



Language Barriers



in Access to
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Language Barriers in Access to Health Care

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▲ Executive Summary

The purpose of this report is to provide an overview of current research describing the impact of language barriers on health care access and quality of care; and the role that language access programs can play in addressing these barriers. While the review includes studies done in other countries, this report aims to provide an analysis of the research evidence from a Canadian perspective. It is intended to serve as the starting point for further dialogue and collaboration among Canadian researchers, health administrators and policy makers, and providers and users of language access programs.

There is increasing awareness that a number of populations are underserved by the health system in Canada. Those who do not speak one of the official languages are one of these underserved groups. In some circumstances French speakers living outside Quebec, or English speakers within Quebec may also face similar difficulties. However, little research has focused on the effects of language barriers on health outcomes, service utilization, patient satisfaction, or overall costs to the health system or to society. In Canada, most research on health service utilization and health status has focused on the effects of socio-economic factors, and to a lesser extent on regional differences. Research examining the impact of culture and ethnicity has tended to focus on differences attributed to cultural beliefs and practices, and not on the effect of systemic barriers to access.

In Canada there are four constituencies who may face barriers to health care due to having a non-official first language: First Nations and Inuit

communities, newcomers to Canada (immigrants and refugees), Deaf persons, and, depending on location of residence, speakers of one of Canada's official languages. Access to necessary health services is a right of every Canadian as guaranteed by the Canada Health Act of 1984. However, access has generally been interpreted to mean the absence of explicit financial barriers to care. Although recent challenges under the Canadian Charter of Rights and Freedoms have confirmed the rights of Deaf persons to be provided with interpreters for health care, the rights of other minority language speakers are not clear.

It is generally agreed that the best communication is achieved where health care providers and patients speak the same language. There are a number of different approaches to increasing the number of language-congruent encounters, ranging from promoting English and French language training for new arrivals to Canada, to increasing the number of providers who speak minority languages. There will, however, always be a need for language interpretation services for some patients.

Increasing awareness of the impacts of language barriers on health status, service utilization and costs, has promoted research related to the effects of language barriers. There are a number of different methodologies utilized in research on language access: descriptive methods, survey methodology, secondary analysis of data, experimental methods, and economic evaluation. Each of these methods has both potential and limitations for further research. Research in the area of language access to health care is still in development and there are a number of additional considerations, including specific issues of definition and measurement that must be taken into account.

▲ Key Findings

Effects of Language Barriers on Patient Access and Care

The body of this report focuses on research related to the effects of language barriers on patient access to, and quality of care.

- There has been limited formal assessment in Canada of the prevalence of language barriers in health care encounters. Attempts to develop estimates are often based on general population estimates, or estimates developed by a specific institution.
- There is compelling evidence that language barriers have an adverse effect on initial access to health services. These barriers are not limited to encounters with physician and hospital care. Patients face significant barriers to health promotion/prevention programs: there is also evidence that they face significant barriers to first contact with a variety of providers.
- Recent research that includes the variables of both ethnicity and official language proficiency suggests that in many cases, language, rather than cultural beliefs and practices of patients, may be the most significant barrier to initial contact with health services. Further research is needed in this area.
- There is inconsistent evidence on the effects of language barriers on access to physician-initiated care. There is limited evidence that patients lacking official language fluency may, in some cases, have higher utilization of specialist and diagnostic services. However, evidence also demonstrates that they have reduced access to mental health and counseling-related services.
- There have been only a few research initiatives that have investigated variation in health outcomes related to language barriers, although this literature review suggests that there are many intermediate effects (such as delays in seeking care, and reduced comprehension and compliance). Language barriers have been associated with increased risk of hospital admission, increased risk of intubation for asthmatics, differences in prescribed medication, greater number of reported adverse drug reactions, and lower rates of optimal pain medication. There is also preliminary evidence that such barriers are related to less adequate management of chronic diseases such as asthma and diabetes.
- Quality of care for those who are not fluent in an official language is affected through interaction with health professionals who may, because of language barriers, fail to meet ethical standards in providing health care. Language barriers may result in failure to protect patient confidentiality, or to obtain informed consent.
- A number of studies have examined different aspects of patient satisfaction with care. Patients who do not speak the same language as their health care providers consistently report lower satisfaction than those who share the same language as their providers. It is not clear to what extent findings from international research can be generalized to Canada, as both the system of health care, and the populations affected by language barriers, may differ significantly from other countries. However, direct assessments of recent immigrant communities frequently find that the lack of interpreters or bilingual providers is the greatest barrier to access reported by newcomers.
- A review of the literature reveals consistent and significant differences in patients' understanding of their conditions and compliance with treatment when a language barrier is present. Findings from these studies are consistent with general research

on provider-patient communication, which finds that communication is a key factor in patient adherence to the treatment plan.

- The research suggests that there are several “pathways” by which language barriers have the potential to effect quality of care and outcomes. Analysis of narrative text of the communication process, when interpreters are used, demonstrates the prevalence of errors and the potential for such errors to affect diagnosis and treatment. Research related to provider-patient communication, health literacy, time spent in the consultation, and the relationship of language barriers to a regular source of care, provide insights as to how language barriers affect satisfaction, utilization and health outcomes.

Indirect Effects of Language Barriers

In addition to the direct effects on patient access and care, the research indicates that language barriers also have a number of indirect effects. These include effects on research participation of language minorities, effects on health care providers, and costs to the health system.

- Both clinical and health services research tend to under-represent ethnic minorities, especially those who are not proficient in an official language. Exclusion of certain ethnic groups from biomedical research may mean that study results cannot be generalized to the entire population, and that less is known about risk factors, disease prevalence, and response to treatment of specific ethnocultural groups.
- Language barriers have a negative effect on provider effectiveness and satisfaction, make it difficult for providers to meet professional standards of care, and increase their exposure to the risk of liability.

- There is some evidence that language barriers may have important effects on health care costs, through their impact on service utilization and health outcomes. However, the potential cost savings of having skilled interpretation has never been adequately assessed. It is not evident to what extent economic evaluation undertaken in one country can be generalized to another. Specific Canadian research is needed in this area.

Models of Service Provision

While there are a number of interpretation programs operating in Canada, they vary in size, resources, models of service delivery and capacity to ensure quality. Additional research is needed to develop models appropriate for the distribution of Canada’s population, and include models appropriate for regions with lower density, and high diversity of non-official language speakers.

▲ Conclusion

There is sufficient evidence on the negative effects of language barriers on health access and care, that attention should now also be directed to the practical issues of developing standards of practice and appropriate models of service for the Canadian environment. Few studies have compared different systems of providing interpretation services. Research is needed in two areas: comparative evaluation of the effectiveness and acceptability of various forms of interpretation; and economic evaluation of the feasibility of various models for the distribution of the Canadian population.

Reliance on family members, or untrained interpreters recruited on an ad hoc basis (the most common responses to language barriers in Canada today) poses too many risks to be

acceptable. While there is continuing debate about how the interpreter role should be defined, there is sufficient consensus on core competencies that these should form the basis for training programs.

There is a need for development of national standards related to language access to health care. This should include: support for development and provision of training for interpreters to work in a number of roles; development of standards for provider training in working with an interpreter; development of policy outlining required use of professional interpreters; and support for, and development of, accreditation processes for interpreters and institutions.

The research has identified the negative effects of language barriers on a range of services, (physician and hospital care; long-term care; speech and occupational therapy; counseling and rehabilitation; community health nursing; pharmacy services; emergency/ambulance services; participation in cardiopulmonary resuscitation (CPR) classes; home care; access to out-of-hours services; abuse prevention and intervention services; support for caregivers of the elderly and disabled; and health promotion and prevention on a variety of topics). Therefore, a comprehensive strategy for addressing language barriers to care must take into account a variety of services and match the form of service to the need.

As important as professional interpretation services are to equitable access to health care for those who do not speak an official language, provision of such services is not a sufficient response. Without addressing the larger issues of equity within health institutions, and continuing

efforts to promote socially responsive and culturally competent care, provision of language services will not have the desired effect.

Recent research has emphasized the complex interaction between ethnicity, socio-economic status and health. The research also suggests that official language proficiency is in itself a determinant of health, and may interact with ethnicity and socio-economic status. Future research should incorporate these broader dimensions. As there are significant differences between countries in terms of history, culture, and organization of health services, Canadian-based research is needed.

▲ Recommendations

Based on this review of the literature the following recommendations are proposed by the author:

- Examine the feasibility of incorporating, as part of health system data collection, information on patient proficiency in an official language.
- Include, wherever possible, proficiency in an official language as a variable for analysis in health services research. This should always occur when ethnicity is one of the factors to be considered.
- Include in the review of health research proposals an assessment of whether those who are not fluent in an official language are eligible to participate, and promote inclusion of language minorities in both clinical and health services research.
- Develop strategies to increase health researcher awareness of the effects of exclusion of language minorities from health

research, and methodological and ethical issues related to conducting health research with participants who have limited official language fluency.

- Develop initiatives to promote awareness of the importance of provider-patient communication and the profession of interpretation within the health professions. Promote training on the effects of language barriers and working with interpreters as a required component of pre-service professional preparation.
- Develop strategies to promote dissemination of research on language access to policymakers and health service planners.
- Develop strategies to assist communities and institutions to develop models of service delivery appropriate for the variety of settings where interpretation is needed.
- Develop a coordinated national research strategy to further understanding of the impact of language barriers on health service utilization and health status of Canadians. This strategy should include and coordinate research on official, immigrant, Aboriginal and visual languages.
- Establish a centralized "clearinghouse" capacity for information and research on language barriers and language access programs in Canada.

- Develop a national strategy for health interpreter training, interpreter accreditation and standards of service provision.
 - Develop national standards of practice and appropriate models of service for the Canadian environment.
 - Coordinate strategies for training and accreditation of interpreters.
 - Include and coordinate strategies for official language, Aboriginal, visual, and immigrant languages.

Language barriers have been demonstrated to have adverse effects on access to health care, quality of care, rights of patients, patient and provider satisfaction, and most importantly, on patient health outcomes. In spite of universal health coverage, patients who lack proficiency in English or French may not have access to the same quality of care as other Canadians. There is also evidence that language barriers contribute to inefficiencies within the health system. Collaboration between health care providers, interpretation programs, researchers and language minority communities is required to promote Canadian-based research and program development related to language access to health care services.

1. Introduction

There is increasing awareness that a number of populations are underserved by the health system in Canada (Federal, Provincial and Territorial Advisory Committee on Population Health, 1999; Bowen, 2000). Those who do not speak one of the official languages are one of these underserved groups. In some circumstances, French speakers living outside Quebec, or English speakers living within Quebec may also face similar difficulties. However, little research has focused on the effects of language barriers on health outcomes, service utilization, patient satisfaction, or overall costs to the health system or to society.

For those who do not speak an official language, lack of access is unlikely to be due only to "language barriers". Those who are not fluent in French or English are also likely to be under-served for other reasons. They may be recent arrivals to Canada, or come from isolated communities; they may face discrimination as Aboriginal people or visible minorities, or be perceived as disabled due to deafness. Cultural beliefs about health and illness, expectations of the health system, and roles of participants in a health encounter may also differ from those of their providers.

Research from a number of disciplines has highlighted the importance of culture to health beliefs and behaviours, and to patterns of communication. Understanding and respecting differences between cultures has been highlighted as a cornerstone of cultural competence. Language can never completely be understood (or addressed) apart from other factors related to culture and ethnicity. Language and culture are inextricably intertwined.

However, while it is simplistic and misleading to assume that all access difficulties arise only from the lack of a shared language, *unless* there is

communication, these alternative understandings will not be revealed. Language is the base, the prerequisite, for further understanding. We are aware that income, gender, socio-economic level, education, and a variety of other factors, such as sexual orientation or presence of a disability, are also part of an individual's "culture". However, without effective communication, this heterogeneity within each ethnic/cultural group, and the needs and characteristics of the individual cannot be assessed.

Language has been described as medicine's most essential technology – its principle instrument for conducting its work (Jackson, 1998). It has been observed that without language, the work of a physician and veterinarian would be nearly identical (Clark, 1983). Establishing communication enables all parties in a health encounter to participate in the exploration of the illness or condition, and to determine together what aspects of the "culture" of both patient and provider must be considered in diagnosis and treatment.

In comparison with other health "technologies" however, interventions to facilitate language access (such as interpretation), like general issues in provider-patient communication, have received little research attention (Kaplan et al., 1989).

1.1 Purpose and Scope of Report

The purpose of this report is to provide an overview of current research describing the impact of language barriers on health care access and quality, and the role that language access programs can play in addressing these barriers. While the review includes studies done in other countries, the report is designed to provide an analysis of the research evidence from a Canadian perspective, and to assess the implications of findings for the provision of health care in Canada. It provides a brief overview of the emerging issues related to models

of service provision, interpreter training and service standards; however the report focuses on assessment of the effects of language barriers on access to health care, and quality of care received. It also examines a number of indirect effects of language barriers within the health system, including the issues of research participation, effect on providers, and health care costs.

It is not within the scope of this report to explore a number of important topics related to the provision of language access services. It does not review the important and substantial body of work on the relationship between language and culture. The case study literature that provided the basis for more empirical research on the effects of language barriers is under-represented in this report. Also not included are discussions of theories of interpretation, or analyses of different methods of interpretation. An additional limitation of this report is that it does not include much research that is part of the 'grey' area of unpublished literature. Much of the work done in Canada related to language access programs is found in such reports.

1.2 How this Report is Organized

The next section provides an overview of issues related to language access to health care – approaches to addressing language barriers, stakeholders and forces promoting current research and program development, and current issues and initiatives. **Section 3** examines the historical and cultural context in which health services are delivered in Canada, including an overview of relevant legislation, and implications for provision of language access services.

Section 4 provides a brief overview of key concepts and research methods commonly used in exploring language access. **Sections 5 – 7**, the focus of the report, examine the evidence related to the impacts of language barriers and the effect of interpreters within health settings.

Finally, **Section 8** – the Conclusion highlights key issues emerging from the research and proposes recommendations for further research and development within Canada.

2. Overview of Issues

2.1 Approaches to Addressing Language Access to Health Care

It is generally accepted that there are two basic approaches to addressing barriers to communication that are caused by the lack of a shared language between client and provider. The first is to increase the number of encounters where client and provider share the same language (i.e. the number of "language-congruent" encounters). The second is to provide some form of interpretation.

2.1.1 Increasing Proportion of Same-Language Encounters

Increasing the proportion of encounters within the health system where there is language congruence between provider and patient is often viewed as the ideal response. Many authors believe that providing an interpreter can never be as satisfactory as direct communication, no matter how skilled the interpreter. This results from the desire on the part of both parties for direct, unmediated communication, and the recognition that even the presence of another person in the encounter can affect rapport and the type of information shared.

Increasing the number of language congruent encounters can be accomplished either by:

- a) Increasing the number of providers who speak other languages, or
- b) Increasing the number of minority language speakers who speak the official language(s) of the country.

Increasing the number of providers who speak other languages

A number of different strategies have been proposed to increase the proportion of health care providers who speak the language of minority language communities.

Employment equity strategies facilitate entry of bilingual providers into the health professions. These strategies may either focus on recruiting members of underserved communities into professional preparation programs (pre-service initiatives), or on facilitating entry of trained professionals into a variety of positions (post-graduation initiatives). Special "access" programs to facilitate entry of Aboriginal students into health professional training programs, are an example of pre-service initiatives. However, not all members of targeted groups have the presumed language ability. In Canada, for example, a relatively low number of Aboriginal access students speak a First Nations language. Strategies for facilitating licensing of foreign-trained medical graduates are examples of post-graduation initiatives. Neither of these responses has traditionally been pursued in Canada, although since the Royal Commission on Aboriginal Peoples, there have been significant initiatives aimed at recruiting and training Aboriginal health professionals.

While this alternative has an important potential for addressing the larger issue of cultural competence within health professions, it cannot by itself fully address all needs for language access:

- ◆ Many Canadian cities have small numbers of individuals from different linguistic and ethnic groups. It is not feasible to offer even primary care to all communities by a provider of the same ethnic or language background.

- ◆ There is great diversity within ethnocultural communities. Placing patients with providers of the same “ethnic” or language background may actually contribute to distrust if the patient and provider are of different political, socio-economic, religious or regional backgrounds (Lin, 1983). This form of matching may also provide only partial language access where there are differing dialects; and significant differences in health care beliefs and practises related to socio-economic status or region may be ignored.
- ◆ While minority language communities advocate for provision of services in the patient’s first language, the concern has been voiced that community members do not want to be “ghettoized” with a choice of only one or two providers. This problem is particularly significant in small communities.
- ◆ Confidentiality and emotional safety may be of concern when visiting a provider from the patient’s own “community”, particularly in small or politically divided communities.
- ◆ Initiatives that focus on increasing representation for only one or more professions will not address all needs. For example, initiatives to increase the number of physicians speaking a minority language are inadequate as the sole response, as physician access is only one component of health care. Comprehensive health system access necessitates dealings with many different health care providers (e.g. nurses, health educators, imaging technicians, dentists, physiotherapists, and psychologists).

