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Online behaviours, offline implications:

A window into the use of the Internet for health
among immigrant women in Malmö

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Abstract

In a country as ‘connected’ as Sweden, it is hard to imagine a setting in which the Internet does not play a significant role in people’s everyday lives. The purpose of this thesis is to analyze the use and/or awareness of online health information and services among female immigrants in Malmö, Sweden. The data collected is based on semi-structured interviews with 11 female immigrants of 7 different nationalities and two interviews with Swedish academics. The topic is approached through a feminist angle as well as a cultural studies perspective, focused specifically on Stuart Hall’s concept of the encoding/decoding process of reading media texts. The findings suggest that immigrant women use the Internet for health in multiple and contested ways but are largely unaware of existing e-Health services. The thesis ends with policy recommendations on how best to maximize the potential of this new media for health promotion and increased health literacy, as well as for coping with the preconceived ideas and cultural expectations with which many immigrants arrive.

Keywords: Internet, health, media, female immigrants, e-Health.

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Finally, it is perhaps only fitting to thank Tim Gunn for the famous mantra which, by the end of this process, became my own: *'make it work!'*

Abbreviations

AEAS	Afghan Engineer Association in Sweden
BACS	Bangladesh Cultural Association in Skåne
BHKS	Bosnien-Hercegovinas kvinnoällskap i Malmö
CCCS	Centre for Contemporary Cultural Studies
DALYs	Disability Adjusted Life Years
EU	European Union
GNP	Gross National Product
HKF Malmö	Herrgårds kvinnoörening
ITU	International Telecommunications Union
ICTs	Information and Communication Technologies
ICT4D	Information and Communication Technology for Development
IKF Malmö	Internationella Kvinnoöreningen i Malmö
IOM	Institute of Medicine
IP	Internet Protocol
LIFS	Lunds Integrations Främjande Samarbetsorganisation
MDGs	Millennium Development Goals
POST	British Parliamentary Office of Science and Technology
RIFFI	Riksförbundet Internationella Ööreningar för Invandrarkvinnor
SALAR	Swedish Association of Local Authorities and Regions
UK	United Kingdom
UN	United Nations
UNDP	United Nations Development Programme
UNWSA	United Nations World Summit Awards
US	United States
WHO	World Health Organization

Table of Contents

Abstract.....	2
Acknowledgments	3
Abbreviations.....	4
Table of Contents.....	5
1. Introduction.....	7
1.1 Statement of purpose	8
1.2 Research questions	8
2. Background.....	9
2.1 Key terms	9
2.1.1 e-Health.....	9
2.1.2 Digital divide.....	9
2.1.3 Health literacy	10
2.1.4 Information and Communication Technologies (ICTs) for health	10
2.1.5 Internet	11
2.2 Why e-Health in Sweden?	11
2.3 Health and immigration in Sweden	12
2.4 e-Health in Sweden.....	14
2.5 Sweden in the international e-Health arena	16
3. Literature Review	17
3.1 Background	17
3.2 Research process	17
3.3 Starting point	18
3.4 Evaluation of the literature	19
3.5 Statistics and international comparisons.....	20
3.6 Methodology of the Literature.....	22
3.7 Development and health literature.....	22
3.8 Immigration and health literature	23
3.9 Summary	24
4. Theoretical framework.....	25
4.1 The historical role of women in western medicine	25
4.2 Feminist theories of technologies	26
4.3 Media theories: The encoding/decoding model.....	27
5. Methods	29
5.1 Aim of the study	29
5.2 Semi-structured interviews	30
5.2.1 Advantages and limitations	30
5.2.2 Finding participants.....	30
5.2.3 The interview process	32
5.3 Secondary analysis	33
5.4 Ethics	34

5.5 Research participants.....	35
6. Findings and discussion	37
6.1 The Internet as an additional resource for finding health information.....	37
6.1.1 Internet access	37
6.1.2 Frequency, use, and types of health searches online	38
6.1.3 Google and online health forums	40
6.1.4 Trust, doctors and negotiation.....	41
6.1.5 Natural remedies, discourses and negotiated readings	44
6.2 The Internet as a tool to cope with issues of access and lack of understanding of the Swedish health care system	47
6.2.1 A cultural divide: the private/public health care dynamic.....	47
6.2.2 Frustration with ‘passive’ responses	48
6.2.3 Lack of understanding from the immigrants’ side	50
6.2.4 Lack of understanding from the system’s side	51
6.3 The Internet as an instrument for increasing awareness and bridging cultural divides	52
6.3.1 Language issues and new discoveries	54
6.3.2 Strategies and potential tactics	56
6.3.3 Acceptance of e-health services	56
6.3.4 Empowerment and the road ahead	58
6.3.5 Policy recommendations	59
7. Limitations.....	60
8. Conclusion	61
References.....	62
Appendix	68
Research summary	68
Interview questions (immigrants).....	69
Interview questions (researchers).....	71
Informed consent form	73

1. Introduction

“Now you use the Internet for everything. And health is one of those things...Now you can find everything on the net.” (Deeba, personal communication, April 7, 2011)

Today, Sweden is one of the top ten countries in the world in terms of percentage of broadband Internet connections (Rahmqvist & Bara, 2007). Over the last five years, Internet use among Swedes has tripled and the Internet has become an increasingly important source of health information for both men and women (ibid). The question is, however: is everyone in Sweden equally ‘connected’ and in tune with the rise of the ‘informed e-patient’?

In recent years, the debate around the impact of new media technologies on health and development has grown exponentially, both in Sweden and worldwide. As Kivits (2009) notes, the “media have [...] a particular role in providing information about health” (p.681). Some argue that the age of the computer has essentially revolutionized the way many women deal with their health, giving women more power and control over their bodies and the health issues they must address. Since the eighteenth century, the valorization of scientific knowledge, at the expense of experiential knowledge (Lupton, 2003), has defined the medical profession as an essentially male domain and women as subordinate to their (male) doctors. In the past, lacking access to health information, women with health concerns often had little choice but to accept a diagnosis. With no easy way to obtain additional information and connect with others in the same situation, they simply lacked the resources to contest it. Today, there is a significant number of female doctors and a range of medical options available to women, including reproductive technologies and non-western traditional medicine. Nonetheless, the Western medical system often remains somewhat hostile and reluctant to deal with female-specific concerns. In this context, the Internet, by way of its accessibility, conviviality and ease of use (Rowland, 1997), has emerged as a powerful tool for women to regain control of their health, most notably by transforming the patient-doctor relationship. Women’s increasing importance as medical professionals and the rise of the informed (female) patient mark a significant intervention into the traditionally male medical world. Effectively, the appropriation of this technology for health purposes signifies a democratizing of the medical process, whereby previously guarded ‘expert’ information becomes increasingly available to the lay citizen. Significantly, it also holds great promise for improving the health literacy of citizens in both developed and developing nations, an issue at the heart of health and development efforts.

1.1 Statement of purpose

Today, there is a growing body of literature on the uses and potential uses of the Internet for health in the developing world. Yet, there is less emphasis on how women in particular can benefit from these advances. There is even less of a focus on how new immigrant women, from developing as well as developed countries, fare in terms of adapting to the Information Communication Technologies (ICTs) available in their new country or in being included in ICT-related health promotion efforts. In fact, it is only recently that the international community has “taken into account the gender significance of migration and thus focused on women’s health and the specific challenges women might face on settling in a new country” (Binfa, Robertson & Ransjo-Arvidson, 2010, p.446). Thus, my idea with this thesis was to look into: ***the role of the Internet in the health behaviour of new immigrants***. There is a simple reason why the Internet’s potential holds such irresistible appeal: (health) knowledge is power. In Sweden and other countries, health care professionals still do not seem to fully comprehend the extent of the role media plays in people’s everyday lives, particularly in terms of their health. For this reason, it is crucial to analyse how a platform such as the Internet can be effectively harnessed as a tool to promote global health literacy. In other words, there is a pressing need to take a closer look at the relationship between health literacy and the Internet as a fairly new information technology. This is relevant for developing countries as much as it is for so-called ‘developed’ countries and the more disadvantaged populations within them, given that health is one of the most important determinants and driving forces of a nation’s development.

1.2 Research questions

In light of this, my research questions are as follows: **do immigrant women in the Malmö region use the Internet for health purposes?** If yes, in which ways and why do they use it? In relation to Stuart Hall’s notion of encoding/decoding messages, how do they make sense of it in their daily lives? Do they access Swedish health resources or other resources? Are they content creators or do they simply browse available resources?

As a secondary set of questions, I define the following: **is this group of the population aware and/or included in efforts by municipal or regional health authorities to use the Internet as a tool for health promotion and health literacy?** Specifically, does this group know about initiatives such as the 1177.se ‘Ask a doctor’ service or Skåne Region’s ‘Mina Vårdkontakter’ programme? What e-Health initiatives, directed at the general population or specific groups, exist in the region?

2. Background

2.1 Key terms

2.1.1 e-Health

The term ‘e-Health’ (electronic health) can be used to refer to any attempts to facilitate the use of ICTs such as the Internet for behaviour change and the improvement of both health care and health outcomes (Gibbons, 2005). Another article describes e-Health as “any electronic exchange of health-related data through electronic connectivity for improving efficiency and effectiveness of health care delivery” (Ouma & Heselrman, 2008, p.194). Within hospitals, e-Health can mean telemedicine services, electronic records, hospital information systems and other Internet services (ibid). The concept of e-Health encompasses fields such as “medical informatics, tele-health, telemedicine, consumer health informatics, public health informatics, among others” (Neuhauser & Kreps, 2003, p.12). Neuhauser and Kreps (2003) explain that “e-Health communication strategies include, but are not limited to: health information on the Internet; computer assisted learning; online support groups; online collaborative communities; information tailored by computer technologies; computer-controlled in-home telephone counselling; [...] and patient-provider e-mail contact” (p.12). In this study, the term e-Health is used broadly to refer to anything related to the electronic exchange of health-related information and services, whether it be in terms of private citizens accessing health resources online or health care providers enabling, for instance, the digital transfer of patient data.

2.1.2 Digital divide

The term ‘digital divide’ can be defined as the socio-economic disparities between groups “with regard to their access to computers and the internet... [and] the gaps [...] in their ability to use ICTs effectively, due to differing literacy and technical skills and the gap in the availability of quality and useful digital content” (Hirwade & Rajyalakshmi, 2006, ¶1). Disparities in access and use can exist *between* as well as *within* countries (POST, 2006). The latter can include education and language barriers, whereby even when physical access to ICTs exists, the literacy and technical skills needed to use these ICTs may not (ibid). According to Hirwade and Rajyalakshmi (2006), a society cannot truly become a Global Information Society until its entire population is, “without distinction, empowered freely to create, receive, share and utilize information and knowledge for their economic, social, cultural and political development” (¶1). To bridge the digital divide, the UN’s World Summit on the Information Society has established the World Summit Awards, a global initiative designed to reward innovation in e-Learning, e-Culture, e-Science, e-Government, e-Health, e-Business, e-Entertainment and e-Inclusion. The initiative has been widely popular and, by 2005, it had 168 participating countries (ibid).

2.1.3 Health literacy

According to an article from the *New England Journal of Medicine*, health literacy is most commonly defined as “the skills and abilities needed to gain access to, understand, and use health-related information” (Rudd, 2010, p.3). It can also be described as “an interaction between the skills of individuals and the demands of health systems” (ibid). One of the broadest understandings of the term is the one proposed by the WHO, which defines it as “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” (quoted in Kickbusch, 2001, p.292).

In the U.S., health literacy has been on the policy agenda since the early 1990s, when research revealed a strong correlation between patients’ readings skills and their health outcomes (Rudd, 2010, p.3). As an article in the *Health Promotion International* journal explains, “health literacy as a discrete form of literacy is becoming increasingly important for social, economic and health development” (Kickbusch, 2001, p.289). The challenge now, according to Kickbusch (2010), is to develop a reliable way of measuring and quantifying the actual impact of health literacy, as well to create and implement public health interventions designed specifically to improve health literacy. A health literacy index measuring the health abilities and competence of a given population, in relation to health, social and economic outcomes, would constitute a “first major step in constructing a new type of health index for societies that complements measures such as the disability adjusted life years (DALYs), morbidity and mortality data” (Kickbusch, 2001, p.293). In this sense, it would also take into account more than just per capita GNP medical experience when analyzing a society’s contribution to the health of its citizens (ibid). The need to bridge the health literacy divide as well the digital one is becoming ever more apparent in the face of population aging, since “societies will be increasingly dependent on healthy populations to manage health care costs” (ibid, p.292).

2.1.4 Information and Communication Technologies (ICTs) for health

The British Parliamentary Office of Science and Technology defines an ICT as “any technology that enables communication and the electronic capture, processing and transmission of information” (POST, 2006, p.1). By facilitating communication and access to information, “ICTs can help developing countries tackle a wide range of health, social and economic problems” (ibid), in the quest to reach the Millennium Development Goals (MDGs) of eradicating extreme poverty, fighting disease and ensuring primary education and gender equality for all. If development is understood as “the process of enlarging peoples choices” (Sumner & Tribe, 2007, p.25), ICTs can be envisioned as one of the means to expand the range of choices people have access to. Today, the role ICTs can play in reaching development goals is

“increasingly recognized in international initiatives such as the MDGs; however, there is debate over the effectiveness of ‘ICT for Development’ (ICT4D) projects” (POST, 2006, p.4). Part of the debate revolves around the cost of new technologies, the lack of infrastructure and human resources, the need for education, and inadequate government support (ibid). ICTs for health are generally understood as “tools that facilitate communication and the processing and transmission of information by electronic means, for the purpose of improving health (including health promotion, human resources for health, and health-service delivery)” (Bukachi & Pakenham-Walsh, 2007, p.1624).

2.1.5 Internet

According to the UN body responsible for information and communication technology, the ITU, the Internet can be defined as “a collection of interconnected networks using the Internet Protocol (IP) which allows them to function as a single, large, virtual network” (ITU, 2011, ¶1). For the purposes of this thesis, it is defined as the global structure, increasingly present in our day-to-day life, that allows IP computer networks to connect with each other and delivers resources and services to billions of users around the world. Since its emergence in the 1960s, the Internet has become an increasingly popular medium of communication, entertainment, education and business. Over the years, it has been alternately embraced or contested. In addition, its uses and potential uses have been hotly debated and investigated by media scholars. In 2010, the Internet had a total of 1.9 billion users (Miniwatts Marketing Group, 2011). From 2000 to 2010, Internet usage grew by 444% at the global level. Users from the top Internet usage countries form 75.8% of total users (ibid). In Sweden, in 2009, seven out of every eight (87%) women aged 18-79 had access to the Internet at home (Nordicom-Sverige, 2010).

2.2 Why e-Health in Sweden?

In April 2009, I finished a joint Bachelor’s in communications and sociology in Vancouver, Canada. Over my four years in the School of Communication at Simon Fraser University, I developed a critical lens through which to view the world around me and wrote on topics such as: alternative media and the public sphere; the impact of social software on democracy and social change; ICTs and the reproduction of gender online; and communicating effectively during disasters such as the 2004 Indian Ocean tsunami. I have been particularly interested in the potential of new and existing media technologies to challenge dominant ideologies and to effect social change. At the graduate level, my goal was to continue researching the media and information technologies’ potential for creating social change but this time to focus on development and its relationship to communication. Specifically, I was keen to explore how communication technologies are being used in developing nations.

My initial idea for this thesis was to do an inventory and evaluation of the uses and potential of the Internet for health in developing countries, in particular telemedicine initiatives. As this is a very new area, inventory-type research in this field is practically non-existent. Thus my thesis would have made a contribution to the literature on the topic –literature which is, in my opinion, crucially needed to lend credibility and secure further funding for development efforts related to the use of the Internet for health purposes. However, given the limited time and financial resources at my disposal, it soon became obvious that the fieldwork this type of project would require was not feasible at this time. This is when I decided to focus on the equally compelling but often less-talked about issue of less developed ‘zones’ and visible minority immigrants within developed countries; in this case, immigrant women in Malmö. The City of Malmo in Southern Sweden is uniquely suited to studies on immigrant groups because of its high proportion of foreign-born residents, in comparison to the rest of the country (Lindström, Sundquist & Östergren, 2001). In 2010, the city had a population of 298,693 (Statistics Sweden, 2011), of which roughly 30% were born abroad (Malmö Stad, n.d.).

2.3 Health and immigration in Sweden

Studies related to immigration and health are particularly relevant for a country like Sweden which has, in the past 20 years, transformed itself from an essentially homogeneous society to a multicultural one, in which immigrants now form almost 15% of the total population (Statistics Sweden, 2010; Wamala, Merlo, Boström, & Hogstedt, 2007, p.409). Sweden’s history of immigration has been shaped by the impact of wars and unrest, with refugee immigration experiencing a sharp spike from the 1970s onwards and replacing labour immigration as the main source of newcomers (Björk, Brämberg, Nyström & Dahlberg, 2010). Today, one in every 7 Swedish residents is born in another country. Over 50% of foreign-born residents come from one of the following countries: Finland, former Yugoslavia, Iraq, Poland, Iran, Germany, Denmark or Norway (Socialstyrelsen, 2010). However, the immigrant groups which experienced the highest increase during the 2000s were those born in Afghanistan, Thailand, Iraq, China and Russia (ibid). In the context of the European and global problem of balancing ageing populations, immigration in Sweden is increasingly being recognized as a complementary measure to deal with the consequences of this population trend (ibid).

The arrival of new immigrants also has implications in terms of public health. As Lindström et al. (2001) explain, today the “continuously rising proportion of people born in countries other than Sweden [...] has made the health of different ethnic groups increasingly important in a public health perspective” (p.97). Recently, Swedish research has revealed a negative correlation between ethnicity and self-reported health and particularly mental health (Binfa et al., 2010). Foreign-born

women have a higher chance than women born in Sweden to be admitted to a psychiatric hospital or report and report long-lasting ill health (Binfa et al., 2010). This finding is confirmed by Björk et al. (2010), who state that “there is an obviously higher risk of contracting ill-health for immigrants” (p.7), a fact partly explained by poor living standards (in immigrants’ native countries), societal segregation and marginalization, as well as the physically-demanding jobs many immigrants take on. Language also plays an important role, as “patients who do not share the language of the majority of the population are extremely vulnerable in their health care” (ibid). Furthermore, according to the 2010 *National report on social conditions in Sweden*, “youths, single mothers and immigrants, especially new arrivals and those from non-European countries, run a high risk of poverty and other general welfare problem” (Socialstyrelsen, 2010, ¶3). The health and general welfare of immigrants are closely intertwined with their degree of acculturation and integration into Swedish society, since “socially integrated people live longer and healthier lives than socially isolated people” (Lindström et al., 2001, p.98). In their study on ethnic differences in self-reported health in Malmö, Lindström et al. (2001) conclude that “structural improvements such as the integration of immigrants in Swedish society and their increased participation on the Swedish labour market are absolutely critical for achieving health equity between Swedish-born people and immigrants” (p.101).

