way translation of instrument into target language by at least two independent translators who are bilingual and preferably bicultural. One should have knowledge of health care terminology and content area of instrument, and the second must be familiar with "colloquial phrases, health care slang and jargon, idiomatic expression and emotional terms used in the community" (p. 270). This translated version should cover medical and usually spoken language and its cultural nuances.	Forward translation by a native Arabic speaker from Syria who is also a certified translator and understands the usually spoken language and its cultural nuances. Did not hire two separate translators for the purpose of this study due to a limited student budget.	AAHLS Arabic Version 1 (see Appendices C
Compare two translated versions for discrepancies/ambiguities	Skipped this step as there was only one translated version.	
Blind back translation by two other independent translators to yield two back translated versions of instrument.	Blind back-translation by a single health care professional who reads and writes in both Arabic and English. The health care professional has knowledge of the health care terminology and content area (health literacy) of the instrument.	AAHLS Back-Translated Version (see Appendices C)
Compare the two back-translated versions as well as original instrument: evaluate the similarity of the "instructions, items and response format regarding wording, sentence structure, meaning and relevance" by a multidisciplinary committee consisting of preferably "one methodologist, one health care professional, as well as all the translators used previously" (p. 270). Things to look for include the "format, wording,	Comparison of the back-translated version by a health care professional and main researcher for content equivalence. Key areas that were considered including the following: has the overall message in each question been retained (conceptual	AAHLS Arabic Version 2 (see Appendices C)

grammatical structure of sentences, similarity in meaning and relevance, any ambiguities regarding cultural meaning and colloquialisms or idioms in words or sentences of the instructions, the items, and the response format between the back-translations and the original should be discussed and resolved through consensus among members" (p. 270). Items which have lost their original meaning should be re-translated and then back-translated again until there are no discrepancies. "These methodological approaches will establish the initial **conceptual** (does concept of the items of the instrument in question exist in both the source and target cultures), **semantic** (sentence structure, colloquialism, idioms) and **content equivalence** of the document" (p. 270).	equivalence)? Does the overall sentence structure make sense (semantic equivalance)? Are they same variables being tested (content equivalence)?	
Pilot testing of pre-final version of instrument with a sample of 10-40 experts who have knowledge of content area and the target population, and whose native language is the Translated language. They should be asked to rate the instructions and items of the instrument using a dichotomous scale (clear or unclear) and provide suggestions on any unclear items. Anything found unclear by at least 20% of the sample should be re-evaluated (p.271).	Asked a group of 4-5 native Arabic speakers to rate each item on the questionnaire as clear or unclear + have them fill out the English version (with 1 week gap to avoid recollection bias) and compare results. This will help to assess equivalency of the translated version. Any items which yielded different scores or were marked 'unclear' by the pilot participants were examined and reformulated by a panel of 3 bilingual individuals to yield a final Arabic version of the AAHLS.	See Appendices B for AAHLS Arabic Version 3 (Pilot version including suggested edits) AAHLS Arabic Final Version (See Appendices B)

2.5 Ethical Considerations

Eligible individuals were told prior to starting the survey that their participation in this study was entirely voluntary and they could withdraw consent at any time. Written or verbal consent was obtained for all participants prior to completing the survey. Early in the research process, I realized that many participants deemed me to be in a position of authority, due to the University logo on my forms and my position as a researcher. I made clear my limitations as a student researcher to every participant and advised them that there would be no personal risks or benefits, in the form of compensation or reward for their willingness or refusal to participate in this study. In addition, by adopting a community-based research approach and employing a bilingual research assistant with lived experience as a refugee, I sought to foster a safe environment in which participants could fully understand the scope of the research from someone who they shared cultural and experiential commonalities with. To further ensure that participants were comfortable, we offered to complete the survey at a location and time which was most convenient for them.

Participant confidentiality was protected by storing completed responses non-chronologically in a binder, without any identifiers. This binder is only accessible to me, the primary researcher. Signed consent forms are stored in a separate binder. Individual results were transcribed and stored on a password protected computer. Paper and electronic data will be kept up to six months beyond the end of the study period should

the researchers wish to re-analyze the data for publication purposes, as is done in many research studies. This study was given ethical clearance by the Hamilton Integrated Research Ethics Board (HiREB).

2.6 Mental Health Considerations during Data Collection

Although this was a minimal risk study, it was recognized that refugees are a vulnerable group, many of whom have endured violence and trauma and therefore may be at increased risk of feeling triggered, or in other words, feeling anxious, nervous or down as a result of an event, circumstance or other thought which reminds them of a previous traumatic experience. This consideration is supported by evidence from the Mental Health Commission of Canada. In a recent report, they stated that refugees have increased rates of post-traumatic stress disorder, depression and are at risk for psychosis. However, they caution that despite this vulnerability, refugees can be incredibly resilient when given adequate supports and it may be counterproductive to over-pathologize them (Agic et al., 2016). In addition, I am aware through personal accounts from Syrian refugees that mental illness is considered a taboo subject and such issues are generally dealt with through community or faith based healing. As a student researcher, I was aware of my limitations and never assumed that a participant had a mental health condition and required assistance. However, I did carry a list of available resources in case a participant directly asked for support accessing mental health services. This list was obtained from Settlement.org Ontario and includes the Mental Health Helpline, (runs 24 hours 7 days a

week and is offered in Arabic), Canadian Mental Health Association, and Ontario Psychotherapy and Counselling Referral Network (Settlement Ontario, 2016). I also noted the number for Sherbourne Health Centre, the closest local health centre to the primary research location (St. Jamestown, Toronto) which provides free drop-in services and workshops to support the mental health needs of immigrants and refugees (Sherbourne Health Centre, 2016). For participants who asked for educational resources on mental health related issues, I kept copies of the Arabic version of "Navigating Mental Health Services in Toronto-a Guide for Newcomer Communities" on-hand (Community Resource Connections of Toronto, 2016). This online document explains terms such as mental health, psychosis and identifies signs of mental health issues. Though such a situation never occurred, I was prepared to call 911 or access any of several mental health crisis lines posted on the Canadian Mental Health Association of Toronto website in the event of an emergency or mental health related crisis (Canadian Mental Health Association Toronto, 2017).

2.7 Data Analysis

2.7.1 Health literacy levels and correlates

Overall health literacy scores were determined by calculating the sum for each individual question and then combining individual question scores to arrive at a final score. These scores were then correlated with participants' age and time in Canada. Variance in categories of gender, sponsorship status (government-assisted versus

privately sponsored), place of origin (country versus refugee camp), education (less than high school versus high school or higher), self-rated health (poor/ok versus good/excellent) and self-reported presence of long -term health conditions were assessed using two-sample Student's t tests assuming unequal variance. This procedure was repeated for sub-scale scores of functional, critical and communicative health literacies as well as personal empowerment. Significant associations between two questions or between a health variable and individual question or sub-scale scores were further explored using cross tabulations.

2.7.2 Validity and reliability of translated AAHLS

The internal reliability of the overall measure, the combined health literacy scales and each individual sub-scale was assessed using Cronbach's alpha. The construct validity was tested using bivariate correlations (Pearson's coefficient) to assess associations between sub-scale scores.

2.7.3 Feasibility as a self-administered screening tool

The feasibility of the AAHLS as a self-administered tool for Arabic-speaking individuals in community or clinical settings was determined by the response rate (i.e. ratio of tests fully completed to those administered), as well as self-rated ability to complete the survey without any assistance.

3.0 RESULTS

3.1 Participant Socio-demographic and Health Factors

Table 1 depicts baseline socio-demographic characteristics of the study population. The sample population was relatively young, with the average age being 35 (SD=12.0 years). Fifty-four percent (N=41) of respondents were youth below the age of 24 and 40% (N=30) were within the middle or adult age range between the ages of 24 and 55. Only 7% (N=5) were seniors age 55 or higher. There were no significant differences in age between the men and women or between sponsorship groups. This population was also relatively new to Canada, with an average time in the country between 6 months and 1 year (SD=10.9 months). The majority, or 72%, were government-sponsored and 23% were privately sponsored. Four participants were independent asylum seekers. When asked about their current occupation, a third (33%) cited "other" as their occupation, with the most common explanation being that they were looking for work.

A survey of pre-migratory factors revealed that the most respondents either arrived from countries other than Syria (38%) including Jordan, America, Turkey and Egypt, or directly from a refugee camp (37%) in Jordan, Turkey or Lebanon. Only about a quarter (25%) came directly from Syria. Among those who came from a refugee camp, almost all (99%) were government-sponsored and most (60%) were women. In terms of educational status, almost half (47%) of men and women had less than a high school

education. One third (32%) of all respondents had at least some college education. Prior to their arrival to Canada, many were working (47%) or in school (17%).

Notable differences between men and women were that women were more likely to have stayed in a refugee camp (49% of women versus 27% of men). Women were more likely to be home-makers, as 46% stayed at home prior to coming to Canada and 54% were currently stay-at-home mother or wives in Canada. Men were more likely (63%) than women (29%) to have been working prior to coming to Canada and to be currently employed part-time (20% versus 3%).

Beyond gender, the sample population also differed along lines of status. Almost half (48%) of all government-sponsored individuals came directly from a refugee camp, whereas most privately sponsored individuals came directly from Syria (50%) or another country. . Government sponsored individuals were less likely to have finished high school, as half of the sample group (50%) had less than a high school education. Among the privately sponsored individuals, 40% had less than a high school education, 23% had finished high school and 36% had at least some college education.

3.2 Total Health Literacy Scores

The average health literacy score was 24 (SD=4) out of a total score of 38. The lowest score was 16 and the highest was 33. Figure 1 shoes average health literacy

performance for different demographic groups. Males and females scored similarly, as did individuals from different age groups and with varying education levels (table 2). Although government-assisted and privately-sponsored individuals scored similarly, the four independent asylum seekers were found to have much higher health literacy scores overall, with an average score of 28.3 (SD=1.5). Individuals who had last resided in Syria (M=24.4, SD=0.60) or another country scored on average 2 points higher than individuals who had last resided in a refugee camp (M=22.6, SD= 0.82); t(56)= 1.75, p=0.04). In addition, individuals who reported having a long-term health-condition scored on average 2 points lower (M=23.0, SD=0.73) than those without a long-term condition (M=24.3, SD=0.74); t(67)=-1.38, p=0.02).

3.3 Sub-Scale Scores

3.3.1 Overall trends

Figure 2 depicts the distribution of health literacy scores for questions testing functional, communicative and critical health literacy, as well personal empowerment. Overall, respondents scored comparatively well on communicative health literacy (M=7/9, SD=1.5), and on empowerment (M=3/5, SD=1.2). Average scores were comparatively lower for functional (M=5.5/9, SD=1.3) and critical health literacy (M=8/12, SD=2.2).

3.3.2 Functional health literacy

More than half of all respondents (52%) reported "often" needing help reading health-related documents. A similar percentage (49%) "often" needed help filling out official documents. The scores in these two areas suggest that this population struggles with basic functional literacy. However, respondents do seem able to find the support needed to process health information or forms, for when asked "when you need help, can you easily get hold of someone to assist you?" 44% reported they were "often" able to and 30% were able to get help "sometimes" (figure 2).

3.3.3 Communicative health literacy

Most participants appear to be relatively confident when communicating with health professionals. When asked if they give their health provider all the information needed to help them, 63% said they "often" do so, while 30% said they do so "sometimes" and only 7% said they "rarely" convey all necessary information to their health provider. When speaking to a health provider, 50% of all respondents reported that they "often" "ask all the questions they need to ask", 33% reported they ask "sometimes" and 17% "rarely" ask. The percentage of respondents who ask their health care provider for clarification was evenly split between those who ask "often" (38%), those who ask "sometimes" (33%) and those who "rarely" ask (29%) (figure 2). Communicative health literacy was significantly associated with self-reported presence of long-term health

conditions, as individuals who reported a chronic condition (M=6.6, SD=1.8) scored on average 0.8 points lower than those without one (M=7.4, SD=1.6) (table 2). Participants' tendency to ask questions ($X^2(1, N = 66) = 6.6, p = .036$) or to request clarification ($X^2(1, N = 66) = 12.5, p = .002$) differed between those who had a long-term health condition and those who didn't. Sixty-two percent of respondents without a chronic condition reported questioning their health care provider "often", compared to only 32.4% of respondents with a chronic condition. In addition, those without a chronic condition were more likely to request clarification from their doctor, as 56% did so "often", and 25% did sometimes. Only 14.7% of individuals with a chronic health issue asked for clarification "often", a larger percentage asked "sometimes" (47.1%) or "rarely" (38.2%) (figure 3).

3.3.4 Critical health literacy

Most participants appear to be regularly or somewhat engaged in critical analysis of health information, in that the majority are "often" (42%) or "sometimes" (38%) able to consult multiple sources to find health-related information. In addition, when respondents were asked if they were the sort of person who would question their health practitioner's advice based on their own research, 40% said "sometimes", while 34% said "often" and 19% said "rarely". However, respondents seemed less likely to critically assess whether health information is credible or applicable to them. When asked how often they think about whether health information makes sense in their situation, 39%

said “rarely” while 35% do so “sometimes” and only 22% do so “often”. When asked how often they try to work out whether information about their health can be trusted, 35% said “often, 35% said “rarely” and 26% said “sometimes” (figure 2). Critical health literacy was also significantly associated with self-reported presence of long-term health issues, as individuals with a long-term health condition (M=8.9, M=2.4) scored on average 1.3 points lower than those without one (M=7.6, SD=2.0) (table 1). Participants’ tendency to use multiple sources for health information were significantly different between those who had a long-term health condition and those who didn’t ($X^2(1, N = 66) = 7.5$, $p = .023$). Individuals with a long-term health condition were less likely to consult multiple sources for health information, as only 29.4% of these individuals reported that they “often” like to find out lots of information about their health, compared to 62.5% of individuals who don’t have a chronic health issue (figure 3).