Another approach to increasing the proportion of shared-language encounters is to increase the fluency of providers in non-official languages through provision of language training. In the United States, some initiatives have been taken to encourage providers to learn the language of minority groups (Prince & Nelson, 1995; Binder et

al., 1988; Koff & McGowan, 1999). The effectiveness of this has not been adequately evaluated. However, our understanding of the limitations of interpretation undertaken by interpreters who are not completely bilingual suggests a number of concerns with this approach. Researchers have highlighted the risks of “false fluency” of providers who, having only limited proficiency in a second language, attempt to communicate without the assistance of an interpreter (Flores et al., 2000). In these cases the provider may believe that s/he understands the patient and is communicating questions and instructions clearly; but serious and dangerous miscommunication can occur.

Increasing the number of minority language speakers who speak English or French.

Rather than developing strategies for increasing the number of providers who speak minority languages, it is often argued that the emphasis should be on assisting minority language speakers to learn English or French. This appears to be the main approach in Canada for addressing language access needs of new immigrants. Lack of fluency in an official language is perceived as a time-limited problem that does not require systemic change. It is assumed that immigrants (who are expected to learn English or French, depending on their province of settlement), will soon be speaking one of the official languages. The number of same language encounters is expected to increase as the newcomer’s language proficiency increases. However, second language training and other support services, designed to assist newcomers in adapting to Canada, are provided for a limited period of time. The same attitude may be expressed regarding Aboriginal languages: as many Aboriginal young people are monolingual in English or French, some suggest that these languages are ‘dying out’, and interpretation services will become less important in the future.

Of course, newcomers generally wish to become independent and to have the same privacy in health interactions valued by all Canadians. Many learn to speak English or French proficiently, and no longer need or use interpreters, even in situations where they are available. It is also true that many Aboriginal people are fluent in an official language.

This response, however, does not address the needs for health care access faced by *new arrivals* who are considered the group with greatest need (Kinnon, 1999). In addition, the reality is that there are a number of immigrants who do not, even after several years in Canada, speak English or French well. These individuals are more likely to be women with young children, the elderly, the poorly educated, or those suffering traumatic events or psychological disorders (Stevens, 1993b; Jackson, 1998). These same groups have been found to have high levels of unmet need for health services. Recent studies have found that even several years after arrival, a number of newcomers lack the language skills to communicate with their health care providers in English or French. Many more are able to communicate adequately for what they believe are straightforward problems, but are unable to understand more complex disorders or cope with highly stressful health-related events in a second language (Stevens, 1993b; Bowen, 1999). Similar findings have been reported in other countries (Jackson, 1998).

In addition, the argument that the need for language access services will diminish over time fails to address either the current reality of many First Nations and Inuit persons who are not fluent in English or French, or the rights of First Nations and Inuit people to maintain their own languages. While services for Deaf people have often been provided within the context of 'disability'-related access services, many Deaf people identify deafness not as a disability, but as a culture. As such, they wish to preserve both their culture and language (Swanson, 1997; Witte & Kuzel, 2000). Promotion of cochlear implants for Deaf children identifies deafness as a disability, and in attempting to incorporate Deaf children into "mainstream" culture, also aims to increase the number of official language speakers.

2.1.2 Providing Interpretation¹ Services

The second major approach to improving language access accepts that there are significant communication barriers between many patients and providers. While individuals (or specific language communities) may gain language fluency, and eventually no longer need interpretation services, it recognizes that there will always be a need for language access services for some members of society. This approach will be the focus of this report.

Interpreter functions may take many forms, and the diversity of program models and interpreter roles creates additional difficulties in designing valid

1 For the purpose of this report, *interpretation* refers to the process by which a spoken or signed message in one language is relayed, with the same meaning, in another language. *Translation* refers to the written conversion of one language into another. Two common forms of interpretation are *simultaneous* interpretation, where the interpretation is delivered nearly instantaneously after the original message. This is the common form of conference interpreting. *Consecutive* interpretation involves interpretation of segments of a conversation, with a lag between the original message and its interpreted form. Interpretation may also be categorized as *proximate*, meaning the interpreter is present in the encounter, or *remote* (e.g. by using telecommunications technology). American Sign Language (ASL) interpretation is most often proximate and simultaneous, while most other health interpretation is consecutive and proximate, although the development of communications technology has increased the availability of remote, and simultaneous interpretation.

research and evaluation models. First, the person performing the interpreter function may be a family member, a community volunteer, a staff member of a health institution, a bilingual health care provider or a trained professional interpreter. The untrained interpreter's level of proficiency in both the official and minority language may vary, as may his or her knowledge of the subject area for which interpretation is needed. Volunteer or untrained interpreters may or may not have received training, either in the skill of interpreting or in professional ethics. The need to maintain confidentiality and objectivity, emphasized in professional ethical codes of conduct in health interpretation, is seldom recognized by informal interpreters.

Second, both the ideal and performed role of the interpreter may vary. The interpreter may be expected to provide anything from straightforward neutral language interpretation, to cultural interpretation, advocacy, or health educator functions (Putsch, 1985). This range of service models and interpreter roles, and variation in skill and training, creates significant challenges in establishing standards or comparing research from one program to another. In addition, significant variation can be found between providers in both their awareness of the impact of language barriers and their skill in working with interpreters. This also affects the effectiveness of the interpretation process. The risks of using untrained, informal interpreters, the various roles played by interpreters, and models of interpreter service provision will be discussed in more detail in the following sections.

2.2 Stakeholders in Language Access Services

At present, there are many varied and often competing demands within the health care system. On the issue of language access, a number of different stakeholders may assert alternative views on the provision of language services. These stakeholders include health care providers, administrators, government policy-makers, human rights bodies, community, advocacy or consumer groups, training institutions, entrepreneurs, and members of First Nations, immigrant and Deaf communities. Some may assume that all stakeholders are concerned about the same thing – the improved health of the client. However, the diversity of stakeholder group interests suggests that they may actually have varying agendas. These may include:

- ◆ meeting funding or legal requirements (as in the United States, where federal funding may be contingent on providing language access services),
- ◆ reducing inappropriate or high cost service utilization,
- ◆ protecting an organization from liability,
- ◆ improving health outcomes for disadvantaged groups, or
- ◆ gathering information to support or justify an existing program.

These varying agendas in policy and program development drive both expansion and containment of language access services. For example, administrators may favour a narrower evaluation of more circumscribed models of objective interpreta-

tion and outcome criteria, and may emphasize costs as the dominant dimension. Health care users and advocacy groups, on the other hand, are more likely to promote a broader evaluation based on rights to access and health outcomes.

Initiatives for Health Reform/Managed Care

Policy initiatives emphasizing "health reform" and "managed care" have as a goal decreasing unnecessary and inappropriate use of the health care system. The impetus for such reform is to contain costs and direct resources more efficiently and effectively. Interpreter services will therefore be expected to receive support *if* they can be demonstrated to decrease costs. The focus on increased efficiency and cost saving appears to have been a major factor in the increase in research related to the impact of language access in the United States.

Fear of Litigation/Legal Challenges

Fear of malpractice suits and legal sanctions are important factors in stimulating the discussion on interpreter services in the United States. This has not been as important a motivator in Canada, although concern about malpractice is growing, and recent cases successfully argued on the basis of the Canadian Charter of Rights and Freedoms, suggest that legal challenges may become a more important force in the future (Champion, 2000).

Competition Between Health Care Providers

Adoption of managed care in the United States has created a situation where, in order to enrol additional members, specific services are offered to attract certain target groups. This has resulted in some managed care providers targeting patients with limited fluency in English for enrolment in their plans, and including language access services in the package provided to them (Herreria, 1998).

One writer states, "Beyond being a culturally sensitive 'nice thing to do', providing interpreter services can give a hospital a significant marketing edge" (Larson, 1997:20).

The same forces are not present in Canada's publicly funded system. Some institutions (e.g. faith-based services) have had a traditional relationship of service provision with specific language communities; however this varies by region and by institution. While there is an expectation that health facilities address the needs of patients within their region, whether the devolution of responsibilities for health care to regional health authorities results in greater responsiveness to the needs of language minorities is yet to be seen.

Technology Development

The development of remote technology for interpreting (such as telephone language lines) has created the opportunity for entrepreneurs to package a simple, easily accessible product, which can be "understood" by health care providers. There is also the potential for innovations in 'tele-health' or 'tele-medicine' to address language barriers in much the same way as they now address distance barriers – both through the provision of multilingual health information, and possibly by limited use of distance consultation.

Human Rights Legislation

Human rights legislation in Canada provides a framework within which rights can be challenged. However, unlike some other countries, where legislation linking funding to addressing language/cultural barriers has been an important force for change (Perkins & Vera, 1998), this has not yet emerged as a major force in Canada.

The Role of Research Evidence

The emphasis on cost containment within the health care system has increased demands for “evidence-based” decision making. Until recently, there was little research available on the effects of language barriers and language access services to guide policy and program development. Although research is still in the early stages of development, there have been several important studies conducted over the past few years. These studies have provided evidence that language barriers are associated with differences in service utilization, patient health outcomes, patient satisfaction, patient “compliance”, participation in health research, protection of patient rights, and patient knowledge of diseases and conditions. The significance of these findings increases when links are made with related research (such as patient/provider communication and literacy in an official language).

The objective of this report is to review this recent research. The environment within which the research is conducted affects the research undertaken, and the responses to it. In the following sections, various cultural assumptions, policy agendas and evaluation traditions will be explored. They have affected the development of models of research and evaluation, priorities for research and the kind of data collected.

2.3 Current Issues and Initiatives

2.3.1 Current Issues in Interpretation

The focus of research to date has been on the question of whether, and to what extent, language barriers (and language access programs) affect patients, providers, and the health care system. In addition, there are four related issues which are currently receiving research attention: defining the

interpreter role; establishing the most effective models of service provision; professionalization of the interpreter role (addressing the issues of training, standards and accreditation); and economic evaluation of language barriers and program responses. A brief overview of each of these follows.

Defining the interpreter role

There has been a debate for many years about what exactly is meant by “interpretation”, how broadly the interpreter’s role can be defined, and whether objective language “translation” can (or should) be combined with other roles (such as cultural interpreter, educator, mediator or advocate). This debate has highlighted crucial issues for service provision, and cannot be resolved easily (Downing, 1995).

On the one hand, both providers and patients express concern about an expanded role for language interpreters, which could include functions such as advocacy or cultural mediation. Professionals want direct communication with the client, and are often uneasy with any role other than exact transmission of messages. A number of case studies in the descriptive literature, describing distortions, censoring and influencing by untrained interpreters, make this a legitimate consideration for providers (Marcos, 1979; Downing, 1992). Those requiring the services of an interpreter may also object to the assumption that they require any assistance other than language interpretation, and identify themselves as capable of doing their own “cultural mediation”.

On the other hand, many recognize the inherent “power imbalance” that exists within the health care provider/client relationship. They also see the risks that arise through miscommunication not simply because of a lack of fluency in the dominant language, but also due to different assumptions

related to roles, health, and appropriate communication (Putsch, 1985; Stevens, 1993b; Jackson, 1998).

Varying interpreter roles, in different programs and contexts, pose important research challenges. One cannot assume, for example, that the impact of a language/cultural interpreter/advocate will be the same as that of an interpreter who limits his or her role to strict language interpretation (as in remote phone interpretation). In addition, interpreters do not necessarily have equivalent levels of experience. A major limitation of much of the research undertaken to date is that the proficiency level or role of the interpreter is rarely considered and/or controlled for in the research design. More research is needed to determine the effect of various interpreter functions, and the role played by health interpreters.

Models of service provision

A related but separate issue is that of models of service provision. The kinds of interpretation services provided to patients may vary considerably. Such services may be provided by:

- ◆ family members or friends of the client,
- ◆ bilingual personnel within the health care system,
- ◆ community language bank volunteers,
- ◆ medical interpreters who are trained and employed by the health institution,
- ◆ paraprofessionals with health, outreach, or educational responsibilities, who include interpretation as part of their role,
- ◆ other programs or services that address language barriers.

As indicated above, many of the current responses to language barriers in the health system in Canada rely on untrained and often unpaid 'volunteers'. These responses are not "models" of service, but

"make-do" solutions in the absence of a formal, defined service. There is however, consensus among experts in the field that untrained interpreters pose many risks to both the patient and the provider – risks that may be greater in many cases than having no interpreter at all. A recent report of the U.S. Office of Minority Health (1999) observes:

"... The error rate of untrained "interpreters" (including family and friends) is sufficiently high as to make their use more dangerous in some circumstances than no interpreter at all. This is because it lends a false sense of security to both provider and client that accurate communication is actually taking place."

Determining which model of trained, professional interpretation is most effective in a given situation is not as clear-cut. The diversity of practice settings, variations in the size of populations of non-official language speakers, as well as differences in supports available in specific communities, pose challenges to determining effective and affordable models. The "model" of service provision cannot be isolated easily from the definition of the interpreter role. The objectives of a particular program (whether to provide core "translation" functions, or alternative roles in cultural mediation), will affect both the expectations of the interpreter's role and the model of service provision.

Professionalization of the interpreter role

Although reliance on untrained interpreters remains the norm in many Canadian centres, there is currently an emphasis on developing competency standards and performance evaluation tools for interpreters. This reflects a movement toward professionalizing and accrediting health interpreters (Downing, 1997; Ozolins, 1998). Paid interpreters are not always *professional* interpreters.

There is great variation in the quality of training obtained, and the level of skill demonstrated by interpreters in Canada, even when they are employed as interpreters.

In other health professions including medicine (Friedson, 1970; Coburn et al., 1983) and nursing (Olesen & Whittaker, 1968), a process has been documented through which health practitioners have attempted to legitimate and legislate defined relationships with the client. Where professions have succeeded in defining membership (by establishing laws, setting internal standards of practice, and adopting professional codes of ethics), clients and practitioners are able to interact on the basis of defined obligations defining conduct and reciprocity. For example, provincial "medical acts" gave physicians control over prescribing many primary diagnostic and treatment activities. They do this by defining roles, establishing standards of practice and restricting the roles of other professions and alternate practitioners (Coburn et al., 1983).

However, this model of professionalization may not be the most appropriate for developing a "profession" of health interpretation. This is because professions such as medicine are based on a unique relationship with the client. In contrast, although interpreters may function as private contractors, their role as intermediaries between health professionals and clients makes it difficult to achieve independent professional status based on having a separate relationship with the client. In fact, the advocates most strongly committed to professionalization are often those most likely to resist definitions of the interpreter's role that are characterized by independent power relationships.

Economic evaluation of language barriers and program responses

While issues of role definition, models of service provision, and professional standards have been the focus of attention from those working in the field, another issue has also been gaining prominence. With greater awareness of the costs of language barriers, there is increasing interest in undertaking an economic evaluation of interpreter services. However, very little research has been done in this area, and the economic evaluation of health care is itself a newly developing, though expanding, area.

Proponents of improved language access in health care often express concern about economic evaluation, fearing that it may result in avoidance of the issue of rights to service. However, economic evaluation is only one component of decision making, which should also include other forms of evaluation (efficacy, effectiveness and availability), and a review of ethical issues related to service provision. There are also concerns that researchers may define costs and consequences of language barriers too narrowly; resulting in an underestimation of the true societal costs of failure to provide language access.

In Section 4, various approaches to economic evaluation, and specific issues related to the economic evaluation of interpreter programs are discussed. Greater awareness of the potential and limitations of the methodologies is required, as economic evaluation is likely to be an important consideration in the introduction of any new program.

2.3.2 Current Initiatives

There is increasing awareness in many countries of the importance of communication in the area of health care access and quality of care, and interest in promoting research on the effects of language barriers. For example, the United States has undertaken a review of national standards for culturally and linguistically appropriate health care. These standards explicitly address the clients' right to bilingual staff or interpretation services, access to information in their own language, professional standards for interpreters, and inclusion of language identifiers in data collection. These standards are based on U.S. legislation and enforcement capabilities, and describe a level of service which is certainly not yet available for minority language speakers in Canada (Office of Minority Health, 1999). Belgium has made a commitment to a "cultural mediator" model for health interpretation, and is actively promoting and disseminating research (Verrept & Louckx, 1998). In Australia, a public inquiry examined rights to interpreter services in the justice system and in health care (Lawrie, 1999).

In Canada as well, there is renewed interest in the issue of language access to health care. National conferences on community interpretation have been held in Toronto (1995) and Vancouver (1998). Since these conferences, panels, networks and internet interest groups have been exploring issues related to the testing and accreditation of interpreters in Canada, with some provinces (such as Alberta and Quebec) developing more advanced programs. In May of 2001, Canada will be hosting the Third International Critical Links (Interpreting in the Community) Conference.