The issue of health equity is a significant one to bring up because of its importance in the Swedish context. In addition to the reasons listed above, Sweden is an interesting country to look into specifically because of its nature as a social welfare state and the traditionally high value it ascribes to the health of its citizens. In 2010, the life expectancy was of 83.4 for women and 79.4 for men, while infant mortality was estimated at only 2.49 deaths per 1000 live births (Statistics Sweden, 2010). Swedish society has always been known for emphasizing health equity, as one study points out: “equity in health and health care is and has been a long-standing goal in Swedish health care politics” (Westin, Åhs, Bränd Persson & Westerling, 2004, p.333) The Swedish government and municipal authorities appear to take public health promotion quite seriously. In 2004, Malmö city authorities endorsed a new action plan, ‘Welfare for all - the double commitment’, designed specifically to reduce poverty, segregation and crime while encouraging further economic growth (National Health Cities Network, 2007). Furthermore, the area of e-Health has been given increasing attention in recent years and has now become a fully-fledged component of national and regional governments’ health planning, as will be discussed in the section below.

2.4 e-Health in Sweden

In 2006, the Swedish government officially adopted the National Strategy for e-Health, a comprehensive plan centered on the notion of providing “safe, accessible health and social care of high quality, based on public need” (Ministry of Health & Social Affairs, SALAR, National Board of Health & Welfare, & Association of Private Care Providers, 2009, p.2). The realisation of this national plan is to be overseen by a special commissioning entity, the National Centre for the Coordination of eHealth, (Ministry of Health & Social Affairs et al., 2009).

In the Swedish system, the provision of health and social care is entirely decentralised to regional and local/municipal authorities, which have the choice between offering care themselves and outsourcing to private companies, cooperatives or non-profits. The National Strategy for e-Health report argues that “the continuing trend towards greater patient and user influence has generated a growing need for comprehensive information, as the number of care options and providers increases: patients and users must have easy to accurate and comprehensible documented information about them” (ibid, p.6). Accordingly, the report proposes six key action areas as part of the country’s national response, presented below.

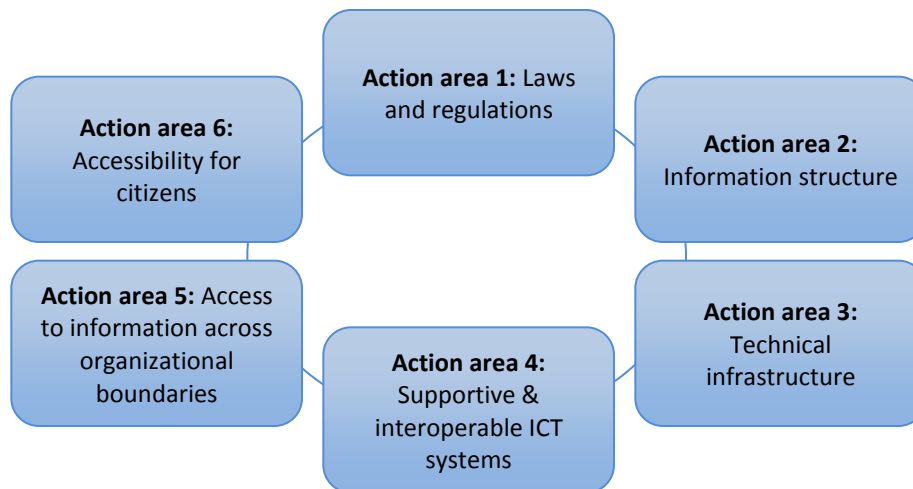


Figure 1. National Swedish e-Health Strategy: Main Action Areas (Ministry of Health Social Affairs et al., 2009)

The first action area concerns efforts to bring laws and regulations up-to-date with the increasing use of ICTs in health, since legislation has lagged on this issue (Socialdepartementet, 2009, ¶1). In response, in 2008, the government adopted a new Patient Data Act to allow health personnel to digitally access the records of any patient (with their consent), regardless of where/by whom the patient has been treated (Ministry of Health & Social Affairs et al., 2009). Given that all primary health care

records and 88% hospital records in Sweden are digital, the implementation of this Act should have a significant impact on the sharing of patient information (Socialdepartementet, 2009). The second area of action involves the creation of a ‘common information structure,’ which entails making information “available to health and social care personnel and to the citizen for use as a basis for decisions, management and follow-up activities and research” (ibid, ¶2). The third area proposes the creation of a common, overarching technical infrastructure to simplify communication and the sharing of information between citizens and health care providers (ibid). The fourth and fifth action areas concern the facilitating of supportive and interoperable ICT systems, while the last area aims to provide citizens with “easy and secure access to health and social care” (ibid, ¶5).

Sweden has several concrete e-Health initiatives currently in existence. The most well-known, the national online health advice and information service, 1177.se, serves as a complement to the widely-used 1177 telephone service. Founded 10 years ago, 1177.se offers “up-to-date, easy-to-read, fact-checked texts on frequently asked questions by patients and members of the public” (Ministry of Health & Social Affairs et al., 2009, p.17). Attracting over a million visitors per month by 2008, it aims to “promote health and advance knowledge of health and medical care among patients and the general public” (ibid). The service is also envisioned as tool to strengthen the position and involvement of patients in their health care (ibid). However, as Figure 2 below shows, 1177.se trails far behind Google searches in the health information seeking behaviour of Swedes. In 2010, 8 out of every ten Swedish users turned to Google word searches to find health information, a trend evident in many other countries which highlights that “the search terms [...] used in Google have proven favourable indicators of people’s health status” (Findahl, 2010, p.30).

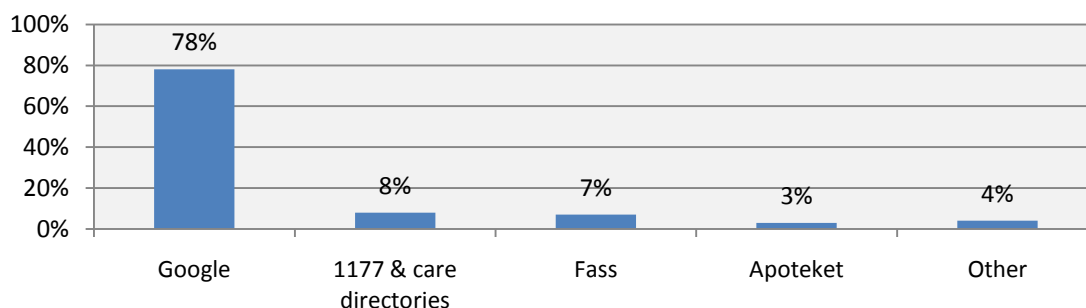


Figure 2. Sources of online health information retrieved by Swedes (Findahl, 2010, p.30)

Sweden also runs a national web-based youth health clinic, UMO.se, which offers young people (13-25) “relevant, up-to-date, quality-assured information about sex, health, relationships & other matters” (Ministry of Health & Social Affairs et al., 2009, p.12). Funded by the Ministry of Integration and Gender Equality, it is jointly run by the Ministry of Health, the Ministry of Integration and Gender Equality, and

the county councils. Since its inception in 2008, the web clinic has received over one million visits, prompting Sweden's Youth Minister, Nyamko Sabuni, to claim that “[it] has become an obvious complement to physical youth centers” (quoted in UMO.se, 2009, ¶4). Research conducted in 2009 found that over 40% of Swedes ages 15 to 20 were aware of UMO.se and considered it a reliable and a good source of answers (ibid). According to a spokesman for the website, the concept has worked well because it allows young people to ask questions anonymously and breaks through gender barriers, as “only 11.5% of those who visit youth clinics are boys, but of those who ask questions at UMO.se, [it] is closer to 30% of boys” (ibid, ¶5).

More recently, in 2009, the government launched a ‘Care Online’ portal to help Swedish citizens find information and choose the right care approach for them. The goal here to create a highly accessible and user-friendly portal, in order to “boost care accessibility, extend better service to patients and the general public, improve public health, enable care to be compared in different parts of the country and contribute to a more efficient use of collective care resources” (Ministry of Health & Social Affairs et al., 2009, p.17). One component of the portal, My Care Contacts [‘Mina Vårdkontakter’], allows citizens to schedule an appointment, apply for a prescription refill, ask a question or obtain advice. The hope of the government is that, as the service is further developed, the workload of health care personnel will be reduced to a more manageable load (ibid).

2.5 Sweden in the international e-Health arena

Over the past few years, the Swedish government has been actively involved and vocal about increasing cooperation within the EU (Ministry of Health & Social Affairs et al., 2009). The primary motivation for cooperation on e-Health has been to improve patient safety, by allowing patients to digitally transfer their medical records to the state they are being treated in (ibid). Sweden is presently engaged in a 12-member state EU project geared to “[establishing] international eHealth services and [improving] safety for patients receiving care in another EU country” (ibid, p.3). The 2009 Swedish presidency of the EU also allowed Sweden to highlight the issue of e-Health (Ministry of Health & Social Affairs et al., 2009).

3. Literature Review

3.1 Background

My interest in this topic arose out of personal experience with health research online and my interest in the ways in which the Internet is being used by women and how this use affects women and gender issues in general. It builds on a research paper I wrote during my Bachelor's, entitled *Women and Internet health resources: Creating real-world change through cyberspace*, in which I explored, through a feminist lens, how women in North America use the Internet for health purposes (Cassells, 2008). In this paper, I marshaled the theories of techno- and cyber-feminism to argue that the Internet has become an important tool for change by providing women with a space to find answers to health concerns, connect with each other and ultimately empower themselves. In particular, I was interested in how this new media can give women the opportunity to connect with each other and find answers where (western) conventional medicine or traditional doctors may have failed them. In a development sense, the study of women's and particularly immigrant women's health-seeking behaviour online touches upon the issues of migration, health, equality, empowerment, media access, health literacy and the extent of a nation's development.

3.2 Research process

Reviewing the literature for the present study was a challenge in that I had to cover several vast and different topic areas, namely health literacy, female migration and health, development, feminist theories of technology, and immigrant-related health activities in Sweden. I started by looking into the literature available on health literacy, the global digital divide and the use of the Internet for health in both developed and developing countries. This drove me to research migrant health issues and the importance of health in the integration of immigrants in Europe and specifically in Sweden. Then I focused my attention on the Swedish context and the health condition of immigrant women in Sweden as well the health promotion initiatives targeted to this population. From there, I looked more closely into the role of health in terms of development and the link between development, health and new technologies such as the Internet. Figure 3 on the following page offers a visual representation of the research process outlined above.

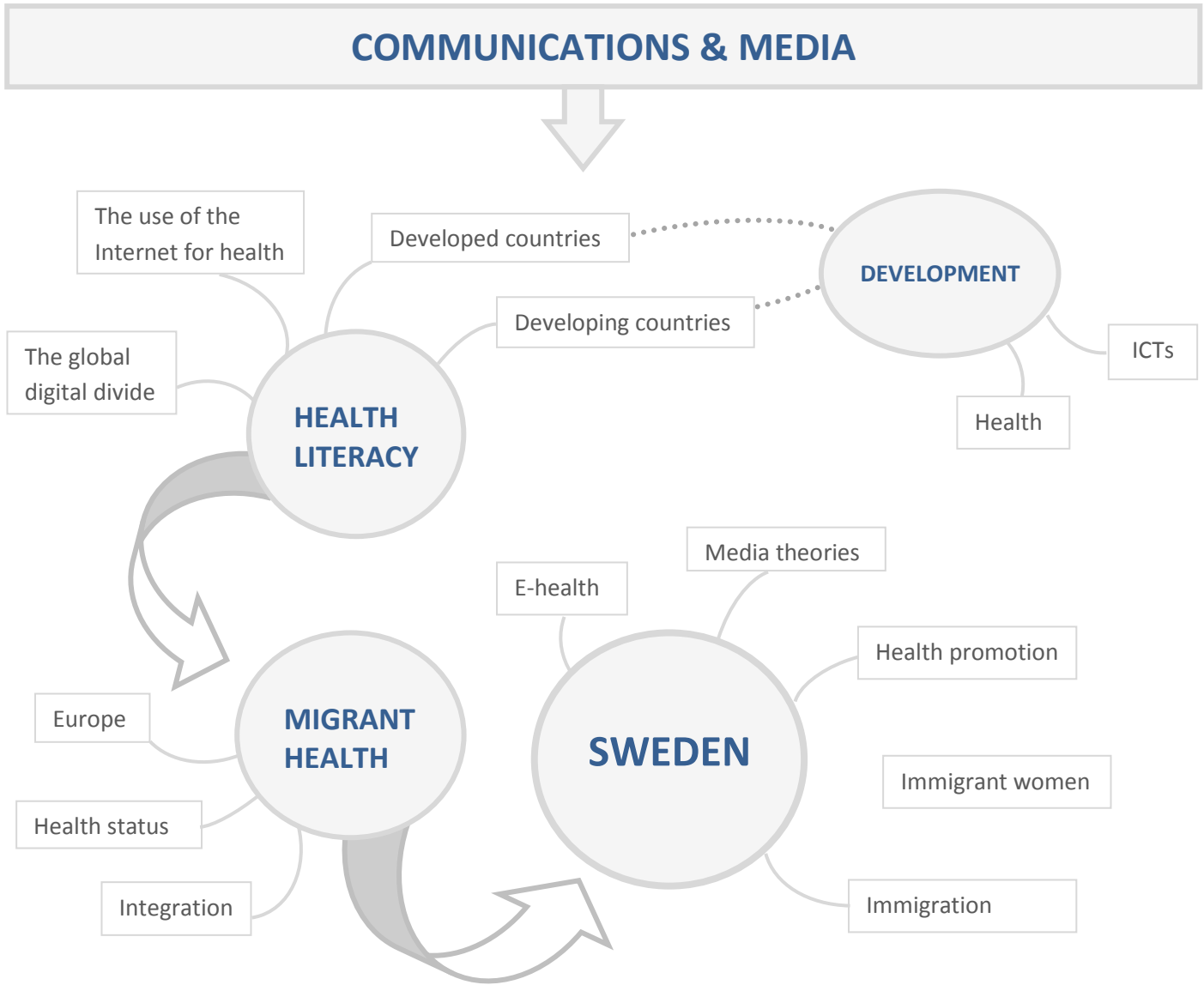


Figure 3. Mind-map of the research process

3.3 Starting point

Several authors (Harding, 1998; Wacjman, 2004; Rosser, 2006) provided the starting point as well as a historical perspective for my initial research. A book entitled *Medicine as Culture: illness, disease and the body in Western societies* (Lupton, 2003) directed me to Michael Hardey’s (1999) compelling article *Doctor in the house: The Internet as a source of lay health knowledge and the challenge to expertise*. In this article, Hardey argues that the Internet has allowed the public to challenge medical dominance “not only by exposing exotic medical knowledge to the public gaze [...] but also by the presence of a wide range of information about and approaches to health” (ibid, p.823). Although Hardey (1999) does not focus his analysis on how women in particular can use the Internet to challenge medical

dominance (which has traditionally held its strongest grip over female patients), he does provide a comprehensive analysis of the Internet and its capabilities, as well as an insightful account of how the Internet can help change patient-doctor relationships.

3.4 Evaluation of the literature

The literature reviewed to establish the context of both this thesis and my past research highlighted numerous issues, namely:

- the marginalization of women from health, science and technology (Harding, 1998; Balka, 2003; Lupton, 2003; Wajcman, 2004; Im & Chee, 2006);
- the patient-doctor relationship and its power dynamics (Thomas, 2006; Rahmqvist & Bara, 2007; Binfa et al., 2010);
- changes in patient behaviour and the shift to an empowered, informed health consumer (Hardey, 1999; Pitts, 2004; Adams & Leah, 2008; Fox, 2008);
- online self-help and support groups (Lupton, 2003; Solomon, 2006);
- issues of access (Lupton, 2003; Cullen, 2006; Fox, 2008);
- theories of cyberfeminism (Wilding, n.d.; Wajcman, 2004; Rosser, 2006) and technofeminism (Wajcman, 2004);
- and finally, the particular features of the Internet as a technology (Cassell, Jackson & Chevront, 1998; Hardey, 1999).

Other research explored the nature of online health information and issues of quantity and quality (Pitts, 2004; Solomon, 2006; Cullen, 2006; Rahmqvist & Bara, 2007; Adams & Leah, 2008); the idea of the Internet as a neutral arena (Wilding, n.d.; Pitts, 2004); the Internet as a site for health behaviour change (Cassell et al., 1998); and the phenomenon of women sharing medical information online (Wajcman, 2004).

Many studies (Harding, 1998; Balka, 2003; Lupton, 2003; Wajcman, 2004; Rosser, 2006) emphasized the exclusion of women from the spheres of health, science and technology to the advantage of men, but disagreed on the degree to which the Internet has changed these power dynamics. Certain sources, decidedly cyberfeminist in perspective, see the Internet as an inherently positive technology for consumers (Cassell et al, 1998; Hardey, 1999; Adams & Leah, 2008) and specifically for women to regain control over their health (Thomas, 2006). However, many are more cautious (Lupton, 2003; Pitts; 2004; Wajcman, 2004), such as Balka (2003), who warns that “database design is political” (p.9). Certain researchers appear almost alarmist in their concern over the quality, bias and overload of health information on the net, as well as over inequities of access and health literacy (Wallace, 2008). As Cullen (2006) writes, “accessing high-quality health information demands a range of skills that few health practitioners and even fewer health consumers possess” (p.83). Others, such as Cassell et al. (1998) or Hardey (1999) show that today’s consumers are more

competent than many believe. Interestingly, almost all the Swedish literature reviewed referred to study subjects as ‘citizens’ as opposed to the North American tendency to frame them as ‘consumers’ first and foremost (Westin et al., 2004; Akhavan, et al., 2007; Jung & Loria, 2010). This is most probably related to the different health care systems and the Swedish emphasis on ‘health care for all’ as well as on more sociologically-oriented research traditions.