3.3.5 Empowerment

The empowerment section included 3 questions. Question 1 asked respondents “do you think there are plenty of ways to have a say in what the government does about health?”, several participants (n=7) did not respond, with the general feedback being that they did not understand what the question was asking. Among those who responded, 34% said “sometimes” and 33% said “often” or “rarely”. Question 2 asked participants whether they had taken any action within the last 12 months to do something about a health issue that affects their family or community, to which 62% said “no” and only 38%

said “yes”. Finally, the last empowerment-related question asked respondents what they think matters most for everyone’s health. Eighteen percent chose option a, “Information and encouragement to lead healthy lifestyles”, while most (82%) chose option b, “good housing, education, decent jobs and good local facilities”. Empowerment scores were significantly associated with place of origin, as individuals who had last stayed in Syria or another country (M=3.3, SD=1.2) scored on average 0.6 points higher on empowerment than individuals how had last stayed in a refugee camp (M=2.8, SD=1.1); ($t(56)=1.74$, $p=0.04$).

3.4 Reliability: Internal Consistency

Cronbach’s alpha for the overall health literacy scale (including empowerment questions 1 and 2) was 0.67, which is acceptable. For the functional scale, without item 2 (which was scored differently from items 1 and 3), Cronbach’s alpha was 0.51 which is poor but acceptable. Alpha was 0.62 for the critical scale and 0.63 for the communicative scale, both of which are satisfactory.

3.5 Content Validity: Equivalence with Original AAHLS

A pilot version of the Arabic AAHLS was tested in a sample of 5 bilingual Syrian refugees. Each participant had the exact same scores for the English and Arabic versions

of the test, which were done a week apart to avoid recollection bias, suggesting high content validity and equivalence of the translated scale.

3.6 Construct Validity: Associations between sub-scale scores

Out of the health literacy sub-scales, communicative and critical health literacy were moderately associated with one another ($r(76)=0.57$, $p=.00$). Figure 5 shows moderate positive correlations between communicative and critical health literacy questions. Respondents who often asked their healthcare provider to clarify information (CommQ3) were also more likely to (a) ask their health care provider questions (CommQ2; $r(76)=0.55$), (b) consider the validity of health information (CritQ2; $r(76)=0.51$) and (c) consider the credibility of health information (CritQ3; $r(76)=0.53$). Responses to empowerment question 3, which asked participants to identify whether they thought social supports or individual health knowledge and behaviours were more important for everyone's health, revealed interesting patterns. Most respondents chose option b, "good housing, education, decent jobs and good local facilities" irrespective of their responses to other questions. However, a majority (62%) of individuals who "often" asked their health care provider for clarification (CommQ3) chose option a, "Information and encouragement to lead healthy lifestyles" compared to 32% who "sometimes" and 9% who "rarely" ask their care provider for clarification. Sixty-two percent of individuals who "often" considered the credibility of health information also chose option a,

compared to 32% of individuals who "sometimes" and 23.5% of individuals who "rarely" consider the credibility of health information.

3.7 Feasibility of AAHLS as a Self-Administered Tool

The overall response rate was 0.86, as 65 out of the 76 respondents completed the entire survey independently. The thirteen individuals who didn't complete the survey were older (Mean age= 44 years, SD= 16.8) than the general study population. They mostly (69%) had a high school education or higher. Otherwise, their demographic makeup in terms of their place of origin, sponsorship status and time in Canada was comparable to that of the general study population. In terms of their health characteristics, 7 individuals (54%) rated their health as poor or fair and 7 individuals reported having a long-term health condition, comparable to the overall study group.

In response to the question, "Was this survey easy to complete without any assistance?", 35 (46%) of respondents said "yes" and 41 (54%) said "no". Seventy-five percent of individuals who found the test hard to complete had less than a high school education, compared to 51% who found it easy to complete. In addition, 68% of those who found the survey difficult to complete rated their own health as "poor" or "fair". In comparison, among those who found the test easy to complete, 67% rated their own health as "good" or "excellent" and 34% rated it as "poor" or "fair". Individuals with a long-term health condition seemed to find the test harder to complete, as they made up

65% of respondents who reported difficulty in completion, compared to only 38% of respondents who could complete the test on their own and had a long-term health condition. As for the actual percentage of completed tests, 85% of the individuals who reported difficulty in completing the survey still managed to complete the full survey, compared to 79% of those who reported having no difficulty (table 4).

Informal feedback from participants suggested that some struggled with the formal tone of the questionnaire, which according to one participant was "in a formal Arabic dialect which is not spoken on an everyday basis". There were certain questions which proved to be challenging, specifically Empowerment 1:" Do you think there are ways for us to have a say in what the government does about health?" which required further explanation in many cases. In fact, from the 13 respondents (0.17) who did not complete the survey, 10 left that particular question blank. The five respondents who struggled with this question cited it as "unclear".

4.0 DISCUSSION

4.1 Representativeness of Study Sample

Recent data from Immigration, Refugees and Citizenship Canada suggests that most Syrian refugees in Canada have settled in Ontario, with their top destination city being Toronto. Approximately 6,000 Syrian refugees settled here as of January 2017. More than half (53%) are government-assisted, with the remaining mostly (34%) privately sponsored and a smaller percentage (13%) arriving through the blended visa program. The population is quite young, as more than half (56%) are under the age of 18 and 44% are over 18. There are slightly more females than males, which is due to the Liberal governments initial restrictions on single adult males from entering the country. In terms of education, almost 60% have a high school education or less (in Ontario it is 56%), around 7% have a university-level degree or higher and around 5% have a certificate, apprenticeship or diploma. In Ontario, around 62% of the recently arrived refugees speak neither French nor English, with Standard Arabic or Syrian Arabic being the main languages spoken. Roughly one in three Syrians can speak some English but most are privately sponsored (Friesen, 2017).

Overall, the current study's sample population is somewhat representative of the broader Syrian refugee population, with some notable exceptions being that government-assisted refugees are slightly over-represented in this sample, as they make up 72% of all

participants. The sample group is similar in terms of educational attainment, as 69% have a high school education or less, 16% have some sort of college education and 16% a Bachelor's degree or higher.

4.2 Health literacy scores overall and in sub-scale areas

Functional health literacy scores consider the fundamental ability of individuals to read or fill out health documents. For refugees entering Canada, this is a necessary first point of access to any health care centre, and an often-integral step to doing the necessary research to locate a health centre or provider. Unfortunately, this patient population's functional literacy skills appear to be quite low. A significant number of participants need help reading forms and filling in health documents. This may be due to differences in health care service delivery in Canadian and pre-crisis Syrian systems, as Syrian refugees may be more used to an oral format when accessing health information. It is imperative for health providers, managers and community support workers to assess clients' comfort with health documents. It is reassuring to see that most can access help to read or fill out health-related documents. Consequently, a necessary component of refugee resettlement may be identifying and strengthening the family or community level supports refugees have to process health information or navigate health systems. An integral question to consider for future adapted health literacy assessment for non-English speaking refugees would be where they get their support from. Supports may be from health providers who speak their language, or family or community members that serve as translators. It would

also be useful to ask if participants are able to find a family doctor who speaks their language, particularly given that the majority of the Syrian refugee population has limited French or English language proficiency.

It was also interesting that most respondents selected social supports such as good education, housing and jobs as key components to the health of individuals and communities, as opposed to information and encouragement to lead healthy lifestyles. This may be due to their precarious status as refugees, which limits their access to basic social supports and thus gives them a unique perspective on their value and importance to health and well-being.

4.3 Link to Chronic Conditions

Previous studies have demonstrated a link between health literacy and understanding of outcomes related to chronic disease. Patients with chronic conditions such as asthma, hypertension, and diabetes and poor health literacy levels were found to know significantly less about their condition than patients with adequate health literacy (Gasmararian et al., 2003). In addition, a study of functional literacy in hypertensive patients found that individuals with poor functional health literacy levels were less likely to correctly identify symptoms of their condition than those with adequate functional health literacy (Williams et al., 1998). Finally, Schillinger and colleagues (2002) found that diabetic with poor health literacy levels were found to have a higher burden of disease and worse health outcomes.

This study had similar findings, as presence of a chronic condition was associated with poorer health literacy scores overall as well as in communicative and critical health literacy areas. A greater percentage of respondents with a chronic condition were less likely to question their health care provider, request clarification for information they did not understand, or consult multiple sources for health information than individuals without a chronic ailment. This may have to do with the trust and understanding necessitated between an individual with a long-term health condition and their health provider. In addition, someone with a long-term health condition is more likely to experience co-morbidities and other complex issues. Due to this, these individuals may be more likely to trust the advice of their health care provider and avoid asking too many questions or consult additional sources for health information. Alternatively, they may lack the basic knowledge or communicative syntax to convey their questions to their provider or to access information related to their condition from various sources.

Previous studies have found that duration of disease and patient age were important predictors of individual patient knowledge of their condition (Gasmararian et al., 2003). Given the established link between poor health literacy levels and adverse health outcomes in patients with chronic conditions, it is vital to understand what contributes to low health literacy levels in Syrian refugees with chronic conditions and whether factors such as patient age and duration of disease mediate their understanding as well as communication with care providers.

4.4 Associations between individual question responses

Communicative and critical health literacy was associated with one another. Respondents who often asked their healthcare provider to clarify information were also more likely to ask their health care provider questions consider the validity of health information and consider the credibility of health information and to believe that individuals knowledge as opposed to social supports are more important for everyone's health. This association makes sense and suggests that some of the items on the scale may be reflective of various personality traits, as individuals who see themselves as being very proactive about their health may be more likely to question their doctor, consult multiple sources of information and think critically about that information. In contrast, individuals who see health as a social outcome or service may not do so. In future health literacy assessments, there should be a component which maps how individuals view their health and their role in it.

4.5 Reliability and Validity

Although the reliability of the overall scale was acceptable and the content validity was high, it is important to note that "validity is not a property of the test or assessment, but rather it is about the meaning of the test scores" (Messick, 1995). Messick also explains that there are two types of validity, one is linguistic validity and the other is cultural. In this sense, content validity cannot truly be measured objectively, but

rather it is a function of context in which it is measured and the participants who complete the assessment. For example, content validity was shown to be high through a pilot testing with individuals who are bilingual English and Arabic speakers and have been in Canada for some time. In this sense, these individuals are privy to English-language culture and syntax. The Arabic version of the AAHLS was in their mother-tongue but also in adherence to Western or English cultural context, both of which they understand. The same cannot be said for the primarily Arabic-speaking research participants, who may understand the Arabic text but not find cultural relevance in the questions being asked of them or in the phrasing of those questions.

4.6 Feasibility of AAHLS as a self-administered tool.

Almost a quarter of all respondents did not complete the full survey. One would assume that the inability of some individuals to complete the survey may have been due to general language or literacy levels. There is a distinction between different Arabic dialects from different parts of Syria and the way Arabic is spoken and written can differ between those who are urban and educated and rural and uneducated. The survey was translated by a Syrian who is from an urban background and holds a Master's degree. Although she did aim to translate the text into a very basic Grade 10 reading level, several participants reported not being able to understand the "formal text of the survey". Another assumption that was made was that government-sponsored refugees would have a harder time completing the survey as the most vulnerable refuges who tend to have lower

education levels. These assumptions did not hold true as there were no associations between response rate and education or sponsorship status. It is important to note that empowerment question 1, "Do you think there are many ways to have a say in what the government does about health" rendered many participants confused. This question may not be applicable to refugees who have come directly from dictator rule and would have had no say in their health options in their home country. In addition, it is possible that they may feel powerless over their precarious situation and not want to question or criticize a new government that has given them refuge.

4.7 Study Limitations

One limitation of the current study's research approach was lack of context provided on Syrian refugees' overall understanding and perception of the Canadian health care system. Greater insight into the health literacy needs of this population could have been gained if more questions were included as part the demographic assessment to understand participants' health experiences to date. For example, it is integral to know if participants are able to understand how an Electronic Medical Record format works, as this is a staple component of many local health care systems. Second, it would be worthwhile to ask how participants rate the Canadian health care system in comparison to their previous system. This should be a critical first step in understanding their health-related expectations and needs. Finally asking participants about their computer literacy may be important as most health information is found electronically today.

Another limitation of the study approach was piloting the Arabic AAHLS bilingual Arabic speakers who have been in Canada longer than the study population. The final AAHLS may have been more legible to newly arrived Syrian refugees if piloted in a similar demographic population. There are also limitations with the AAHLS. Empowerment question 1 does not seem to be relevant to a refugee population and should be omitted when the AAHLS is administered to these groups.

5.0 CONCLUSION

The first aim of this paper was to quantify health literacy levels in this patient population and identify correlates. The Syrian refugee community seems considerably prepared to navigate the Canadian health care system, but will require supports from the wider community and from the health care community to do so. Significant correlates of health literacy include presence of chronic conditions and sponsorship status. The second aim of this paper was to translate and validate the AAHLS for use in Arabic-screening populations. The version created demonstrates acceptable reliability or equivalence to its English counterpart and high content validity. However, the language can be re-adjusted to suit individuals with lower basic literacy levels and have some questions eliminated or changed to allow more cultural relevance to the patient population being tested. Finally, the last aim was to determine whether the tool can be administered independently in community or clinical settings. This does seem possible, as long as translators or interpreters are available or certain difficult questions are omitted. This may mean that a slightly modified tool with its own measure of validity and reliability is adapted for this particular patient population.