In 1999, Health Canada published *Canadian Research on Immigration and Health* (Kinnon, 1999), and some research funded through the Metropolis Project is expected to contribute to the knowledge on health access issues. Kinnon noted the lack of research on the effects of health system support on immigrant health, and the associated scope for initiating new research in this area.

A preliminary review, funded by the Department of Canadian Heritage (Bowen & Kaufert, 2000b), identified several critical ethical and methodological issues related to language access research. A Health Canada report, *Access to Health Care for Underserved Populations in Canada*, provided a framework for exploring barriers to access for a number of populations, including those facing language barriers (Bowen, 2000).

In Canada, few health jurisdictions or institutions have implemented policies requiring that some form of language access service be provided to all patients. Additionally, each of the communities for whom language access is an issue is viewed differently in terms of rights to language access. Services for specific communities have tended to develop in isolation from one another.

A landmark ruling in 1997 by the Supreme Court of Canada determined that hospitals were required to provide interpreters for Deaf patients (Eldridge vs. British Columbia [Attorney General], 1997). This recognition, that effective communication is an integral part of the provision of health services, has focused attention on the rights of other language minorities in the country.

In November 2000, a day-long national symposium, *Communication Barriers: Challenges and Responsibilities of Caregivers and Institutions*, supported by Health Canada, brought together representatives from a number of different areas: health care providers, government representatives, Deaf and immigrant community representatives, and providers of language access services. It explored the implications of language barriers for the health professions, focused attention on the specific issue of health interpretation, and emphasized the need for a coordinated national response to the development of standards, training and certification of

interpreters. It also endorsed the need for Canadian research (Rochefort, 2000). Specific interest was expressed in evaluating evidence of the impact of language barriers on health and utilization of health services.

The next section provides a review of rights to language access in health care, and the cultural context within which planning and research related to language access services takes place in Canada.

3. The Canadian Context of Service Provision

3.1 Introduction

In many ways the issues faced in the provision of health services to those who lack proficiency in an official language may appear similar between countries. Certainly, from the perspective of users of health services, many of the difficulties and risks involving communication are the same. In many jurisdictions there is no organized health professional interpretation service. Because the health care system does not take responsibility for ensuring communication between patient and provider, the problem of finding, evaluating, booking and even compensating an interpreter remains the responsibility of the patient.

There is, however, significant variability between health systems, and between countries. While much research and evaluation undertaken in other countries may have important implications for Canadians, every health care system is an expression of “the political culture, the social and moral values, and economic imperatives” of the

society it serves (Canadian Bar Association Task Force on Health Care, 1994:1). This section is therefore intended to provide an overview of the context within which health care is delivered in Canada, how issues of access and equity related to health care have been understood, and how research related to language access has developed.

3.2 Constituencies Affected by Language Barriers to Health Care

In Canada there are four constituencies who may face barriers to health care due to having a non-official first language²:

- ◆ First Nations and Inuit communities,
- ◆ Newcomers to Canada (immigrants and refugees),
- ◆ Deaf³ persons, and
- ◆ Depending on location of residence, speakers of official languages (French and English).

Provision of language access services, and rights to such services for each of these constituencies are shaped by a distinct historical, legal and political

2 This report focuses on those who face language barriers due to having a non-official first language. It is also recognized that many official language speakers with low literacy also face ‘language barriers’, particularly to written material. However this group is not the focus of this report.

3 The word deaf, when the d is capitalized, as in *Deaf*, refers to those who belong to the cultural community of Deaf people. Many of these persons are pre-lingually deaf, and while they may learn to read and write English or French, they learn these as second languages. In contrast, the words *deaf*, or *deafened* (with a lower case “d”) refers to lack of hearing. Not all those who are deaf are members of the Deaf community or use sign language, the focus of our discussion here. While persons who are hard of hearing also face communication barriers, this review of the research focuses on barriers faced by Deaf persons.

context. Although many of the issues faced by patients may be the same, there has historically been little joint advocacy or even sharing of expertise between these four language constituencies.

3.2.1 Health Needs of Language Constituencies

There are significant differences in health status and prevalence of disability between the various constituencies. Aboriginal people are recognized to have lower health status than the general Canadian population, as measured by almost every health indicator (Health Canada, 1999). These differences are attributed to widespread and historical inequities. In contrast, newly arrived immigrants are generally healthier than those born in Canada, and have longer life expectancy and disability-free years (Chen, Wilkins & Ng, 1996; Chen, Ng, & Wilkins, 1996). This is often explained by the "healthy immigrant effect": people who emigrate tend to be in better health, are often younger, and are medically screened before being accepted into Canada. Over time, the health status of immigrants tends to become more similar to that of persons born in Canada. While this is often understood to result from the fact that they are exposed to the same environmental factors as the Canadian born, it may also be because they face additional health risks, such as discrimination (Kinnon, 1999) or reduced access to health services. Among immigrants there are significant differences in health status based on country of origin, socio-economic status and education (Dunn & Dyck, 2000). Refugees tend to have lower health status and higher health care needs than other immigrants, and are less likely to speak English or French. There is evidence that Deaf persons also report lower health status (Zazove et al., 1993; McEwan & Anton-Culver, 1988), although one study found that pre-lingually deaf adults were at no greater risk of mortality (Barnett & Franks, 1999).

3.2.2 Similarities and Differences Between Constituencies

Little research has examined the similarities or differences in the effects of language barriers between the four constituencies. In particular, the Deaf community is typically not considered a language minority in the same sense as speakers of other minority languages, although some authors have described the similarities between them (McKewan & Anton-Culver, 1988; Barnett, 1999). Similarities include: limited access to official language information, exclusion from "ambient" sources of information, infrequent encounters with physicians or other health care providers from their own cultural group, and language barriers to appropriate care (Barnett, 1999). One U.S. study compared the self-reported experiences with health communication of 119 immigrants with a grade four to five level of English comprehension, with 22 Deaf persons. The two groups were similar in age and education. Participants were asked a variety of questions about communication with their physicians, as well as demographic information. The authors found no significant differences between the groups in their ability to correctly identify commonly used medical words, or in their assessment of how often they failed to understand their physician or ask clarifying questions. There were, however, significant differences in responses in three areas: deaf participants were more likely to feel their physician did not understand them, and were less likely to attempt to re-explain themselves. They were also less likely to report being able to speak to a physician in their language of fluency (McEwan & Anton-Culver, 1988).

3.3 Historical and Cultural Context of Language Service Provision

3.3.1 Official Languages

Canada has defined itself as a bilingual, multicultural country. Passage of the Official Languages Act in 1969 entrenched in law the rights of both English and French speakers to a range of services in their first language (Bastarache et al., 1987). However, Francophones living outside of Quebec (and some Anglophones living in Quebec) may also face language barriers to care in their first language, depending on the location of their residence (Martin, 1992). There is no specific legislation mandating provision of language services in other than the two official languages, except for criminal proceedings.

3.3.2 First Nations and Inuit Languages

Aboriginal languages have special recognition as protected languages in some regions (Bastarache et al., 1987). Before 1999, Aboriginal languages had special legitimacy in the Northwest Territories, and with the creation of Nunavut, Inuktituk has become an official language of the government. Federal administrative and service delivery systems, such as the First Nations and Inuit Branch of Health Canada, have provided some interpretation services for northern communities, and for some patients requiring tertiary care in urban hospitals. While 80-90% of urban Aboriginal people in Eastern Canada speak an official language, a significant proportion of Aboriginal people in Western cities may lack the functional language capability to communicate in an official language during encounters with the health care system. The needs of urban Aboriginal people were not seen as a priority target population for interpreter services provided by the First Nations and Inuit Branch, although hospital-based programs such as those in Winnipeg, Brandon, Thompson and Regina serve

the needs of all Aboriginal peoples who require language access services. This includes a significant number of northern Inuit and First Nations people who come to urban areas for treatment. Increasing sensitivity to the rights of First Nations peoples, increasing self-management of health programs, and lobbying by First Nations political organizations are contributing to greater responsiveness to language/cultural access in health care for Aboriginal peoples. This creates a very different context for service provision than for immigrant minority language speakers.

3.3.3 Visual Languages

Most of the Deaf community in Canada uses American Sign Language (ASL) for communication, although French Sign Language (LSQ) is also used. Although the Deaf community has differentiated its advocacy for recognition of Deaf culture from other disabling conditions, provision of sign language interpretation services for the Deaf community has followed a different path – that of advocacy for *disability rights*. These rights are more clearly specified in Canadian Human Rights legislation; and a landmark Supreme Court ruling (*Eldridge v British Columbia [Attorney General]*, 1997), determined that failure to provide a sign interpreter when necessary for effective communication in delivery of health care services constituted a violation of the Canadian Charter of Rights and Freedoms (Stradiatto, 1998). There is an accrediting body for interpreters for the Deaf in the U.S. (Registry of Interpreters for the Deaf) and an Association of Visual Language Interpreters of Canada (Bird & McDonald, 1998). Interpretation services for Deaf people are generally more developed than for other language minorities.

3.3.4 “Immigrant” Languages

Language barriers faced by immigrants in Canada are generally considered to be “newcomer” issues, rather than minority issues, as in some countries such as the United States. While “minority” issues are more likely understood in terms of rights of marginalized or racially/ethnically different groups, “newcomer” issues are seen to be time-limited, related more to the adaptation of the newcomers than to inherent barriers within societal systems. It is not surprising then, that in many cities, it is “settlement agencies” or ethnocultural groups themselves that provide most or all of the interpretation services. However, many settlement services are only funded to provide services focusing on “settlement” for a limited time after arrival, and do not have the health expertise, the authority, or the financial resources to address health access needs. Unfortunately, in most cases, community-based interpretation services provided through immigrant-serving agencies have not been integrated with health services, and do not receive health funding. This marginalization has resulted in little sharing of expertise between settlement and health services, limited funding for service provision, training, or research, and limited impact on policy development. For immigrants, language access to health has remained a “settlement” and not a health issue, even though many immigrants require assistance communicating with their providers for many years, or even their whole life.

3.4 The Canada Health Act: Principles of Accessibility, Universality and Comprehensiveness

The health care system in Canada grew out of a commitment to removing financial barriers to health care. The Canada Health Act provides universal medical coverage to *all* its citizens. “The primary objective of Canadian health care policy is to protect, promote and restore the physical and

mental well-being of residents of Canada, and to facilitate *reasonable access to health services without financial or other barriers*” (Canada Health Act, 1984). Canada is therefore committed both to keeping people healthy, and to treating them when they become ill. Three of the five key principles of the Canada Health Act (CHA) are of particular relevance in this context: *access, universality, and comprehensiveness*. It is important to remember that the “Canadian health system” is not a federal health system. Rather, it is comprised of multiple provincial and territorial systems, which vary in many aspects of service provision. However, to be eligible for federal funding, provinces must meet the standards of the Canada Health Act.

The Canada Health Act requires that provinces “provide for insured health services on uniform terms and conditions and on a basis that does not impede or preclude, either directly or indirectly, whether by user charges made to insured persons or otherwise, *reasonable access* to those services by insured persons”. This is the principle of *accessibility*. However, because *access* is not defined, it is not clear what would constitute *reasonable* access. Often, access is defined simply as the absence of explicit financial barriers (such as user fees). *Universality* requires that 100% of the residents of a province be entitled to insured services on uniform terms and conditions. *Comprehensiveness* requires that a health insurance plan cover all “insured health services provided by hospitals, medical practitioners and dentists, and where the law so permits, similar or additional services rendered by other health care practitioners.” All services that are “medically necessary for the purpose of maintaining health, preventing disease, or treating an injury, illness or disability” are included. However, there has been continuing debate about what services should be considered medically necessary.

Health interpretation services have not to date been considered medically necessary. Instead they are seen as ancillary services that are not universally insured. Similarly, many preventive and health promotion initiatives (with the exception of programs such as immunization and cancer screening programs) are not insured, and so do not fall under the scope of the Act, although they are critical for “protecting and promoting” health. Rights to access to preventive information in one’s own language are therefore even more tenuous than those of language access for facilitation of diagnosis and treatment of illness.

Those arguing for the right to language access in health care point out that access can be prevented or hindered by the absence or lack of access to interpretation services. Requiring a client to find and pay for an interpreter in order to have the same access to care as those speaking an official language, may prevent provision of services under *uniform terms and conditions*.

An important distinction should be made between access for assessment of needs, and access for treatment (Culyer, 1991; Bowen, 2000). Recent research (outlined in the next section), suggests that it is often exactly such assessment services (which indicate a need for treatment services) that are less utilized by those facing language barriers. It is therefore insufficient for treatment to be provided on an equitable basis only once a need has been identified.

Most of the research related to health care access that has been done in Canada has been based simply on the impact of socio-economic status, not factors such as employment, or immigrant/First Nation status. However, there have been initiatives which have promoted awareness of other barriers to access. For example, an Ontario Health Reform panel acknowledged the importance of ethnocultural factors to access, stating:

“All residents of Ontario have the right to high quality, accessible, appropriate and comprehensive health services – independent of age, gender, level of functional ability, language, ethnocultural origin or geographic location” (emphasis added). Accessibility should be understood to include psychological, social, emotional and economic aspects” (Panel on Health Goals for Ontario, Health for All Ontario, 1987:87).

Although rights to language access in health care are not specifically addressed, the *principles* enshrined in the Canada Health Act provide an important context for discussion of government and provider responsibility.

3.5 Rights to Language Services in Health Care

Claims involving rights of language access in health care in Canada are principally based on interpretations of the Canadian Charter of Rights and Freedoms, the Canadian Human Rights Act, provincial and territorial Human Rights Codes, the Canada Health Act, provincial Health Acts and the Criminal Code of Canada. The section that follows provides a brief overview of some of the relevant legislation.

3.5.1 The Canadian Charter of Rights and Freedoms

There are two sections of the Canadian Charter of Rights and Freedoms that appear to have applicability to the issue of rights to health care access. Section 15 states that:

“Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or

ethnic origin, colour, religion, sex, age or mental or physical ability.”

This section requires that all Canadians be treated equally. In addition, Section 7, states that:

“Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.”

This section would apply if lack of access could be demonstrated to result in the loss of life, liberty or security (Canadian Bar Association Task Force on Health Care, 1994).

Recent interpretation of the Charter declared that where sign language interpreters are necessary for effective communication, the failure to provide them was unconstitutional under the Charter of Rights and Freedoms, Section 15(1). *Eldridge vs. British Columbia* represented a challenge to limited language access made by three individuals who were born deaf and preferred to use American Sign Language. Their claim was that British Columbia’s Health Care Services Act violated the provision of the Canadian Charter of Rights and Freedoms (*Eldridge vs. British Columbia [Attorney General]*, 1997). The plaintiff contended that the lack of provision of sign language interpreters impaired their ability to communicate with caregivers, and increased the risk of misdiagnosis and ineffective treatment. They asserted that this communication barrier (i.e. the lack of hospital-provided American Sign Language interpretation services, which were discontinued in 1990 because of budget cutbacks), caused them to receive a lesser quality of care.

“Interpretation services should not be conceived of as “ancillary services”, which, like other non-medical services such as transportation to a doctor’s office or

hospital, are not publicly funded. Effective communication is quite obviously an integral part of the provision of medical services.” (Eldridge vs. British Columbia, [Attorney General], 1997).

It was argued before the court that the situation of deaf persons could not be meaningfully distinguished from that of other non-official language speakers. However, the court stated that while, from the perspective of a patient, there may be no real difference between sign language and oral language; from the perspective of the state, there may well be (Stradiatto, 1998). Therefore, it is not clear whether the failure to provide interpretation services for other non-official language speakers would constitute a violation of the Charter, although many of the principles affirmed in the ruling also apply to other groups facing language barriers.

3.5.2 The Canadian Human Rights Act

The purpose of the Canadian Human Rights Act is to:

“Extend the laws in Canada to give effect, within the purview of matters coming within the legislative authority of Parliament to the principle that all individuals should have an opportunity equal with other individuals to make for themselves the lives that they are able and wish to have and to have their needs accommodated...without being hindered in or prevented from doing so by discriminatory practices based on race, national or ethnic origin, colour, religion, age, gender, sexual orientation, marital status, family status, disability or conviction for an offence for which a pardon has been granted” (Canadian Human Rights Act).

The act also states that it is, “a discriminatory practice in the provision of goods, services, facilities or accommodation customarily available to the general public to deny, or deny access to, any such goods, services, facilities or accommodations to any individual.”

However, the issue of accessibility standards is directly addressed only in the case of those having a disability, where “the Governor in Council may prescribe standards of accessibility to services, facilities or premises.” The specific right to language access is nowhere specified, and it appears that any challenge would be based on alleged discrimination on the basis of national or ethnic origin.