3.5 Statistics and international comparisons

Several reports from the Pew Internet & American Life Project provided a wealth of information on the context and demographics of Internet use for health in the U.S., highlighting that 61% of Americans have looked for health information online (Fox & Jones, 2009). Seeking health information online is now “the third most popular online pursuit among all those tracked by the Pew Internet Project, following email and using a search engine” (Fox, 2011a, ¶1). These sources also established that women are more likely than men to search for health information online and use online chat groups, and presented findings on how users search for information and which topics they research (Fox; 2008; Reuters, 2010, Fox, 2011a). This seems to indicate that women attribute a higher importance to health or perhaps to preventing the appearance of health problems than men. One reason for this may be the socialization of women as natural ‘caregivers’ and the deeply ingrained behaviour this kind of ‘caring’, nurturing role implies. Internet users living a chronic disease were also more likely to turn to what is now termed ‘peer-to-peer help’, with nearly one in four reporting going online to connect with others facing a similar condition (Fox, 2010). Despite patients’ growing engagement with the virtual world (Fox & Jones, 2009), the Pew reports do not find any evidence of “the oft-expressed fear that patients are using the Internet to self-diagnose and self-medicate without out reference to medical professionals” (Fox, 2010, ¶3). In other words, the Internet’s role remains a supplemental one (Fox, 2011b). Interestingly, a 2009 report highlights that “half of all online health inquiries [...] are done on behalf of [someone else]” (Fox & Jones, 2009, ¶4). In addition, over 40% of adults maintain that the information obtained through these searches have helped them or someone they know, a significant increase from the 25% who claimed the same in 2006 (ibid).

In Sweden, statistics on Internet use reflect those of the U.S. Swedish women, like American ones, turn to the Internet for health information significantly more than their male counterparts (Rahmqvist & Bara, 2007). In 2010, 72% of female users did, in contrast to only 55% of Swedish men (Findahl, 2010). One study on a Swedish ‘Ask a doctor’ online service found that 71% of users were women (Umeåfjord et al., 2003, ¶21). The Findahl (2010) report notes that gender, age and education are all significant factors in determining Internet use among the general population but also points out that, in terms of Internet users only, the differences these factors may

account for are much less significant. Research on internet use in Sweden also confirms the Pew report finding on the Internet’s complementary role, highlighting that “the Internet [...] seems to supplement other sources of information rather than render them irrelevant” (Findahl, 2010, p.34). In other words, Swedes still primarily turn to doctors, nurses and other health care personnel for their health information needs (ibid). Still, “Swedish patients, especially the young and middle-aged, are to a substantial degree using the Internet to gather additional information on their disease” (Rahmqvist & Bara, 2007, p.533). The implications of this in terms of trust in doctors and nurses requires further study, especially in relation to new immigrants who may or may not have the same trust in doctors as their Swedish-born counterparts.

In international terms, Sweden ranks first in Internet usage, particularly among elderly citizens. In 2010, the country also scored the top place in three major IT indexes that “all attempt to ‘measure’ various countries readiness and conditions to become successful information-technology countries” (Findahl, 2010, p.8). One of these indexes, the UN International Telecommunications Union’s (ITU) ICT Development Index, is based on combining measures of a country’s Internet access, total users and proficiency (ibid). In terms of internet distribution and usage, Sweden remains at the forefront in global diffusion comparisons, with a recent report (Findahl, 2010) estimating that 85% of all Swedes use the Internet, ahead of the Dutch (84%), the Americans (77%) and the Japanese (74%).

According to Findalh (2010), two out of every three Swedish users use the Internet to find health-related information – double the percentage of those who did in 2000. Furthermore, “8 out of 10 use Google to find answers to health and medical questions” (ibid, p.9). As expected, the most active users (16-45 year olds) and those with health problems are the most engaged in searching for health information online (ibid). Doctors and nurses compose the majority of users who conduct searches on a daily or weekly basis. For most users, however, searching for health information online is an occasional rather than a daily activity, as evidenced in the figure below.

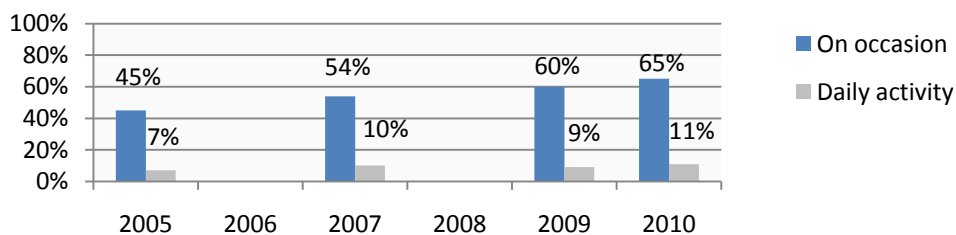


Figure 4. Percentage of Internet users (15+) who use the Internet for health and medical information on occasion or on a daily basis, i.e. daily or 1-3 times weekly (Findahl, 2010, p.30)

Finally, the Findahl report highlights that, although the Internet has been a part of Swedish society for over 15 years and “while an increasing number of people are utilizing [its] possibilities [...] about half the population still does not feel as though

they belong to the new information society” (ibid, p.9). Less-educated retirees are the primary group which identify with this statement, which may be a reflection of their inexperience, unfamiliarity and/or fear of using new technology (ibid).

3.6 Methodology of the Literature

Much of the North American and British literature relied on case studies (Hardey, 1999; Fogel, 2004; Solomon, 2006; Thomas, 2006) and the majority focused on breast cancer, an illness which has been heavily publicized in the last decades. Most of these studies used a medium to large sample size, except for Hardey (1999), whose final sample involved only 10 households. The Hardey study also strayed from the pack by selecting a group of participants with no chronic medical conditions, as opposed to other studies (Fogel, 2004; Pitts, 2004) which selected participants based on their health condition. The Swedish research tended to be qualitative in nature and primarily based on semi-structured interviews and content analysis of small- to medium-sized sample groups (Akhavan, et al., 2007; Hedelmalm, Schaufelberger & Ekman, 2008; Binfa et al., 2010; Björk et al., 2010; Jung & Loria, 2010). The rest of the Swedish literature involved quantitative data from large samples (1,223 to 24,000 informants), cross-sectional and/or longitudinal surveys (Rahmqvist & Bara, 2007), including public health surveys (Lindström et al., 2001) as well as web surveys (Umefjord et al., 2003; Umefjord, Hamberg, Malker & Pettersson, 2006).

3.7 Development and health literature

The literature obtained through the above searches has tended to address several key themes, namely: the notion of health literacy (Rahmqvist & Bara, 2007; Wallace, 2008; TED Conferences LLC., 2009; Rudd, 2010); health literacy and development (Kickbusch, 2001); ICTs for development and the bridging of the digital divide (Gibbons, 2005; Bukachi & Pakenham-Walsh, 2007; Ouma & Herselman, 2008); migrant health policy (Mladovsky, 2007; IOM, 2009); and the importance of integration and acculturation on the health of immigrants (Linström et al., 2001; Wiking, Johansson & Sundquist, 2004; Akhavan, et al. , 2007). Several authors highlighted the importance of health literacy (Rudd, 2010, Sellers, 2010), notably in resolving public health issues around the global problem of lack of (health) information (TED Conferences LLC., 2009). In India, for instance, a recent study shockingly revealed that “35-50% of women incorrectly believe reducing fluids intake was key to helping their children recover from diarrhea” (ibid, ¶2). In this sense, discussions about global health promotion revolve partly around the question “how do we get people to make better decisions about their own health and that of their family members?” (Sellers, 2010, ¶22). In this and surrounding discussions on ICTs for development, it is important to avoid an overly deterministic standpoint on

technology and offer instead serious and critical analyses that go beyond issues of exposure and access. Indeed, it is not a simple matter of providing people with access; discussions on how ICTs can be used for health promotion need to take into account structural inequalities and factors such as power relations within communities or reticence to adopt new technologies.

3.8 Immigration and health literature

The literature on immigrants and health in Sweden in specific was generally concentrated on: the relation between acculturation and self-reported or general health status (Linström et al., 2001; Samarasinghe & Arvidsson, 2002; Wiking et al., 2004; Akhavan et al., 2007); equity issues (Linström et al., 2001; Westin et al., 2004), including unequal access and discrimination towards immigrants and/or refugees in the Swedish health care system (Samarasinghe & Arvidsson, 2002; Wiking et al., 2002; Mulinari, 2004); and immigrants' disappointment or frustration with the Swedish health care system (Umefjord et al., 2003; Rahmqvist & Bara, 2007; Binfa et al., 2010). Other authors focused on: the importance of women's health-seeking Internet behaviour for the health of their families (Samarasinghe & Arvidsson, 2002; Bowen, Meische, Bush, Woolridge, Robbins, Ludwig & Escamilla, 2003); the role of information in patient participation (Björk et al., 2010); and patient-doctor interactions (Binfa et al, 2010; Rahmqvist & Bara, 2007).

Many studies highlighted the high rates of mental health problems and psychological distress among immigrants, especially female immigrants (Linström et al, 2001; Rundberg, Lidfeldt, Nerbrand, Samsioe, Romelsjö, & Ojejagen, 2006; Binfa et al., 2010). According to one study on ethnic differences in self-reported health among immigrants in Malmö, the strongest risk factors for psychological distress were "economic difficulties in exile, a low sense of coherence, poor acculturation (men only), and a poor sense of control" (Lindström et al., 2001, p.100). In another study on patient participation among female immigrants, Björk et al. (2010) explain that language barriers also come into play, noting that "patients who do not share the language of the majority of the population are extremely vulnerable in their health care and more attention must be paid to this" (p.7).

Finally, others authors delved into the more specific, namely: Swedish health promotion initiatives (Wiking et al., 2002; National Healthy Cities Network, 2007; Rahmqvist & Bara, 2007; Skånes Universitetssjukhus, 2009); the need for more health promotion and interventions targeting immigrants (Wiking et al. 2004); and e-health in Sweden (Umefjord et al., 2003; Umefjord et al., 2006; Rahmqvist & Bara, 2007; Jung & Loria, 2010). Three studies investigated specific online services provided by Swedish public health system, such as 'Ask a doctor' services (Umefjord et al., 2003; Umefjord et al., 2006; Jung & Loria, 2010). One such article, based on a

web survey, revealed that people used the service primarily because they considered it 'convenient'; adding that it "may also be of value for individuals with needs regular health care services have not been able to meet" (Umefjord et al., 2003, ¶1). However, a later article concluded that future research is needed on the "cost-effectiveness, patient security, responsibilities of the Internet doctor and role of 'Ask a doctor' services compared with regular health care" (Umefjord et al., 2006, p.165).

3.9 Summary

Thus, the literature reviewed addresses most of the issues related to my topic, including: how women use the Internet for health purposes; how immigration and health are interconnected; and what role e-Health can play in improving access to health information and services. Generally-speaking, much of the research on the uses or potential of the Internet for health information, support and/or other patient-centered services has focused on North America. It has also focused on how this changes the patient-doctor relationship and potential problems surrounding the availability of large amounts of health information of varying quality on such large a platform as the Internet. There is an exhaustive amount of material on the topic of health literacy and the Internet as a tool for development, covering a wide range of issues varying from user demographics to the emergence of a new type of patient, the informed consumer (or citizen, depending on the nationality of the researcher). Almost all sources reviewed for this paper recognized the growing importance of the Internet for health resources and most highlighted that these resources are sought out especially by women. However, very few draw on any specific feminist theory. In fact, many sources do not focus on women in their study of health research online or do so only in reference to one particular disease, despite the fact that women are more likely than men to use the Internet to access health resources.

The literature reviewed on the Swedish context has followed a similar trend and has been more limited than the American body of writing. In fact, the topics of health and immigrant women in Sweden (as opposed to immigrants as a whole) are rarely studied conjointly. Most importantly, to the best of my knowledge, there has not been a single study done on how immigrant women in the Malmö region may or may not use the Internet as a source for health answers, a site for support and/or a space for empowerment. This clearly reinforces the need for such a project. Thus, building on the existing literature, I would like to explore this angle through a feminist lens in order to gain a better understanding of some of the experiences of immigrant women in the Malmö region in terms of health and Internet usage.

4. Theoretical framework

4.1 The historical role of women in western medicine

Knowledge about the body and its various afflictions has always been contentious. Throughout history, men and women have argued about what constitutes such knowledge, who has the right to use it and how it should be used. Although it appears natural to us today, the “rise to power of the medical profession in western societies is historically recent” (Lupton, 2003, p.88). Until as late as the eighteenth century, medical practitioners were rarely sought out by the general population, with patients preferring to seek other forms of help and cure themselves through lifestyle changes. Until this period, women had largely depended on other women, such as experienced midwives, for their health care needs. During the Enlightenment however, new ideals replaced old medical discourses with ones infused with a “faith in the progress of society assisted by developments in science and technology, and belief in the power of reason in shaping human understanding” (Lupton, 2003, p.88). Medicine based on anything other than pure science was dismissed and traditional healers were ridiculed. The example of midwives, who mostly facilitated childbirth until the eighteenth century, is particularly illustrative of this phenomenon. These midwives’ “experience and knowledge about birthing was passed from one generation of women to the next” (ibid, p.158). However, during the eighteenth century, scientific knowledge was constructed as the only acceptable form of medical ‘truth’ and midwives were gradually pushed out through their exclusion from medical school and the emergence of professional licenses and associations (Lupton, 2003; Stetson & McBride, 1997).

In childbirth and in other practices, the medical professional gained a privileged status because of his ability to detect illness invisible to the human eye through the use of *technical* instruments, such as the microscope (Lupton, 2003). It became less important to consult with and consider the views of the sick person, who simply became a passive patient (ibid). According to Foucault (1973, 1979), it was during this time that medicine became a veritable institution of power and the body became the “ultimate site of political and ideology control, surveillance and regulation” (Lupton, 2003, p.25). The medical encounter thus becomes a site for surveillance, in which “the doctor investigates, questions, touches the exposed flesh [...], while the patient acquiesces, and confesses, with little knowledge of why the procedures are carried out” (ibid, p.26). Second wave feminists point out that this also led to a feminization of illness; as the patient, by “relinquishing control of his body to another” (ibid, p.28) became associated with weakness, a feature opposite to dominant constructions of masculinity. The power of such ideologies is expressed by their translation into medical practices. When natural conditions and their complications, such as menstruation, childbirth and menopause were medicalized – i.e. “placed in medical categories of disease and dysfunction requiring not comfort but cures, through medication and surgery” (Stetson & McBride, 1997, p.104), women became subordinate in the patient-doctor relationship. This relationship was

structured by the construction of the 'good' patient as one which does not challenge the authority of the doctor (Lupton, 2003). As Stetson & McBride (1997) argue, "under the guise of professionalization and raising standards, men went beyond improving health care to establish hegemony over women's bodies" (p.104).

4.2 Feminist theories of technologies

This progressive appropriation of public health and dominion over female bodies in particular has not gone unchallenged. As Lupton (2003) explains, "feminist writing has been an important commentator upon medicine as an agent of social control and the social construction of gender in medical discourse" (p.142). In the last decades, feminist debate around women's bodies and their health has centered on discussions of science, technology and power. Authors such as Haraway (1988) have argued that "science is a contestable text and a power field" (p.577) from which women have been traditionally excluded. In *The Science Question in Feminism*, Harding (1986) justly points out that "neither God nor tradition is privileged with the same credibility as scientific rationality in modern cultures" (p.16). In the medical world, the doctor (male until only recently) represents the embodiment of this scientific rationality and thus gains a privileged status over the lay person. With the rise of information technologies such as the Internet, there emerges a tool for women to access scientific knowledge and contest this authority, as well as men's traditional monopoly over technology, and challenge the medical professional.

One feminist approach of the early nineties, cyberfeminism, has championed cyberspace as the ultimate sphere for female empowerment and liberation and embraced its potential "to level the playing field" (Rosser, 2006, p.38). The Internet and the subsequent 'digital revolution' heralded "the decline of the traditional hegemonic structures and power bases of male domination because it [represented] a new kind of technical system" (Wajcman, 2004, p.64). Cyberfeminists viewed the free, instantaneous, non-hierarchical Internet as a neutral site free of gender, race and class power relations. However, as Rosser (2006) and Wajcman both note, the reality of the virtual world is that it is shaped by the inhabitants of the real world. In other words, "technology and society are bound together inextricably; [...] power, contestation, inequality and hierarchy inscribe new technologies" (Wajcman, 2004, p.83). Although cyberfeminists are right to herald the emancipatory *potential* of the Internet, their embrace of this technology as *inherently* liberatory is mistaken. This thesis proposes that Cyberfeminists' study of the internet should thus be complemented by Judy Wajcman's theory of 'technofeminism.'

Criticizing feminist scholars for being inherently simplistic and deterministic, Wajcman (2004) attempts to provide a more balanced understanding of technology and its implication for feminist politics, arguing, that, despite cyberfeminists' exaltations to the contrary, technological change must not be "uncritically

[embraced]” (p.6). Technologies such as the Internet are by no means gender neutral and are in fact very much governed by real-life gender relations and hierarchies. The Internet, Wajcman argues, is clearly “marked by its military origins and the white male hacker world that spawned it” (ibid, p.4). Essentially, Wajcman aims to bridge the gap between feminist scholarship and technology studies, highlighting that gender and technology are mutually constitutive.