There are many directions that future research can take, a critical one being the link between health literacy levels and health outcomes in Syrian refugees and other precarious populations, particularly for those living with a chronic condition. It was also found that living in a refugee camp was associated with lower health literacy and empowerment scores, and that the majority of refugees felt that social supports were

critical to better individual and community health. Syrian refugees have a unique standpoint as individuals living with precarious status, and it may be worthwhile to explore how the precarity of one's living conditions affects their personal empowerment, knowledge and literacy as well as their beliefs around health.

Much of these results can be placed into context by understanding the health care system Syrian refugees came from as well as their expectations and experience with the Canadian system. For example, it would be telling to learn that Syrians are accustomed to a paternalistic relationship with their physicians which would explain their low communicative health literacy levels. Understanding their expectations of the Canadian system would help to interpret their personal empowerment scores. Finally, a better understanding of how the ways in which they are used to receiving health information can inform measures to improve patient functional and communicative health literacy in clinical or community settings.

6.0 REFERENCES

ABC Life Literacy Canada. (2016). The case for health literacy in Canada. *ABC Life Literacy Canada. Abclifeliteracy.ca.* http://abclifeliteracy.ca/case-health-literacy-canada

Access Alliance. (2017). *Research summary report: refugee health and resettlement, lessons learned from the Syrian Response*. Toronto, ON: Access Alliance Multicultural Health and Community Services. Retrieved from http://accessalliance.ca/wp-content/uploads/2017/06/SyrianResettlement_ResearchHighlightsReport_2017.pdf

Ajic, B., Kwame, M., Tuck, A., & Antwi, M. (2016). *Supporting the Mental Health of Refugees to Canada*. Ottawa, ON: Mental health Commission of Canada. Retrieved from: http://www.mentalhealthcommission.ca/sites/default/files/2016-01-25_refugee_mental_health_backgrounder_0.pdf

Al-Jumaili, A.A. Al-Rekabi, M. D., & Sorofman, B. (2015). Evaluation of instruments to assess health literacy in Arabic language among Iraqis. *Research in Social and Administrative Pharmacy,* 11(6), 803-13.

BBC News. (2016). How is the migrant crisis dividing EU countries? BBC News. Retrieved from http://www.bbc.com/news/world-europe-34278886

Brean, J. (2015). No Country is an island: compassion vs. cold economic calculus when dealing with the refugee crisis. *National Post.* Retrieved from http://nationalpost.com/news/canada/canada-cant-hide-behind-the-atlantic

Canadian Council for Refugees (CCR). 2010. *Refugees and Immigrants: A Glossary*. Ccrweb.ca. Retrieved from http://ccrweb.ca/en/glossary

Canadian Mental Health Association. (2017). *Contact Us.* Canadian Mental Health Association Toronto. Retrieved from http://toronto.cmha.ca/about-us/contact-us/#.WcMGJfOGOM8

Chinn, D., & McCarthy, C. (2013). All Aspects of Health Literacy Scale (AAHLS): Developing a tool to measure functional, communicative and critical health literacy in primary healthcare settings. *Patient Education and Counseling*, *90*(2), 247-253. http://dx.doi.org/10.1016/j.pec.2012.10.019

Citizenship and Immigration Canada (CIC). (2107). *Refugees and asylum.* Cic.gc.ca. Retrieved from http://www.cic.gc.ca/english/refugees/index.asp

City of Hamilton. (2017). *Syrian Newcomers, City of Hamilton, Ontario, Canada.* Hamilton.ca. Retrieved from https://www.hamilton.ca/city-initiatives/strategies-actions/syrian-newcomers

Coleman, C.A., Hudson, S., & Maine, L.L. (2013). Health literacy Practices and educational competencies for health professionals: a consensus study. *Journal of Health Communication*, 18(sup1), 82-102.

Community Resource Connections of Toronto. (2016). *Navigating Mental Health Services in Toronto-A Guide for Newcomer Communities (available for download in multiple languages).* Settlement.org. Retrieved from http://settlement.org/ontario/health/mental-health-and-addiction/basics/navigating-mental-health-services-in-toronto-a-guide-for-newcomer-communities/

DeWalt, D., Berkman, N., Sheridan, S., Lohr, K., & Pignone, M. (2004). Literacy and health outcomes. *Journal of General Internal Medicine, 19*(12), 1228-1239. http://dx.doi.org/10.1111/j.1525-1497.2004.40153.x

D Sousa, V., & Rojjanasrirat, W. (2011). Translation, adaptation and validation of instruments or scales for use in cross-cultural health care research: a clear and user friendly guide. *Journal of Evaluation in Clinic Practice,* 17(2), 268-74.

European Civil Protection and Humanitarian Aid Operations (ECHO). (2017). *Lebanon: Syria Crisis*. Brussels, Belgium: ECHO. https://ec.europa.eu/echo/files/aid/countries/factsheets/lebanon_syrian_crisis_en.pdf

Friesen, J. (2017). *Syrian exodus to Canada; one year later, a look at who the refugees are and where they went*. The Globe and Mail. Retrieved from https://beta.theglobeandmail.com/news/national/syrian-refugees-in-canada-by-the-numbers/article33120934/?ref=http://www.theglobeandmail.com&

Gazmararian, J.A., Williams, M.V., Peel, J., & Baker, D.W. (2003). Health literacy and knowledge of chronic disease. *Patient Education and Counseling*, 51(3), 267-275.

Inter-Agency Coordination Lebanon. (2016). *Increasing vulnerability among Syrian refugees.* UNHCR. Retrieved from file:///E:/Lebanon_Increasing_Vulnerabilities_Mar2016_onePage.pdf

Kwan, B., Frankish, J., & Rootman, I. (2006). *The development and validation of measures of "health literacy" in different populations.* Vancouver, BC: University of British Columbia Institute of Health Promotion Research.

Lifeline Syria. (2016). *Interim Federal Health Program- Care for Syrian refugees.* Lifeline Syria. Retrieved from http://lifelinesyria.ca/interim-federal-health-care-for-syrian-refugees/

McKeary, M., & Newbold, B. (2010). Barriers to Care: The Challenges for Canadian Refugees and their Health Care Providers. *Journal of Refugee Studies*, *23*(4), 523-545. http://dx.doi.org/10.1093/jrs/feq038

Medavie Blue Cross. (2016). *Important information for heath care providers: changes made to the Interim Federal Health Program (IFHP).* Immigration, Refugees and Citizenship Canada. Retrieved from https://www.manitobadentist.ca/PDF/IFHP%20Changes%20EN%20Final%20association.pdf

Mercy Corps. (2017). *Helping meet the needs of Syrian refugees in Jordan*. Mercy Corps. Retrieved from https://www.mercycorps.org/helping-meet-needs-syrian-refugees-jordan

Messick, S. (1998). Test validity: a matter of consequence. *Social Indicators Research*, 45, 35-44.

Murray, S., Hagey, J., Willms, D., Shillington, R., & Desjardins, R. (2008*). Health literacy in Canada: a healthy understanding.* Ottawa, ON: Canadian Council on Learning. Retrieved from https://mips.ca/assets/healthliteracyreportfeb2008e.pdf

Nutbeam, D. (1998). Health promotion glossary. *Health Promotion International*, 13(4), 349-364.

Nutbeam, D. (2000). Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. *Health Promotion International*, 15(3), 259-267. http://dx.doi.org/10.1093/heapro/15.3.259

O'Connor, J. (2015). Canada's other refugees: 26,000 arrive annually without fanfare or an official welcome. *National Post.* Retrieved from http://nationalpost.com/opinion/canadas-other-refugees-26000-arrive-annually-without-fanfare-or-an-official-welcome/wcm/b7e4ec94-1928-4bd7-a644-59a78843257e

O'Neil, P. (2015). Ottawa exempts Syrian refugees from loan repayment. *Vancouver Sun.* Retrieved from http://www.vancouversun.com/life/ottawa+exempts+syrian+refugees+from+loan+repayment/11546821/story.html

Ontario Council of Agencies Serving Immigrants (OCASI). (2017). *Frequently Asked Questions, Syrian Refugee Assistance Information*. Welcomeontario.ca. Retrieved from http://welcomeontario.ca/questions#n1947

Ontario Ministry of Health and Long-term Care. (2015). *Ontario Health System Action Plan: Syrian Refugees*. ON: Ministry of Health and Long-term Care. Retrieved from http://www.health.gov.on.ca/en/pro/programs/emb/syrianrefugees/docs/health_system_action_plan.PDF

Public Health Association of BC. *An inter-sectoral approach for improving health literacy for Canadians*. Victoria, BC: Public Health Association of BC. Retrieved from http://phabc.org/wp-content/uploads/2015/09/IntersectoralApproachforHealthLiteracy-FINAL.pdf

Puzic, S. (2015). *Record number of refugees admitted to Canada since 1980.* CTVNews. Retrieved from http://www.ctvnews.ca/canada/record-number-of-refugees-admitted-to-canada-in-2016-highest-since-1980-1.3382444

Schillinger, D. et al. (2002). Association of health literacy with diabetes outcomes. *Journal of the American Medical Association*, 288(4), 475-482.

Schwartz, D. (2015). Canada's refugees by the numbers: the data. CBCNews. Retrieved from http://www.cbc.ca/news/canada/canada-s-refugees-by-the-numbers-the-data-1.3240640

Settlement Ontario. (2016). *Where can I get help with my mental health?* Settlement.org. Retrieved from http://settlement.org/ontario/health/mental-health-and-addiction/basics/where-can-i-get-help-with-my-mental-health/

Sherbourne Health Centre. (2016). *Counselling Services.* Sherbourne Health Centre. Retrieved from http://sherbourne.on.ca/mental-health-services/counselling-services/

United Nations High Commissioner for Refugees (UNHCR). (1967). *Convention and protocol relating to the status of refugees*. Geneva, Switzerland: UNHCR. Retrieved from http://www.unhcr.org/3b66c2aa10.pdf

Wesley Urban Ministries. (2014). *Syrian Refugee Information Portal.* Wesley.ca. Retrieved from http://wesley.ca/refugee-information-portal/

Wild, D., Grove, A., Martin, M., Eremenco, S., McElroy, S., Verjee-Lorenz, A., & Erikson, P. (2005). Principles of Good Practice for the Translation of Cultural and Adaptation Process for Patient-Reported Outcomes (PRO) Measures: Report of ISPOR Task Force for Translation and Cultural Adaptation. *Value in Health*, 8(2), 94-103.

Williams, M.V., Baker, D.W., Parker, R.M., & Nurss, J.R. (1998). Relationship of functional health literacy to patients' knowledge of their chronic disease. A study of patients with hypertension and diabetes. *Archives of Internal Medicine*, 158(2), 166-172.

World Health Organization (WHO). (2016). *The mandate for health literacy.* Health Promotion. Retrieved from http://www.who.int/healthpromotion/conferences/9gchp/health-literacy/en/

7.0 RESULTS- TABLES AND FIGURES

Table 1.
Participant Demographic Characteristics

Demographic and Health Categories	Population (N=76) Mean (±SD) or N (%)
Age (years)	35 (±12.0)
Time in Canada (months)	12.6 (±10.9)
The Last Country you Resided In	
Syria	19 (25%)
Refugee Camp	28 (37%)
Other	29 (38%)
Sponsorship-Status	
Privately Sponsored	17 (23%)
Government-Assisted	54 (72%)
Independent Asylum Seeker	4 (5%)
Education	
Less than High School	36 (47%)
High School or Higher	40 (51%)
Previous Occupation	
Working	36 (47%)
Studying	13 (17%)
Stay-at-Home	18 (24%)
Unemployed/NA	9 (12%)
Current Occupation	
Employed Full Time	3 (4%)
Employed Part Time	9 (12%)
Self-Employed	5 (7%)
In School	11 (14%)
Home Maker	23 (30%)
Other	25 (33%)
Self-Rated Health	
Poor/Fair	41 (54%)
Good/Excellent	35 (46%)
Do you have any long-term health issues?	
Yes	34 (45%)
No	32 (42%)
Choose not to Answer	10 (13%)
Was this test easy to complete?	
Yes	35 (46%)
No	41 (54%)

Table 2.
Analysis of variance in overall and sub-scale health literacy scores according to demographic and health-related categories, t statistic for student's t tests with unequal variance assumed.

Demographic Category	**Health Literacy Component**				
	Functional	*Communicative*	*Critical*	*Empowerment*	*Total*
Gender	0.09	0.06	1.51	0.76	-0.61
Place of Origin	0.19	1.22	1.46	1.73**	1.75**
Sponsorship-Status	1.29	-0.97	-1.03	-1.06	-1.39
Education	-0.15	-0.19	-0.25	-0.14	-0.41
Long-term Health Issues	1.04	-2.00*	-2.27*	-0.29	-1.94**
Self-Rated Health	-1.86	-1.86	1.05	0.21	-1.38

*Two-tailed significance at p of 0.05
** One-tailed significance at p of 0.05

Table 3.
Correlation of overall and sub-scale health literacy scores with participant age and time spent in Canada.

Demographic Category	**Health Literacy Component**				
	Functional	*Communicative*	*Critical*	*Empowerment*	*Total*
Age (Years)	-0.01*	0.27	0.26	-0.06	0.22
Time in Canada (months)	0.16	0.15	0.30	-0.04	0.24

*Significant at p of 0.05

Table 4.
Comparison of Participant Self-reported ability to complete the AAHLS without assistance, according to demographic characteristics of age, time in Canada, sponsorships status, education level, self-rated and health and self-reported presence of long-term health conditions as well as total completion of all questions on the measure.