Each province also has its own human rights legislation, and the wording may be different in each. For example, the Manitoba Human Rights Code recognizes that:

“...to protect this right it is necessary to restrict unreasonable discrimination against individuals, ...and to ensure that reasonable accommodation is made for those with special needs” (emphasis added).

Such statements appear to provide the basis for a complaint regarding language access to health care.

3.5.3 The Canadian Multiculturalism Act

The Canadian Multiculturalism Act of 1988 acknowledges multicultural diversity as a fundamental characteristic of Canadian society. It focuses on equality of opportunity, participation, contribution and partnership of all Canadians. The act itself also commits the Government of Canada to:

“...promote the full and equitable participation of individuals and communities of all origins in the continuing evolution and shaping of all aspects of Canadian society,

and assist them in the elimination of any barrier to such participation” [3(1)(c)].

The Act makes a commitment to “ensure that all individuals receive equal treatment and equal protection under the law”. It commits the Government of Canada to assisting communities and institutions in bringing about “equality of all Canadians in the economic, social, cultural and political life of Canada”. However, there is no specific mention of commitment to ensuring equal treatment and protection in access to health and social services.

3.5.4 The Right to Informed Decision Making

In addition to general rights legislation, there are specific legal and ethical provisions guaranteeing client rights in medical decision making, including the right to be informed of treatment options and make an informed voluntary decision about treatment (Etchells et al., 1996).

Provisions for consent in law

There is specific legislation that protects patients from procedures for which they have not provided informed consent. “An institution has the duty to require, by organizational policy, evidence of informed consent in the medical record. Failure by the health care provider to take steps to remove any communication barriers that may result in misunderstandings by the patient, therefore providing invalid consent to treatment, could result in hospital liability” (Tang, 1999).

Common law in Canada has recognized that where a patient does not speak an official language, it is incumbent on the physician to ensure that the patient understands the information that is communicated before administering treatment (Champion, 2000). However, the onus is on the patient (or another person) to take complaints of negligence or malpractice through the legal system. Champion (2000) reviewed a number of cases

concerning the issue of consent where a language barrier was present. One case, *Anan vs. Davis*, concerned a refugee who was sterilized after she consented to what she thought was a procedure to treat an infection that had occurred after birth. The ruling in this case concluded that the duty to ensure the patient understood the information included an obligation to be attentive to the language ability of the interpreter, and to ensure that the patient was returning reasonable and responsive replies. In another case, *Korollos vs. Olympic Airways*, a physician obtained, by telephone, consent from a family member for a patient's surgery. This person had evident difficulty with English and later stated that he gave consent only because he misunderstood the urgency of the situation. The court concluded that the duty of the doctor extended beyond communication of the facts, but also required a positive duty on the doctor to ensure that the patient actually understood the information.

Professional codes of ethics

Codes of ethics that regulate the conduct of health and social service professions stress the need for the provider to obtain informed consent, provide explanations, ensure confidentiality, and refrain from practicing the profession under conditions that may impair service quality. This means that in addition to a requirement to comply with external regulations defined in law, professionals are also required to meet the standards of their professional associations. For these ethical standards to be achieved, it is necessary to address language barriers.

It should be noted that while these codes are ideal standards, they are culturally based. For example, the concept of individual autonomy in health decision making is not supported by all cultural groups. Creative strategies are required to apply these standards appropriately in a diverse society (Kaufert & Putsch, 1997).

3.6 Canadian Research Related to Diversity and Health

How we understand the effects of language, culture, class, racism and poverty, both on utilization of health services, and on health status itself, is largely shaped by our assumptions as a society. These assumptions also determine what data is considered important to be collected, and what research areas are prioritized. This research, in turn, contributes to our beliefs about culture, ethnicity, class and poverty.

There are significant differences in research focus between the United States, the United Kingdom, and Canada. In the U.S., there has been an emphasis on the variables of race or ethnicity on health status and patterns of use, even though there have been varied understandings of what these variables represent (Krieger & Fee, 1994b; Goodman, 2000). In the U.K., there has been a greater emphasis on the importance of social class, which has shaped data collection and research differently (Krieger & Fee, 1994a).

In Canada, as a result of our unique history and culture, we have been most concerned about inequities in health and health access that are related to income, and to a lesser extent, to region (whether urban/rural or by province/territory). Research in Canada has focused on different patterns of utilization by "income status" rather than on differences related to language, culture or ethnicity. This is because Medicare in Canada was designed to address financial barriers to access. Data collection in Canada reflects these priorities. Canadian data on health status and service

utilization does not usually designate ethnicity⁴ (Robinson, 1998; Sheth et al., 1997). Research in Canada has focused instead on strategies for assessing accessibility of services by income

status. This emphasis is not accidental, but flows from our beliefs about ourselves as a nation, and our understanding of what affects health.

Canada has deliberately defined itself as a multicultural country, and has recognized and promoted awareness of differences between cultures. There has been promotion of Canada as a cultural "mosaic", often without a critical analysis of sources of inequity. This has resulted in a body of research that focuses on beliefs and practices of specific ethnic groups, and almost never on "race". As in many countries, there has been confusion about the meaning of "race" in research. There has been a gradual evolution from defining race as a biological category, to understanding its importance as a social construct (Krieger & Fee, 1994a; Goodman, 2000), and increasing interest in researching the health effects of discrimination (Krieger, 1999, 2000).

Research has also been influenced by the approaches to cultural competence adopted by both the health system and the larger society. Where there is sometimes an emphasis on structural changes aimed at ensuring culturally competent care (e.g. bicultural providers, provision of interpreter services or development of culturally specific resources), other approaches have focused on providing "cultural sensitivity" training to providers. This approach often emphasizes culture-specific learning on the part of providers (often leading to stereotyping by ethnic group and ignoring socio-economic, gender and other issues), rather than learning of skills that facilitate cross-cultural communication (Stevens, 1993b; Carrillo et al., 1999; Hamilton, 1996).

One unintended result of this research emphasis has been a tendency to attribute differences in health behaviours to underlying traditional beliefs held by various ethnic groups, while tending to ignore both the characteristics of "health culture" that may create structural barriers to equitable care, and the significant diversity found within a particular ethnocultural group.

"The use of culture as a way of accounting for whatever is seen as emotional, irrational, or illogical in the behaviour of the patient is commonplace in the literature on multiculturalism and health. The problem is that the focus becomes the patient and his or her cultural identity. Attention is diverted from other actors and other factors, and references to culture become simply another way of blaming the victim" (Kaufert, 1990).

3.7 Summary

The international research on both the effects of language barriers, and strategies for addressing these barriers, cannot necessarily be generalized to the Canadian context. Any assessment of its applicability must acknowledge the historical, political and cultural context within which services are delivered and research is conducted.

Services for various constituencies that require language access services in Canada are uncoordinated and operated by a variety of community groups and institutions. Rights to language access also differ between these constituencies. The absence of legislation specifically requiring that health interpreters be provided in the health care setting has contributed to the failure of the health care system to take responsibility for provision of such services.

Some guarantees for access to health care in Canadian legislation, and more global rights provisions in the Canadian Charter of Rights and Freedoms, suggest that the rights to language access for speakers of non-official languages could be challenged. However, there are few provisions for enforcement of language access. In the United States, the federal government monitors and *enforces* rights of individuals to access public institutions without discrimination on the basis of language (Perkins & Vera, 1998). In Canada

however, federal support for enforcement has been limited. Despite legislation such as the Canada Health Act, there appears to be significant inter-provincial and territorial variation in access services for individuals who face communication barriers. The lack of enforcement capability may be one reason why there have been so few challenges

brought forward. It may also be because the cultural context of language services in Canada may discourage rights challenges.

Until recently, lower courts in Canada have traditionally applied a cautious approach to guaranteeing minority language rights. However, the judgment in the Eldridge case provided a thoughtful analysis of access issues that have the potential for broader interpretation than the rights of deaf patients to communication with their health care providers. As the research discussed later in this report demonstrates, there is evidence that absence of language access services is also resulting in substandard health care to speakers of other minority languages.

4. Overview of Research Design Issues

4.1 Introduction

This section provides a brief overview of the methodologies commonly used in health-related research, and their appropriateness and utilization in addressing issues of language access. In addition, some of the challenges of designing valid research in this area are outlined, and a framework for identifying the variables to be considered is proposed.

Research questions related to language access may suggest either qualitative or quantitative methodology. Qualitative methods, such as interviews or focus groups, are used to address questions such as, “*What types of problems do language barriers create?*” or “*How are these experienced by patients or providers?*” They are often recommended where little is known about a subject. Quantitative methods are appropriate to testing theories or determining the prevalence of a topic of concern. They require a good understanding of the issues and are used to answer such questions as, “*How many patients face language barriers?*” or “*How do those who face language barriers differ in use of specific services compared to those who don’t?*”. These two methodologies are not mutually exclusive, and in most cases multi-method designs are recommended to describe problems and build and test theories.

Earlier descriptive research, such as case study-based research, graphically illustrated the risks of using untrained interpreters, and the effects on patients. With greater awareness, there has been more attention paid to *measuring* the effects, and other research designs have attained prominence. Administrative data is being used to compare utilization and health outcomes. Large population surveys are being analyzed to identify

differences in health utilization or health status based on ethnicity or language ability. Most important has been the increase in the number of studies specifically designed to compare language groups on some outcomes (ranging from service utilization to differences in physician practice patterns), while controlling for a number of potentially confounding variables. Multivariate analysis has allowed for the exploration of the effect of language barriers while controlling for a number of other variables (e.g. age, severity of illness, insurance status, ethnicity, income, education) that may also affect the outcomes measured. This has enabled researchers to “disentangle” the multiple effects of ethnicity, language and economic status.

There are a number of research design principles that apply to any health research area. While it is beyond the scope of this review to provide a thorough overview of research principles, a number of points with particular applicability to research on topics of language access should be highlighted.

Before initiating a research project, it is essential to undertake a review of the literature in related areas. This can not only alert the researcher to important findings which guide further research (and avoid duplicating work already completed), but it also provides important direction as to what type of research is best suited to the topic of study. It is necessary to be able to precisely frame the research questions and select an appropriate methodology. If quantitative methods are utilized, the outcome measures and any interventions must be defined, and valid and reliable measurements developed.

Any variables that may affect results must be clearly identified and controlled for. Within the area of language access and health care there are many potential intervening or confounding variables. These may include client demographic factors (socio-economic status, gender, education or

ethnicity), type or severity of disease, the client's regular source of care, and the practice style and experience of the provider. There is also often an assumption that the provision of *language access service* is the key or only intervention of interest, and this may lead to error. For example, studies indicate that simply being accompanied by another person can improve health outcomes (Kaufert et al., 1999). Another principle is that the subjects of research interventions must be similar, and that no bias should exist in who uses certain services and who does not. Selection bias (of institutions, providers, interpreters and patients) can easily occur and may affect results.

Research related to language access is governed by the same ethical principles as other forms of health research. All health researchers working with human subjects are required to abide by the guidelines of the Tri-Council Policy Statement (Medical Council of Canada, 1998), and obtain approval from specific ethics committees in the institutions with which they are affiliated. In addition, there is an increasing expectation that community consent for research will be obtained where feasible. This is an important requirement of working in First Nations and Inuit communities (Kaufert & Kaufert, 1998). It may be more difficult to obtain such consent in ethnocultural communities that have multiple subgroups and no elected community representatives (Bowen, 1999).

Research conducted directly with those who are not proficient in an official language presents additional ethical and methodological issues, and may increase research costs. Information on language proficiency is generally not available in routinely collected data in client records. Recruitment may be difficult, and communication barriers must be addressed for the research to occur (Marshall & While, 1994; Bowen, 1999). For example, one author noted that in doing research for an article on cochlear implants, interviews took place using many different methods: oral speech,

lip reading, sign language with interpreter, fax, teletypewriter (TTY) for the deaf, and telephone relay services (Swanson, 1997). Validation of instruments in other languages poses additional challenges. Interpretation of data can be problematic, as different meanings of the use of language, unless addressed, may threaten reliability and validity (Marshall et al., 1998). Significant difficulties in translating data for analysis are also found (Twinn, 1997). There are also specific and additional challenges regarding consent when research participants face a language barrier. Some specific challenges in defining and measuring research variables related to language access are discussed later in this section.

4.2 Methodological Approaches to Language Access Research

This section provides an overview of general categories of research design, including descriptive research, survey methods, secondary analysis of data, experimental methods, and economic evaluation. Each section briefly describes the methodology, gives examples of studies utilizing this methodology, and discusses the potential of each methodology for further language access research.

4.2.1 Descriptive Research

Descriptive research includes such methods as program ethnographies, case studies, observational methods, and focus groups. These approaches are a powerful descriptive method in the early development of a research area and may also assist in deepening our understanding of problems that have been identified using other methods (such as survey, quasi-experimental or experimental research). Case studies were among the first approaches used to research the effect of language barriers. They have the potential to:

- ◆ identify models of health delivery in an environment where there is insufficient data to develop valid experimental studies or analyze secondary data;
- ◆ present data in a form that is easily understandable to lay persons, the public and the media;
- ◆ deal with issues of meaning and political context of social interaction;
- ◆ assist in validating measures and defining the limits of research utilizing quantitative designs;
- ◆ form the basis of an in-depth assessment of long-term costs and benefits of providing language access via interpreter services;
- ◆ assist in sampling approaches with both qualitative and quantitative research.

A survey of both the published and "grey" literature suggests that several forms of case studies exist in the literature. These include:

- ◆ case examples of program models, or examples of interpreter functions where the interpreter's role is defined in a specific manner (Stevens, 1993b);
- ◆ case examples of the experience of individual patients with language barriers and interpretation services (Holden & Serrano, 1989; Haffner, 1992; Flores et al., 2000);
- ◆ case examples of the experiences of ethnocultural communities with language and wider sociocultural barriers (Kaufert et al., 1984);
- ◆ case studies demonstrating conflict situations or structural issues (Kaufert et al., 1991);
- ◆ case studies developed for teaching providers, students or trainee interpreters.

Potential for descriptive methodologies

In recent years, there has been less interest in descriptive studies as the research emphasis has shifted to quantitative research methods. Descriptive studies, such as case study research, have a number of limitations. It is difficult to determine whether, and to what extent, the experience represented can be generalized to the experience of other patients and other program settings. This methodology also does not allow us to determine how common or prevalent certain events may be. In spite of these limitations, there appears to be a continuing role for case study research. By identifying the kinds of problems experienced by patients and providers, they have the potential to help design studies in what remains an under-researched area. This may include identifying patterns of help seeking, exploring how participants experience existing programs, and providing a framework for identifying costs in economic evaluation studies. They also put a human face on a theoretical problem, and can alert us to how users experience programs and services.

4.2.2 Surveys

Surveys are commonly used to assess client satisfaction and comprehension, and patient or provider estimates of need. They have been used in many studies related to language barriers and health care access. Cross-sectional surveys describe or measure populations at one point in time. They can give quick descriptive results and may identify significant differences between populations (e.g. comparison of the level of satisfaction with care between English, French or other language speakers). Longitudinal surveys describe or measure a population at several points in time, either by re-surveying them, or by monitoring individual experience over time. They can be used to link data with health outcomes or service utilization patterns in the future. Surveys may be undertaken at the level of the institution,

the community, the province or the nation, and may seek data from users, families or providers. In many cases, while surveys may be useful in demonstrating correlations between factors (e.g. ethnicity and utilization of preventive care), they may not be able to demonstrate a causal relationship (e.g. that ethnicity causes differences in utilization of preventive care).

Another way to use survey methodology is to analyze results of large national or provincial population health surveys, such as the National Population Health Survey. Such studies are limited to the quality of information in the survey data. "While use of large national data sources ensures an accurate overall perspective on the health of Canadians, there are often insufficient numbers to make reliable observations about sub-categories within specific demographic groups." (Federal, Provincial and Territorial Advisory Committee on Population Health, 1999:5) Most national and provincial surveys exclude people who cannot communicate in English or French, one group at highest risk for access difficulties (Woloshin et al., 1997). Telephone surveys are particularly likely to exclude non-official language speakers (Barnett & Franks, 1999a).

Validity and reliability of instruments

An important consideration for survey research is establishing the validity and reliability of research instruments. Reliability refers to the extent to which a measure gives consistent results. A reliable study is one that if repeated would give similar results. Validity, on the other hand, refers to the extent to which a tool measures what it intends to measure. A measure may be reliable but not valid. For example, if a translated instrument consistently documents that members of a particular group score higher satisfaction than others in the same situation, this may not necessarily mean that the level of satisfaction is higher, but rather that the

way satisfaction is expressed using this instrument may differ. In this case, the instrument (while reliable) may not be valid.