4.3 Media theories: The encoding/decoding model

According to the Encyclopedia of Communication Theory, cultural studies is generally understood as “an academic field of study that crosses disciplinary boundaries such as political economy, literary studies, cultural anthropology, philosophy, American studies, gender studies, film studies, and communication studies” (Chávez, 2009, ¶1). Key issues in cultural studies include: the importance of popular culture; the divide between ‘high’ and ‘low’ cultures; the relationship between language and meaning creation; agency and the process of ‘reading’ polysemic media texts; and the centrality of ideology and hegemony (ibid). The field of cultural studies emerged in the U.K. during the 1950s and 60s, spearheaded by Marxists and Critical theorists such as Richard Hoggart, Raymond Williams and Stuart Hall, from the Birmingham Centre for Contemporary Cultural Studies or CCCS (ibid). In the U.S., communication theorists were some of the first to fully embrace cultural studies (ibid). Throughout the years, cultural studies has been increasingly recognized as a legitimate field of studies, despite being heavily criticized for its explicit political commitment, its deep Eurocentrism and its rejection of methodological purity (ibid).

One of the most prominent cultural studies theorists and a founder of the CCSS is Jamaican-born sociologist Stuart Hall. In his influential essay “Encoding, decoding”, Hall analyzes the process of communication and the construction and dissemination of (television) messages. Dismissing the traditional, linear view of mass communication as a simple transmission loop, he argues instead that there are four ‘more or less autonomous’ stages in the process: production, circulation, consumption and reproduction (Hall, 1993). In other words, communication is not “a perfectly equivalent circuit” (ibid, p.100), just as every message is not “an instance of ‘perfectly transparent communication’” (ibid). Media texts and codes are polysemic in nature: “any such already constructed sign is potentially transformable into more than one connotative configuration” (ibid, p.98). In other words, they can be read in multiple, complex ways and can have different meanings for different audiences (Chávez, 2009). Making sense of media texts involves a series of encoding and decoding “determinate moments” (Hall, 1993, p.91). In this process of meaning-making, “meaning is created and altered every step along the way” (O’Brien & Szeman, 2004, p.89), not only by the production side (e.g. TV producers) but also by the ones the

text is distributed too (e.g. the audience of the show). It is this idea of *reading* as opposed to passively consuming media texts which I really wished to draw upon here.

According to Hall, there are three principal ways in which audiences read media texts, which can be defined as “any artifacts that require reading or interpretation” (Chávez, 2009, ¶8). Either they adopt the dominant or preferred reading, whereby they largely accept the dominant cultural order, ideological framework which permeate the text (imparted by the producers and the structure within which they operate); or they assume an oppositional reading, whereby the preferred reading is fully rejected in favour of an alternative interpretation. A third option is to take a more nuanced approach through a ‘negotiated reading’ of the media text in question (Hall, 1993). It is this last position which I am particularly interested in relating to audience strategies in terms of ‘reading’ Internet discourses. Hall argues that audiences who decode texts in a ‘negotiated’ way are well aware of the ‘hegemonic definitions’ present in media texts but choose to adapt, re-appropriate or oppose certain aspects of these definitions, as opposed to rejecting them entirely. According to Hall, a viewpoint is hegemonic if it “defines within its terms [...] the universe of possible meanings of a whole sector of relations in a society or culture and carries with it the stamp of legitimacy –[if] it appears coterminous with what is ‘natural’” (ibid, p.101). In other words, a negotiated reading “acknowledges the legitimacy of hegemonic definitions to make grand significations (abstract), while, at a more restricted, situational (situated) level, it makes its own ground rules” (ibid).

In incorporating Hall’s encoding/decoding model of meaning-making in my work, I was interested in analyzing how people decide on and choose information for their everyday life and, specifically, how women ‘read’ health information online and selectively pick the information that fits their needs. My hypothesis going into the research was that they do not simply take at face value or uncritically accept the information: there is a process of ‘negotiated reading’ of health information. Indeed, the strength of the encoding/decoding model lies in its dispelling of the myth that audiences are merely passive recipients of information and cultural texts. This model also fits in particularly well with my focus on feminist theories of technology because neither takes a deterministic approach to media and the reading of media texts.

5. Methods

5.1 Aim of the study

My primary aim was to provide an in-depth understanding of a small sample of immigrant women's use of the Internet in terms of health, marshalling feminist theories of technology with the encoding/decoding model, in order to observe this phenomenon. As a secondary aim, I strived to explore the context and some of the initiatives of local and regional health authorities to better promote health literacy and health-seeking online. Like Akhavan et al. (2007) in their study on the health of female Iranian immigrants in Sweden, I wished to interview female immigrants who had lived in the country for at least 5 years and who came as adults or young adults, as this time frame reflects a reasonable estimate of how long it would take to start learning Sweden and integrate the labour market or start studying. For the purposes of this study, the term 'immigrant' will be used in reference to Hedemalm et al.'s (2008) definition of immigrants as being "those [...] born abroad, who have another mother tongue than Swedish and who are living in Sweden at the present" (p.2).

I approached my proposed research project using a case study design, in that I focused only on the particular experiences of a small group of immigrant women in the Malmö region of southern Sweden. After much deliberation on the advantages and disadvantages of each research method, I decided that the most appropriate to my project would be: semi-structured, qualitative interviews and secondary analysis. The advantages and limitations of both of these methods will be discussed in the sections below. While content analysis and surveys would have been possible, they would have generated very different data from that which I hoped to collect and would not have permitted the same depth of analysis. Thus, the study was carried out between March and April 2011 through secondary data analysis as well as 11 qualitative, semi-structured interviews with recent immigrant women from a variety of backgrounds as well as 2 interviews with health and applied health academics. Adopting a qualitative research design was a conscious choice designed to emulate Jung and Loria's (2010) aim to "explore and describe, not to explain and generalize" (p.57). However, the goal was also to move beyond the descriptive and try to achieve a greater understanding of the experiences of this particular group, as well as possible directions for future research and/or policy decisions. Fieldwork as "a methodology of knowledge creation" (Fox, 2006, p.347) can be tricky but it can also be a highly enriching, insightful experience resulting in the emergence of in-depth new knowledge about a particular group, culture, activity or experience.

This kind of project will, I hope, make a contribution to the academic world by providing a comprehensive overview of the role of the Internet in some of the health-related behaviour of immigrant women in the Malmö region, given that

interdisciplinary and recent analyses of this kind are rare, and by offering an updated take on one aspect of the Internet's potential as a health promotion tool.

5.2 Semi-structured interviews

5.2.1 *Advantages and limitations*

The first method employed for this thesis consisted of semi-structured interviews, which, through their informal nature, generally promote openness (Neale, 1998). One of the most popular social sciences research approaches, the interview can be defined as “[a] conversation with a purpose” (Burgess, 2006, p.302). Interviews can be very helpful in gaining in-depth knowledge about individuals' perceptions and experiences, but may also be difficult to conduct in some settings and may be discounted if there are any suspicions that the interviewer is ‘leading’, confusing the interviewee or even being fooled by him/her (Dodge & Geis, 2006). On the other hand, interviews, especially those of an informal nature, can be an excellent source of first-hand accounts of experiences, events and cultures. For this study, I chose to conduct informal individual interviews in order to gain some form of understanding of if and how immigrant women use the Internet to find health information, as I felt this would be more appropriate than group interviews, where speaking up or ‘being heard’ can be difficult for some.

Another advantage of choosing interviews was the fact that I had previous experience with conducting interviews and experience in interviewing immigrants or temporary migrants in particular. During my Bachelor's degree in Canada, I had several occasions to try my hand at fieldwork and worked with immigrants or temporary migrants on two occasions. For one project, I interviewed Vietnamese immigrants living in Vancouver on their sense of loss, gain and belonging, while for another, I talked to members of the Filipino domestic worker community (‘nannies’) on their experience of living in Canada as female domestic workers. Both these experiences prepared me for the interviews I conducted for this thesis in that I felt comfortable dealing with potentially sensitive issues, being aware and attentive to intercultural differences and, most importantly, being patient and understanding of any possible difficulties informants may face in being interviewed in English.

5.2.2 *Finding participants*

In choosing a population group for this thesis, I was aware of the limitations that can come from choosing to interview people from a community with which I have no real ties. However, I felt confident that with a little time, patience, and luck, I would find people willing to talk to me. I anticipated that I would rely on a snowball sampling strategy, whereby a few initial, key informants (from select organizations) would be

able to put me in touch with other members of their group (Bryman & Teevan, 2005). According to Burgess (2006), key informants are those “individuals with whom the researcher associates and who will assist him/her in the collection and analysis of data about events in the field” (p.295). This approach, while perhaps ill-suited to quantitative research wishing to generalize findings (ibid), was appropriate to my case study of female immigrants in the Malmö region.

Language was also a key factor in my selection of a research topic, since I am not fluent in Swedish and thus would probably have had difficulty doing fieldwork in a seniors’ residence for example, where most of the interactions and conversations would be in Swedish. Thus, I concentrated on English-speaking immigrants. Although this certainly did restrict my analysis, I did not feel it was too much of an impediment. Furthermore, I felt it was not unrealistic to expect that some if not many of the immigrants coming to Sweden would have some kind of English skills. However, I did feel the handicap of not being able to speak fluent Swedish when some of the people I contacted wrote back to me in Swedish. I handled this by replying thanks to the very helpful if not always exact tool that is Google Translate.

Gaining access to informants involved contacting a wide range of different ethnic, immigrant or women’s organizations in/around Malmö, as well as organizations based in Stockholm which might have contacts or local chapters in Malmö. I first attempted to find participants through a few contacts at Malmö Stad. Several of these were able to direct me to other individuals or organizations but most of these initial contacts did not yield any real results. Thereafter, I concentrated most of efforts on doing Internet searches to find different organizations in the Malmö region. My strategy was to contact these organizations or individuals by email (using my official Lund university email address) to briefly introduce myself and my research and ask if any of their members might be willing to participate in the project. I also contacted three associations through their Facebook group page as they did not have an official website. I predicted that gaining access to informants would not be excessively difficult as my topic is not a very controversial one and as some of the organizations might be quite interested in the results of my research. However, as can be expected with qualitative work of this kind, finding people willing to be interviewed took longer than expected.

In total, I contacted 56 different organizations and/or individuals, ranging from ethnic, immigrant or women’s organizations to local health care contact persons to various public health professionals and/or academics doing research on immigrants, women, health, e-Health or migration issues. I looked first for women’s health organizations and immigrant women’s associations then widened my search to general immigrant associations as well as other related groups. As can be expected in fieldwork (Clifford, 1988), during this whole process, one of my biggest challenge was accommodated varying schedules and waiting for possible informants to reply.

Some of the immigrant and/or women's organizations I contacted include: the IKF Malmö (Internationella Kvinnoföreningen i Malmö); the BHKS-SEDEF (Bosnien-Hercegovinas kvinnoällskap i Malmö); HKF Malmö (Herrgårds kvinnoförening); RIFFI (Riksförbundet Internationella Föreningar för Invandrarkvinnor); the Polish Women's Organization; the Sudanese Association of Lund (Sudanesiska föreningen i Lund); the Iranian-Swedish Association of Malmö; the Filipino Community Leaders' Association in Sweden; the Bangladesh Cultural Association in Skåne (BACS); the Thai Association of Malmö (Thailändska Föreningen); the Sri Lanka Association in Sweden; the Nepal-Sweden Association; and the Red Cross (Malmö chapter). In addition, I emailed 9 academic researchers from Lund, Malmö and Blekinge Universities, the majority of whom were affiliated with Health and Society faculties. Finally, I contacted 7 different public health officials/professionals, including: a Malmö Stad Public Health Coordinator; a spokesperson for the national youth website UMO.se; the Deputy Director of the Social Ministry (who has been spearheading the national e-Health strategy); and the District Medical Officer and Director of the Centre for Primary Health Care Research (Skåne). The latter was out of the country during the time of the research and thus could not meet, while the others did not reply or declined to be interviewed.

5.2.3 The interview process

Once I established contact with one member of a small ethnic association in Malmö, Nim [all names are pseudonyms], she was able to put me into contact with 5 other women in her organization. Later, one of these women introduced me to another two of her friends. Two of my friends were also able to put me in touch with one or more of their acquaintances or colleagues, who subsequently helped me find more participants. In this sense and as expected, a snowball sampling strategy was the most useful. Before conducting the real interviews, I ran my questions by a friend first in order to verify that the research questions were clear and comprehensible. The actual interviews were audio-recorded (unless participants opposed this when asked, which none of them did) and subsequently fully transcribed. During my first few interviews, I also paid close attention to the way informants responded to my questions and remained open to altering my questions throughout the research.

In total, I conducted 13 semi-structured interviews: 11 with women from Thailand, Hungary, Iran, Brazil, Bolivia, Sri Lanka and Uganda; one with a Health and Society professor specialized in psychiatry; and one with a PhD candidate studying e-Health within a Health and Technology programme. I chose to conduct the interviews in the location most convenient for my informants, which turned out to be a popular bakery/café, a shopping mall lounge area and an office. As Stein (2006) notes, "public places have the real advantage of easy accessibility" (p.70). The interviews were carried out with the help of a loose interview guide and were aimed at answering my principal research question by giving individuals a chance to share

their experiences with using or not using the Internet. Codes emerged as the data was collected and as the interviews were transcribed; these codes were then used to identify key themes or concepts and answer my research questions. I started by quickly scrolling through the interview transcripts to identify a few keywords or codes for each interview and then going through the interview in detail to analyze participants' responses on the different issues at hand.

All the interviews were semi-structured, face-to-face interviews (lasting between 15 minutes and one hour; 35-45 minutes on average) carried out with the help of an interview guide consisting of 27 closed and open-ended questions (see Appendix). These questions were grouped into four subject areas – background, Internet access and use, health and internet use, and immigration and health in Sweden. I also created a separate set of questions for the interviews I conducted with health care professionals and/or academics, based on the same four themes (see Appendix). Semi-structured interviews were useful in my particular research as they provided the necessary guidance and structure for my participants to open up about their experiences. Having a set of open-ended, easy-to-understand questions made it simple for my participants to voice their experiences in a relatively short time-frame. However, semi-structured interviewing also somewhat restricted my research to topics chosen by myself, an outsider, instead of approaching the topic from a more participant-focused perspective. (Note: one way I countered this was by asking participants at the end of the interview if there was anything else they felt had not been addressed and would like to discuss).

During the interviews, I compiled detailed field notes, typically understood as the sum of the first-person observations and accounts recorded by the researcher during his or her time 'in the field' (Burgess, 2006). I relied on these to guide the research process and generate new questions, insights and conclusions. In this, I followed Burgess' idea that "writing is not something that should be confined to the end of a research project, but should take place throughout a study" (ibid, p.304). This being said, it is important to acknowledge that ethnographic writing is only "a partial, selective and purposed re-presentation of [...] ways of life gleaned through the researcher's efforts to get physically and socially close" (Emerson, 2001, p.20-21).

5.3 Secondary analysis

Finally, the above method of semi-structured interviewing was complemented through secondary analysis of existing research on female immigrants, health and migration issues in Sweden, using the data collected by others to add to my own research (Bryman & Teevan, 2005). Despite a certain loss of familiarity, secondary analysis can be advantageous in that it presents the researcher with a time- and cost-effective way of obtaining high quality data that can be analyzed in different ways

(ibid). To this end, I relied mostly on the works of Lindström et al. (2001), Akhavan et al. (2007), and Rahmqvist and Bara (2007), a group of academics who have done considerable research on immigration or health issues in Sweden as well the work of another group of academics, Umefjord et al. (2006) and Jung and Loria (2010), who conducted research on the use of Swedish e-Health services. The analysis of the works of these authors allowed me to gain a better grasp of the issue and draw on the results of much larger samples to complement my own research.

5.4 Ethics

In most settings, researchers have to be careful about the way they go about researching topics, in particular if they plan on conducting interviews. Indeed, it is crucial to take “due consideration of the ethical implications of [one’s research] strategies” (O’Dowd, 2010, slide 9). In terms of researching the health information seeking behaviour of immigrant women, I started with the assumption that some women may feel worried about how the research would portray them, what kind of questions I intended to ask and how this information might be used in the future. Thus, it was important to me to reassure interviewees that I was interested only in understanding part of their experiences as recent immigrants to Sweden, not in judging or interrogating them. At the beginning of the interview and/or when I approached my informants, I made sure to briefly discuss the purpose of my research and state that I was open to any questions or concerns they might have. When I met my informants, I gave them an informed consent form to carefully read and sign, as well as a one-page summary of my research project and goals (see Appendix). I felt this was helpful in quickly presenting my research and thus making participants more comfortable talking to me. I also gave them verbal assurance that all names would be systematically changed, in order to protect their confidentiality and privacy. In conducting my interviews, I strived to establish with my informants good rapport, reciprocity and a “non-hierarchical relationship” (Bryman & Teevan, 2005, p. 204), through which the interviewees’ viewpoints could emerge. This included everything from the way I dressed for my interviews to the way in which I first approached participants by email. I also tried to put them at ease, especially about the interview being audio-recorded, by using humour and joking that my memory or lack thereof gave me no other choice but to use an audio-recorder (sadly this is all too true!).

A key challenge throughout the research process was to recognize the influence of personal biases and feelings around the issue. The notion of reflexivity, defined by Taylor (1998) as “the idea that subjective experience, including actions and feelings that derive from the researcher’s own social location, influences the production and interpretation of research” (p.12), was thus central to my study. Similarly, the research process was guided by Haraway’s (1988) notion of ‘situated knowledges,’ which contends that research is never bias-free and always reflects the researcher’s

personal situation. According to Emerson (2001), a reflexive fieldworker must be “more and more sensitive to the previously unappreciated complexities of observation” (p.20). As a straight, white, middle-class, university-educated non-Swedish female from a Western country, I may hold a different social location and certainly a different set of perceptions and biases than some of the members of the ethnic/immigrant associations I recruited participants from.

When I met participants for the first time, I always introduced myself briefly and told them of my personal interest in the topic, often beginning with the fact that I was curious to learn how they use or do not use the internet for health because of personal experience as well as prior research on the subject, in a North American setting. By employing a reflexive strategy throughout my research, I hopefully made my own biases clear and tried to avoid having them shape the research too heavily. Although no study can be fundamentally bias-free, it is important to recognize and concede biases from the onset of research. Similarly, it is crucial to view informants as multidimensional, complex individuals. As Clifford (1988) argues, “while ethnographic writing cannot entirely escape the reductionist use of dichotomies and essences, it can at least struggle self-consciously to avoid portraying abstract, ahistorical ‘others’” (p.23). In this study I made the conscious choice to refer to research participants as ‘informants’ or ‘interviewees’ as opposed to mere ‘respondents’ because the latter denotes individuals who offer only brief answers *in response* to a researcher’s questions and are not considered as much more than research objects with a knee-jerk response mechanism. Applying a feminist perspective was central in my research and was achieved notably by considering my informants as more than mere “instruments of data production” (Taylor, 1998, p.366) and by seeking to provide a safe and open interview setting.