Characteristics	*Easy to Complete*	*Difficult to Complete*
Total Number	35	41
Mean Age (years)	36 (±9.2)	36 (±14.0)
Mean Time in Canada (months)	11 (±8.7)	13 (±12.7)
Sponsorship-Status		
Private	30%	20%
Government-Assisted	70%	80%
Education		
Less than High School	59%	75%
High School or Higher	41%	24%
Self-Rated health		
Poor/Fair	34%	68%
Good/Excellent	67%	32%
Presence of Long-term Health Conditions		
Yes	38%	65%
No	63%	35%
Completed Full AAHLS Survey		
Yes	79%	85%
No	21%	15%

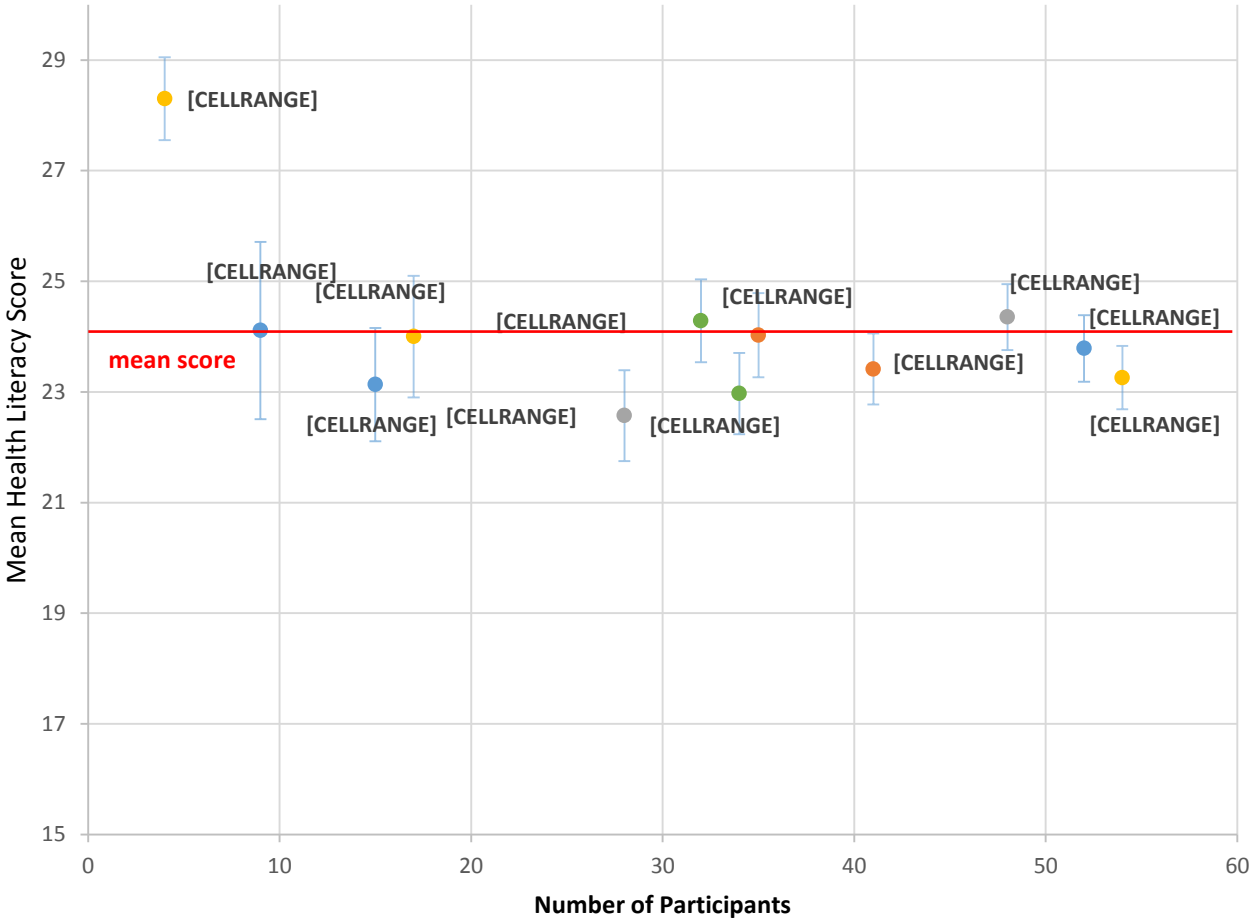

Figure 1: Average health literacy performance for key groups, by total number of participants. Error bars depict standard error of the mean.

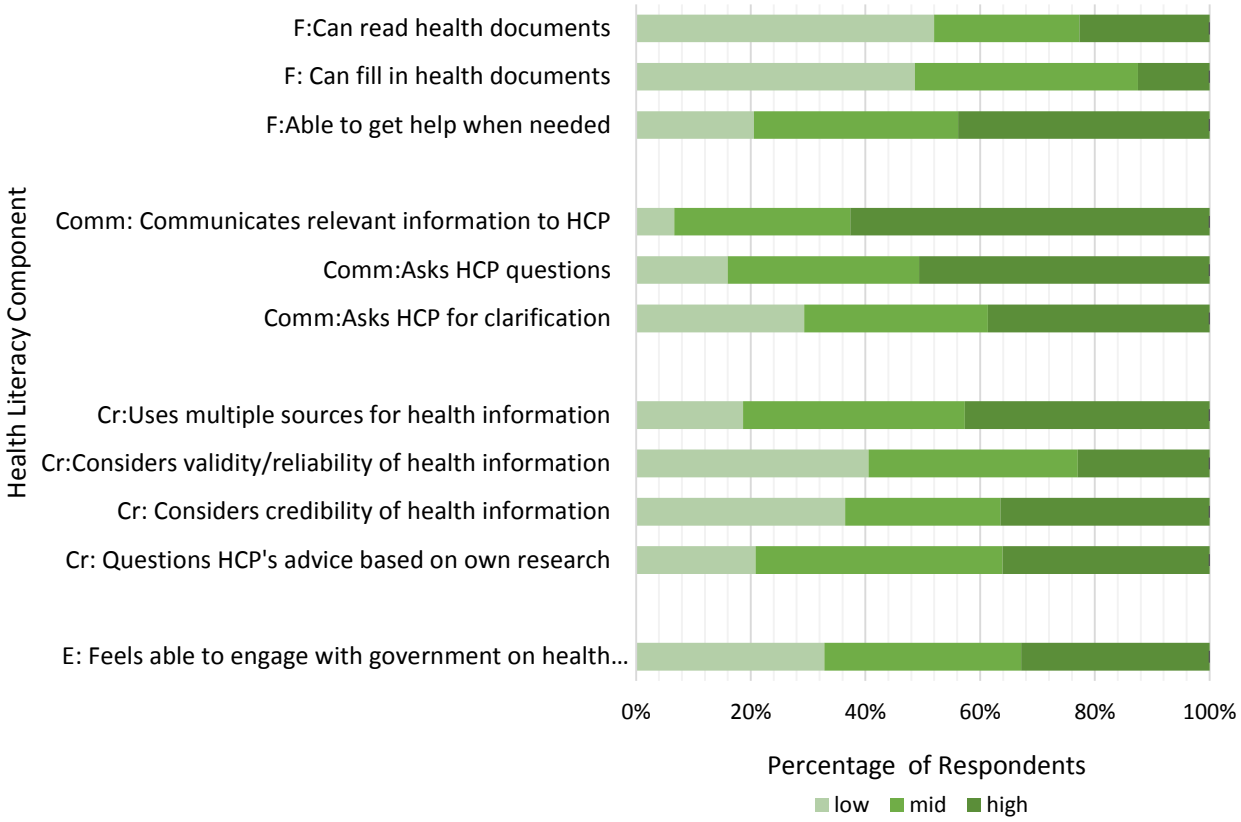

*Figure 2: Distribution of health literacy scores, broken down by individual questions in each sub-scale area. Each bar depicts percentage of respondents who scored high, average or low on a question and includes standard error bars with 95% confidence. * HCP=Asks Health Care Provider*

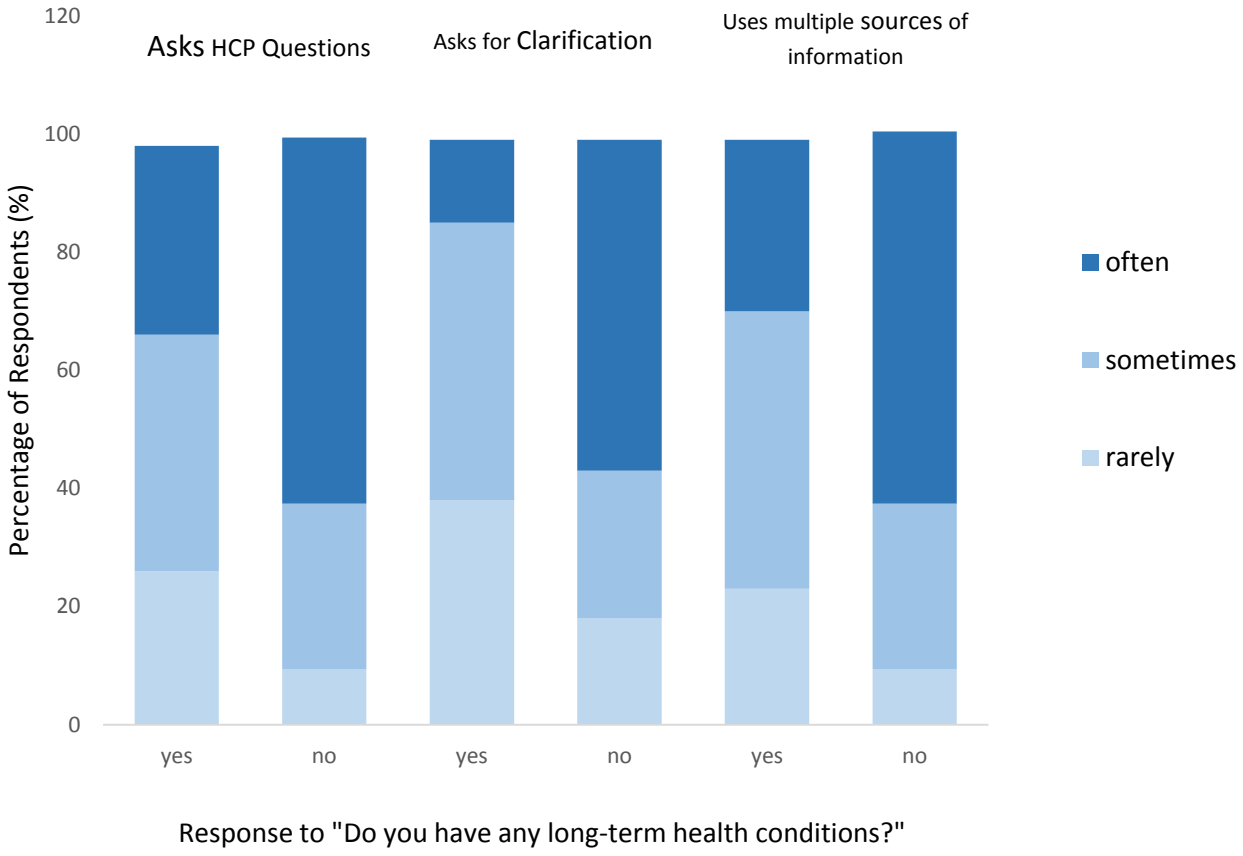

*Figure 3. Participant Scores on Communicative Health Literacy Questions 2 and 3 as well as Critical Health Literacy Question 1, broken down according to self-reported presence of long-term health condition. *HCP= Health Care Provider.*

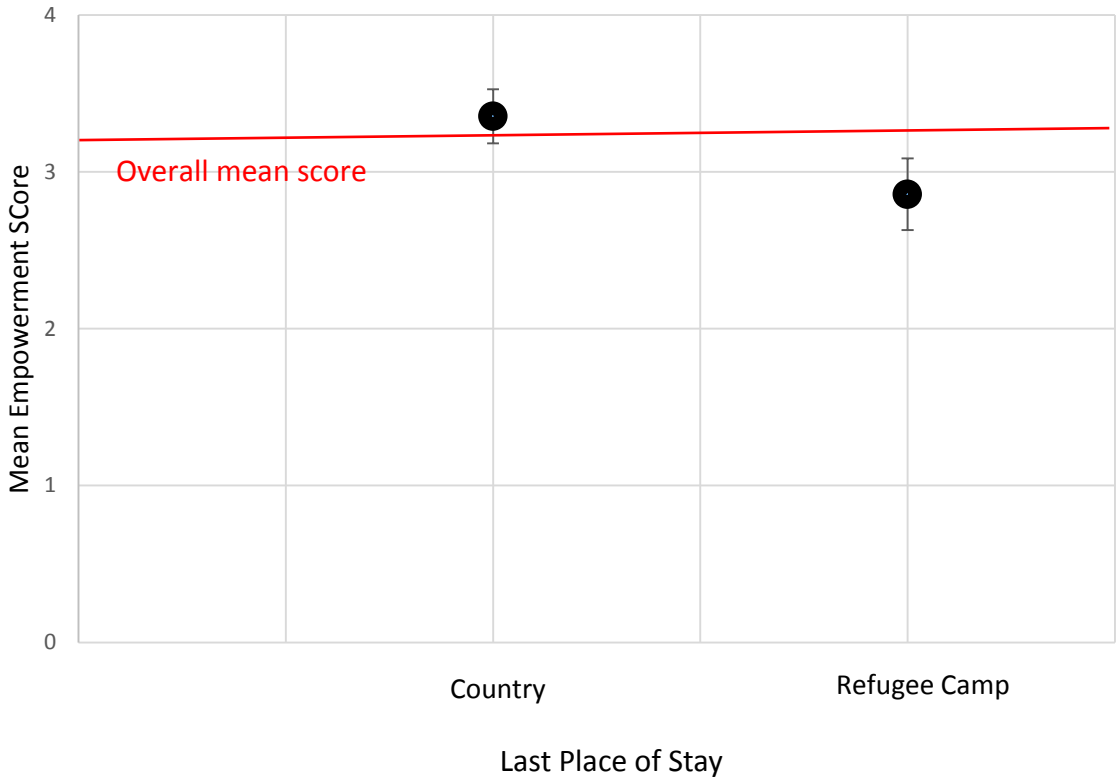

Figure 4: Mean Empowerment Scores (with SEM bars) for individuals who last stayed in Syria or another country, compared to those whose last place of stay was in a refugee camp.