Many research methods use patients' assessment of their own symptoms, functioning, satisfaction and preference. However most of these measures have been developed in English (Ren & Amick, 1998). This creates two challenges for developing valid instruments. First, it is necessary to accurately translate the material. It is recommended that a process of "back-translation" be undertaken to ensure an accurate translation for the target audiences. There may be many differences in the translation needed, even among those who speak the same language, depending on regional variations and education levels. Translation of materials is a complex skill and one that must recognize differences in health concepts between members of ethnic and linguistic groups.

Second, it is important to ensure that *concepts* can be translated. This perspective addresses the question of cultural equivalency, not simply language equivalency (Jackson et al., 1997). Often the instrument may require adaptation, not simply translation, to ensure that the questions are appropriate for individuals of a particular background. There is evidence from the social and behavioural sciences of variability in reporting symptoms and interpretation of health among different linguistic and ethnic groups. This may affect survey results, even when the other language versions are accurately translated. Several researchers have explored the difficulties in ensuring reliability and validity of patient satisfaction instruments and rating scales (Berkanovic, 1980; Flaskerud, 1988; Hayes & Baker, 1998).

While most of the researchers undertaking the studies described in this report have taken steps to ensure accurate translation of materials, fewer have ensured that the instruments themselves are valid.

It should be noted however, that many of the studies make comparisons, not between different ethnic groups, but between those who have difficulty communicating with their health care providers, and those who do not. For example, Latinos who are fluent in English may be compared to those who have difficulty communicating in English. However, there is evidence that the same respondent may give different answers if interviewed in different languages, and that different symptoms may be expressed (Marcos et al., 1973; Oquendo, 1996).

Kirkman-Liff and Mondragon (1991) analyzed a survey that investigated health status, access, satisfaction and barriers to care. They compared the dependent measures with the interview language (Spanish or English). The survey, which took place in Arizona, included 3,104 randomly selected adults and 1,113 adults who provided information on a randomly selected child. The interviews with self-identified Hispanics were conducted in Spanish for 139 of the 469 adult interviews, and 70 of the 235 child interviews. Multivariate analysis was then undertaken to control for a number of demographic variables between Spanish and English-speaking Hispanics. The authors concluded that it was important to separately analyze responses to interviews conducted in two languages – not only to ensure validity, but also to identify groups at higher risk. Significant differences were found between English-speaking and monolingual Hispanic children in health status, access, satisfaction and barriers to care.

Potential for survey research

Surveys show good potential for incorporating the experiences of both patients and providers, and for capturing a great deal of detail on language measures (e.g. specific language, characteristics of interpreter, level of official language fluency) and health-related behaviours that are not measured by

any data collection system. They can provide estimates of the incidence of language barriers and the adverse effects of such barriers, particularly from the perspective of clients. Another potential use of surveys is to link them with routinely collected data in order to begin to explore differences in utilization and cost.

However, there are crucial considerations for the design of the survey instrument and the selection of the survey sample. A significant skill level is needed to design surveys that provide valid and useful results. Consumer surveys also present an additional design step; that of translating and testing of the survey instrument. This requires skill and appropriate methodology to ensure that the translation is accurate and does not risk invalidating study results.

4.2.3 Secondary Data Analysis

Secondary data analysis consists of analyzing data collected for another purpose, in order to determine whether there are differences in utilization patterns or health outcomes between different user populations. There has been limited use of this method in the past. However, it has been achieving greater attention over the past several years as policymakers attempt to identify best practices and determine the effects of various practices on patient health. For example, the Manitoba Centre for Health Policy and Evaluation uses claims data to trace the impact of particular service interventions on subsequent service utilization and morbidity.

Unfortunately these methods have limited usefulness at this time for assessing the impact of communication barriers or language access services. This is because the data necessary to undertake the analyses is not routinely collected (Sheth et al., 1997). In Canada, provincial and territorial claims systems record data on inpatient and outpatient service utilization patterns,

diagnostic and service information, mortality and morbidity, and information on admission and discharge from health facilities. Some provincial and territorial health information systems record demographic characteristics of system users, including age, gender and home address. However, data on language use patterns, ethnic identity or community of origin is not available in Canadian claims data (with the exception of codes that identify Aboriginal peoples with treaty status and designate Anglophone or Francophone patients). While there may be more potential for such data to be included at the institutional level, this remains a contested area.

While collecting information on language proficiency as part of routine data collection would facilitate research on language barriers and interpreter services, this must be undertaken with caution. Developers of Canadian systems have been reluctant to collect data related to ethnicity. This concern is mirrored in other countries. The U.S. Office of Minority Health states that, "*Confusion exists as to whether the collection of these data should be mandatory, voluntary, or even permissible*". (Office of Minority Health, 1999) It is also possible that the measure recorded would be a poor approximation of the variable of concern. For example, patients may be asked ethnic origin or language spoken in the home. Neither of these would necessarily provide information on whether an individual was facing communication barriers or requiring interpreter services, although they would indicate a higher likelihood of such need. An individual who identified herself as ethnically Vietnamese, or who spoke Vietnamese in the home, may have lived in Canada for 20 years and be fluent in English, or may obtain many health services from a Vietnamese-speaking provider. Differences attributed to language may also be the result of income-related factors or other access difficulties unrelated to language or ethnicity (Robinson, 1998). However, if

such information is not included, there will continue to be limits to the use of health data in assessing the effects of language barriers.

Ecological approaches

One way to address the absence of language information in secondary data is to use an *ecological* approach. Ecological approaches attribute socio-demographic characteristics to individual service users on the basis of their place of residence. This involves comparing one *group* of individuals, which is known to have certain characteristics, with another group, which is known to have other characteristics.

Using an ecological approach, demographic characteristics could be linked with provincial/territorial claims registries to investigate associations between demographic characteristics and health indicators among inhabitants of a census tract or small area. Data on ethnicity and language usage from census data could be linked with claims data for a particular region or hospital area.

However, ecological approaches have many of the same limitations identified earlier. In theory, ecological approaches could link, for example, higher service utilization rates to *groups* known to have higher language access needs. However, it could not be assumed that either a) the greater utilization was found among those facing language barriers or b) the language barriers were the *cause* of the greater utilization (rather than a confounding measure such as poverty or educational level). It is known, for example, that many Aboriginal peoples and new immigrants settle in core areas of major Canadian cities. Any observed differences in health status or utilization therefore could not be attributed to language difficulties, as many other factors (e.g. income, or neighbourhood environment) could also explain the findings.

Potential for secondary data analysis

There are a number of difficulties in using secondary analysis of data to provide useful information for research related to language access. The fundamental limitation is that the data currently does not include information that could identify those facing language barriers. If information on language ability were to be included in data collection systems in the future, secondary data analysis could be an extremely useful and cost effective source of information for large scale analysis. If such data were collected however, it would be imperative that care be taken to incorporate a measure of *communication*, not simply ethnic origin or first language.

There is also potential for secondary data to be linked with other data sources (Blais & Maiga, 1999). Because Canada has a publicly insured system, there is much greater scope for this methodology than in many other countries.

4.2.4 Experimental Designs

In an era emphasizing rationalization and cost-effectiveness of evidence-based health care, there is increasing pressure to move directly to test the impact of well-designed interventions using true experimental designs such as randomized controlled trials (RCTs).

Randomized controlled trials allocate subjects to either an intervention group or a control group (i.e. different treatments) in a random manner. RCTs have a number of advantages:

“One advantage of a randomized trial is that it ensures that all the relevant health status and cost data are collected. For example, data can be obtained from medical records, facility cost-accounting records and patient diaries. Just as important, the randomized trial has achieved a major role in medicine

for comparing different strategies for care. It protects against the risk of inferring a treatment effect on outcomes when other factors (e.g. a patient’s underlying health status or clinician’s attitude about how to use medical services) may explain the observed outcomes. The randomized trial also permits a definitive statement about a cause and effect relationship between the strategies being studied and the outcomes.”
(Hornberger, 1998)

An example of an RCT to assess language access would be the random allocation of patients to either an intervention group with a trained interpreter, or a control group (no interpreter provided), in order to determine any differences between the two groups on some measure (e.g. compliance, accuracy of diagnosis, return visits).

Potential for RCT methodology

There is general agreement that the most compelling way to contrast the effects of two methods is through a randomized control trial. It may initially appear that this is the best methodology for research related to the effects of language access programs. However, there are important implications in utilizing RCTs to assess the impact of language access services:

a) Ethical limitations

There are serious ethical limitations to the use of RCTs in language access research. It is a basic principle of medical ethics that each patient must receive the best possible health care currently available. This means that once there is real evidence that one treatment is superior to another, it is unethical to continue with the inferior treatment. There is already clear evidence that communication barriers pose clear risks to patients. Therefore it would be unethical to design a study that

deliberately assigned some patients to a clearly inferior treatment (no interpretation). As Hornberger comments in his discussion of RCTs:

“... Administrators, clinicians and consumer groups may be uncomfortable with or at least believe it is unethical to assign patients to some types of language services. In particular, many experts participating in the jointly sponsored 1995 Kaiser Family Foundation/Health Care Financing Administration/Office of Civil Rights Forum on Responding to Language Barriers in Health Care strongly recommend against doing a randomized study that includes, as one of its interventions, the use of family members as interpreters.” (Hornberger, 1998)

However, these limitations do not necessarily prevent an RCT from attempting to differentiate what *form* of language service was most effective, *if* there were no clear evidence that indicated one of the “treatments” was better or worse. Therefore, a study that randomly assigned clients to on-site versus telephone-line interpretation may be acceptable. However, it would not be ethical to assign clients to alternatives known to be inferior, such as family, ad hoc or untrained volunteer interpreters.

b) Methodological limitations

There are also methodological limitations to the use of RCTs. Researchers who have explored the design constraints of randomized controlled trials have recognized that RCTs are not always either feasible or appropriate (Hornberger, 1998). Randomized controlled trials are most successful when there are limited, well-defined and easily monitored service alternatives. However, there is a wide range of alternative models of interpreter service provision, and significant difficulty in ensuring consistency in provision of the interpreting “intervention”. Even if the same “type” of interpreter is used, the differences between individual interpreters and clients, and the demands of the particular health encounter, create significant challenges. Research is needed to define the interpreter models to be tested and the range of variation in expected outcome measures, to determine whether the interventions can be meaningfully delineated.

4.2.5 Economic Evaluation

The current interest in economic feasibility research emerges from a need for informed economic as well as effectiveness data on health interventions. Both policymakers and managers of language access programs increasingly request research that can demonstrate the cost-effectiveness of interpreter services.

Economic evaluation may be defined as the comparative analysis of alternative courses of action in terms of both their costs (inputs) and consequences (outputs). An evaluation may be

conducted from the perspective of an individual stakeholder (e.g. a particular hospital), the health system in general, or society at large (Drummond et al., 1997). The purpose of economic evaluation is to help determine whether a program or service is worth doing compared with other things that could be done with the same resources (Robinson, 1993; Drummond et al., 1997).

Costs in evaluating interpreter programs would include the costs of both providing, and not providing, a professional interpreter service. From a hospital perspective, the costs of providing a program may include the interpreter's salary, training costs, office space, and overhead expenses. Costs of *not* providing a program could include a component of salaries for staff re-directed from their duties to provide ad hoc interpretation, or used in attempting to locate interpretation assistance. A number of possible *consequences* could be measured based on indicators emerging from the research (e.g. admission rates, use of emergency department services, tests ordered, or complaints made).

An evaluation from the perspective of the health system would expand to include costs and consequences to *all* parts of the health system. A larger societal viewpoint in the evaluation could include such consequences as time lost from work, caregiver burden, cost of increased social services, and patient-reported well being.

It should be noted that economic evaluation addresses only one dimension of health system decision making. Ideally, economic evaluation should be preceded by three other types of evaluation: efficacy (Can the program work?) effectiveness (How well does it work in real life situations?) and availability (Is it reaching those who need it?) (Drummond et al., 1997). It should also be noted that economic evaluation does not address ethical or legal issues, and so cannot be

used in isolation to answer the question of whether a service *should* be provided.

A partial economic evaluation addresses only costs or alternatives, or measures costs and consequences of only one alternative without comparing it to another. Many assessments of costs of interpreter programs fall into this category. For example, a *cost analysis* reviews only the costs of two or more alternatives, without attempting to measure the consequences.

Full economic evaluation requires that all applicable costs and consequences not only be identified and measured, but also valued and compared to other alternatives. Methods include cost-minimization analysis, cost-effectiveness analysis, cost-utility analysis, and cost-benefit analysis. If the outcomes of two interventions are known to be equivalent, then *cost-minimization* may be used to search for the least costly alternative. There is good evidence that the outcomes of professional and ad hoc interpretation are not equivalent, making cost-minimization inappropriate for evaluation of interpreter programs. However, should there be a decision that professional interpretation programs will be provided, cost-minimization approaches allow comparison of methods with the same outcome.

Cost-effectiveness analysis (CEA) is appropriate where the outcomes of different programs may be expected to vary. These outcomes can be measured either in dollars, or in natural units (e.g. adverse drug reactions, mortality rates). This method is often used where costs are related to a single common effect that differs in magnitude between alternative programs. While in theory this method could be used in assessment of interpreter programs, there are a number of practical problems. The availability of data on the effectiveness of the programs or treatments being assessed is critical for CEA. As only partial and preliminary studies on effectiveness of health interpreter

programs have been undertaken to date (and there is limited information on outcomes), a cost-effectiveness analysis of an interpreter program would have limited potential at this time. *Cost Utility Analysis* (CUA) attempts to measure the subjective level of well-being experienced by individuals in different states of health, usually through use of quality of life measures such as Quality Adjusted Life Years (QALYs). This method does not appear applicable to the study of language access.

Cost-Benefit Analysis (CBA) appears to be the most useful method for evaluating economic impacts of interpreter programs. This method also has a number of practical problems, specifically related to the need to value health outcomes in monetary terms. However, willingness-to-pay methods (e.g. interviewing people as to whether they would support a tax increase of \$X in order to support language access services) show some potential. This is because CBA does not require specification of all the possible consequences of various alternatives in detail. Cost-benefit analysis would give some indication of the value of the proposed service to the general public. Willingness-to-pay (or contingent valuation) methods also have inherent challenges. They require that a realistic and understandable question be asked, and that participants in the exercise understand the meaning and implications of the question, including the uncertainty involved.

Economic evaluation in health care is a rapidly developing research area. Researchers face a number of challenges, due to the paucity of data on which to base their studies. Generally only crude measures for health are available (e.g. mortality, limited morbidity data). Less dramatic health effects or those that do not result in differences in health care behaviour may not be measurable, but may have a major influence both on health status, and future patterns of utilization.

One of the major challenges in undertaking an economic evaluation lies in determining what costs and consequences are to be included, and how these are to be measured. There is a tendency to focus only on immediate and easily measurable costs for which data collection systems have been established (e.g. physician visits). However, because language barriers can have a number of immediate and long-term effects (particularly in such areas as mental health, maternal child health and management of chronic illness or disability), it is important to capture more than the immediate costs to the health care system. Longer-term costs to the whole health system (e.g. community health nursing, rehabilitation), as well as societal costs (e.g. unemployment, social service costs) should also be included (Bowen & Kaufert, 2000a, 2000b). Because only some of the "costs" can be easily tracked through existing data collection systems, there may be a temptation to limit assessment to these more easily measurable costs.

There are a number of other questions that must be addressed in designing an economic evaluation. These include whether and how to include start-up and training costs, at what rate costs and benefits occurring in the future will be discounted, and how uncertainty of outcomes will be incorporated into the evaluation.

It is important to note that the "costs" of language barriers may differ depending on the research focus. Barriers to initial access may result in decreased initial costs (but increased costs of care for those who present at later stages of illness), while barriers faced within the health care system may result in overuse of some services. Case studies have been suggested as one strategy to assist in identifying the range of potential costs and consequences (Bowen & Kaufert, 2000a).

4.3 Measurement Issues

Perhaps the greatest challenge in undertaking research on the outcomes of language service interventions is the number of variables that must be taken into account. While, as outlined in the previous section, there has been important and useful work done in the area of interpretation services, all too often these variables are not controlled for (or at times, even recognized). This may be, in part, due to the marginal position of health interpretation within the health service system, and the identified shortage of researchers with expertise in this area (Puebla Fortier & Shaw-Taylor, 1999). Often there is a lack of clarity in what is being measured, and why. There is also a large number of potentially confounding variables (e.g. poverty or ethnicity) that must be identified and recorded.