5.5 Research participants

The participants in this study consisted of 11 middle-class immigrant women, aged 26 to 43, who immigrated to Sweden from 7 different countries: Thailand (5), Hungary, (1), Iran (1), Bolivia (1), Brazil (1), Sri Lanka (1), and Uganda (1). All of the women came to Sweden between 2004 and 2009, except one, which arrived from Uganda in 1989. Although I had initially planned to restrict my interviews to women who had lived in Sweden between 5 and 10 years, I made an exception for the last participant in order to broaden my data and obtain the perspective of someone coming from the African continent, since I had not been able to recruit any other African nationals. I also interviewed one senior Health and Society professor, specialized in psychiatry, Lena, as well as one lecturer completing a PhD in health and communication, Bilan.

As Table 1 below shows, at the time of the interviews: 6 of the women were studying, of which three were studying at the Master's or PhD level; two were on maternity leave; one was a teacher; one worked in online sales; and one was unemployed. Six of the women were married, 4 were in a relationship and one was divorced. Two were married with children and two were pregnant, while three were trying to conceive. All the participants reported good or excellent health, despite minor problems like toothaches, migraines, or a pregnancy-related rash. Of the 11 women interviewed, 7 were fluent in Swedish and two had conversational Swedish; the others had basic skills and were studying Swedish at the time of the research.

Table 1. Research participant backgrounds and demographics

Participant	Nationality	Age	Profession	Marital Status	Year of arrival	Level of Swedish
<i>Chanthra</i>	Thai	32	Student	Married	2007	Basic
<i>Nim</i>	Thai	33	On maternity leave	Married, one child	2008	Fluent
<i>Amy</i>	Thai	33	On maternity leave	Married, pregnant	2009	Good/ conversational
<i>Somsri</i>	Thai	34	Thai teacher	Married	2008	Fluent
<i>Kalaya</i>	Thai	26	Student	Married	2008	Basic
<i>Anna</i>	Hungarian	31	PhD student, bio-ethanol	In a relationship, two children	2005	Fluent
<i>Deeba</i>	Iranian	29	PhD student, biotechnology	In a relationship	2004	Fluent
<i>Maria</i>	Brazilian	28	Master's student, architecture	Engaged & pregnant	2008	Good/ Conversational
<i>Isabel</i>	Bolivian	33	PhD student, biotechnology	In a relationship	2004	Fluent
<i>Sitha</i>	Sri Lankan	42	IT support	In a relationship	2006	Fluent
<i>Dembe</i>	Ugandan	43	Unemployed	Four children	1989	Fluent

6. Findings and discussion

6.1 The Internet as an additional resource for health information

6.1.1 Internet access

Sweden is one of the countries with the highest rates of Internet usage worldwide so naturally the first question to ask the women who participated in this study was if and what they used the Internet for. Despite popular belief that immigrant women, traditionally typecast as low-income and vulnerable, do not access the Internet as much as those who have grown up in a country as ‘connected’ as Sweden, this was not the case for the women I talked to, nor the view of the two researchers I interviewed. In terms of health, this echoes the conclusion of a recent study on online information seeking among breast cancer patients, that “contrary to popular expectation, lower-income, less educated women and those lacking in information-seeking competence actually use the computer and online services to the same or a greater degree than more privileged patients if those services are made available to them” (Kreps & Neuhauser, 2010, p.365). All of the women interviewed were experienced Internet users and reported everyday Internet use, primarily for email, Facebook, keeping in touch with family and friends, research, and work.

All the participants had access to the Internet at home. Only one, a 42 year old woman from Sri Lanka, Sitha [all names are pseudonyms], said she did not use the Internet a lot outside of work. However, she did book her doctor’s appointments online, through the minavårdkontakter.se online service. Maria, a 28 year old architect who arrived from Brazil three years ago, explained that she uses the Internet for everything: “*I have [Internet] on my phone and on my computer, so I talk to my friends, my family, my boyfriend, make research, emails, for everything I use it the Internet*” (personal communication, April 12, 2011). Isabel, a 33 year old Bolivian PhD student, said she uses the Internet to find health information more now that she lives in Sweden because: “*here everything is online, you can do everything...now you can even do it from your mobile!*” (personal communication, April 12, 2011). Two participants mentioned using the Internet on their mobiles phones but Maria was the only one who talked about receiving health-related information through this medium (in English), explaining that, ‘there’s an app for that’:

“I have a [mobile phone] application about pregnancy so every week I’m updated what’s supposed to happen with my body...I don’t know [where it’s from], you can download applications for free from the internet, somebody created it. So I’m quite updated, like ‘this week the baby should open his eyes, you should feel some cramps like this...etc. [...]’. It tells me a lot of things , so I usually read it to [my boyfriend] so he knows what to expect from me that week, like if I’m going to be complaining too much [...]. It’s just fun that you receive updates on your phone every week.” (personal communication, April 12, 2011)

6.1.2 Frequency, use, and types of health searches online

A common theme among the women interviewed was that seeking health information online was an occasional activity, rather than a daily one, often done only to satisfy one's curiosity. As Somsri, a 34 year old Thai teacher, explained: *"it's not that I check it every day or often, it's from time to time, if I'm curious about something"* (personal communication, March 25, 2011). However, the age and health status of the participants in this study might be a factor in the reported use of online health resources, as the majority of those interviewed were relatively young and reported no significant health problems. Maria summarized it this way: *"I don't go that often to the doctor, so it's not quite often that I need to make research on health"* (personal communication, April 12, 2011). This being said, Deeba, an Iranian PhD student, reported that she uses the Internet for health a lot, despite having approximately the same age and health status as the other women interviewed.

Being pregnant or trying to become pregnant was also cited as a reason to turn to the Internet and pregnancy and women's health issues were common topics of research. Birth control, nutrition and natural remedies were also popular searches, as we shall see later on. Of the 11 women interviewed, 7 said they looked for pregnancy-related information while pregnant or while they were trying to conceive. These women all reported that they used the Internet to search for health information *more* now than before. Maria, for instance, who was expecting her first child, noted that: *"now that I'm pregnant sure, I look way more...I look every week and anything I feel like any pain or something, I might look, just to understand if what I have is normal or to be expected"* (personal communication, April 12, 2011). Amy, a Thai woman who at 33 was also expecting her first child, told a particularly interesting story about finding a solution to a pregnancy-related rash from an American online health forum, where other women wrote in about their experiences and shared helpful tips on what to try. In this case, it was her husband who did most of the searching online but what was significant was that both of them were willing to order a product online on the recommendation of women they had never met before:

"Two months ago I have allergy or something, I go to doctor here and check my blood test and everything is normal but I still have itch, all over my body...And the doctor say 'ok maybe something with food so I say 'ok how can I know now?' because the doctor said nothing and cannot use the medicine or something because not good for baby. [...] so my husband search on the Internet [...] and then we know it's something they call PUPPP, this kind of pregnant women allergy...from the DNA of baby, especially boy baby, because [...] I have a boy. [...] My husband read and we use baby cream and some [people] recommend tar-soap... I use that, order from America. It's helpful! It's very good...Some women wrote [comments] and discuss, discuss, discuss...'oh I have this problem, same as you, I use this, try this'. I order everything. [Researcher: Did you tell your doctor after?] Yes and she said 'wow'. She never heard about that. It's the same in Swedish, PUPPP. Not so much pregnant women have [it]. Now I'm happy. Now you know a new thing!" (personal communication, March 21, 2011)

However, Amy's story was an unusual one, as none of the other women in the group said they ordered health products online. Sitha, for instance, specifically stated that, though she used the Internet to find specific (health) information, *"I never buy any medicine in the Internet"* (personal communication, April 13, 2011).

Another factor in determining the extent of Internet use for health research could be the existence of a serious medical condition in one's circle of family or friends. Participants were asked this question in order to assess if having a close friend or family member with serious health problems resulted in an increase in their health information seeking behaviour. Building on Rahmqvist and Bara (2007) finding that "decreased health status provides a natural incentive to go online to access health-related information" (p.534), I expected that having a close friend or family in poor health might be just as much of an incentive as being sick and searching for oneself. However, since only two of the women had any relatives or friends in this situation at the time of the interviews, a pattern could not be established. Nevertheless, the responses of several of the women seem to confirm this theory. When asked for whom she looked for information online, Sitha responded:

"Most of the time it is for me but I also search for one of my friends because [...] he has skin cancer... he got operated so I tried to find some info for him about why, I want to advise him about how to avoid...he like to be sunbathed. So I found some info in the Internet that said that especially Scandinavians must avoid the sun because their skin has hardly any protection and more info...so I mailed him." (personal communication, April 13, 2011)

Another woman, Nim, a 33 year old Thai mother, looked for information about lung cancer (in Thai) after her Swedish father-in-law was diagnosed with the disease. Generally-speaking, the women interviewed looked for information for themselves first and foremost and then for their partners, kids (if any), parents, and/or friends. Maria noted that usually it was for herself but said she once searched for information in English for her boyfriend because *"he looked probably in the Swedish sites so then I helped him to widen up his research, so I can add something to his research"* (personal communication, April 12, 2011). Kalaya from Thailand, the youngest participant (26 at the time), said her father, who still lives in Thailand, had problems with a skin rash *"so I saw on the Internet how to take care...how to help him and what [medicine] to use"* (personal communication, March 21, 2011). She found this information on a health forum after a Google search. An interesting side note in Kalaya's case was the fact that her health-seeking behaviour (on behalf of her father) was related to the socio-economic and cultural context of her home country: *"you know for people in Thailand, it's difficult to go to hospitals because you have to pay and people [are] very scared of doctors, so I like to find out natural remedies"* (ibid).

Another finding was that looking for health information on the net is not necessarily reserved for pressing, 'serious' health issues, it could also be used for prevention or

‘softer’ health topics such as diet and nutrition advice. As Maria puts it: *“the research doesn’t have to be that serious, just curiosity”* (personal communication, April 12, 2011). The high prevalence of prevention-oriented searches (e.g. how to protect oneself from the flu or chicken pox) supports the gender pattern identified by Rahmqvist and Bara (2007). In this study, the authors contend that “women initially have a relatively more active seeking behaviour which is not that much influenced by deteriorating health and repeated healthcare encounters [...] women use the Internet in a proactive manner for health promotion” (p.538). This coupled with the fact that women search for others as well as themselves suggests that providing women with high quality, easily accessible health information online has important implications for the health of the population as a whole (i.e. secondary effects). This echoes the fact, now univocally recognized in the aid world, that better informed and educated women raise healthier families. It also corroborates Rahmqvist and Bara’s (2007) finding that “information acquired from the Internet is spread by online seekers to others in their communities by print, word of mouth or other multimedia applications...therefore the Internet may be important for the healthcare and health status of non-users as well” (p.534).

6.1.3 Google and online health forums

As the interviews progressed, a key finding to emerge was that Google is the primary gateway through which participants access health information. As one participant put it: *“I would first go to Google and Google leads you to many websites”* (Maria, personal communication, April 12, 2011). All the women interviewed privileged Google searches first and foremost and said they read health blogs and forums only if directed to such sites by Google. Asked about her use of health forums, Maria explained that she reads them: *“I Google and it ends up in a forum...If it [...] looks interesting, I may read. Besides that, no”* (ibid). Interestingly, if they do read health forums, they almost never post comments, that is, they are not content creators. Indeed, all but one of the women reported that they never wrote or commented on such sites; rather, they simply browsed existing content. Most could not be bothered to because, like Maria explains, then she would have to know a specific forum, login or become a member...etc. Another participant, a 43 year old Ugandan woman, Dembe, had a similar reaction: *“I have never really thought about writing any comments...probably I should because I’ve really benefited from those natural healings, but it’s not so easy to just start writing...unless you’re furious or really excited! [laughs]”* (personal communication, April 18, 2011). I think Dembe touches on an important point here in explaining why women such as those interviewed do not create new content, which is that people tend not to post comments on health forums or blogs unless they are very upset or eager to share information. In these situations, it would seem, the time and patience it takes to post content online is deemed ‘worth it’. Despite never commenting or posting information themselves, the women did seem to value hearing and learning from the experiences of other lay

individuals, especially in terms of women's health issues. Nim, for instance, indicated that she has visited online blogs for parents, as well specialized blogs for pregnant women (in Thai) during her own pregnancy. Another participant, Deeba, explained that she reads blogs for things like finding out about new medicine, such as the different types of birth control pills available to her:

“It’s really good to read the blogs because people describe their [side effects]: if they’re happy, what thing is most common...you can get an idea, of what can happen or what kind of symptoms, side effects you can get. It’s good to read blogs [...] for not very important things, just to see how the public reacts to things that happen or when they went to the doctor, what kind of information they got...especially things specific for women. It’s perfect because women [...] know best and it’s a personal experience. [...] Because people have different experiences, maybe they recommend new medicines. (personal communication, April 7, 2011)

In this sense, health blogs and forums can be said to function somewhat like an virtual repository of experiential knowledge (Harding, 1998), akin to being able to talk to every single person in the waiting room of your doctor's office, instead of only getting one doctor's advice (by no means an insignificant one but nevertheless different). In other words, patients take the information provided to them by their doctor, their own experiences and confirmed by their online research, and present it to others in an informal and accessible manner. Rather than replacing the doctor, for Deeba, the possibility of being able to access this type of lay-person knowledge is an important part of *maintaining* a healthy patient-doctor relationship: *“that is really helpful, that is one of the things I use mostly, this health information on the net, because symptoms could be different and you get always some new information, so you can discuss it with your doctor”* (personal communication, April 7, 2011). From a feminist perspective, this can be interpreted as part of an important shift from a traditionally subordinate patient-doctor relationship towards one in which women have more of a say over their health, as a result of having access to more information and experiential knowledge (Lupton, 2003; Stetson & McBride, 1997). By relating the experiences of a range of women, women's health forums can be seen as valid and valuable sites of “situated knowledges” (Haraway, 1988, p.581). Indeed, one participant, Anna, explained that she found blogs and forums useful because: *“it is based on experience...you read what somebody other has already experienced”* (personal communication, April 7, 2011). I also agree with Umeffjord et al. (2006) that there is something to be said for written communication (e.g. a message posted on a blog), because it “[allows] the patient to be able to read the answer repeatedly and to reflect on it without hurry” (p.165); a feature of Internet-based consultations which the authors believe to be currently underused in traditional care settings.

6.1.4 Trust, doctors and negotiation

Another important finding, briefly mentioned above, was that searching for health information online does not replace the doctor –an often-voiced concern of health care professionals and academics wary of the Internet's foray into the free-for-all

distribution of medical knowledge. The majority of the women in this study had a high level of trust in doctors and indicated they would trust a doctor far more than information found online. This should come as no surprise given the deeply embedded authority accorded to scientific rationality in most modern cultures (Harding, 1998; Haraway, 1988); a rationality of which doctors are one of the key embodiments. For most participants, the Internet was regarded as a complement, not something which replaces the doctor, confirming the findings of other e-health studies done in Sweden (Umeffjord et al., 2006, Jung & Loria, 2010). Sitha, for instance, turned to online health resources to find the answer to her health questions: “*if I want to know small information, I can go to the Internet and search things, because it is not possible to go to the doctor and ask every question!*” (personal communication, April 13, 2011). From a feminist perspective, this is important because, until recently, women with health questions and issues had to satisfy themselves with the answers provided by their doctor. It was, as Lupton (2003) terms, “simply a matter of faith, of belief in the ‘magic’ of medicine and the credentials of the practitioner” (p.137). The safe, open and anonymous environment of the Internet enables women to find answers to their health questions, even embarrassing or difficult ones. This is, Hardey (1999) notes, a “very different venue from the consulting room with its trappings that reinforce medical dominance” (p.830).

In addition, almost all of the women in the study stressed that online health resources are not necessarily something they turn to *before* going to see a doctor. As Maria explains, for her: “*[the Internet is] just an extra tool to understand more what’s going on with your body and how you should deal with problems, it’s not the only [one] and [it] won’t substitute the doctor*” (personal communication, April 12, 2011). Neither would the information found online necessarily cause her or other participants to challenge a doctor’s advice:

“I read about my birth control that I got from my doctor here in Sweden. And what I got [...] was ‘danger! This birth control pills does this and that...and cancer and this’. But I think I have to trust my doctor more than the internet. I didn’t have any bad symptoms and I was doing well with my pill so I chose to trust my doctor. The internet is not a source I would consider the most trustful because you never know when it starts from, where it begun...it’s just something more that you consider.” (Maria, personal communication, April 12, 2011)

Deeba also explicitly stated she still trusts her doctor more, having grown up trusting her doctors. This being said, she did mention that, in terms of birth control, finding out about different kind of pills online was important to her because it meant she could go back to her doctor and ask for something different. However, this seemed not to be interpreted as a rejection of her doctor’s authority but rather a desire to be more informed and more proactive in her health care decisions: “*the birth control is a perfect thing...it actually made me say no to things that I really got the prescription for...I called and said ‘no I don’t want this!’ [laughs]...so it’s perfect*” (Deeba, personal communication, April 7, 2011). As a side note, Deeba’s experience confirms

Fountain's (2000) finding that "better educated women have demanded higher quality care" (p.56). In other words, women are using the Internet to educate themselves about health issues and, in some cases, demand more or better from their doctors, thus translating this new knowledge and putting it into practice in their everyday lives. Thus, it would seem that, on this point, cyberfeminists are right in heralding the Internet's emancipatory *potential* –though their uncritical embrace of this technology is misguided (Wajcman, 2004). In her research, Pitts (2004) finds that this trend of women 'arming' themselves with health information is in part motivated by a desire to "demand that doctors share the power over their bodies and health care" (p.43). In particular, the Internet can be a place for women to find answers to the questions their physician may not have answers to or may not *want* to answer, such as questions concerning alternative medicine and unconventional treatments (Lupton, 2003; Hardey, 1999). This is confirmed by Hardey's 1999 study which found that a number of research participants "had renegotiated treatment for themselves or their children with their GP on the basis of information they had found on the Internet" (p.829).