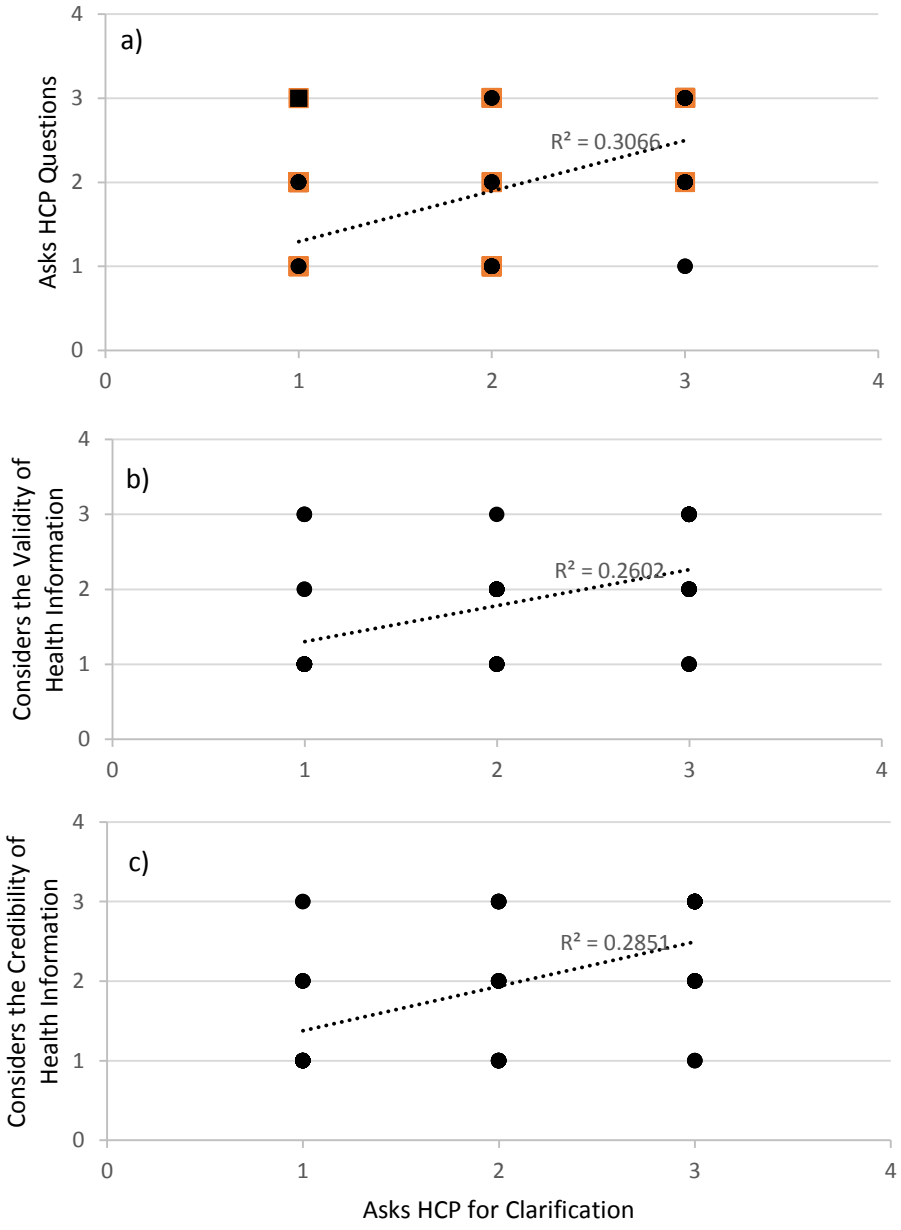

Figure 5. Scatter Plots depicting correlations between respondent scores on communicative health literacy question 3 ("When you talk to the doctor, do you make sure they explain anything you do not understand?") to (a) communicative health literacy question 2 ("When you talk to a doctor or nurse, do you ask all the questions you need to ask?"), (b) critical health literacy question 2 ("How often do you think carefully about whether health information makes sense in your particular situation?"), and (c) critical health literacy question 3 ("How often do you try to work out whether information about your health can be trusted?').

8.0 APPENDICES

APPENDIX A: IMPORTANT DEFINITIONS

Community Sponsor: An organization that sponsors refugees but has not signed a formal agreement with CIC. A community sponsor would normally sponsor fewer refugees than a **Sponsorship Agreement Holder (SAH)**" (Citizenship and Immigration Canada (CIC), 2017a).

Convention Refugee: A person who "meets the refugee definition in the 1951 Geneva Convention related to the Status of Refugees. This definition is used in Canadian law and is widely accepted internationally. To meet the definition, a person must be outside their country of origin and have a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion" (Canadian Council for Refugees (CCR), 2010).

Government-Assisted Refugees (GAR): A person who is "outside Canada and has been determined to be a Convention refugee and who receives financial and other support from the Government of Canada or Province of Quebec for up to one year after their arrival in Canada. GARs are selected from applicants referred by the United Nations High Commissioner for Refugees (UNHCR) and other referral organizations" (CIC, 2017a).

Group of Five: "A group of five or more Canadian citizens or permanent residents, each of whom is at least 18 years of age, who agree to work together to sponsor a refugee" (CIC, 2017a).

Immigrant: A person who has "settled permanently in another country" (CCR, 2010).

Immigration and Refuge Protection Act: enacted in 1979, this is an "Act respecting immigration to Canada and the granting of refugee protection to persons who are displaced, persecuted or in danger" (Canada Justice Laws Website, 2011).

Internally displaced person: A person who is "forced to leave their home, but who is still within the borders of their home country" (CCR, 2010).

Migrant: A person who is "outside their country of origin. Sometimes this term is used to talk about everyone outside their country of birth, including people who have been Canadian citizens for decades. More often, it is used for people currently on the move or

people with temporary status or not status at all in the country where they live" (CCR, 2010). For the purposes of this paper, this term will be recognized as a derogatory term used to describe refugees, refugee claimants and those with precarious status and immigrants.

Newcomer: This term will be used to describe those who have arrived in Canada within the last 0 to 5 years, irrespective of their status. "Newcomer" is considered a friendly term because it is less stigmatizing than words like "refugee" or "immigrant" (Khanlou, 2009, p. 3; Sadiq, 2004, p.1).

Precarious Status: "Precarious status is a term used to describe the immigration status of those who may or may not be legally residing in Canada. Legal precarious status is held by those who are: sponsored family members, temporary residents, or live-in caregivers (Khanlou, 2009, p. 3; Oxman-Martinez et al, 2005, 248).

Privately Sponsored Refugee: A person "outside Canada who has been determined to be a Convention refugee or member of the Country of Asylum class and who receives financial and other support from a private sponsor for one year after their arrival in Canada. Private Sponsors are **Sponsorship Agreement Holders** (**SAH**s), **Groups of Five** or **Community Sponsors**" (CIC, 2017a).

Protected Person: A person who has "been determined to be a Convention refugee or person in similar circumstances by a Canadian visa officer outside Canada, a person whom the Immigration and Refugee Board of Canada has determined to be a Convention refugee or in need of protection in Canada, or a person who has had a positive pre-removal risk assessment (in most cases)" (CIC, 2017a).

Permanent Resident (PR): A person who "has legally immigrated to Canada but is not yet a Canadian citizen" (CIC, 2017a).

Refugee: A person who is "forced to flee from persecution and who is located outside their home country" (CCR, 2010).

Refugee Claimant (Asylum Seeker): A person who has "fled their country and is asking for protection in another country" (CCR, 2010). A refugee claimant whose claim is accepted can apply for permanent residence status in Canada.

Social determinants of Health (SDOH): These are "the myriad social, political, economic, and environmental factors that can affect an individual's or a group's general level of health" (Khanlou, 2009, p.4).

Sponsorship agreement-holder (SAH): "An incorporated organization that signs an agreement with CIC to sponsor refugees abroad" (CIC, 2017a).

APPENDIX B: RESEARCH ETHCS MATERAL

Research Flyer

McMaster University

Are you a Syrian Refugee? Are you over the age of 18?

هل أنت لاجئ من سوريا؟ هل أنت فوق سن الـ 18؟

Are you able to read and write in Arabic?

هل أنت قادرة على القراءة والكتابة باللغة العربية؟

We are trying to look at how you are able to access, understand and apply health-related information in order to promote your well-being.

قادراً على الوصول، وفهم وتطبيق المعلومات المتعلقة بالصحة من أجل تعزيز رفاه الخاص بك.

What to do?

- **Fill out a short questionnaire and demographic survey**
- **All information you provide will be kept confidential**

Time required : 10-15minutes

ما يجب فعله؟

املأ استبيان قصير والمسح الديموغرافي
سيظل سرية جميع المعلومات التي تقدمها

الوقت المطلوب: 10-15دقيقة

Please contact:
Raafia Siddiqui

siddiqr@mcmaster.ca
[redacted]

الرجاء الاتصال
رافيا صديقي
647 787 7680
siddiqr@mcmaster.ca
[redacted]

Hamilton Integrated Research Ethics Board

In Person Recruitment Script

Hi, my name is Amal Kanafani, are you a newcomer from Syria?
*** if participant says yes, proceed*

I would like to see if you may be interested in a research study I am conducting with Raafia Siddiqui, a student at McMaster University. This study looks at Health literacy in Syrian newcomers. We wish to know if you can get the health information you need and use it to improve your health. Are you interested to hear more about this study?
If no, thank them for their time and say good-bye
If yes, continue to explain the study details to them based on the letter of information

As a newcomer to Canada, your health literacy is very important to your ability to manage your own health. The reason we are doing this study is to see what the existing health literacy levels are in Syrian refugees, and see if health literacy can easily be measured in the Arabic language. This research will require you to complete a health literacy test and a brief follow-up questionnaire. This will take you approximately ten to fifteen minutes to complete and requires a one-time commitment only. There are no benefits or risks to participating in this study. If an any time, you wish to stop participating, you may do so. If you are interested, I can set up an appointment for you to meet the researcher, Raafia Siddiqui and I to complete the test.

Do you have any questions?
{Answer any questions they may have}

Do you agree to participate in this study?
**If yes, continue with the study*
**If no, thank them for their time and say good-bye*

Thank you for agreeing to participate in this study. What day and time would you like to meet for an appointment? Would you like to do it now or can I take your number and call you to set up a meeting for another time?
If participant asks to set up the appointment at another location, please do so

Thank you.

Hamilton Integrated Research Ethics Board

Phone Recruitment Script

Hello, may I please speak with {name of the potential participant}.
**If the potential participant is not home ask if there is a better time to call. Do not leave a message as it may be a confidentiality issue for the participant **
If they are home, continue with the conversation

Hi, {name of the potential participant}, my name is Amal Kanafani and I have received your number because you have accessed services through Auntie Amal Community Centre. I am calling you to see if you may be interested in a research study I am conducting with Raafia Siddiqui, a student at McMaster University. This study looks at Health literacy in Syrian newcomers. We wish to know if you can get the health information you need and use it to improve your health. Are you interested to hear more about this study?
If no, thank them for their time and say good-bye
If yes, continue to explain the study details to them based on the letter of information

As a newcomer to Canada, your health literacy is very important to your ability to manage your own health. The reason we are doing this study is to see what the existing health literacy levels are in Syrian refugees, and see if health literacy can easily be measured in the Arabic language. This research will require you to complete a health literacy test and a brief follow-up questionnaire. This will take you approximately ten to fifteen minutes to complete and requires a one-time commitment only. There are no benefits or risks to participating in this study. If an any time, you wish to stop participating, you may do so. If you are interested, I can set up an appointment for you to meet the researcher, Raafia Siddiqui and I to complete the test.

Do you have any questions?
{Answer any questions they may have}

Do you agree to participate in this study?
**If yes, continue with the study*
**If no, thank them for their time and say good-bye*
Thank you for agreeing to participate in this study. What day and time would you like to meet for an appointment? Would you like to meet at your home, or at 250 Wellesley Street? If you feel that these spaces are not convenient or safe for you, is there somewhere else you would like to meet?
If participant asks to set up the appointment at another location, please do so

Thank you. If you have any questions, please call me at (insert phone number).
** end call**

Hamilton Integrated Research Ethics Board

Informed Consent Form- English

Principal Investigator:
Raafia Siddiqui
MSc candidate, Global Health
McMaster University
Hamilton, ON Canada
siddiqr@mcmaster.ca

Supervisor:
Dr. Bruce Newbold
School of Geography & Earth Sciences
McMaster University
Hamilton, ON Canada
newbold@mcmaster.ca
(905) 525-9140 ext. 27948

Research/Organizational Partner: Low Income Families Together (LIFT), Auntie Amal Community Centre

I am Raafia Siddiqui, a Masters student in the Global Health Program at McMaster University. I am conducting a research study on health literacy levels amongst Syrian refugees living in Toronto, ON under the supervision of Dr. Newbold. Amal Kanafani from Auntie Amal Community Centre is a research assistant for this study. Low Income Families Together (LIFT) is also a research collaborator. You have been invited to participate in this study because you are a Syrian refugee, who is over the age of 18 and speaks Arabic. If at any time, you do not understand any of the information in this form or have any questions, you can ask myself (the student investigator). Please note the student investigator does not speak Arabic, but the research assistant does and will translate for you.