This section will review the variables under the following headings:

- 4.3.1 Defining “*language barriers*” and “*language proficiency*”
- 4.3.2 Variables related to the interpreter role and model of service delivery
- 4.3.3 Variables related to the individual interpreter
- 4.3.4 Variables related to the client
- 4.3.5 Variables related to the client community
- 4.3.6 Variables related to the individual provider
- 4.3.7 Variables related to the health system

While each of these categories will be discussed separately, it is important to note that these variables may often interact, either within a category, or between categories. For example, within the category *Variables related to the individual client*, the level of the patient’s official language skill may interact with the type of illness or concern. For example, a woman who has some English but has taken prenatal preparation in her own language

may be able to “cope” in English for a normal labour, but not have adequate language proficiency to understand that the child has been born with a serious congenital abnormality. Similarly there may be an interaction between categories. For example, a client from a community whose health belief system is significantly different from that found in North America may benefit more from the services of an interpreter than a client from a Western European country, particularly if the interpreter includes cultural interpretation as part of his/her role.

4.3.1 Defining “Language Barriers” and “Language Proficiency”

Studies differ significantly on how “language proficiency” is defined and measured. Most studies focus on the patient’s ability to speak an official language by, for example, categorizing patients as “English speaking” or “non-English speaking”. Various terms are used to categorize language proficiency. The U.S. literature commonly refers to Limited English Proficiency (LEP), or non-English speakers (NES). Other definitions focus on the status of the patient’s first language (e.g. “minority language” or “non-official language” speakers).

Other researchers focus on the concept of *language congruence* (whether the provider and patient share a common language). For example, Lee et al. (1998), determined whether the preferred language of patient communication differed from that of their primary physician. Analyses were undertaken on “language-matching” compared to “language-disparate groups”.

Defining language access as language congruence between patient and provider is a more precise measure for an individual encounter. One would expect the quality of interaction and care to be similar between all language-matching pairs, no matter what the language of communication. However, for large scale monitoring of health

effects, it is more feasible, and likely more useful, to focus on the person's ability to speak an official language. Interaction with many different health care providers is required, and access to information about service availability, health promotion activities and prescribed treatment, will be affected by official language capability. In addition, data is not recorded on the language proficiency of the provider, or whether an interpreter is needed or utilized in each health encounter.

Self vs. provider assessment of need

There are also differences in how ability to speak an official language is assessed. Some studies focus on *provider* assessment of patient language proficiency (Rader, 1988; Andrea & Renner, 1995; Drennan, 1996), while others look to the *patient's* assessment of need (Baker et al., 1996; Derose & Baker, 2000).

While both approaches have limitations, a commitment to patient-centred care would suggest that patient assessment of need would be more accurate. Many studies (and case reports) have demonstrated that providers often overestimate the client's ability to understand and communicate (Holden & Serrano, 1988; Stevens, 1993b). An Australian study (Shaw et al., 1977), in the course of an investigation to determine the number of non-English patients who received medications from a hospital pharmacy, discovered that of the 72 patients who required an interpreter for the interview, only 31 had been previously identified as needing one. A recent U.S. study found that in a significant number of cases where an interpreter was not used, the patient felt that one was required (Baker et al., 1996). Estimates based on need from the clients' perspective would also facilitate establishment of estimates of overall community need, rather than the needs of a particular institution.

Measuring language fluency

Another issue relates to the actual measurement of language fluency. A number of researchers highlight the limitations of studies that dichotomize language ability into, for example, English-speaking and non-English speaking groups, as there is a significant range of language ability within each of the two groups. Some recent studies have used such strategies as self-rating scales, where patients are asked to rate their English fluency as excellent, good, fair or poor (Derose & Baker, 2000).

Not only is there a continuum of language ability among members of any minority language population, but the complexity and specific nature of medical vocabulary also poses difficulties (Jackson, 1998). It is commonly assumed that if an individual can carry on an everyday conversation in English or French, he or she does not require health interpretation. However, even fluent official language speakers may face communication difficulties in a health encounter. The complexity and social acceptability of the condition, previous knowledge of the patient, similarity of health beliefs and practices between patient and provider, and degree of emotional distress (Peck, 1974), can all affect the client's ability to communicate in a second language *in a specific situation*. An individual who may not need an interpreter for a visible injury (for example, a broken ankle) may not be able to understand communication of a cancer diagnosis and recommended treatment. Mental health and sexuality concerns have been highlighted as health areas where there is often a greater need for interpretation services based on cultural beliefs and values, and the emotionally laden content of the health encounter (Stevens, 1993b; Dolman et al., 1996; Jackson, 1998; Betancourt & Jacobs, 2000).

Institutional vs. community estimates

Many of the studies undertaken to date are limited to assessment of needs as experienced within a particular institution or catchment population. However, many of those who are highest users of health services (mothers with young children, persons with chronic illness, the elderly) may use a variety of health-related services for which interpretation is needed (physician office visits, public health visits, rehabilitation services, health promotion activities). However, as will be discussed in the next section, the research indicates that many who lack proficiency in an official language underutilize prevention programs in general, or avoid seeking services where interpreters are not available. Estimates of need based on current service utilization of one institution may therefore dramatically understate the actual need.

4.3.2 Variables Related to Interpreter Role and Model of Service Delivery

As discussed earlier, there is continuing debate over what exactly is meant by “interpreting”, how broadly the interpreter’s role is defined, and whether objective language interpretation can (or should) be combined with other roles (such as cultural interpreter, educator, or advocate). In other words, an “interpreter” in one program may not be equivalent to an “interpreter” in another. It may not be possible to attribute effects to various components of the interpreter role (e.g. language interpretation, cultural interpretation, emotional support) even if the presence of these different components is recognized.

A related but separate issue is that of design of the program model. Several other factors may interact with the service model and affect outcomes. For

Diagram 4.3.2

Issues Relating to Interpreter Role and Model of Service Delivery	Possible Effects
Different models of interpreting	<ul style="list-style-type: none"> • amount and type of information exchanged • interventions during the encounter • client-provider relationship outside the health encounter
Different models of program design	<ul style="list-style-type: none"> • goals of program • clientele of program • additional roles of interpreters which impact results (e.g. health educator) • non productive time (e.g. wait time) • ability to calculate cost/benefit of other roles
Training of interpreter	<ul style="list-style-type: none"> • interpreters’ language ability • interpreters’ ethics • interpreters’ understanding of role • interpreters’ ability to elicit information • interpreters’ ability to accurately transmit concepts
Sponsor of program (To whom is the interpreter accountable?)	<ul style="list-style-type: none"> • data collected • role of interpreter • loyalty to patient or provider?
Continuity of care (Can the interpreter ‘follow’ the patient?)	<ul style="list-style-type: none"> • information transmitted between encounters and providers • client confidence • efficiency of encounters

example, who is sponsoring the program? To whom is the interpreter accountable? If s/he is paid, by whom? Does the form of service allow continuity of service? For example, if a patient sees an obstetrician for a complicated pregnancy, can the interpreter also “follow” the patient for imaging and lab tests, be available to assist the public health or home care nurse, and attend the labour and birth?

Various service models may also differ in the degree of training and experience of those interpreting. From a research perspective it is important to note

that “training” is not a dichotomous variable, but a continuum which can range from a few hours orientation to several months or even years of professional skill development.

Researchers must be aware of all these variables and use clear definitions in their studies. The following table summarizes the variables related to definition of the interpreter’s role and the model of service provision, and suggests some of the possible research effects of such variables.

Diagram 4.3.3

Issues Related to the Individual Interpreter	Possible Effects
Previous education	<ul style="list-style-type: none"> • understanding of health related concepts, professional role, etc.
Previous experience	<ul style="list-style-type: none"> • skill as interpreter • biases, or habits contrary to program
socio-economic class, age, gender, political orientation, standing in community	<ul style="list-style-type: none"> • types and amount of information shared • avoidance/compliance with follow-up care
Personal and professional ethics, personality, reputation in community	<ul style="list-style-type: none"> • information shared by client • ability of interpreter to reinforce provider instructions • avoidance of follow-up care
Level of English or French language skills	<ul style="list-style-type: none"> • interpreting ability
Level of other language skills	<ul style="list-style-type: none"> • knowledge of correct medical/health terms in first language • knowledge of local idioms and dialects
Interpreting skills	<ul style="list-style-type: none"> • degree to which concepts and messages are accurately conveyed
Understanding of role	<ul style="list-style-type: none"> • function played in interview • attributing effects to various roles
Relationship of interpreter to patient (family, colleague, political friend or foe, stranger)	<ul style="list-style-type: none"> • type and amount of information shared • degree of compliance • editing of information by interpreter • addition of information by interpreter • continuity, follow-up after encounter
Knowledge of medical/health concepts/ vocabulary (<i>i.e. training in this area</i>)	<ul style="list-style-type: none"> • ability to accurately translate and/or explain concepts
Medical training (<i>i.e. International Medical Graduates who may bring previous expertise, or role to position</i>)	<ul style="list-style-type: none"> • facilitation of communication of pertinent information • role confusion (e.g. diagnosis, screening, promotion of patient information within context of provider role)

4.3.3 Variables Related to the Individual Interpreter

In this category, many of the issues overlap with the issues of “definition and scope of the interpreter role”. However, it is important to recognize that even within the same program, individual interpreters may bring varying philosophies of practice, skill, experience, and relationship with their “community”. Therefore, the type and quality of service delivered by individual interpreters, even within the same program, may be significantly different. A number of these factors are outlined in diagram 4.3.3.

As we will see in the next section, many studies have not adequately controlled for the presence of an interpreter in a language discordant encounter, or analyzed differences between types of interpreters (e.g. family or medical staff) used in the study.

4.3.4 Variables Related to the Individual Client

There are several key issues related to the individual client that may also affect research results. First, accurate interpretation is not necessarily equally important for all types of illnesses or conditions (Carr, 1995). This topic has not received sufficient attention in the research. All medical encounters are often considered to be of equal need (or “emergency” care may be seen as of higher need.) However, in some cases, language barriers in emergency care which is not life threatening, may not pose serious concerns. Take for example a patient with a broken leg:

- ◆ the injury may not be “sensitive” or personal, so having informal interpretation, (e.g. through a family member or even a child) is less likely to cause concern;
- ◆ the injury may be a type that is readily understood by most laypersons;

- ◆ the injury may be accurately assessed, even without language interpretation.

Mental health or reproductive health (sexuality) matters are more likely to cause concerns for the following reasons:

- ◆ information is sensitive and confidentiality is extremely important;
- ◆ use of family members or interpreters who are not trained in professional ethics risk patient confidentiality and may cause serious ramifications for the patient and family;
- ◆ assessment depends heavily on history, cultural expression, and/or subjective experiences of the patient;
- ◆ conditions may involve concepts which are less likely to be understood by laypersons (e.g. HIV, reproductive issues, schizophrenia).

Studies such as those undertaken by Manson (1988) or Le Son & Gershwin (1996) have also highlighted the long-term health risks and costs of managing chronic, life-threatening diseases, such as diabetes or asthma.

It is important to note that many areas where descriptive studies outline the highest need for language services (e.g. pediatrics, childbirth, chronic serious illness) are also areas where much health education, preventive intervention, and “social/emotional” care is needed. It is exactly in these areas that data on effectiveness is lacking. This absence of data is not limited to questions of language access, but presents challenges to many areas of health research.

There are also many individual demographic factors that are linked in the literature with health status and the need for additional interventions. Not all patients presenting with the same problem have the same needs. As indicated in diagram 4.3.4, such

Diagram 4.3.4

Variables Related to the Individual Client	Possible Effects
General health status	<ul style="list-style-type: none"> • related conditions, use of medications, importance of assessment • risks of misdiagnosis
Type of illness or concern	<ul style="list-style-type: none"> • probability of negative outcomes • differences in need for subjective history • prior knowledge of client which may moderate effect of presence of interpreter • level of client anxiety • severity of symptoms • sharing of private/personal information • clarity of symptoms/ease of diagnosis • need for preventive/educational component • emotional/mental health issues
Level of education	<ul style="list-style-type: none"> • ability to self-advocate • ability to screen advice
Level of English or French language proficiency	<ul style="list-style-type: none"> • ability to monitor and intervene in interview
Gender, age, socio-economic level, etc.	<ul style="list-style-type: none"> • type of information shared with particular interpreter
Level of acculturation (time in country, gender, age, education, personal factors)	<ul style="list-style-type: none"> • awareness of health system, practices • personal health practices
socio-economic class	<ul style="list-style-type: none"> • health status • presence of other health risks • access to additional resources
Previous experience <ul style="list-style-type: none"> • with interpreters • with health system 	<ul style="list-style-type: none"> • ability to manage the health encounter • preconceptions re. interpreter role • type and amount of information shared
Expectations of language service	<ul style="list-style-type: none"> • types of information shared
Minority status <ul style="list-style-type: none"> • racism, discrimination • genetic characteristics • cultural stereotypes 	<ul style="list-style-type: none"> • presence or absence of stereotyping by provider • likelihood of differences in disease prevalence, differing drug reactions, etc. • lower level of overall care

factors as length of time in Canada, previous experience with health care providers, age, gender, educational level, or experience of past trauma will have a major impact on the health interaction.

All individuals requiring or utilizing interpreters do not have the same level of English or French fluency. Clearly the risk of negative consequences is much less for educated, acculturated individuals who have sufficient language skills to monitor the health interaction, even if they require an interpreter to help express themselves.

4.3.5 Variables Related to the Client Community

There is no research base that indicates the extent to which research on one constituency of language service users can be generalized to another. Is research related to the Deaf community applicable to First Nations communities? Are the issues similar and does interpretation address the same needs?

Even within each of the language groups however, there may be significant differences. The language access needs of different First Nations/Inuit communities or different newcomer communities cannot be assumed to be the same. Most estimates of

need focus only on the *numbers* of persons within a community who lack official language fluency, rather than the intensity or type of needs that necessitate language services. A high prevalence of trauma, the presence of cultural health beliefs which are significantly different from that of providers, or large numbers of young women of childbearing age, are just a few examples of community characteristics which may present higher needs for language access (Stevens, 1993b).

While providers often prioritize language services for those communities where large numbers of minority language speakers are found, individuals from smaller communities may actually face greater

Diagram 4.3.5

Variables Related to the Client Community	Possible Effects
Language constituency (official language, newcomer, First Nations/Inuit, Deaf)	<ul style="list-style-type: none"> • cultural and political context may make intervention of interpreting different • no studies comparing similarities and differences are available
Political context and divisions	<ul style="list-style-type: none"> • trust – degree of information shared
Homogeneity/heterogeneity of linguistic community	<ul style="list-style-type: none"> • probability of match (belief system, knowledge) between interpreter/client • likelihood of health system awareness of cultural/community issues
Size and institutional completeness	<ul style="list-style-type: none"> • availability of first language providers • access to same language resources • economics of interpreter provision • model of service provision
Specific demographics (age structure, educational levels, prevalence of trauma, percentage speaking official language)	<ul style="list-style-type: none"> • health status of population • types of health risks • likelihood of all relevant information shared
Specific language (similarity to English or French)	<ul style="list-style-type: none"> • likelihood of partial understanding • length of time services needed
Specific health system, beliefs (similarity to Canadian system)	<ul style="list-style-type: none"> • risk of misunderstanding, non-compliance
Racial/ethnic group	<ul style="list-style-type: none"> • likelihood of difference in risk factors, disease prevalence, drug response, etc. • likelihood of provider awareness of research which may affect treatment

barriers to care. The size and institutional completeness⁵ of a specific community also affects need. The degree of institutional completeness depends both on the numbers of individuals in that community, and the length of time the community has existed in Canada. A larger, more established community, is more likely to have providers who speak the same language, and to have developed organized responses to addressing language access needs. Non-official language speakers who live in communities where only a few individuals require language access services may have fewer options to either alternate/supplementary care, or to trained interpretation. A study at one medical centre found that although Spanish was the predominant language among groups not speaking English, those speaking other languages were most likely to be involved in crises (Corso, 1997). A Canadian study reported that greater barriers to care may be experienced by Inuit than by First Nations patients due to a smaller number of Inuit resource people available in some urban centres (Canadian Nurses Association, 1995).

Both availability of interpretation services, and the quality of the service provided, differs significantly depending on the languages for which interpretation is needed. For example, in Canada, the development of interpretation standards and practices in French and English is far more advanced than for First Nations or non-European immigrant languages.

There are many ways that community history may affect the relationship between the interpreter and the patient. It is fairly common for interpreters to be hired simply because they speak the same "language", with little consideration given to political, ethnic or other divisions, regional or idiomatic differences in language, or major cultural differences which may affect health practices and beliefs. Such issues are particularly problematic in refugee communities where past trauma and distrust may even result in avoidance of care or withholding of information if the "interpreter" is seen as untrustworthy (Stevens, 1993b).

The actual language for which interpretation is needed is also relevant. Speakers of languages that share the same alphabet and root language (such as Spanish) can more easily and quickly learn English or French, or "decipher" simple messages (Minkler & Looper, 1978).