To return to the issue of trust: the women interviewed seemed to trust the resources they found online more if it came from an 'authoritative' source (i.e. an official medical site such as Stockholm county's vårdguiden.se or a doctor's response on a health forum). When it was not, they evaluated the information depending on how recent and helpful it was and took a very conscious approach to decoding the information found online. For Somsri, a 'reliable' website was one which came from an official source (a hospital or a doctor): "*often I don't trust the website or the blog, I just read and think for my own opinion but often if it's the hospital or doctor website I trust it*" (personal communication, March 25, 2011). The interviews also revealed that trust seems to depend in part on one's level of education, as several of the more highly educated women (i.e. doing masters or PhD programmes) talked in greater length about their mistrust of Internet sources and their appreciation of more 'reliable' sources such as online peer-reviewed journals. However, regardless of their level of education, none of the women appeared to blindly follow the first advice they found online. Instead, they seemed aware of the possibility of misinformation and reported reading several sources before making up their own mind. Neither were they unaware of the possible pitfalls of searching for health information on the net: "*it depends what kind of information you're looking for, the disadvantage is you get wrong information if you look in the wrong place you can get misled*" (Deeba, personal communication, April 7, 2011). In other words, they had a negotiated reading strategy, whereby they navigated the wealth of information online consciously and carefully, accepting some messages while rejecting others. The argument that lay individuals lack the skills to recognize high quality health information online can be largely dismissed because most of the women who use the Internet for health research, including the women in this study, are now 'veteran' Internet users with several years of online experience (Fox, 2005). They know how to 'decipher' the web: they are used to rummaging through the (cyber) trash to find the

useful and they typically consult several websites to check the information provided by one against another (Adams & Leah, 2008). Furthermore, as Cullen (2006) argues, a large part of the information is valuable and “there are few indications [...] of actual harm arising from use of the Internet” (p.86). The women I interviewed also appreciated the possibility to access a wide range and a diversity of opinions, shifting through them and forming their own opinion through a negotiated reading of a number of options. As Maria explains, the Internet offers a larger range of opinions:

“because doctors can even have different opinions among themselves...and then if you start reading like 10 opinions in that direction and two in the other direction, then you may feel like, which one has more force in opinions and maybe give more credibility to one that you have found more people saying.” (personal communication, April 12, 2011)

Deeba echoed this feeling, stating that the information she found was mostly useful: *“there’s a bunch of blablas as well but normally it’s easy to get, like if you read 10 of them, you get the idea, you can summarize”* (personal communication, April 7, 2011). For Dembe, the process of finding useful health information, in her case, effective natural remedies, revolved around Googling and reading health forums:

“You read on the comments, people say ‘I use this, it works for me’. Of course some people say it didn’t work for them but I think I have a simple system that works with most things that I look at on the internet. I just find what works for me. I Google it and then I get it.” (personal communication, April 18, 2011)

6.1.5 Natural remedies, discourses and negotiated readings

Another interesting finding is that some women use the net to find alternative medicine, that is, natural remedies to minor health care problems. In this way, as Lupton (2003) argues, the Internet effectively “blurs the boundaries between orthodox medical knowledge, consumer knowledge and alternative medical knowledge” (p.140). Dembe, for instance, used Google searches and health forums to find natural remedies for herself and for her children:

“[Once] my son was bleeding in his nose. I had no idea what to do so I went to read on the internet. They just said I should put garlic under his nose...or vinegar, so I mixed both. And it stopped! I look for natural remedies and I’ve looked at things like vinegar and baking powder. When we were kids, my mom used to give us baking powder...if you had an upset stomach. Recently I had some problems with my teeth. So I decided to look at ‘tooth ache’ [...] then I read [something about] pineapple, with the stomach and when I went to Uganda I found that semi-ripe pineapple [...] was used when the women give birth and have a lot of pain in their stomach, and then I used it for my period pain and it just disappeared. You just eat it, the middle part of the pineapple. It has something [...] which is a pain killer. And the teeth it is the cloves...I use them for my tea now, they reduce pain, if you chew on one, it works. Now I don’t even have any toothache.” (personal communication, April 18, 2011)

The amazing thing about this example is that Dembe was able to use the Internet to unwittingly find information which draws on the traditional medicinal knowledge of

her home country, while sitting at her computer halfway across the world in Sweden. A little digging into the pineapple story highlights the importance of this knowledge coming out: pineapple extract, a traditional remedy used by people in Latin America, Africa and the Pacific Ocean Islands, has recently become the subject of scientific study. Scientists have demonstrated that the anti-inflammatory and analgesic properties of pineapple extract may be a safer and cheaper option for treating arthritis than standard anti-inflammatory drugs (Brien, Lewith, Walker, Hicks & Middleton, 2004).

The example above, of using this media to access alternative medical discourses, brings up the question of agency and going against the naturalized idea that a pill is always the solution. In a small way, it is a stand against what feminists have identified as the pushing out of traditional knowledge in favour of the medicalization of health conditions and discourses of western scientific knowledge (Haraway, 1988; Stetson & McBride, 1997; Lupton, 2003). Here, the term ‘discourse’ can be understood as “the web of cultural meanings that congeal on a particular topic or idea” (Chávez, 2009, ¶9). In communication and cultural studies, a key goal is to become aware of how certain discourses become naturalized and are made to appear as ‘common sense’ or the only truth (Hall, 1993; Chávez, 2009). This process, Hall (1993) explains, has “the (ideological) effect of concealing the practices of coding which are present [...] but we must not be fooled by appearances” (p.95). Health information on the Internet, like any other media text, is hardly detached from social and cultural processes; “texts and audiences within any context are not innocent” (Chávez, 2009, ¶9). The ideologies and codes found in media texts mean that an individual’s “relationship to a particular text is thus a product of a range of cultural processes that are heavily infused with specific ideologies about who they are and how they should be” (ibid, ¶11). In the health and medical landscape, scientific western knowledge is usually given precedence over traditional remedies and experiential knowledge (e.g. the knowledge of midwives). A large portion of the health information online, including official hospital websites and websites sponsored by pharmaceutical giants, exists in a setting where the ‘dominant, preferred reading’ is one which privileges modern, pharmaceutical cures to medical problems. In other words, they have “the whole social order embedded in them as a set of meanings, practices and beliefs” (Hall, 1993, p.98). However, as Hall notes, “we say dominant, not ‘determined’, because it is always possible to order, classify, assign and decode an event within more than one ‘mapping’” (ibid). Thus, the women interviewed who actively seek out natural, home remedies to minor health concerns, for themselves or for others, can be seen as agents operating a negotiated reading of Internet texts. In this sense, the Internet seems to have “opened up many new spaces where ideas about health and illness are created, exchanged and negotiated” (Hardey, 2006, p.229).

To summarize, findings from my conversations with the 11 immigrant women presented above indicate that the Internet appears to be used as a *complement* to

traditional sources of health information (doctors, print media, telephone communication...etc.), which the women interviewed use in order to be informed, increase their understanding of health issues and be able to discuss health-related matters with their doctor. Just as the participants in Kivits' 2009 study, the women who participated in my research can thus be understood as inquisitive 'information seekers', in an age where the Internet has led to "the formation of reflexive health consumers taking responsibility for their health by means of information" (p.683). The women interviewed privileged the wealth of information they could find online and were actively involved in appropriating and decoding the information for their own personal use. Deeba, for instance, stated that "*for general information, you get more familiar with what you're looking for*", despite adding that "*for specific information it's not easy to find because you don't know the terms...or [...] you don't know where to start*" (personal communication, April 7, 2011). Generally-speaking, however, the Internet is regarded as a helpful tool providing easy, fast and convenient access to a vast amount of (recently updated) information from a variety of different sources. As Maria explains:

"I'm an immigrant here but even if I were not [...] nowadays you can reach so much information on the Internet. Sometimes even before looking for a doctor, sometimes you're curious and you can Google how you feel and what you suspect you may have, so you have a clear understanding of [what it] could be" (personal communication, April 12, 2011).

For Nim from Thailand, the ability to use the Internet to find health information made her feel "*more confident [...] so for me, it's very useful*" (personal communication, March 21, 2011). For Anna, a PhD student with two children, the possibility of finding out about shared experiences was also important. When researching information on children's development and 'selective mutism', for her 5-year old daughter, she came across health forums and Youtube videos in which others wrote about their experiences. One video in particular stood out among the rest: "*one movie I found, a girl made it about herself, she had the same problem when she was a child and then she made a movie like this...what happen, with pictures and music*" (personal communication, April 7, 2011). For Anna, finding this video was a rewarding moment because "*that feels good to see that, ok, it happens to others and it can be solved*" (ibid). Nevertheless, some of the uses several of the women make of the information they find online, in terms of relying more heavily on Internet resources than offline health services, hold important implications in terms of immigrants' access to and understanding of the Swedish health care system, an issue which we turn to in the next section.

6.2 The Internet as a tool to cope with issues of access and lack of understanding of the Swedish health care system

6.2.1 A cultural divide: the private/public health care dynamic

One of the key findings to emerge from my discussions with the 11 women and the two academics I interviewed for this thesis was that there is a real lack of understanding of the Swedish health care system and frustration about the difficult access (real or perceived) to Swedish health care services. The majority of the women expressed confusion about how to get an appointment with a doctor or specialist in Sweden. Many felt that information about the health care system or how to obtain check-ups or appointments was not easily accessible and were frustrated with how difficult and time-consuming it was to book an appointment. Maria, for instance, said it was not easy to contact her doctor: *“they have a specific time you can call and quite often it’s ring and ring...and when I go there, there is nobody specific sitting by the phone, if they have time they go there and answer it”* (personal communication, April 12, 2011). Maria’s strategy was to book her next appointment every time she went to the doctor and choose the right time so she would not have to change it. But on one occasion, when she was not able to do this, she had to call and *“it took a whole week till I could reach one of them so I could make appointment...so it’s not very easy”* (ibid). Isabel concurred on this point, remarking that *“[if] you get an appointment, you’re lucky”* (personal communication, April 12, 2011). On the topic of specialists, Deeba explained that getting an appointment with a specialist can be particularly difficult, especially when one is used to a different kind of system:

“In Sweden, it’s not that easily accessible. [...] I’m from Iran and there you have a lot of private doctors. If you have something very emergency, you can always go to private hospitals. [...] Here...if it’s a specialist it’s 6 months. 8 months I waited for my knee once. When I went to the doctor I didn’t have any problem anymore! [laughs] [...] To get to a specialist here, it’s very difficult...now it’s getting better actually, I feel like it’s shorter times but still, if you’re used to easy access to specialists, it’s quite boring here...you have to wait and first you get to go to the general GP and then they decide, if they’re good! [laughs] [...] They decide if you need a specialist or not and after months you get a mail ‘no’ or you have to wait 6, 7 months...so, it sort of sucks!” (personal communication, April 7, 2011)

Maria¹, who hails from Brazil, had a similar reaction, though she also expressed appreciation of the system:

¹ Roughly six months pregnant at the time, Maria later said she liked watching a Swedish television show, ‘Unge i minuten’, because it allowed her to see exactly what it is like to give birth in Sweden, *“it’s not a specific doctor, it’s a lot of midwives [...] in Brazil, [my mom] had one doctor through prenatal and the delivery, but here it’s not really like that”* (ibid). This sheds light on a small piece of information, insignificant to most but which, for Maria, goes a long way in making her feel more confident about giving birth in Sweden. In this case, the information was obtained through a television show but it is not hard to imagine how this type of information could be provided online by health care authorities, in order to reassure new, expectant immigrant women.

“In my home country we have both private and public. The private one is better of course, you have way more resource, much less waiting time and because of my economics in Brazil I would have private health care [...] but here in Sweden I think it’s quite good health care for everybody. You don’t feel that difference. Of course I hear some people complaining of waiting times and things that could be better but that’s how it is when it’s public...But in general it’s very good. Once [...] I had to go to emergency. [...] I cut my finger at night, maybe 9 o’clock and then I went [there] and had to sit there till almost 1 o’clock. It was super painful, my hand was like burning...but there was no doctor, it had to be orthopaedist to see my finger and it was just one to see a lot of people. I had to sit there...being very scared. Apart from that the doctor was great, the material they use, everything...I just wish there was more personnel to help you and less waiting time.” (personal communication, April 12, 2011)

Many of the women also held a view of Swedes as a stoic, tough people who do not easily accept or seek out medical help. In this context, several of the women seemed to have adapted by learning to take care of their (minor) health problems themselves, partly through health information found online. As Chanthra, a 32 year old Thai woman, explained: *“Swedish [people] try to be strong. [...] here people try to not go to the doctor...when I get pain, some headache or something, I have to help myself, from the Internet”* (personal communication, March 21, 2011). The problem is not that people are accessing more and more health resources online but that some of them do so *because* their expectations of the Swedish health care system are not fulfilled and, as a result, they stay away from it as much as possible. In other words, online behaviours are directly related to offline situations. Dembe, for instance, explicitly stated that: *“I know the hospital is not effective so I don’t bother going there...if I can find a way of curing ailments I have, unless it’s really a serious problem, it’s better to not go [there]”* (personal communication, April 18, 2011). The troubling part is that Dembe has been living in Sweden for 22 years. In Chanthra’s case, confusion, lack of understanding of the process and frustration with access to Swedish doctors also caused her to refrain from going to the doctor. As a result, she used the information online to find answers to her health questions, adding that if she could not find an answer, then she would go to the doctor:

“The hospital system is not good, I mean, they have hard to understand what you seek or whatever. [In] my country it’s easy to go to the doctor, you can go whenever, if you feel pain or headache. But here they give all the information step by step, you can learn and if you have a lot of problems, you can decide to go to the doctor. It’s a little bit hard to understand the doctor. Because the process not like my country. They don’t need money from people. You have to take care yourself.” (Chanthra, personal communication, March 21, 2011)

6.2.2 Frustration with ‘passive’ responses

Along with concerns about lack of access, several women also conveyed a certain amount of frustration with the ‘wait and see’/‘go home and get better’ mentality they associated with Swedish health care professionals. Nim, one of the most vocal participants on this topic, felt frustrated by what she perceived as the ‘passive’ or ‘reluctant’ response of Swedish doctors and nurses:

“They treat patients like ‘wait and let nature, you become better by nature...’. A couple of years ago my husband got [an ankle] infection and we go to Vårdcentralen. He become worse because they didn’t do anything, just a prescription for a pill...two weeks no better so go there again, wait a little, so totally one month. One month much worse and he have to buy a cane to walk. They didn’t do the sample of the [bone] water to check if he’s got infection or something. I was so angry I called my friend who’s a nurse in Thailand, working in the private hospital [...]. So next visit when my husband had to go to the doctor. I asked why [the doctor] didn’t do like my friend said. ‘Why do you have to wait?’ He doesn’t care. It was a Swedish doctor. I was so upset and disappoint. Why you have to wait until I tell him what he should do? I’m not a doctor! It’s ridiculous. I told my husband if you don’t get better I bring you to Thailand to get the treatment! He has to work. And we get paid only 80% of the salary. It doesn’t make sense, so that’s why I’m upset.” (personal communication, March 21, 2011)

This view of Swedish health care professionals as being ‘passive’ was also expressed by Anna, who explained how she turned to the Internet to find information when she was concerned about her five year old daughter, who has trouble talking to people:

“For years she didn’t talk to anyone in kindergarten. So I was doing research on the net. Then I found information...it’s [...] a kind of selective mutism. [...] Wikipedia, you can find anything there, it’s amazing! And then Youtube, there were like stories, that it’s quite common, there are kids who don’t speak, even in school. There was a list of what can you do and actually we followed some...and it is getting slowly better...Nobody could say anything, I went to the nurse and I told her since she turned three she’s still not speaking, should we meet someone to help her? ‘oh no, no, no, we can wait’. So we wait one more year and then it was still the same and [...] ‘oh yeah she is shy’. But I feel they are quite passive, to be honest, they hardly want to admit that there is a problem. And now the last check-up, when she turned five, it was still the same case...it has gone like four years without... ‘yeah yeah okay, do you want me to contact a psychologist?’ And I said ‘yes please’. I got the call a couple of weeks later ‘well they don’t think it’s serious’, without seeing her...apparently they have no time, because there are more serious cases. And because she can speak she’s not a worry. (personal communication, April 7, 2011)

As for Nim, when she gave birth to her son almost a year ago, she had some complications and when she requested an epidural, the Swedish nurses told her to wait a while. When she requested it again, they told her she was already dilated and it was too late for an epidural. This angered Nim, who expressed disappointment and incomprehension at how Swedish nurses expect women to give birth:

“I was so angry. I heard so many friends say exactly the same. They just let you give birth like the nature. Or maybe the pill is so expensive so they want to save...I don’t know just heard a lot of rumours about it. They treat you like an animal when you give birth, it’s natural [birth]. But in Thailand it’s very common to do a C-section. Also when the baby catch a cold or something I have no idea what should I do, I still have to think about it. I get the information from the midwife, call first...I think maybe 1177...” (ibid)

In her case, Nim’s concern was more with ‘minor’ health issues and the feeling that Swedish nurses/doctors do not take these seriously enough, leading her to think that:

“I have to do something to make it better. It’s important you have to be healthy, make sure you get the right treatment; if you not sure, go to Internet. And maybe you have to teach the doctor here, I think I have this symptom, ‘can you check?’, ‘I want to x-ray of my breast’ or blablabla, you have to push them.” (personal communication, March 21, 2011)

As strongly as she felt about her own experiences with the Swedish health care system, Nim maintained that it was a good system, especially for ‘big cases’ such as cancer, in which case the equipment and technology used is top notch. This feeling was echoed by several women, who believed that, although the Swedish health care system excels at taking care of patients with ‘serious’ medical conditions, it is not so effective at the other end of the spectrum. Maria, for instance, felt that *“it’s not very easy to get service for very small needs but for very big ones you’re completely insured”* (personal communication, April 12, 2011). The fact that in Sweden everybody had (equal) access to health care was another point participants such as Maria appreciatively commented on:

“Here is good health care because it reach everybody in a very good level, they have this system that there is a maximum that you supposed to spend a year...and that’s very good because [...] you know you’re going to get everything you need” (ibid).