Purpose of the research:
Health literacy looks at how well you can get the health information you need, understand it and use it to improve your health. As a newcomer to Canada, your health literacy is very important to your ability to manage your own health. The reason I am doing this study is to see what the existing health literacy levels are in Syrian refugees, and see if health literacy can easily be measured in the Arabic language.

What you will be doing in the research:
This research will require you to complete a health literacy test and a brief follow-up questionnaire. This will take you approximately ten to fifteen minutes to complete and requires a one-time commitment only.

Voluntary Participation:
Your participation in this research is entirely voluntary. It is your choice whether to participate of not. Whether you choose to participate or not, you are still able to attend all events, programs and services offered through LIFT and Auntie Amal Community Centre. If at any time, you no longer wish to participate in this study, you can stop. This will not affect your relationship with LIFT, Auntie Amal Community Centre or myself. Please note that if you wish to have your individual test results withdrawn, you must notify the researcher immediately after completing the study.

Risks and benefits:
The risks involved in participating in this study are minimal. However, you may feel embarrassed or upset if there are questions you cannot answer. If at any time, you feel any discomfort or stress you can

stop immediately. If at any time, you feel you are in crisis and would like to speak to a medical professional, we will have a list of appropriate services and will help you access them. There are also no anticipated benefits. You will not be provided any incentives for participating in this research study. However, your participation may help clinicians and providers better understand and meet the health needs of newly arriving Syrian refugees and other Arabic-speaking groups.

Confidentiality:

The information that is collected from you for this research project will be kept confidential. Your personal information and test results will be kept anonymous and will only be known to the researchers. The findings of this study will be shared with the wider public and may be published. If this happens, the personal information you have provided will be kept confidential and will not be shared.

Questions about the research?

If you have any questions you may ask them now or later, even after the study has started. If you wish to ask questions later, you may contact the student investigator: Raafia Siddiqui, siddiqr@mcmaster.ca.

Rights and Signatures:

Participant:

I have read the preceding information thoroughly. I have had an opportunity to ask questions and all my questions have been answered to my satisfaction. I agree to participate in this study. I understand that I will receive a signed copy of this form.

Name	Signature	Date

Person obtaining consent:

I have discussed this study in detail with the participant. I believe the participant understands what is involved in this study.

Name, Role in Study	Signature	Date

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB). The HIREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the REB Chair, HIREB at 905.521.2100 x 42013

Hamilton Integrated Research Ethics Board

Informed Consent Form-Arabic

مشرف:
الطبيب بروس نيوبولد
كلية الجغرافيا و علوم الأرض
جامعة ماكماستر
هاميلتون ، أونتاريو كندا
newbold@mcmaster.ca
(905) 525-9140 ext. 27948

الباحث الرئيسي:
رفيعة صديقي
مرشح ماجستير، الصحة العالمي
جامعة ماكماستر
هاميلتون أونتاريو
كندا
siddiqr@mcmaster.ca

البحث\المنظمة المشتركة:

عائلات ذوي الدخل المحدود معا ومركز الخالة امل الاجتماعي.

انا الطالبة رفيعة صديقي، طالبة ماجستير في برنامج الصحة العالمي في جامعة ماكماستر. انا إجريء دراسة بحثية عن مستوى الثقافة الصحية بين افراد اللاجئين السوريين الذين يعيشون في تورونتو تحت إشراف الدكتور نيوبولد. أمل كنفاني من مركز الخالة امل الاجتماعي هي مساعدة أبحاث لهذه الدراسة. كذالك يقوم مركز عائلات الدخل المحدود معا بالمساهمة في المساعدة والدعم لهذا البحث. لقد تم توجيه هذه الدعوة اليك للمشاركة في هذه الدراسة لأنك من اللاجئين السوريين، الذين اعمارهم فوق سن 18 عاما ويتحدث العربية. في أي وقت، صعب عليك فهم اي من المعلومات الورادة في هذا النموذج أو لديك أي أسئلة، يمكنك ان تسأل ايا من الطالبة الباحثه اوو المساعدين في الترجمة الحاضرين. يرجى الملاحظة الطالبة الباحثة لا تتكلم العربيه, ولكن مساعدة باحثة تستطيع ان تترجم لك كلا من السؤال الورد لك و اليك.

الغرض من البحث:

.
تبدو محو الأمية الصحية في مدى يمكنك الحصول على المعلومات الصحية التي تحتاج إليها، فهم واستخدامه لتحسين صحتك. كما الوافد الجديد إلى كندا، ومحو الأمية الصحية الخاص بك هو في غاية الأهمية لقدرتك على إدارة صحتك. السبب أقوم به هذه الدراسة هو معرفة ما هي مستويات محو الأمية الصحية القائمة في اللاجئين السوريين، ومعرفة ما إذا كان يمكن بسهولة قياس محو الأمية الصحية في اللغة العربية.

ما هو المطلوب منك عمله في هذا البحث؟
هذا البحث سوف يتطلب منك ان تتم الردعلي اسئله خاصة بامتحان مدى ثقافتك الصحية يليه الرد علي اسأاله ملحوظة قصيرة. هذا الامر سيستغرق حوالي ١٠ الي ١٥ دقيقة من الوقت للاجابة علي الاسئله و يتتطلب منك التعاون مع هذا الاجراء مرة واحدة فقط.

المشاركة تطوعيه:
مشاركتكم في هذا البحث هو تطوعي تماما. ومن اختيارك ما إذا كانت ستشارك ام لا. سواء اخترت المشاركة أم لا، فانك لا تزال قادرا على حضور كافة الفعاليات

والبرامج والخدمات المقدمة من خلال الأسر ذات الدخل المنخفض معا، ومركز الخاله امل الاجتماعي. يمكنك التوقف عن المشاركة في أي وقت ان كنت لم تعد ترغب في المشاركة في هذه الدراسة، هذا لن يؤثر على علاقتك مع LIFT، او مركز الخالة امل الاجتماعي او معي شخصيا. يرجى ملاحظة أنه إذا كنت ترغب في الحصول على نتائج الاختبارات الفردية الخاصة بك فحسب، يجب أن تبلغ الباحثة على الفور بعد الانتهاء من الدراسة.

المخاطر و الفوائد:
المخاطر التي تنطوي عليها المشاركة في هذه الدراسة تكاد تكون معدومة. ومع ذلك، قد تشعر بالحرج أو بالضيق إذا كانت هناك أسئلة لا يمكنك الإجابة عليها. إذا في أي وقت، كنت تشعر بأي انزعاج أو ما الي ذالك يحق لك أن تتوقف على الفور. إذا في أي وقت شعرت أنك في أزمة وترغب في التحدث إلى اخصائي طبي، سيكون لدينا قائمة من الخدمات المناسبة وسوف نساعدك على الوصول إليها. ليس هناك اي فوائد متوقعة. لن يكون متاحا لك أي حوافز للمشاركة في هذه الدراسة البحثية. ومع ذلك، مشاركتكم قد تساعد الأطباء و مقدمي الخدمات الصحية علي تقديم أفضل فهم وتلبية الاحتياجات الصحية للوصوله للاجئين السوريين الحديثين والجماعات الأخرى الناطقة بالعربية.

السرية:
المعلومات التي سيتم جمعها منك من خلال هذا البحث سوف يتم ابقائه سريا للمحافظه علي الخصوصية. معلماتك الشخصية ونتائج الاختبار التي يستقوم بتقديمها يسيتم تقديمها عموميا بدون ذكر اسماء و هذي الاسما ء يستكون معروفة فقط للباحثة. النتائج من هذي الدراسة سوف يتم تقاسمها علي نطاق عام و قد يتم نشرها ايضا. في حال حدوث ذلك, فسوف يتم الاحتفاظ بالمعلومات الشخصية و لن يتم نشرها .
الحقوق والتواقيع

مشارك:
لقد قرأت المعلومات السابقة كافة . لقد أتيحت لي الفرصة لطرح الأسئلة و كل من أسئلتي تم الرد عليها بشكل كافي . أوافق على المشاركة في هذه الدراسة . وأنا أفهم أني سوف أحصل على نسخة موقعة من هذا النموذج.

شخص الحصول على موافقة :

_____

تاريخ التوقيع اسم

لقد ناقشت هذه الدراسة بالتفصيل مع المشاركين . وأعتقد أن المشاركين يفهمون ما تنطوي عليه هذه الدراسة .

_____

تاريخ التوقيع اسم

8.3 APPENDIX C- TRANSLATION DOCUMENTS AND ASSESSMENT TOOLS

ALL ASPECTS OF HEALTH LITERACY SCALE (AAHLS) (from Chinn et al., 2013)

Please tick one response only for each question by placing a tick in the box

If you prefer, a member of staff or the research team can read out questions to you

FQ1	**How often do you need someone to help you when you are given information to read by your doctor, nurse or pharmacist?**	☐ often	☐ sometimes	☐ rarely	
FQ2	**When you need help, can you easily get hold of someone to assist you?**	☐ often	☐ sometimes	☐ rarely	☐ not applicable
FQ3	**Do you need help to fill in official documents?**	☐ often	☐ sometimes	☐ rarely	
ComQ1	**When you talk to a doctor or nurse, do you give them all the information they need to help you?**	☐ often	☐ sometimes	☐ rarely	
ComQ2	**When you talk to a doctor or nurse, do you ask the questions you need to ask?**	☐ often	☐ sometimes	☐ rarely	
ComQ3	**When you talk to a doctor or nurse, do you make sure they explain anything that you do not understand?**	☐ often	☐ sometimes	☐ rarely	

Cr1	**Are you someone who likes to find out lots of different information about your health?**	☐ often	☐ sometimes	☐ rarely
Cr2	**How often do you think carefully about whether health information makes sense in your particular situation?**	☐ often	☐ sometimes	☐ rarely
Cr3	**How often do you try to work out whether information about your health can be trusted?**	☐ often	☐ sometimes	☐ rarely
Cr4	**Are you the sort of person who might question your doctor or nurse's advice based on your own research?**	☐ yes, definitely	☐ maybe/ sometimes	☐ not really
Emp1	**Do you think that there plenty of ways to have a say in what the government does about health?**	☐ yes, definitely	☐ maybe/ sometimes	☐ not really

Emp2	**Within the last 12 months have you taken action to do something about a health issue that affects your family or community?**	yes	no
Emp3	**What do you think matters most for everyone's health? (tick one answer only)**	a) Information and encouragement to lead healthy lifestyles	b) Good housing, education, decent job and good local facilities

AAHLS Arabic Version 1

جميع جوانب جدول محو الأمية الصحي

يرجى وضع علامة ( ) في المربع برد واحد فقط لكل سؤال
او ممكن ان نسال أحد الموظفين أو فريق البحث لقراءة الأسئلة لك.

FQ1	كم مرة تحتاج شخص لمساعدتك عندما يتم إعطاء المعلومات لقراءتها من قبل الطبيب او الممرضة أو الصيدلي؟	☐غالبا	☐أحيانا	☐نادرا	
FQ2	عندما تكون بحاجة إلى مساعدة هل بسهولة يمكنك الحصول على شخص ما لمساعدتك ؟	☐غالبا	☐أحيانا	☐نادرا	☐ليس قابل للتطبيق
FQ3	هل تحتاج إلى مساعدة لملء مستندات رسمية؟	☐غالبا	☐أحيانا	☐نادرا	
ComQ1	عندما تتحدث إلى الطبيب أو الممرضة ، هل نعطيهم كل المعلومات التي يحتاجونها ليساعدوك؟	☐غالبا	☐أحيانا	☐نادرا	
ComQ2	عندما تتحدث إلى الطبيب أو الممرضة ، هل تسال الأسئلة التي تحتاجها؟	☐غالبا	☐أحيانا	☐نادرا	
ComQ3	عندما تتحدث إلى الطبيب أو الممرضة ، هل تتأكد من يشرحون كل شيء لا تفهمه؟	☐غالبا	☐أحيانا	☐نادرا	
Cr1	هل أنت شخص يحب معرفة الكثير من المعلومات الصحية عن تفسك ؟	☐غالبا	☐أحيانا	☐نادرا	
Cr2	كم مره حاولت التاكد ان المعلومات الصحية عنك صحيحة؟	☐غالبا	☐أحيانا	☐نادرا	
Cr3	كم مره اكتشفت إذا كانت المعلومات	☐غالبا	☐أحيانا	☐نادرا	

	عن صحتك موثوق به؟			
Cr4	هل أنت من النوع الذي يسال الطبيب أو الممرضة استنادا لبحث قمت به بنفسك ؟	☐نعم فعلا، قطعا	☐يمكن/ أحيانا	☐يمكن / أحيانا
Emp1	هل تعتقد أن هناك الكثير من الطرق للحكم في ما تفعله الحكومة حول الصحة؟	☐نعم فعلا، قطعا	☐يمكن/ أحيانا	☐يمكن / أحيانا

Emp2	خلال ال 12 شهرا الماضية هل اتخذت إجراءات لنفعل شيئا في القضية الصحية التي تؤثر عائلتك أو مجتمعك ؟	☐نعم	☐لا
Emp3	ماهو الأهم لصحة الجميع ؟ (إجابة واحدة فقط)	☐أ) المعلومات و التشجيع لضمان أنماط الحياة الصحية	☐ب) السكن الجيد ، التعليم و الوظيفة اللائقة والمرافق المحلية الجيدة

AAHLS Back-Translated Version

Please tick () in the box only for each question and one response
Or possible to ask one of the staff or the research team to read the questions to you.