Similarities or differences in health belief systems between the patient's country of origin and Canada also affect the need for interpretation, and the kind of interpretation needed. For example, "objective language translation" for a Southeast Asian patient whose health belief system is based on an understanding of 'hot/cold' is likely to be inadequate: "cultural" interpretation will also be needed. Risks of poor communication may also be higher in certain groups and for certain conditions if these groups have been excluded from clinical research.

5 Ethnocultural communities that can provide a wide range of health, social, educational, economic and cultural services through providers of the same background may be described as "institutionally complete". In an institutionally complete community one can get all or most service needs met in one's first language.

4.3.6 Variables Related to the Individual Provider

Another category of variables relates to the differences between individual providers. First of all, providers who identify problems and are most likely to initiate or agree to study participation may be those with the greatest awareness of the issues. A risk of selection bias then exists. The experience of individual providers in using interpreters, and whether or not they have received training in working with interpreters can also be expected to impact the quality of communication. The self-defined role of the provider, and the importance assigned by him or her to interpersonal communication, preventive education, or gathering of social history, as well as the *personality* of the provider, will also impact the nature of the health interaction, regardless of the quality of language services provided.

Significant differences (based on the type of speciality or service provided) can also be expected in the types of problems faced by clients, the short and long-term risks of limited communication, and the costs of errors in diagnosis or inadequate patient communication. In addition, the administrative setting in which a provider practices will affect overall efficiency and costs.

The location of the service provider may also affect the philosophy of the program, the target group, and the services expected by clients.

Diagram 4.3.6

Variables Related to the Individual Provider	Possible Effects
Self-selection	<ul style="list-style-type: none"> • lack of representation of provider sample
Type of speciality	<ul style="list-style-type: none"> • severity and type of risks linked to misunderstanding • importance of preventive information • importance of educational component • generalizability to other areas
Location of service	<ul style="list-style-type: none"> • continuity of care-type of health problem • non-productive time (i.e.. waiting) • data collected • payer of service
Experience with interpreters	<ul style="list-style-type: none"> • quality of information gathered
Perceived role, personality, and philosophy of provider	<ul style="list-style-type: none"> • type of information gathered • length of encounter • provision of education components • client confidence • safeguards to informed consent

4.3.7 Variables Related to the Health System

The final category of variables includes those related to the health system. This category can further be subdivided into *institutional differences* (e.g. differences between hospitals) and *larger system variables* (e.g. provincial/territorial health policies and priorities).

Some variables overlap with those in the category of *Variables Related to the Individual Provider*. However, it is important to distinguish between the factors over which the individual provider may have some control, and those that are systemic in nature. For example, even if all of the providers in an institution with whom a patient comes into contact are concerned and caring, if institutional policy does

Diagram 4.3.7

Variables Related to the Health System	Possible Effects
Institutional policy, e.g. multicultural/ diversity policy/commitment	<ul style="list-style-type: none"> • other internal factors that affect access and quality of care
Provider training (type, comprehensiveness, philosophy)	<ul style="list-style-type: none"> • ability of providers to provide culturally competent care, recognize and address language/cultural barriers
Variable overhead and infrastructure costs	<ul style="list-style-type: none"> • "cost comparison" between studies and programs may not be valid
Variable data collection <ul style="list-style-type: none"> • Types of encounters on which data is collected (hospital, physician, laboratory, specialist, auxiliary, preventive information) 	<ul style="list-style-type: none"> • research may be limited to data available • ability to assess longer-term consequences • difference between acute and chronic conditions • incomplete measurement of costs or consequences
Health system efficiency-related differences (e.g. waiting times)	<ul style="list-style-type: none"> • different costs, utilization, satisfaction
Provincial/territorial policies and priorities <ul style="list-style-type: none"> • Changes in health policy over time of study 	<ul style="list-style-type: none"> • funding for access and other preventive/ outreach services • limits on before/after strategies
Service changes during duration of study (hospital closing, loss of individual physicians in private practice, funding of community-based alternatives)	<ul style="list-style-type: none"> • availability of supplementary information/orientation which interacts with research variables • changes in service availability confound outcomes
Changes in health personnel over time of study	<ul style="list-style-type: none"> • may affect choice and satisfaction

not allow or require certain services or protect rights, the effect is systemic racism or discrimination. One example of this is the presence or absence within an organization of a specific policy related to cultural diversity, which requires provider training in working with interpreters. It is useful to note that research is most likely to be conducted in a centre where some program development and education has already taken place. These centres may not be representative of all organizations.

In a larger community context, the provision of outreach or preventive services to marginalized communities may affect the need for certain interpretation services. For example, if there is a program to provide childbirth education in the patient's first language within a community setting,

the scope of information for which a patient requires interpretation in a clinical setting may be less. This preventive program may then decrease the need for physician-patient interpretation. However, at the same time that the focus on "costs" of interpretation services is emerging, such community or preventive services are often being cut back or eliminated.

Changes that occur over the duration of a program (such as closing of some programs, or providing additional educational outreach initiatives) may also affect study findings. It is for this reason that "before and after" studies (e.g. measuring the differences in health status and/or utilization of services before and after the introduction of a health interpreter program) should be undertaken with caution.

4.4 Summary

It has been noted that research related to language access is still in the early stages of development (Puebla Fortier & Shaw-Taylor, 1999). As this section suggests, there are many challenges in design and evaluation of research on issues related to language access to health care. Many of these challenges are related to the number, complexity and interaction of variables that must be considered in research design.

In Canada, the absence of both a coordinated system of health interpretation, and of any requirements that non-official language speakers be provided with professional interpreters, have likely contributed to the paucity of research. There

are few researchers with experience in the area, and the isolation of language access issues from mainstream health research has resulted in little attention being paid to the issue. There are also particular methodological issues that present challenges to the use of certain research methods. Several methodologies show good potential for furthering research in this area. However, there are a number of limitations to use of these methods, related to the presence of language and cultural barriers and to the availability of data, that must be addressed.

In the following sections we will review several recent studies and discuss the implications of this research for Canadian health services.

5. Models of Interpretation Services

5.1 Introduction

Health interpreters have only recently been recognized as critical professionals in the delivery of health care to patients who do not speak an official language (Jackson, 1998). With greater awareness of the risks of language barriers and inaccurate interpretation, there is increasing demand from providers and advocates for research related to models of interpretation services. As awareness of the need for skilled interpretation grows, so does the understanding that it is necessary to distinguish between various "types" of interpreters, and to identify problems that may arise through the use of interpreters. Research questions in this category include those related to:

- 5.2 definition of the interpreter's role;
- 5.3 models of service provision;
- 5.4 effects of interpreters on communication; and
- 5.5 standards of service provision (training, accreditation and evaluation).

5.2 The Interpreter's Role

What it means to be a "health care interpreter" (even when the discussion is limited to the role of "professional interpreters") is ill-defined. While the principal responsibility of an interpreter is to bridge the language barrier between individuals speaking different languages in order that they may communicate freely with each other (Downing, 1995), there is no consensus on the best way to achieve this. An interpreter may be viewed as a bilingual community worker, where interpretation is only one part of a larger role – including advocacy or cultural mediation. At the other extreme are those who view health interpreters in the same category as court or conference interpreters – where they are

expected to limit their role to accurate transmission of messages. This debate highlights the complexity of both the interpreters's role, and the challenge of "measuring" the input of interpreters in the provision of health services.

One result of the lack of consensus is often conflicting expectations of the interpreter's role (Kaufert & Koolage, 1984). However, little research has focused on the effect of interpretation on interpreters themselves, and their perspectives are often not included in planning or research. It appears that the view of interpreters as neutral "language processors" has often made their experiences invisible. Interpreters often report their role to be stressful, frustrating and unsupported. (Esperon-Rayson et al., 1991; Loutan et al., 1999). In addition, interpreters often deal with painful and conflictive communication, which may (particularly in the case of trauma or abuse) affect them personally. This is a very real issue for interpreters from refugee communities, many of whom have had experiences similar to those of the patients for whom they are interpreting (Tribe, 1999; Loutan et al., 1999; Bowen, 1999). In other cases, interpreters are called on to provide emotional support, not only to clients, but also to providers. They may also feel personally responsible for failures in diagnosis and care (Stevens, 1993b).

Descriptive research has documented the range of roles, functions and program models that have been developed in North America. For example, the expanded role of the community cultural mediator (which combines functions of language interpretation, cultural mediation and community-oriented cultural advocacy) has been documented in the Cultural Mediator Handbook, developed in the Harborview Medical Centre program (Jackson-Carroll et al., 1998). Putsch (1985) drew on descriptive case studies of several models of interpreter-mediated communication in his description of alternative models of interpretation.

Kaufert et al., (1984) used case examples drawn from observation of the work of Aboriginal interpreter advocates in working as translators, advocates, cultural informants and brokers between Aboriginal and biomedical culture. Case examples of interpreters who assumed each role were used to illustrate how interpreters adopted roles and functions that extended beyond objective language “translation”, and how these expanded roles and functions contributed to the communication process. The ways in which interpreters may act in controlling or adversarial roles have also been described. Hatton & Webb (1993) described three types of interactions observed among community nurses, interpreters and clients.

It is essential for those planning and administering interpretation programs to have an understanding of the complexity of the task of interpretation, the roles expected by providers, clients and interpreters, and the way that assumptions within the “culture” of health care may prevent equity of care. It has been noted that often interpreters are called on for assistance – even when the patient speaks an official language – in order to help mediate the cultural expectations of both client and provider, and provide support to the patient (Hemlin & Mesa, 1996; Kaufert et al., 1998).

In spite of the lack of consensus on what the interpreter’s role should be, it is generally accepted that effective interpretation must involve more than just interpreting “words”. Interpretation must also be able to interpret meanings, and clarify misunderstandings that may arise due to differences between the cultures of the two participants in the health exchange (Dias & O’Neill, 1998). This recognizes that the culture of the patient includes more than his ethnicity. Individual values, beliefs, and previous experiences may or may not be similar to others in the client’s ethnic

community. There is also a need to explain and “translate” the culture of the medical system – the technical (and often exclusionary) language, the assumptions and practices, and the rights and expectations of patients (Jackson, 1998).

The presence of an interpreter as a third party makes the communication dynamics between provider and patient more complex. With the exception of the research related to impacts of “untrained interpreters”, little attention has been paid to the effects of interpreters on the interview itself, and the various roles they play (Rivadeneira et al., 2000).

With greater awareness and acceptance of the need for interpreters, it is expected that more research will focus in this area, building on the work of authors who have highlighted the effects of role conflict, lack of linguistic equivalence, and power imbalances to the complexity of the health interaction (Putsch, 1985; Kaufert et al., 1998).

5.3 Models of Service Provision

Common approaches to the provision of interpretation services in Canada were outlined in Section 2. Many of these relied on the use of family and friends, or ad hoc, untrained interpreters. In this section we will focus on models of provision of trained or professional interpretation services. (It should be noted that “paid” interpreters are not necessarily trained interpreters, and also that professional quality of service may be provided by trained volunteers). Much of the research related to the effects of language barriers and the provision of interpretation has identified the risks of using family members or untrained, ad hoc interpreters. However, there has been limited research on the effectiveness of various models of professional service provision. A review of models of professional service finds that a combination of one or more of the following is commonly used:

- a) hospital or clinic-based interpreters;
- b) community-based health interpreters;
- c) generic professional interpreters;
- d) telephone interpreters;
- e) bilingual staff; or
- f) combined roles (including case management roles).

Various authors categorize these alternatives differently (Riddick, 1998), and in practice, these “models” may overlap or be combined. Models will also vary depending on whether interpreters are full or part-time employees, or work on contract or on a per-session basis. While larger populations of non-official language speakers may support full-time interpreters, many Canadian centres find that contract interpreters are a more cost-effective response.

Most of the research in this area is descriptive – it describes the development of programs, the service model and how it works, and often includes service statistics and evaluations from patients, providers or collateral agencies (Cross Cultural Health Care Project, 1995; Hemlin & Mesa, 1996). Much of the unpublished or non-peer-reviewed literature also provides case examples that describe the historical development and organizational structure of specific interpretation programs (Stevens, 1993b). Newsletters of interpreter organizations (e.g. Massachusetts Medical Interpreter Association or Critical Links) often include program descriptions. While many different models of interpretation service have been established in Canada, little comparative research is available. Therefore, rather than outlining examples of existing services, this section will outline some of the issues arising from various models of service.

5.3.1 Hospital/Clinic-based Interpreters

Because provider needs are often experienced at the level of the institution, a common response is to employ hospital or clinic-based interpreters. This response meets the immediate needs of the institution and many needs of patients. Issues of organizational efficiency and liability may be addressed, and patients may have a higher level of satisfaction and compliance. One variation of this approach is to have an inter-hospital system, where interpreters are shared between a number of institutions. This is particularly useful where smaller numbers of minority language speaking clients are found in the same area, and where hospitals may be relatively close together.

However, this is not necessarily the optimal solution from the perspective of the client. This is because in many situations, interpretation is required for a number of health interactions, not all of which occur within the walls of the same institution.

Two examples come to mind. A pregnant woman may benefit greatly from interpretation during any fetal assessment procedures, the birth and the postpartum hospital stay. She may even, if available through the hospital, choose to receive prenatal care where interpretation assistance is available. However, from the perspective of the woman and her family, this is not a comprehensive service, as family practice visits to community-based physicians, public health or pharmacy visits, and “well baby” follow-up are also important, and may present the same barriers to access. Similarly, a trauma victim may benefit from hospital-based interpretation in the Emergency Department. However, the same service may not be available for ongoing rehabilitation therapy, counseling or home care.

In other words, relying on a hospital-based service has two major limitations. It emphasizes acute rather than preventive care (and in this way is not consistent with the current emphasis on moving resources towards both health promotion and prevention); and it fails to provide continuity of service (risking service inefficiencies at the level of the health system itself).

Interpreters in this situation are clearly accountable to the institutions that employ them. While this makes monitoring of training and performance easier, it may accentuate the role conflict often experienced by interpreters. As they owe their loyalty to the institution (provider), they may be less likely to promote or protect the interests of the client.

While hospital-based interpretation services are the most visible examples of this model, clinics, community health centres, or Public Health departments may also establish their own interpretation program (Sent et al., 1998). However, they may be more likely to use interpreters in expanded roles (such as health education or community outreach), as described later in this section.

5.3.2 Community-based Health Interpreters

Another model of service provision is to base interpreters in the community. In this model the interpreter typically “follows the patient” and is available for a variety of different kinds of health encounters. The interpreter’s primary responsibility is to the patient. Quality of training and service provision may vary significantly, based on the standards set by the sponsoring group. One example of this model is the Immigrant Refugee Health Program established at Planned Parenthood Manitoba (Stevens, 1993; 1993a). This program is also an example of a combined interpreter role, as interpreters also serve in other roles, particularly in provision of culturally appropriate first language health education. Because the interpreters are

accountable to a community-based organization, their role is to act on behalf of the client. This program also illustrates some of the limitations of community-based programs: as the mandate of the organization is limited to sexual and reproductive health, interpretation services are also limited to this function. As responsibility for such services remains external to the formal health system, limited impact on hospital policy or utilization of interpreters may be achieved.

5.3.3 Generic Professional Interpreters

Like community-based health interpreters, generic interpreters are not limited to a particular institution or service area. Unlike them, they typically provide broader access to social services, educational and legal services. This model is often more efficient, as it can provide services in a greater number of languages, and many of the training components (e.g. ethics) would be similar for a number of service areas. It may also provide continuity for clients, as they often require services from a number of systems. In this model, interpreters are centrally coordinated, and the coordinating body usually provides training and supervision. One Canadian example of this model is the Inter-Regional Interpreter Bank in Montreal. Operated by the Montreal Centre Regional Board of Health and Social Services, it employs a number of freelance interpreters who provide service in over 50 languages (Hemlin & Mesa, 1996; Mesa, 1997).

Many community “language banks” are also based on this model, as are most visual language interpretation programs. In practice, there is a wide variation in the quality of service achieved by different programs, and interpreters may be paid or volunteer. While the model has the potential to ensure coordination, monitoring and training on professional/ethical standards for interpretation, many programs (particularly community-based “language banks”) lack the resources to ensure training and standards. A potential limitation of

this model is the challenge of ensuring the needed level of training in health vocabulary and concepts, when interpreters are also expected to perform in other areas, such as the court room. The effectiveness of this model depends on the ability to provide appropriate health-specific training and supervision. Institutions contracting with such programs may or may not be aware of the qualifications of interpreters.

5.3.4 Telephone Interpreters

There are two forms of telephone interpretation. Remote telephone interpretation services, or "language lines" are used commonly in the U.S. and many parts of Canada. These services can be invaluable in emergency situations (e.g. ambulance attendants at an accident scene), as they are available in many languages on a 24-hour a day basis. However, they are also expensive on a per-minute basis, although the service can be cost-effective where there is only occasional demand for a certain language. While considered superior in quality to ad hoc interpretation, telephone interpreters may not have the specific health training required. Accountability is also unclear.