6.2.3 Lack of understanding from the immigrants’ side

Thus, with a lot of the women I talked to, there seemed to be a general lack of basic understanding of how the system works in Sweden, a problem related to the cultural expectations the women arrive with (notably their experience with private and public care). Many participants felt that the health care system in Sweden was not as accessible as the (private) care they were able to obtain in their home countries². Long waiting times, for example, which are common in public facilities but practically non-existent in expensive private ones, were often cited as a problem here in Sweden. In this sense, there was a sort of cultural expectation that came into play and made it hard for them to adjust to the concept of ‘equal care for all’ that characterizes the Swedish health care system. Because all of those interviewed would have had some form of access, because of their socio-economic status, to private health care in their home country, it appeared to be a bit of a challenge for them to understand and come to terms with the equality-based Swedish system. Several of the women from Thailand, for example, explained that in their country, if you can afford private health care, you can get it at the snap of a finger:

“One time [I used the 1177 phone service]. But I don’t think they help. My husband had teeth pain very much and then he ask me [to call]. I called and they said ‘call ambulance or

² Other participants, like Isabel, mentioned they felt that, in Sweden, there is not much emphasis on prevention and regular check-ups: *“This is weird because in Latin America we do a pap smear every year, here it’s every 3. They don’t have this preventive medicine...they expect you to get sick, then they check you. They will never check you when you are healthy”* (personal communication, April 12, 2011)

something or sleep, maybe better...take a pill or something'. In Thailand a thing like that, emergency [snaps her finger], like that.” (Kalaya, personal communication, March 21, 2011)

As Kalaya, a 26 year old student from Thailand, remarks that her country:

“If you have money, you can get paradise service, they [treat] you like a guest. But here you must understand that people are the same level, exactly. But I think it’s okay. Of course we, people come from Thailand always compare because we can see. I have experience from my husband, emergency. Very good. Didn’t pay any one kroner. They ask for that [in Thailand], but here no. My husband had cancer before and very good care.” (ibid)

This issue of differing expectation was also touched upon by one academic, Bilan, who explained that most of the immigrants she talked to found the Swedish health care hard to understand and complained about not being taken seriously:

“One of the guys said ‘you feel like an idiot, because they say ‘no you can’t do that’. But nobody has taken the time to say ‘ok you go to the GP if you have a fever [but] you should wait 5 days’, to explain why you should wait 5 days with a high fever, ‘because fever in my country is lethal but then here you have to wait for 5 days, but why?’ Nobody has taken the time to explain. I think it’s frustrating both for the health care workers and the immigrants.” (personal communication, April 6, 2011)

6.2.4 Lack of understanding from the system’s side

The fact that immigrants arrive with their own set of cultural assumptions about health care and varying extent of understanding of how the Swedish system works is an important point because lack of understanding or plain ignorance is also a problem on the side of the Swedish health care authorities. From what I gathered for the discussions with the immigrant women I talked to, as well as the two academics I interviewed, the Swedish health care authorities tend to approach and frame the issue of immigration and health simply as a language one, i.e. if immigrants can just learn Swedish, everything will work out for the best, in health and in other areas. However, as Dembe, a woman from Uganda who has been living in the country for the past 22 years, explains: *“it’s not just to learn the language”* (personal communication, April 18, 2011). Lack of access and understanding of services is related to a language barrier but it is also related to the cultural expectations and the frame of minds immigrants arrive with. This is not to say that language is not an important piece of the puzzle. Language in general emerged as a central element throughout the research. In simple terms, language matters: immigrant women tend to search in English first and in their own language or in Swedish second. Of the 11 women interviewed, 7 expressed a preference for searching for health information on the net in English. Of these, three said they also searched in their own language, though much less frequently than in English, like Anna, who explained that: *“I search in English. In Hungarian sometimes, but that’s limited...English, that’s the*

widest...that's the best. Maybe Swedish is somewhere in between" (personal communication, April 7, 2011). Anna and most of the women attributed the choice to search in English to the belief that more information is available in that language. Searching in Swedish was much less common and was used more or less only to look for specific terms and/or learn the language. Maria, who was expecting her first child, stated that "[searching in] Swedish would be rare, it could happen that I research a word in Swedish...Like if I met a doctor and she said something that I couldn't really identify" (ibid), while Chanthra explained that "I search from Google first, in Thai, sometimes in Swedish...like now, I looked [...] because I prepare to be a mom, and then I look in Swedish because I need to learn Swedish also" (personal communication, March 21, 2011). Three of the women stated that they only searched in their own language while only, Deeba from Iran, said it did not matter and she searched in Swedish as much as or perhaps more than in English: "Vårdguiden.se...that one is really good, [...] it's in Swedish, mainly...it's very good especially when this influenza and this kind of things, you know [...] so I use that one a lot, because it's something actually in Sweden" (personal communication, April 7, 2011). Deeba added that: "most of the time if you need to talk to a doctor, it's good to use the Swedish [resources], if you can read it and understand so you can at least learn the terms and be able to discuss it" (ibid). Not being able to get one's message across to the Swedish doctor was a point discussed by Nim, who said that using the Internet for her was very important because if she fell sick here:

"I couldn't communicate exactly my symptoms with the Swedish doctor and I'm not so happy with the treatment here. The doctors here, it's not so good...the way they treat the patient. So mostly I'm searching the Internet...it's easier." (personal communication, March 21, 2011)

In this sense, the women seemed to have a strategy of 'selective picking' of health information, accessing resources in the language perceived to offer the most, assessing their value, re-appropriating it for their own use. For Dembe, it was a case of "*just find[ing] what works for me*" (personal communication, April 18, 2011). Each viewer also brings "their own individual and cultural storehouse of meanings" (O'Brien & Szeman, 2004, p.89) Indeed, audiences are not passive consumers but rather active readers and producers of complex cultural texts, involved in what Stuart Hall terms the 'encoding' and 'decoding' of meaning.

6.3 The Internet as an instrument for increasing awareness and bridging cultural divides

Given the large role the Internet already plays in the lives of the immigrant women interviewed in this study, as well as the apparent lack of access to and understanding of the Swedish health care system, there is a clear need to increase the amount and scope of e-Health services in Sweden. In fact, I would argue that, if properly used, the Internet can be an effective instrument for increasing immigrants' awareness and

understanding of the Swedish health care system, thus bridging the cultural divide that currently leads to frustration for both immigrants and health care professionals. Internet health resources can be a way of empowering new immigrants and reducing the problems caused by the different expectations they arrive with. As outlined in the 'e-Health in Sweden' section of this thesis, at present the Swedish government has a range of different e-health initiatives in place as well as a detailed national e-health strategy. However, the responses of the immigrant women who participate in my study revealed that most of them were unaware of the main Swedish telephone and Internet health care services. Of the 11 women interviewed, six were aware of the existence of the national health hotline (1177) but only two knew of the 1177.se website, where people can anonymously ask a medical professional a question. This echoes the findings of Jung and Loria (2010), who explain that "simple lack of awareness was the main reason why [none of the] interviewees had previously made of use [the three e-health services investigated]" (p.61). This point was also confirmed by one of the researchers I interviewed, Bilan, who is working on empowerment and e-Health issues. None of the participants in Bilan's project had ever heard about the 1177 phone or web service; but the pilot project was very well received from both sides (nurses and patients). Of the women in my study who had heard of the 1177 hotline, only 3 reported they had used the service themselves. The two participants who did know about 1177.se both knew it because of the minavårdkontakter.se service and were not aware of the 'Ask a doctor' section of the website. Even participants who regularly went to the doctor did not know about the 1177 hotline, much less its Internet version. Maria, for instance, said: "*is that like 911? I don't know about it...that's funny because I never got this information and I go to the doctors quite regularly these days*" (personal communication, April 12, 2011). Isabel, on the other hand, felt that the lack of awareness was a problem not only for immigrants but for the rest of the population as well: "*I don't even know [these services] exist! So this is the thing, it's bad communication...because my boyfriend doesn't know either and he's Swedish*" (personal communication, April 12, 2011). Despite having been here for over 7 years, Isabel said she still did not understand how the Swedish health care system works and where she should go to if she fell sick.

Even when people *are* aware of the e-health resources at their disposal and try to use them, the services are not always reliable. As Anna explains, when she learnt she could book her pap smear test online on the minavårdkontakter.se website, about a year ago, she tried to book a time but it did not work:

"It said 'full booked', 'full booked' and then I tried to book for next [time] and it was still booked and I said 'hmm maybe it's not working'. And then I tried to call but you can call in 2 hours, only 2 hours...and then I always just miss it and so I still haven't gone!" (personal communication, April 7, 2011)

In other cases, it is not merely a question of providing access to health services but also of explaining why they are important and being culturally sensitive about certain

types of services. For instance, Somsri describes some immigrants' reluctance to go for a pap smear in the first place:

“When I arrive here the first time, they send me the letter, kind of invitation to check for [cervical cancer]. They say every 3 years. I did that, went to the Vårdcentral and it was all okay. But I know some Thai ladies here; they have been living here 3 or 4 years. They don't go because they feel ashamed to lay there and somebody look at their genitals. But I recommend they should do because there is nothing to be ashamed of.” (personal communication, March 25, 2011)

6.3.1 Language issues and new discoveries

One factor potentially related to this is the lack of information available in English or other languages, a common complaint in terms of local and national Swedish e-Health resources. Maria, for instance, remarked that *“some websites you can see at the top ‘in English’ and then when you click on it you can see the amount of information is like this [very small] and exactly what I want to know perhaps is in Swedish ”* (personal communication, April 12, 2011). However, because she could speak some Swedish and had a Swedish boyfriend, she was not greatly inconvenienced by this and she was generally happy with the amount of Swedish websites translated into English. In contrast, when asked if she thought the Swedish government does enough in terms of health promotion and services for immigrants, Deeba answered the following:

“No, I don't think so...hey, actually that's something that caught my attention this morning when I was looking for a telephone number. It's easy to ignore it since I'm using Swedish now for four, five years but...there is no English link on Skåne Vårdcentralen! That was really disappointing. Because I can read it but I was going to send it to my sister who is not good in reading Swedish and I [...] thought 'how is she going to understand what it says here?' [...]If you looked 7 years ago, there was so bad English information and now they have some information in PDF files, in specific languages, for major immigrant groups. Vårdcentralen doesn't give information, that one is missing.” (personal communication, April 7, 2011).

This fact became apparent to me very early on in the research and was reinforced in the writing phase of my thesis, during which I personally experienced the lack of support in languages other than Swedish, being a foreign woman currently living in Sweden myself. I recently had a health question and decided to put to good use the information gathered for my thesis and use the ‘ask a doctor’ service on 1177.se (‘Stall din fråga’) myself. Both this service and the rest of the website are available only in Swedish, but since almost all Swedes speak (near-perfect) English, I did not think asking a question in English would be a problem. Curious to see the response of a Swedish doctor, I eagerly waited for an answer. Two days later, I opened my inbox

only to find disappointing news – an automatic message from the 1177 nurse coordinator, explaining:

“I am sorry, but the doctors and nurses answering in the service Fråga 1177.se do not answer questions written in English or any other foreign language. If not consequently using Swedish in 1177.se there might easily come up different sorts of misunderstanding and difficulties in communicating, and thus we have decided not to answer any questions written in foreign languages at all.” (personal communication, April 26, 2011)

The most disappointing part was not the lack of answers to my questions but rather the fact that I was given no possibility to receive answers through an alternative channel, nor indications on where to go to access more information (in Swedish or otherwise). In my case, the question was not a very important one but had it been, I would have been much more frustrated with the response I received (or lack thereof). Either way, it was certainly not an encouragement to use the service again, even if I was able to translate my question into Swedish. It also gave me a little more of a sense of where some of the women I talked to were coming from when they told me they would rather go to the doctor in their home country (especially for routine appointments like yearly check-ups) than have to deal with the Swedish health care system –of which 1177.se is of course only a small part. This finding astonished me and really drove home the point that lack of awareness, understanding, and access (real or perceived) can have disastrous consequences on the use of the health care services by immigrant populations, in Sweden or beyond. The Internet should be an additional resource and tool for women to be better informed, not a media they rely more heavily because they feel it is too hard to access local health services. Isabel, for instance, was so thwarted by her negative experiences with the Swedish system that she would rather do all her check-ups in Bolivia (which she does, when she goes there on holiday). When asked whether she used any Swedish e-health resources (like minavardkontakter.se), she replied that she had never thought about it because :

“I was so blocked, ‘oh this is so bad’ that I didn’t even look in that. I would never think to go to the webpage of the hospital and look for things there. That’s not good.” (Isabel, personal communication, April 12, 2011)

Dembe had a similar outlook and expressed great frustration about the long waits and the waste of time she associated with the Swedish health care system:

“There is a problem with their hospital...there is no time for anything, even when you get the time they keep on extending it...you even forget what you went there to check for! I wanted to get a general check-up [...]. They give me an appointment, then they call to change it to a date when I was travelling. I told them I would not be here and they said ‘you can come in 1 year’ and I said ‘I don’t think I’ll be needing that, I’ll do the check-up in Uganda’. Which I did, I just walked in and did [it]. At least [...] they should do it properly. Because you wait for the time and then when you get [it] you don’t even get the proper thing because they keep on asking ‘do you have any problems?’. ‘You’re here to tell me! I want a general check-up’. ‘But

we don't do these...who is your doctor?' 'I don't have a doctor! It's very frustrating, the hospital, I never go there.' (personal communication, April 18, 2011)

6.3.2 Strategies and potential tactics

Asked if she believed the Swedish health care system does enough to help immigrants, Dembe responded no, explaining that: *"I don't think they have the right strategies [...] they want an easy way out and it doesn't work that way, I think it's going to be a burden on the community because I see a lot of obese children..."* (personal communication, April 18, 2011). This last point is extremely relevant considering the huge increase in child and adult obesity worldwide and the risk this poses in terms of health. In this context, it is even more important that the Internet be recognized as an avenue for raising awareness among immigrants, especially recent arrivals, of how the Swedish health care system works, why it works that way and how to best access health services. Information of this type is crucial for promoting better health among immigrants and the community as a whole, especially in the face of problems such as rising obesity and population ageing. One of two researchers interviewed, Bilan, explicitly touched upon population ageing and the potential of the Internet to become a tool for health promotion in Sweden:

"I believe the Internet is the future of health promotion, mainly because it's cost effective and secondly because we are going to have an ageing population so to make room for the people who really need to come in to the hospital, we'll need to empower people to be able to take care of their own health." (personal communication, April 6, 2011).

However, thus far, the Swedish government has not capitalized on this potential, much less for the health and integration of the country's immigrant populations. In this sense, it seems to have fallen somewhat short of the goals of the national e-Health strategy, as well the core principle of 'equal care for all'. The policy in terms of immigration seems to be almost primarily focused on helping immigrants learn Swedish (Lena, personal communication, April 13, 2011), while the other needs, such as the importance of access to health resources and information about health services, are left unaddressed. According to Dembe, this is not due to discrimination or bad intentions, rather, it comes down to simple ignorance:

"I think it's ignorance...on the side of the Swedish community because they are ignorant about the needs of immigrants. They take it for granted that if you learn the language and whatever, you are okay. They don't realize that you're a stranger, you don't know anybody, you have more needs than just learning the language, you know?" (personal communication, April 18, 2011)

6.3.3 Acceptance of e-health services

From the 11 interviews conducted for this study, it was immediately obvious that more and better e-Health services would be enthusiastically welcomed, as long as they are easy, reliable and useful. All the participants stated that if they had the

possibility to book their appointments online, they would definitely do so. Most said they would also use an ‘Ask a doctor’ online service if it was easily available to them, like Maria, who thought it would save her some time: *“if I feel that I need, I would, definitely, it’s so simple”* (personal communication, April 12, 2011). However, she was not keen on online video consultations with doctors, as she thought it would be awkward to use a webcam, except in certain cases (e.g. for getting a follow-up on a wound). Isabel, in contrast, would prefer a video consultation to a chat or ‘Ask a doctor’ service because for her it is very important to be able to ‘see’ the doctor:

“Because in South America, you have always direct contact with the doctor. I cannot imagine saying to someone that I don’t see, what I feel, how I feel. It’s like wasting of time, I need to see the person and [...] show my thing. Because [...] that’s a lot, to see a face.” (ibid)

Lena, the Health and Society professor, agreed that if there were more e-health services people would use them and pointed out that their particular relevance for individuals or relatives of people with psychiatric illnesses. She also said these services could be particularly well-adapted to female immigrants and women in general, who often take on the role of caring for their health of their families:

“Since a lot of [immigrant] women aren’t allowed to move freely around [...] because they can’t leave their apartment without having someone with them or something, it would be very very convenient for them to look at...if they know where to look. [...] They can be a little more self-dependent that way. I think that women often take care of illnesses in the family.... And then it will be perfect, to reach to that group. I’ve seen figures that [...] especially in terms of psychiatry, we are looking even more for others than for ourselves. [...] There are some small projects starting to support relatives of family members for those who are very mentally ill [...]. My former PhD student has [a website]...a support for relatives, she has thought about doing it in other languages but she doesn’t have money [...] to build it.” (personal communication, April 13, 2011)

The issue of funding, always a present one, was also discussed by the other academic I interviewed, Bilan. For her PhD, Bilan looked into how to develop “sustainable, relevant, health communication infrastructures for health care systems” (personal communication, April 6, 2011). In her opinion, the worrying part about the current e-Health strategy is that it does not seem to take into account those who cannot (yet) speak Swedish: *“[they should] have [websites] at least in English and the main foreign languages...those are the people who really need it, but I was told there are no funds”* (personal communication, April 6, 2011). Under the national e-health strategy of Sweden, Bilan explained, each county is left entirely to its own devices in terms of adapting the strategy to its region, with no ‘example county’ to follow. In her opinion, the strategy has not yet had any real impact, in part because it is not binding. As far as she knew, the only e-health projects currently in place in Sweden (apart from the main ones: 1177.se, UMO.se...etc.) focus exclusively on elderly or specific types of patients (e.g. cancer patients). In other words, *“you have to be a patient, they don’t do anything that is preventative or even just promotion”* (Bilan, personal communication, April 6, 2011). For Bilan, this is problematic because health

should be dealt with more holistically, since *“health is not the absence of a disease...it’s wider than [that]”* (ibid).