	☐ Rarely	☐ Sometimes	☐ Often	How many times you need someone to help you when you are given information to be read by a doctor or nurse or chemist?	FQ1
☐ Not applicable	☐ Rarely	☐ sometimes	☐ Often	When you are in need of help can you easily get someone to help you?	FQ2
	☐ rarely	☐ sometimes	☐ Often	Do you need help to fill official documents?	FQ3
	☐ rarely	☐ sometimes	☐ Often	When you talk to your doctor or the nurse, do you give them all information they need to help you?	Com Q1
	☐ rarely	☐ sometimes	☐ Often	When you talk to your doctor or the nurse, do you ask them important questions that you really need?	Com Q2
	☐ rarely	☐ sometimes	☐ Often	When you talk to your doctor or the nurse, do you make sure that you understand whatever they explain?	Com Q3
	☐ rarely	☐ sometimes	☐ Often	Are you a person who likes to know a lot of health information about yourself ?	Cr1
				How many times you tried to make sure that health information about yourself is accurate?	

☐ rarely	☐ sometimes	☐ Often		Cr2
☐ rarely	☐ sometimes	☐ often	How many times have you discovered if the information about your health is trusted?	Cr3
☐ Can sometimes	☐ Can sometimes	☐ Yes, definitely	Are you the kind of person who asks questions to the doctor or nurse based on the search you've done it yourself ?	Cr4
☐ Can sometimes	☐ Can sometimes	☐ Yes, definitely	Do you think there a lot of ways to judge what the government is doing about health?	Emp 1

☐ No	☐ yes	During the past 12 months Are procedures To do something Health issue affecting Your family or Your community?	Emp2
☐ Good housing, education and decent careers and good local facilities	☐ Information and encouragement to ensure healthy lifestyles	What is more important regarding everyone's health? (Only one answer)	Emp3

AAHLS Arabic Version 2

جميع جوانب جدول محو الأمية الصحي

برد واحد فقط لكل سؤال في المربع ( )يرجى وضع علامة
او ممكن ان نسال أحد الموظفين أو فريق البحث لقراءة الأسئلة لك.

All aspects of health literacy illiteracy agenda

Please tick () in the box only for each question and one response
Or possible to ask one of the staff or the research team to read the questions to you.

	☐نادرا Rarely	☐أحيانا Sometimes	☐غالبا Often	كم مرة تحتاج شخص لمساعدتك عندما يتم إعطاء المعلومات لقراءتها من قبل الطبيب او الممرضة أو الصيدلي؟ How many times you need someone to help you when you are given information to be read by a doctor or nurse or chemist?	FQ1
☐ليس قابل للتطبيق Not applicable	☐نادرا Rarely	☐أحيانا sometimes	☐غالبا Often	عندما تكون بحاجة إلى مساعدة هل بسهولة يمكنك الحصول على شخص ما لمساعدتك ؟ When you are in need of help can you easily get someone to help you?	FQ2
	☐نادرا rarely	☐أحيانا sometimes	☐غالبا Often	هل تحتاج إلى مساعدة لملء مستندات رسمية؟ Do you need help to fill official documents?	FQ3
	☐نادرا rarely	☐أحيانا sometimes	☐غالبا Often	عندما تتحدث إلى الطبيب أو الممرضة ، هل نعطيهم كل المعلومات التي يحتاجونها ليساعدوك؟ When you talk to your doctor or the nurse, do you give them all	Com Q1

			information they need to help you?	
نادرا☐ rarely	أحيانا☐ sometimes	غالبا☐ Often	عندما تتحدث إلى الطبيب أو الممرضة ، هل تسال الأسئلة التي تحتاجها؟ When you talk to your doctor or the nurse, do you ask them important questions that you really need?	Com Q2
نادرا☐ rarely	أحيانا☐ sometimes	غالبا☐ Often	عندما تتحدث إلى الطبيب أو الممرضة ، هل تتأكد من يشرحون كل شيء لا تفهمه؟ When you talk to your doctor or the nurse, do you make sure that you understand whatever they explain?	Com Q3
نادرا☐ rarely	أحيانا☐ sometimes	غالبا☐ Often	هل أنت شخص يحب معرفة الكثير من المعلومات الصحية عن نفسك ؟ Are you a person who likes to know a lot of health information about yourself ?	Cr1
نادرا☐ rarely	أحيانا☐ sometimes	غالبا☐ Often	كم مره حاولت التاكد ان المعلومات الصحية عنك صحيحة؟ How many times you tried to make sure that health information about yourself is accurate?	Cr2
نادرا☐ rarely	أحيانا☐ sometimes	غالبا☐ often	كم مره اكتشفت إذا كانت المعلومات عن صحتك موثوق به؟ How many times have you discovered if the information about your health is trusted?	Cr3

Cr4	هل أنت من النوع الذي يسال الطبيب أو الممرضة استنادا لبحث قمت به بنفسك Are you the kind of person who asks questions to the doctor or nurse based on the search you've done it yourself ?	☐نعم فعلا، قطعا Yes, definitely	☐يمكن/ أحيانا Can sometimes	☐يمكن / أحيانا Can sometimes
Emp 1	هل تعتقد أن هناك الكثير من الطرق للحكم في ما تفعله الحكومة حول الصحة؟ Do you think there a lot of ways to judge what the government is doing about health?	☐نعم فعلا، قطعا Yes, definitely	☐يمكن/ أحيانا Can sometimes	☐يمكن / أحيانا Can sometimes

Emp2	خلال ال 12 شهرا الماضية هل اتخذت إجراءات لنفعل شيئا في القضية الصحية التي تؤثر عائلتك أو مجتمعك ؟ During the past 12 months Are procedures To do something Health issue affecting Your family or Your community?	☐نعم yes	☐لا No
Emp3	ماهو الأهم لصحة الجميع ؟ (إجابة واحدة فقط) What is more important regarding everyone's health? (Only one answer)	☐أ) المعلومات و التشجيع لضمان أنماط الحياة الصحية Information and encouragement to ensure healthy lifestyles	☐ب) السكن الجيد ، التعليم و الوظيفة اللائقةوالمرافق المحلية الجيدة Good housing, education and decent careers and good local facilities

Please note that this version includes the back-translated text (English) as well as the subsequent corrections that were made to AAHLS Arabic Version 1 after discrepancies were identified

between the back-translated and original English version of the AAHLS (highlighted in yellow).

AAHLS Version 3

جميع جوانب جدول محو الأمية الصحي

برد واحد فقط لكل سؤال في المربع ( )يرجى وضع علامة
او ممكن ان نسال أحد الموظفين أو فريق البحث لقراءة الأسئلة لك.

						/Clear unclear please) (indicate
	☐نادرا	☐ أحيانا	☐غالبا	كم مرة تحتاج إلى شخص لمساعدتك عندما يتم إعطاء المعلومات لقراءتها من قبل الطبيب او الممرضة أو الصيدلي؟	FQ1	
☐ليس قابل للتطبيق	☐نادرا	☐ أحيانا	☐غالبا	عندما تكون بحاجة إلى مساعدة هل بسهولة يمكنك الحصول على شخص ما لمساعدتك ؟	FQ2	
	☐نادرا	☐ أحيانا	☐غالبا	هل تحتاج إلى مساعدة لملئ مستندات رسمية؟	FQ3	
	☐نادرا	☐ أحيانا	☐غالبا	عندما تتحدث إلى الطبيب أو الممرضة ، هل تعطيهم كل المعلومات التي يحتاجونها ليساعدوك؟	ComQ1	
	☐نادرا	☐ أحيانا	☐غالبا	عندما تتحدث إلى الطبيب أو الممرضة ، هل تسال الأسئلة التي تحتاجها؟	ComQ2	
	☐نادرا	☐ أحيانا	☐غالبا	عندما تتحدث إلى الطبيب أو الممرضة ، هل تتأكد من أنهم	ComQ3	

	يشرحون كل شيء لا تفهمه؟				
	هل أنت شخص يحب معرفة الكثير من المعلومات عن صحتك؟	Cr1	☐غالبا	☐ أحيانا	☐نادرا
	كم مره حاولت التأكد من أن المعلومات الصحية عنك صحيحة؟	Cr2	☐غالبا	☐ أحيانا	☐نادرا
	كم مره اكتشفت إذا كانت المعلومات عن صحتك موثوق بها؟	Cr3	☐غالبا	☐ أحيانا	☐نادرا
	هل أنت من النوع الذي يسال الطبيب أو الممرضة عن حالتك الصحية استنادا لبحث قمت به بنفسك؟	Cr4	☐نعم فعلا، قطعا	☐ يمكن/ أحيانا	☐يمكن / أحيانا
	هل تعتقد أن هناك الكثير من الطرق التي يمكنك القيام بها في ما تفعله الحكومة حول الصحة؟	Emp1	☐نعم فعلا، قطعا	☐ يمكن/ أحيانا	☐ لا ليس صحيحا

(Clear/Unclear (please indicate				
	Emp2	خلال ال عام شهرا الماضية هل اتخذت إجراءات لتفعل شيئا في القضية الصحية التي تؤثر على عائلتك أو مجتمعك ؟	☐نعم	☐لا
	Emp3	ما هو رأيك نحو أهم شيء لصحة الجميع ؟ (إجابة واحدة فقط)	☐أ) المعلومات و التشجيع لضمان أنماط الحياة الصحية	☐ب) السكن الجيد ، التعليم و الوظيفة اللائقة والمرافق المحلية الجيدة

AAHLS Arabic Final Version

جميع جوانب جدول محو الأمية الصحي

برد واحد فقط لكل سؤال في المربع يرجى وضع علامة
او ممكن ان نسال أحد الموظفين أو فريق البحث لقراءة الأسئلة لك.

	1	2	3	Scoring	
	☐نادرا **(3)**	☐أحيانا **(2)**	☐غالبا **(1)**	كم مرة تحتاج إلى شخص لمساعدتك عندما يتم إعطاء المعلومات لقراءتها من قبل الطبيب او الممرضة أو الصيدلي؟	**FQ1**
☐ليس قابل للتطبيق	☐نادرا	☐أحيانا	☐غالبا	عندما تكون بحاجة إلى مساعدة هل بسهولة يمكنك الحصول على شخص ما لمساعدتك ؟	**FQ2**
	☐نادرا (3)	☐أحيانا **(2)**	☐غالبا **(1)**	هل تحتاج إلى مساعدة لملئ مستندات رسمية؟	**FQ3**
	☐نادرا	☐أحيانا	☐غالبا	عندما تتحدث إلى الطبيب أو الممرضة ، هل تعطيهم كل المعلومات التي يحتاجونها ليساعدوك؟	**ComQ1**
	☐نادرا	☐أحيانا	☐غالبا	عندما تتحدث إلى الطبيب أوالممرضة ، هل تسال الأسئلة التي تحتاجها؟	**ComQ2**
	☐نادرا	☐أحيانا	☐غالبا	عندما تتحدث إلى الطبيب أو الممرضة ، هل تتأكد من أنهم يشرحون كل شيء لا تفهمه؟	**ComQ3**
	☐نادرا	☐أحيانا	☐غالبا	هل أنت شخص يحب معرفة الكثير من	**Cr1**

	المعلومات عن صحتك؟			
Cr2	كم مره حاولت التأكد من أن المعلومات الصحية عنك صحيحة؟	☐غالبا	☐أحيانا	☐نادرا
Cr3	كم مره اكتشفت إذا كانت المعلومات عن صحتك موثوق بها؟	☐غالبا	☐أحيانا	☐نادرا
		3	**2**	**1**
Cr4	هل أنت من النوع الذي يسال الطبيب أو الممرضة عن حالتك الصحية استنادا لبحث قمت به بنفسك؟	☐نعم فعلا، قطعا	☐يمكن/ أحيانا	☐يمكن / أحيانا
Emp1	هل تعتقد أن هناك الكثير من الطرق التي يمكنك القيام بها في ما تفعله الحكومة حول الصحة؟	☐نعم فعلا، قطعا	☐يمكن/ أحيانا	☐ لا ليس صحيحا

			1
Emp2	خلال ال عام شهرا الماضية هل اتخذت إجراءات لتفعل شيئا في القضية الصحية التي تؤثر على عائلتك أو مجتمعك ؟	☐نعم	☐لا
Emp3	ما هو رأيك نحو أهم شيء لصحة الجميع ؟ (إجابة واحدة فقط)	☐أ) المعلومات و التشجيع لضمان أنماط الحياة الصحية **(a)**	☐ب) السكن الجيد ، التعليم و الوظيفة اللائقة والمرافق المحلية الجيدة (b)

Demographic Questionnaire- English

What is your age (please write)?	
What is your gender?	□ Male □ Female
When did you come to Canada? (please write)	
From where did you move to Canada?	□ Syria □ Refugee Camp □ Other: _____
Sponsorship status	□Government-assisted □ Privately sponsored
How far did you go in school?	□less than high school □ High school graduate or GED □Some college □ Bachelors degree or higher
What was your occupation/position before you became a refugee?	
Current employment	□Employed full time □ Employed part time (<35hrs/wk) □Self-employed □ In School □Home-maker □Other _____
How would you rate your own health?	□Poor □ Fair/OK □Good □ Very good/excellent
Do you have any long-term health conditions?	□Yes □ No □I don't know
Were you able to complete the previous survey without any assistance?	□Yes □ No

Demographic Questionnaire- Arabic

كم تبلغ من العمر؟	
ما هو نو الجنس الخاص بك؟	انثى □ ذكر □
عندما أتيت إلى كندا؟	
من أين مكان انتقلت إلى كندا؟	□ سوريا □ ملجاء للاجيئن □ غير
نوعية كفالة الهجره؟	□ المدعومه من الحكومه □ كفالة شخصيه
ما هو اعلى مستوى تعليمي حصلت عليه؟	□ اقل من الثانويه □ خريج ثانويه عامة □ شي من دراسه جامعيه □ شهادة بكلوريورس او اعلى
ما هي حالتك الوظيفية قبل أن تصبح لاجئا؟	
الحالة الوظيفية	□ موظف دوام كامل □ موظف دوام جزئي □ ابحث عن عمل □ طالب في المدرسة □ رب او ربة منزل □ شي اخر _____
كيف تقييم صحتك الشخصية؟	سيئة □ مقبولة □ جيدة □ ممتازة □
هل يوجد لديك حالة مرضية مزمنة؟	لا □ نعم □ □ لا اعلم
هل كنت قادرا على استكمال الأسئلة السابقة دون أي مساعدة ؟	لا □ نعم □

8.4 APPENDIX D- STATISTICAL SUMMARIES

Table 1.
Test for normal distribution of data.

	F value	**P value**	**F critical**
Self Rated health	1.74	0.17	2.73
Education	0.11	0.74	3.97
Long term health conditions	3.57	0.06	3.99

Table 2.
Descriptive statistics for two-sample t-test, with unequal variance assumed.

Health Literacy Component	**Functional**		**Communicative**		**Critical**		**Empowerment**		**Total**	
Gender (F=female, M=male)	*F*	*M*	*F*	*M*	*F*	*M*	*F*	*M*	*F*	*M*
Mean	5.5	5.5	7.0	7.0	8.5	7.7	4.3	4.3	24.0	24.4
Variance	1.7	1.8	3.3	2.4	5.4	4.5	1.6	1.9	20.3	16.9
Observations	35	41	35	41	35	41	35	41	35	41
Place of Origin (C=Country, R=Refugee Camp)	*C*	*R*	*C*	*R*	*C*	*R*	*C*	*R*	*C*	*R*
Mean	5.5	5.5	7.2	6.7	8.3	7.6	3.4	2.9	25.3	22.6
Variance	2.0	1.4	2.7	2.9	5.5	4.0	1.4	1.5	17.0	19.0
Observations	48	28	48	28	48	28	48	28	48	28
Education (a=less than high school, b= high school or higher)	*a*	*b*	*a*	*b*	*a*	*b*	*a*	*b*	*a*	*b*
Mean	5.5	5.5	7.0	7.0	7.9	8.1	3.2	3.2	23.5	24
Variance	1.8	1.7	2.5	3.4	4.6	5.9	1.4	1.7	17.0	21.4
Observations	51	25	51	25	51	25	51	25	51	25
Sponsorship Status (G=government, P=private)	*G*	*P*	*G*	*P*	*G*	*P*	*G*	*P*	*G*	*P*
Mean	5.7	5.1	6.8	7.3	7.8	8.5	3.1	3.2	23.3	24.0
Variance	1.7	2.3	2.7	3.4	4.6	6.5	1.4	1.6	17.8	20.5
Observations	53	16	53	16	53	16	54	16	54	16
Long-term Health Conditions	*yes*	*no*	*yes*	*no*	*yes*	*no*	*yes*	*no*	*yes*	*no*
Mean	5.6	5.3	6.6	7.5	7.6	8.9	3.1	3.2	22.9	24.8
Variance	1.4	2.2	3.2	2.6	4.2	6.2	1.5	1.5	15.7	20.3
Observations	33	31	33	31	33	31	44	32	44	32
Self-Rated Health (a=poor/fair, b=good/excellent)	a	b	a	b	a	b	a	b	a	b
Mean	5.3	5.7	6.7	7.3	7.8	7.3	3.2	3.1	23.0	24.3
Variance	1.6	1.9	2.4	3.0	3.4	3.1	1.4	1.6	14.5	22.1
Observations	41	35	41	35	41	35	40	36	40	36

Table 3.
Summary statistics for two-sample t-test, with unequal variance assumed.

Health Literacy Component	Functional	Communicative	Critical	Empowerment	Total
Gender					
T (df)	0.09 (73)	0.06 (67)	1.51 (69)	0.76 (73)	-0.61 (70)
t one-tail (p)	1.67 (.47)	1.67 (.48)	1.67 (.07)	1.67 (.22)	1.67 (.26)
t two-tail (p)	1.99 (.93)	2.00 (.95)	1.99 (.14)	1.99 (.45)	1.99 (.53)
Place of Origin					
T (df)	0.19 (64)	1.22 (55)	1.46 (64)	1.73 (56)	1.75 (56)
t one-tail (p)	1.67 (.43)	1.67 (.11)	1.67 (.07)	1.67 (.04)*	1.67 (.04)*
t two-tail (p)	2.00 (.85)	2.00 (.23)	2.00 (.15)	2.00 (.08)	2.00 (.09)
Education					
T (df)	-0.15 (44)	-0.19 (37)	-0.25 (38)	-0.14 (44)	-0.41 (43)
t one-tail (p)	1.68 (.44)	1.69 (.43)	1.69 (.40)	1.69 (.44)	1.69 (.34)
t two-tail (p)	2.02 (.88)	2.03 (.85)	2.02 (.81)	2.02 (.88)	2.02 (.68)
Sponsorship Status					
T (df)	1.29 (22)	-0.97 (23)	-1.03 (22)	-1.06 (25)	-1.39 (38)
t one-tail (p)	1.72 (.11)	1.71 (.17)	1.72 (.16)	1.72 (.28)	169 (.09)
t two-tail (p)	2.07 (.21)	2.07 (.34)	2.07 (.31)	2.06 (.55)	2.02 (.17)
Long-term Health Conditions					
T (df)	1.04 (57)	-2.00 (62)	-2.27 (58)	-0.29 (68)	-1.94 (62)
t one-tail (p)	1.67 (.15)	1.67 (.03)*	1.67 (.01)*	1.67 (.38)	1.67 (.02)*
t two-tail (p)	2.00 (0.30)	2.00 (.05)*	2.00 (.03)*	2.00 (.77)	2.00 (.06)
Self-Rated Health					
T (df)	-1.86 (69)	-1.86 (68)	1.05 (73)	0.21 (72)	-1.38 (67)
t one-tail (p)	1.66 (.09)	1.67 (.03)	1.67 (.15)	1.67 (.41)	1.67 (.09)
t two-tail (p)	2.00 (.19)	2.00 (.06)	2.00 (.30)	2.00 (.82)	2.00 (.17)

*significant at p of 0.05

Table 4.

Cross tabulation of long-term health conditions (LTH) and communicative health literacy questions.

			LTH				
			yes	**no**	**Total**	**Chi Square (p)**	**Phi and Cramer's V (p)**
Comm1	"rarely"	Count	3	1	4	1.016 (.60)	.12 (.60)
		% within Comm1	75.0%	25.0%	100.0%		
		% within LTH	8.8%	3.1%	6.1%		
	"sometimes"	Count	10	9	19		
		% within Comm1	52.6%	47.4%	100.0%		
		% within LTH	29.4%	28.1%	28.8%		
	"often"	Count	21	22	43		
		% within Comm1	48.8%	51.2%	100.0%		
		% within LTH	61.8%	68.8%	65.2%		
Comm2	"rarely"	Count	9	3	12	6.6 (.036)*	.32 (.036)*
		% within Comm2	75.0%	25.0%	100.0%	.	
		% within LTH	26.5%	9.4%	18.2%		
	"sometimes"	Count	14	9	23		
		% within Comm2	60.9%	39.1%	100.0%		
		% within LTH	41.2%	28.1%	34.8%		
	"often"	Count	11	20	31		
		% within Comm2	35.5%	64.5%	100.0%		
		% within LTH	32.4%	62.5%	47.0%		
Comm3	"rarely"	Count	13	6	19	12.5 (.002)*	.46 (.002)*
		% within Comm3	68.4%	31.6%	100.0%		
		% within LTH	38.2%	18.8%	28.8%		
	"sometimes"	Count	16	8	24		
		% within Comm3	66.7%	33.3%	100.0%		
		% within LTH	47.1%	25.0%	36.4%		
	"often"	Count	5	18	23		
		% within Comm3	21.7%	78.3%	100.0%		
		% within LTH	14.7%	56.3%	34.8%		

Table 5. *Cross tabulation of long-term health conditions (LTH) and critical health literacy questions*

			LTH		Total	Chi Square (p)	Phi and Cramer's V (p)
			yes	no			
crit1	"rarely"	Count	8	3	11	7.5 (.023)*	.337 (.023)*
		% within crit1	72.7%	27.3%	100.0%		
		% within LTH	23.5%	9.4%	16.7%		
	"sometimes"	Count	16	9	25		
		% within crit1	64.0%	36.0%	100.0%		
		% within LTH	47.1%	28.1%	37.9%		
	"often"	Count	10	20	30		
		% within crit1	33.3%	66.7%	100.0%		
		% within LTH	29.4%	62.5%	45.5%		
crit2	"rarely"	Count	17	8	25	5.1(.079)	.28 (.079)
		% within crit2	68.0%	32.0%	100.0%		
		% within LTH	51.5%	25.0%	38.5%		
	"sometimes"	Count	10	13	23		
		% within crit2	43.5%	56.5%	100.0%		
		% within LTH	30.3%	40.6%	35.4%		
	"often"	Count	6	11	17		
		% within crit2	35.3%	64.7%	100.0%		
		% within LTH	18.2%	34.4%	26.2%		
crit3	"rarely"	Count	14	11	25	2.85 (.24)	.21 (.24)
		% within crit3	56.0%	44.0%	100.0%		
		% within LTH	42.4%	34.4%	38.5%		
	"sometimes"	Count	10	6	16		
		% within crit3	62.5%	37.5%	100.0%		
		% within LTH	30.3%	18.8%	24.6%		
	"often"	Count	9	15	24		
		% within crit3	37.5%	62.5%	100.0%		
		% within LTH	27.3%	46.9%	36.9%		
crit4	"rarely"	Count	4	9	13	2.6 (.28)	.20 (.28)
		% within crit4	30.8%	69.2%	100.0%		
		% within LTH	12.9%	28.1%	20.6%		
	"sometimes"	Count	14	10	24		
		% within crit4	58.3%	41.7%	100.0%		
		% within LTH	45.2%	31.3%	38.1%		
	"often"	Count	13	13	26		
		% within crit4	50.0%	50.0%	100.0%		
		% within LTH	41.9%	40.6%	41.3%		

Table 6.

Cross tabulation of place of origin and empowerment questions.

			Origin			Chi Square (p)	Phi and Cramer's V (p)
			country	refugee camp	Total		
Emp1	"not really"	Count	12	11	23	.29 (.12)	.29 (.12)
		% within Emp1	52.2%	47.8%	100.0%		
		% within ORIGIN	26.1%	47.8%	33.3%		
	"maybe/sometimes"	Count	17	6	23		
		% within Emp1	73.9%	26.1%	100.0%		
		% within ORIGIN	37.0%	26.1%	33.3%		
	"yes/definitely"	Count	17	5	22		
		% within Emp1	77.3%	22.7%	100.0%		
		% within ORIGIN	37.0%	21.7%	31.9%		
Emp2	"yes"	Count	28	18	46	-.03 (.77)	.03 (.77)
		% within Emp2	60.9%	39.1%	100.0%	.	
		% within ORIGIN	60.9%	64.3%	62.2%		
	"no"	Count	18	10	28		
		% within Emp2	64.3%	35.7%	100.0%		
		% within ORIGIN	39.1%	35.7%	37.8%		
Emp3	"a"	Count	37	24	61	.34 (.56)	.
		% within Emp3	60.7%	39.3%	100.0%		
		% within ORIGIN	80.4%	85.7%	82.4%		
	"b"	Count	9	4	13		
		% within Emp3	69.2%	30.8%	100.0%		
		% within ORIGIN	19.6%	14.3%	17.6%		

Table 8.
Correlations between health literacy sub-scale scores.

	Functional Health Literacy	**Communicative Health Literacy**	**Critical Health Literacy**
Empowerment	-0.05	-0.26*	0.34**
Critical Health Literacy	0.02	0.57**	/
Communicative Health Literacy	0.03	/	/

*Significant at p of 0.05
*Significant at o of 0.01

Table 9.
Correlations between Individual Question Scores.

	Emp 3	Emp 2	Emp 1	CritQ 4	CritQ 3	CritQ 2	CritQ 1	ComQ 3	ComQ 2	ComQ 1	FQ 3	FQ 2
FQ1	-0.07	0.16	0.2	0.01	0.09	0	0.11	0.24	0.23	-0.24	0.34	-0.1
FQ2	-0.11	-0.07	-0.30	0.08	0.33	0.24	-0.01	0.15	-0.10	0.32	-0.25	/
FQ3	0.05	0.05	0.23	-0.11	-0.07	-0.31	-0.10	-0.24	0.00	-0.27	/	/
CommQ 1	-0.15	0.21	-0.07	0.25	0.32	0.29	-0.05	0.37	0.11	/	/	/
CommQ 2	0.13	0.40	0.29	0.27	0.32	0.23	0.43	0.55	/	/	/	/
CommQ 3	0.00	0.44	0.26	0.43	0.53	0.51	0.20	/	/	/	/	/
CritQ1	0.14	0.22	0.26	0.12	0.19	0.18	/	/	/	/	/	/
CritQ2	0.06	0.36	0.11	0.43	0.46	/	/	/	/	/	/	/
CritQ3	0.00	0.43	0.04	0.35	/	/	/	/	/	/	/	/
CritQ4	0.21	0.38	0.27	/	/	/	/	/	/	/	/	/
Emp1	-0.05	0.39	/	/	/	/	/	/	/	/	/	/
Emp2	0.07	/	/	/	/	/	/	/	/	/	/	/