Bilan also explained that *“the national health policy states that everybody is responsible for their health...but it also states that we have to create conducive environments for health, so what does that mean? How do you create a conducive environment for health?”* (personal communication, April 6, 2011). For her, e-Health projects are one part of the equation. Yet the Internet is only informally recognized as tool for creating conducive environments in the national public health policy. Bilan believes e-Health should be more broadly acknowledged because of the importance the Internet has taken on in people’s lives, especially in a country as ‘connected’ as Sweden: *“in the Ottawa charter it says that health is created where people live, love and play, so where is that? More than the home or the house... [online], that’s where people live”* (ibid).

6.3.4 Empowerment and the road ahead

In other words, the demand is there, Swedish health authorities just need to step it up. If we understand ‘empowerment’ and, specifically, women’s empowerment as “a process that leads women to perceive themselves as capable of undertaking decisions and making choices about their lives” (Vodanovich, Urguhart & Shakir, 2010, p.3), then it is not hard to see how access to useful and reliable online health resources and services can be empowering for women around the world. As cliché as it may sound, it is no overstatement to say that e-Health holds great potential for the empowerment of women, especially immigrant women who may be less aware of health services and perhaps more isolated than other women. Furthermore, as Bilan explained, ‘empowerment’ is not only measured by the level of health literacy and the ability to make informed choice: involving local communities and health care professionals in *developing* of e-Health services can be just as empowering. In other words, participatory-based e-Health projects can involve “a whole process of empowerment...from the design to the content” (Bilan, personal communication, April 6, 2011). Of course, there exist a range of problems related to the use of Internet for health (Jung & Loria, 2010), no less the possibility of individuals ignoring or inappropriately using the information. As Kivits (2009) notes, the “relationship of a lay audience to mediated messages about health is far from being univocal, leaving open the possibility to ignore health messages” (p.681). Still, I believe the benefits far outweigh any possible disadvantages. One of the most important benefits may be the Internet’s potential to reduce the load on health care professionals and on the system (Jung & Loria, 2010), a particularly relevant issue in the face of population ageing and “the increasing cost of providing health care and social security to older groups” (Potter, Binns, Elliot & Smith, 2004, p.198). This is a point Maria touched upon when she noted that: *“if they had a lot of things on the internet, maybe they reduce the amount of people who just show up in the hospital*

that doesn't really need to be there" (personal communication, April 12, 2011). Sitha also agreed on this issue, pointing out that:

"Otherwise everybody goes to the doctor for everything. Now if we have serious problems only we go to the doctor otherwise we wait, we have other options like 1177 or go to the internet or go to the vårdcentral via internet. It saves money and time too." (personal communication, April 13, 2011)

In addition, Rahmqvist and Bara (2007) argue, "as patients use the Internet to become more informed, the information asymmetry between lay people and health care professionals will have a chance to decrease or at least change in some way" (p.538). In other words, it also contributes to a certain levelling of the doctor-patient relationship, thus "demystifying medical expertise" (Pitts, 2004, p.43). Therefore, providing immigrants and Swedes alike with effective e-Health solutions has the potential to make things easier for both patients and health care professionals. It also has important repercussions for the next generations, as informed women with sound health literacy skills make healthier decisions for their entire family.

6.3.5 Policy recommendations

Thus, the findings outlined above allow me to concur with the authors of previous studies (Wiking et al., 2004; Akhavan et al., 2007) that there is a clear need for more online health information and promotion among immigrants in Sweden, especially female immigrants and recent arrivals. This is particularly important considering that "information has been shown to be an important factor for success in doctor-patient communication and patient satisfaction" (Umeåfjord et al., 2006, p.165). It also could mean significant savings of time and money, as well as increases in efficiency and convenience for patients (Jung & Loria, 2010). Unless all citizens are aware of the existence and benefits of online health care services at their disposal, "they will continue to turn to the health care center each time a question arises and investment in Internet services will be wasted" (ibid, p.51).

Furthermore, public health policies must take into account the fact that "primary health care staff [need] more education about the migratory process, different cultures and the risks of poor health for immigrants" (Wiking et al., 2004, p.581). As Rahmqvist and Bara (2007) justly point out, the increasing number of patients who use the Internet for health makes a strong case for the Internet's "potential to empower those patients who want to know more about their diseases, ailments and treatments; however, [...] it must be the health professionals who pave the way so the Internet becomes useful for patients" (p.538). However, local and national authorities must also be careful not to 'dump' new systems and expectations on health care workers, without first seeking their input and ensuring the new services are

compatible with their needs (Bilan, personal communication, April 6, 2011). Ideally, the authorities should consult and include local health care workers and people from the community in the process of designing, developing and implementing e-Health services adapted to the needs of all parties concerned. However, this will not happen until the current national e-health strategy becomes binding and presents clear guidelines on how to achieve the goals it purports, preferably through the use of one county as an example of best practices for the rest. Strategies to include all members of the Swedish population within the national e-Health scheme are also needed. Given the high proportion of immigrants in the Malmö area, it would make sense to consider Skåne as a potential example county, to kick-start a more hands-on, effective and focused national e-Health strategy.

7. Limitations

The chief limitations to this study were: difficulties in gaining access and finding informants, personal biases, the short-time frame involved, and the study's ability to be replicated. As discussed in the 'Methodology' section, getting in touch with potential participants was one of the biggest challenges and involved a long process of contacting as many relevant associations and contacts as I could find. In this sense, my lack of familiarity with the immigrant organizations and non-profit community in Malmö may have hindered my ability to find participants from a greater diversity of backgrounds. On a related-note, the fact that most of my participants were highly-educated women leaves room for further studies on immigrant women with less high levels of education. My personal biases of the positive and empowering potential of the Internet as ICT may also have influenced my selection of research questions and/or key themes. In addition, the amount of interviews conducted and the depth of analysis reached could have been enhanced if the time frame for this thesis had been wider. A final limitation of this study is its lack of applicability to other groups. This is common feature of fieldwork, in the sense that fieldwork's "*authority* stands in tension with its *range*" (Fielding, 2006, p.278), as generalizability is limited and sample sizes are typically small. This is discussed by Asis, Huang and Yeoh (2004), who contend that although in their own research "the small number of [...] interviews and the process of selecting informants through personal networks do not allow us to generalize our findings to the larger population" (p.8), it is adequate to the aims of their research. However, I would argue that though the findings of qualitative studies such as my own cannot be statistically generalized, conceptual generalization are possible. In fact, one could argue that qualitative researchers have a responsibility to extrapolate the data from even a small sample to a broader scale, in order to identify how this new knowledge fits into the larger body of knowledge of the topic and how it can be used, i.e. to highlight a need and suggest avenues for further research.

8. Conclusion

Thus, the findings of this study suggest that immigrant women in the Malmö/Lund region use the Internet to find health information in multiple and negotiated ways. For the 11 women interviewed, the Internet represents as: (1) an additional resource for accessing health information as well as (2) a key tool for coping with issues of access and lack of understanding of the Swedish health care system. For local and/or national health authorities, the Internet can be regarded as (3) an instrument for increasing awareness of health services and reducing the cultural divide between Swedish health care providers and female immigrants, especially new arrivals. In other, words, online behaviours have important offline implications.

However, as of yet, the Internet's potential for health promotion has not been fully capitalized on by Swedish health authorities, despite the fact that, as Bilan notes: *"we live in the 21st century, everybody lives on the Internet...we literally live online"* (personal communication, April 6, 2011). Furthermore, there is a worryingly high amount of confusion, frustration and lack of understanding of the Swedish health care system among female immigrants of diverse nationalities. In this context and from a feminist perspective, the Internet should be recognized as a flexible technology that can help create change by providing women with a place to find answers to their health questions, capitalize on the experiential knowledge of others, and, ultimately, become empowered to make informed health decisions for themselves and/or their family. Today, cyberspace has become a stage for the challenging of theories of what constitutes (medical) 'knowledge' and what patient-doctor relationships should entail. Although initially conceived of as a male domain, the Internet has been appropriated by women for their own uses, including the reclaiming of another typically male domain: the medical sphere. Such a democratization of medical knowledge and the process of its creation, from which women have been excluded for so long, can only be beneficial from the point of view of gender equality, in Sweden and beyond.

This thesis provide a starting point for further in-depth research on how immigrants in Sweden use the Internet for health purposes and how their needs can be integrated into the implementation of further e-Health services in the coming years. Future research could also be directed towards the Internet use of elderly as well as lower-income immigrants. As the Internet becomes more and more entwined in our daily lives, more research will be needed on the implications of this in terms of health promotion and literacy, especially in the context of global population aging. Closing the health literacy divide, as well the digital one, will require serious commitment and carefully-considered, participatory-based e-Health strategies. Who knows, in a few years, there might even be an 'app' for that.

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Appendix

Online behaviours, offline implications: A window into the use of the Internet
for health among immigrant women in Malmö

Research summary

Researcher

My name is Alison and I am a Canadian student at Lund University. I am interested in researching if and how immigrant women in the Malmo region use the internet for health purposes (for example, for finding health information or support groups). I am interested in this topic because I have personal experience with doing health research online and because I am fascinated by how women in North America are using the internet to connect with other and find answers to their health care questions. I would like to see if immigrant women in Sweden use the internet for similar reasons and if they feel they are well-served by the Swedish health care system and its e-health initiatives.

Project details

This project is for my masters' thesis in Development Studies and Communications (SIMT27), currently being completed under the supervision of Helena Sandberg of the Lund University Communication Department (<http://www.kom.lu.se/index.php?id=2208>).

Project description and aim

This study examines the topic of health, immigration and health-seeking behaviour in Sweden. I am interested in talking with female immigrants in Malmö in order to gain a better understanding of their own personal experiences with seeking health information online. I would also like to talk to health care professionals and/or academics to find out more about e-health in Sweden and the different health care initiatives targeting immigrant populations. To the best of my knowledge, there has not been a singly study done on how immigrant women in Sweden may or may not use the Internet as a source for health information, a site for support and/or a space for empowerment. My research ultimately aims to look at how female immigrants feel about the role the Internet plays, as an Information Communication Technology (ICT) tool, in their health and their families' health. As a secondary aim, are they aware of and/or satisfied with the online health services the Swedish health care system offers? Do they feel these resources and services are adequate for immigrant populations?

Methods

I wish to interview 10 to 12 women from a variety of immigrant communities, who came to Sweden as adults or young adults in the last 5 to 10 years, as well as 1 to 5 health care professionals and/or academics. I hope to be able to interview women who speak English, French, Italian or Spanish – as unfortunately my Swedish is not (yet!) good enough to allow me to conduct the interviews in Swedish. All interviews will be **confidential**. The interviews should last approximately one hour and could be conducted through Skype, if necessary.

Thank you very much for your time!

Online behaviours, offline implications: A window into the use of the Internet
for health among immigrant women in Malmö

Interview guide

Project description

This study examines the topic of health, immigration, and health-seeking behaviour in Sweden. I am interested in talking with female immigrants in Malmö in order to gain a better understanding of their personal experiences with seeking health information. I am interested not in media representations of immigrant groups but in the health and internet usage experiences of immigrant women from a variety of different backgrounds, as expressed by these women themselves. To the best of my knowledge, there has not been a singly study done on how immigrant women in Sweden may or may not use the Internet as a source for health information, a site for support and/or a space for empowerment.

My research ultimately aims to look at how female immigrants feel about the role the Internet as an ICT tool plays in their health and their families' health. In other words, do they believe that their experience with the internet lives up to its much-hyped potential to revolutionize health care and empower patients, especially female patients? As a secondary aim, are they aware and/or satisfied with the online health resources and services the Swedish health care system offers? What resources exist? And do they feel these resources and services are adequate for immigrant populations?

Questions

BACKGROUND

- *When did you first come to Sweden? What reasons motivated you to immigrate to Sweden?*
- *What is your level in Swedish?*
- *What is your current occupation?*
- *Do you have a family (husband/long-term partner and/or kids)?*

ACCESS & USE

- *Do you currently have access to the Internet? If yes, is this access from home, from work or from another location (e.g. public library)?*
- *Do you use the Internet? If yes, how frequently do you use it? Would you describe yourself as an experienced internet user?*
- *What do you primarily use the Internet for?*
- *Do you feel there are any barriers to your internet use (e.g. language, cost, time, usefulness, familiarity, competition for computer use...)?*
- *Do your friends and family use the internet?*

HEALTH & INTERNET USE

- *Have you ever used the internet to find health information or anything related to health?*
- *If yes, what did you search for? Which kinds of websites did you go to (e.g. local health care authorities' websites, blogs, specific disease support groups...)?*

- *What do you think about the quality of the information online? Is it easy to understand?*
- *Do you think this information is helpful? To you or to others? How do you use it?*
- *Has the information found ever affected your behaviour (e.g. on how to treat a condition or getting a second opinion; changed how you cope with a chronic condition...)?*
- *Do you search for health information for yourself or on behalf of others? Do you ever discuss what you found during your internet searches with anybody?*
- *Does anybody in your close family and friends have a serious medical condition?*
- *Have you ever heard about or used the 'Ask a doctor' service on www.1177.se [Ställ din fraga]? If yes, what did you use it for? How often have you used it?*
- *If your doctor recommended a service like the 'Ask a doctor' service, would you use it? Has your doctor or any other health care worker told you about this/other online health services?*
- *Do you feel you have a good relationship with your doctor?*

IMMIGRATION & HEALTH IN SWEDEN

- *Do you feel the Swedish health care system does enough to help immigrants in terms of health?*
- *Have you ever heard of immigrants experiencing discrimination in terms of accessing Swedish health care services?*
- *Overall, how do you feel you have been received and treated by Swedish society?*
- *How has your health been since you moved to Sweden?*
- *How would you describe your social life since moving here? Is it easy to make friends?*
- *Do you use social networking sites like Facebook or MySpace?*
- *What you ever posted comments, questions or information about health-related matters in an online discussion group, blog, or other online forum? If yes, please describe.*
- *Do you see yourself doing this in the future? What would motivate you to do this?*

Is there anything else you feel has not been addressed and which you would like to share?

Thank you very much for your time!

Online behaviours, offline implications: A window into the use of the Internet
for health among immigrant women in Malmö

Interview guide (researchers)

Project description

This study examines the topic of health, immigration, and health-seeking behaviour in Sweden. I am interested in talking with female immigrants in Malmö in order to gain a better understanding of their personal experiences with seeking health information. I am interested not in media representations of immigrant groups but in the health and internet usage experiences of immigrant women from a variety of different backgrounds, as expressed by these women themselves. I would also like to interview health care professionals or academics working on health, e-health and/or immigration issues, in order to obtain a broader understanding of the topic. To the best of my knowledge, there has not been a singly study done on how immigrant women in Sweden may or may not use the Internet as a source for health information, a site for support and/or a space for empowerment.

My research ultimately aims to look at how female immigrants feel about the role the Internet as an ICT tool plays in their health and their families' health. In other words, do they believe that their experience with the internet lives up to its much-hyped potential to revolutionize health care and empower patients, especially female patients? As a secondary aim, are they aware and/or satisfied with the online health resources and services the Swedish health care system offers? What resources exist? And do they feel these resources and services are adequate for immigrant populations?

Questions

BACKGROUND

- *What is your current occupation?*
- *How long have you been working in this field?*

HEALTH IN SWEDEN

- *How would you describe the health care system in Sweden? What are its core principles?*
- *Are you involved in any health-related projects? If yes, what kind?*
- *What do you think are the most common complaints about the Swedish health care system?*

HEALTH & INTERNET USE

- *Have you ever used the internet to find health information or anything related to health?*
- *If yes, what did you search for? Which kinds of websites did you go to (e.g. local health care authorities' websites, blogs, specific disease support groups...)?*
- *What do you think about the quality of the information online? Is it easy to understand?*
- *Do you think this information is helpful? To you or to others? How do you use it?*
- *What do you think of the Internet as a tool for promoting health literacy or empowerment? Do you think it is empowering to be able to access health information online?*
- *Have you ever heard about/used the 'Ask a doctor' service on www.1177.se [Ställ din fråga]?*

- *Do you think many people in Sweden use this type of services? Do many people use the Internet to find health-related information?*
- *What level of trust do you think Swedes generally place in their doctors?*

IMMIGRATION & HEALTH IN SWEDEN

- *Do you think the Swedish health care system provides adequate services for new immigrants? Do you know of any resources, services or projects specifically targeted to this population?*
- *Are you aware of any e-Health projects targeting this group or the Swedish population as a whole?*
- *Are you involved in any immigrant-related projects?*
- *Have you ever heard of immigrants experiencing discrimination in terms of accessing Swedish health care services?*
- *Do you think the Swedish government should provide more online health resources and services to the general population? To its immigrant population?*
- *What trends do you foresee in terms of immigration in Sweden in the coming years?*
- *What do you think will be the implications of population ageing in Sweden?*

Is there anything else you feel has not been addressed and which you would like to share?

Thank you very much for your time!

Online behaviours, offline implications: A window into the use of the Internet
for health among immigrant women in Malmö

Informed consent form

Thank you for agreeing to this interview. You have been invited to take part in this research on immigration, internet use and health because your experience as an immigrant woman or as a health care professional and/or academic can help the researcher better understand if and how immigrant women in the Malmö region use the internet to find health information and gain more insights into the Swedish health care system, e-health initiatives and health promotion efforts among Sweden's immigrant population.

Your participation is entirely **voluntary**: it is your choice whether to participate or not. You do not have to answer any question you do not want to and you can stop the interview at any time and for any reason. The interview will be recorded but only the researcher will listen to it. All the information collected is **confidential** and all names will be changed to make sure your answers are kept anonymous. The knowledge obtained from this research will be shared with you before it is finalized. Once you have given your feedback (if any) and any corrections have been made, the final thesis will be published in the Lund University database of thesis publications.

If you have any questions or concerns, either during or after this interview, please feel free to contact the researcher:

Alison Cassells
MsC Development Studies Candidate
Department of Communication
Lund University
Email: mas09aca@student.lu.se
Tel: 07 67 96 64 15

By signing this form, you consent to be a participant in this study. You agree that you have read the information above and that all your questions, if any, have been answered by the researcher. You will receive a copy of this form for you to keep.

Thank you for participating!

Signed: _____

Name: _____

Date: _____