Another form of remote interpretation is described by Hornberger et al. (1996). This involves using hospital-employed interpreters who provide simultaneous interpretation through telephone headsets from another part of the building. Limited research has been done on comparing the effectiveness of remote and proximate interpretation models (Hornberger et al., 1996; Hornberger, 1998), and more research is required.

5.3.5 Bilingual Staff

Another way to address language barriers is to rely on bilingual staff employed within health care institutions. It should be noted that in this section we are not referring to use of bilingual staff in their role as direct service providers, but the ad hoc use of staff employed in other positions. In some situations these ad hoc interpreters may be staff with medical training, while in others they will have no medical experience. Generally, they have not received training in interpretation skills or ethics. One exception to this is the Toronto-based Inter-hospital Interpreter Project (Wlodarczyk, 1998), a joint project of the Ontario Ministry of Citizenship and seven Toronto hospitals – where bilingual staff, who had been volunteering services as interpreters, received additional training in interpretation.

However, unless there are systems for training and quality control, one cannot assume that the quality of interpretation delivered by bilingual staff is any better than that provided by family members or community volunteers. While it is often assumed that hospital staff trained as medical professionals in their own countries would be ideal interpreters, this is not always the case. There may be significant class or political differences between the participants; the "interpreter" may have had no training in interpretation skills; and the potential for role conflict (including intervening as a health professional) may be greater.

A related concern is the inefficiency of removing staff from their regular duties (Rader, 1988; Drennan, 1996). Resentment often arises when additional duties are placed on staff without recognition or compensation. This resentment may also be experienced by colleagues who are required to "pick up the slack" while the staff member provides interpretation services.

5.3.6 “Combined” Roles

The final model discussed here includes a number of variations. In many situations the role of interpreter may be combined with other roles that are intended to ensure patient access, orientation, cultural mediation, or health promotion. This model may be found both within community and in hospital settings. For example, staff of the Aboriginal Services Department, at the Health Sciences Centre in Winnipeg, serve in a variety of functions – including orientation, liaison, advocacy, counseling, and participation in service coordination and planning. This is in many ways a “case management” role (Jackson, 1998). The “case managers”, in addition to providing interpretation services, can ensure that culturally appropriate health promotion information is provided for the community, and use of primary care services over emergency department use. They can provide a link between many different providers, encouraging efficiency by ensuring that information is shared and clients are informed. In addition, as salaried members of a health care team, they are in a position to provide education within the health system, and in this way promote cultural competence.

The use of “ethno-specific” positions, where clients are matched with workers of their own background, has been of particular interest in the area of mental health services. There are two approaches to this. One is to emphasize the recruitment of skilled bilingual, bicultural mental health professionals to work directly with clients of the same language background. The other is to create para-professional positions that work closely with qualified mental health professionals (Tobin et al., 2000).

It is useful to note that a “combined” model of interpretation services combines two different responses to addressing language needs. The bilingual worker not only provides professional language and cultural interpretation between

patient and provider, but also increases the number of *language-congruent* encounters by providing some services directly in the client’s first language. It is a model that has proven especially useful in sensitive health care areas such as sexual or mental health (Stevens, 1993b; Musser-Granski & Carrillo, 1997).

5.4 Effects of interpreters on Communication and Utilization

A number of studies have identified differences in utilization, satisfaction and compliance between patients with and without official language fluency. Fewer have attempted to directly compare patients for whom professional interpreters were available, with those who did not have such access.

A study by MacKinney et al. (1995) was designed to test the hypothesis that enrolling Deaf patients in a primary care program that provided American Sign Language (ASL) interpreters would improve preventive care, compliance and physician-patient communication. It compared patients from a primary care program for the Deaf in Baltimore (that provided full-time ASL interpreters and subsidized health care costs for some patients), with a control group of friends of these patients drawn from the community. Questionnaires were administered to 90 patients (cases) and 85 of their friends (controls), in either written English or ASL, depending on their preference. Those in the program were significantly more likely to report receiving preventive testing (pap tests, mammography and rectal examinations). They were also much more likely to report receiving counseling, in ASL, for psychiatric and substance abuse problems (49% compared to 5%). The investigators found that 84% of patients in the program used ASL interpreters, compared to 20% of control patients. More cases reported satisfaction with care than controls (92% vs. 42% were moderately or extremely satisfied).

There are, however, some limitations to this study. There may have been selection bias, as patients in the program may have had more health problems, or different behaviours in seeking health care. There were some significant differences in characteristics between the groups. Cases tended to be poorer, and less likely to be married or have commercial health insurance. In addition, self-reported health utilization may not match health records. However, this study is of interest as it is one of the few that has compared patients in a program where professional interpreters are always available, with the situation faced by most who lack official language fluency. The difference in use of ASL interpreters between cases and controls provides an indication of the under-utilization of interpreters, even when they are needed.

Few studies have compared different models of interpretation services. Kuo & Fagan (1999) implemented a survey of Spanish-speaking patients and medical residents about their experience and satisfaction with various methods of language interpretation (friend or family member, professional hospital interpreter, hospital employee who is not an interpreter, telephone interpreter, and physician who is proficient in the patient's first language). Levels of satisfaction with each method differed significantly between the two groups. While residents and patients had the highest level of satisfaction with professional interpreters, patients were more satisfied with using family members and friends, and less satisfied with telephone interpretation than were residents. The two groups also differed in the characteristics they felt to be important in an interpreter. Residents felt that availability and understanding of customs and beliefs were important, whereas patients felt that personal familiarity, gender concordance, and ability of the interpreter to assist them after the visit were more important. The desire for continuity may be the reason that family and friends continue to receive

high satisfaction ratings from most in the study. This finding is also confirmed by the experience of many community-based programs (Stevens, 1993b).

In an experimental study, Hornberger et al. (1996) directly compared two methods of interpretation service provision – "remote-simultaneous" and "proximate-consecutive". Fifty-four Spanish-speaking mothers of new infants were randomly assigned for a first visit to a well baby clinic in either the experimental (remote simultaneous) or control (in person interpreter) group. The two services were alternated over the course of subsequent visits.

Three interpreters, who provided traditional proximate consecutive interpretation, were given 15 hours of training in simultaneous interpretation. All encounters were taped and analyzed as to the duration of visit, quality of medical discourse, and accuracy of interpretation. Utterances by physicians were coded as questions, instructions, explanations or requests for clarity. Utterances of the mother were coded as questions, explanations, or requests for clarity. The quality of interpretation was assessed as being correct, or having an addition, omission, or substitution. Physicians, interpreters and mothers completed self-administered questionnaires at the end of the study that compared the quality of the interpretation and their preferences between the two systems. Questions used a five point Likert scale. The remote-simultaneous model had 10% more physician utterances, and 28% more mother utterances. Mothers also asked significantly more questions, and physicians reported improved eye-to-eye contact with patients in this model. The remote-simultaneous interpretation service had a 13% lower rate of inaccurately reported mother utterances. There was also a trend towards a lower rate of inaccurately interpreted physician utterances. Mothers and physicians significantly preferred the simultaneous system. Interpreters

reported a perception of better understanding between patients and physicians, but tended to prefer to work in the proximate-consecutive model.

The authors concluded that the remote-simultaneous model may be an acceptable or even preferred alternative to the traditional model of interpretation services. They suggest that one of the reasons interpreters prefer the traditional model is that they perform tasks beyond just interpreting, and the rigors of performing simultaneous interpretation at a remote site may result in lower job satisfaction. It is interesting to note that this study found higher levels of patient satisfaction with remote interpretation, whereas the study by Kuo and Fagan (1999) reported lower levels. This may be due to differences between programs. Hornberger et al. (1996) used existing and experienced in-house hospital interpreters, and the quality of interpretation provided to the two groups may have been similar. The training of the telephone interpreters in the study by Kuo & Kagan was not stated. It would therefore not be advisable to generalize the effects of this study to all telephone interpretation services.

A Canadian study of clients, health professionals and interpreters working with the Inter-regional Interpreters Bank in Montreal, surveyed 288 health care workers regarding their expectations of interpreters and satisfaction with the interpreters of the bank compared to volunteer interpreters (Mesa, 1997). Health care providers and clients expressed significant differences in satisfaction with professional vs. volunteer interpreters, preferring professional interpreters on measures of both interpreting skill and professionalism (e.g. maintaining confidentiality). This study found significantly larger differences in satisfaction with volunteer and professional interpreters than the study by Kuo and Fagan (1999) described above. However, a low response rate from participants and awareness that the study was an evaluation of

satisfaction with a specific program may have introduced selection and response bias.

5.5 Interpreter Training

Recently, the issue of interpreter training, standards and certification has been receiving increased attention (Downing, 1997). Training programs have been developed in many countries (Roat, 1995; Bischoff and Loutan, 1998; Weiss & Stuker, 1998).

In Canada, training and accreditation for Sign Language interpretation has been more advanced than for other minority languages (Bird & McDonald, 1998). Processes for certifying translators, court interpreters and conference interpreters have also been more developed than for what is termed "community interpreting". Training for community interpreters is often provided outside the academic setting (Roberts, 1995). Much training is still provided by organizations that hire interpreters, such as hospitals or community organizations.

There are a number of interpreter training programs in Canada, however they vary from one-time pilot programs (Stevens, 1993) to established certificate and diploma courses. A 1997 survey identified seven interpreter training programs in Canada that prepare interpreters for health care settings (Roat & Okahara, 1998). All but one of the programs embedded health interpreter training into programs for general community interpreting. Program length and content varied. They were offered by community colleges in some provinces, as well as community organizations. Some courses were offered on a project basis only and had not been offered for some time. In addition, a number of community colleges and a few universities offer courses in Visual Language interpretation (Bird & McDonald, 1998).

Almost all programs in Canada simultaneously train interpreters from a number of different languages. Exceptions to this are training programs for Inuktitut speakers in Nunavut and Nunavik. Both the Nunavut Artic College (Penney & Sammons, 1995) and the Adult Education Department of the Kativik School Board (KSB) provide interpreter training programs for Inuit interpreters. The KSB program provides basic modules in the areas of Education, Social Services, Law and Medicine, and includes supplementary modules on a number of topics such as mental health (Raymond, 2001).

Training has been developed at regional and provincial levels, with significant differences found between provinces (Steyn, 1994). Ontario has adopted a model of "cultural interpretation", and some provinces have undertaken activities to develop provincial standards and services (Affiliation of Multicultural Societies and Services Association of British Columbia, 2000). In other provinces there has been little attention to the development of standards, and health interpretation programs may only be available through specific agencies (Stevens, 1993b). Although training programs have been developed in many provinces and territories, there has been relatively little coordination and information sharing between programs (Dubieniski, 1998).

At a recent national symposium on language access to health care, the "Catch 22" of interpreter training and employment was identified (Rocheffort, 2000). The absence of standards and policies requiring professional interpreters results in low demand (although not low need) for trained interpreters. Many interpreter training programs therefore do not have enough students to offer the courses regularly, as students are unlikely to pay for courses when employment is uncertain. A review of the Montreal Inter-regional Interpreters Bank found that the yearly salary of interpreters averaged \$1,587 (Mesa, 1997). A lack of trained interpreters contributes to a situation where there is continuing

reliance on untrained interpretation. Participants recommended the development of a coordinated, national response to promote implementation of policies regarding health interpreter use, training and standards.

One initiative that has formed the basis for current work in setting and evaluating professional standards of practice for health interpreters, is the DACUM analysis. It was first commissioned by the Massachusetts Medical Interpreters Association (MMIA) and conducted by Dr. Maria Paz Avery for Educational Development Center Inc. (MMIA, 1996). The DACUM (Developing a Curriculum) is a method of occupational analysis for professional and technical professions.

This process is also used in Canada for defining needed competencies for interpreters. The process involves a panel of experts with experience in the field who describe and define the tasks that make up their jobs. Panel members then define core knowledge, and identify skills and attitudes that are required to perform these tasks appropriately.

In the MMIA-sponsored study, 12 experienced medical interpreters who were selected from the membership of the organization, participated in a workshop directed by an experienced facilitator. The initial stage of the process involved asking the panel to define the total universe of duties and responsibilities performed within their roles as medical interpreters. Because the universe of tasks generated at this initial session could have been influenced by the characteristics of the particular panel of interpreters selected, the organizers included participants with a wide range of experience, representing six language groups. This group was able to identify a wide range of tasks that reflected the range of interpreter roles and models of service delivery.

This approach must differentiate and measure two types of skills – linguistic proficiency and interpretation skills. These two dimensions are included in some, but not all proficiency tests that are utilized to test and accredit interpreters. The DACUM study included, and distinguished between, interpretation skills that provided the basis for effective communication and those that were used to make strategic interventions to ensure accuracy and completeness. The actual standards of practice were based on the assumption that an interpreter's primary task is interpretation, rather than including other tasks such as health education. Tasks identified by the expert panel were organized into three basic dimensions: 1) interpretation, 2) cultural interface, and 3) ethical behavior.

The MMIA Standards of practice were developed for four purposes:

- a) to serve as guidelines for the development of educational and training programs;
- b) to act as an evaluation tool to rate the performance of students and working interpreters;
- c) to form the basis for educating and preparing providers to work with interpreters; and
- d) to create a foundation for certification examinations of medical interpreters.

Following their adoption by the MMIA in 1996, these standards have been widely distributed and used as the basis of policy development among interpreter/provider/administrator networks in Canada and the United States. Several interpreter organizations and governmental authorities have developed, or propose to develop, alternate standards. At the 1998 meeting of the network that became the National Council for Interpretation and Health, the MMIA-based task-oriented measures were re-examined by participants representing

major programs and providers. Although there was some discussion of the breadth of the roles and functions that were included in the tasks, the instrument was generally endorsed.

Some provinces and territories have developed their own standards of practice for interpreters (e.g. Health Care Interpreter Partnership Project, 1996). For example, this competency-based method was used to develop the Translation and Interpretation Program of the Kativik School Board for Inuit interpreters in Nunavik (Raymond, 2001).

The DACUM has proved to be a useful development tool for a number of health roles, and the development of standards shows great promise in clarifying one of the variables of interpretation research (i.e. controlling for the variable of interpreter competence).

An additional challenge related to standard setting is the need for policy development and training for providers in working with interpreters. Even with skilled interpretation, optimum quality of communication cannot be achieved without provider awareness of the need for, and competence to work effectively with, interpreters. Providers from a number of health professions have recognized this and developed specific guidelines for working with interpreters (Phelan & Parkman 1995; Smart & Smart, 1995; Massachusetts General Hospital Interpreters Office, 1998; Poss & Beaman, 2000).

Training must recognize not only the needs of the patient and provider, but also of the interpreter. Studies that analyze the dynamics of the interpretation process (Putsch, 1985; Kaufert et al., 1998; Vissandjee et al., 1998a) provide insight into the demands on the interpreter and the complexity of the interpreter role. These courses must also prepare students to practice in "combined" roles where needed.

5.5.1 Accreditation and Evaluation

Closely related to issues of training are those of accreditation. Accreditation generally involves a test of skill that is external to any course taken, and as such is a mechanism for ensuring equivalent standards across a variety of training programs. It is important that accreditation be coordinated at the national level, and that the process incorporate both the complexity and the scope of the interpreter's role.

Quality evaluation refers to the ongoing assessment of skill and performance, and is the responsibility of the employing agency. Little research has focused on evaluation of interpreter quality. The descriptive literature provides in-depth descriptions of the types of errors made in interpretation, and content analysis has also proved effective. However detailed content analysis is not feasible for ongoing evaluation of the quality of an interpreter's work. One of the difficulties in evaluation is that few institutions systematically collect data related to problems with interpreters. Another problem is that many providers rely on external services (e.g. community language banks) for health interpretation. One approach is to survey users, however most health service evaluations do not include a component on satisfaction with language access services. Additional research is needed to obtain feedback from service users themselves (Garber & Maufette-Leenders, 1995). These strategies must recognize the difficulties in adapting and translating survey instruments. There is also an additional challenge: the risk that clients' reliance on a particular interpreter, and uncertainty about the implications of negative feedback, may bias survey results.

5.6 Research Priorities

Many jurisdictions are requesting assistance in determining the most effective model of service provision. Research is needed in two areas. One relates to comparative evaluation of various forms of interpretation – through assessment of patient and provider satisfaction, and by content analysis of interpretation accuracy. The second need is for economic evaluation of models for a particular setting. Institutions, cities and regions vary dramatically in the number of health encounters requiring interpretation services, and the number of languages in which these services are needed. A practical challenge then, is to design models that are both acceptable and cost-effective for a variety of situations. Developing appropriate models is a particular challenge in a country such as Canada, where there is a relatively small population spread over a large area. While the majority of non-official language speakers live in a few large Canadian cities, most smaller cities and towns also have smaller populations who face language barriers. In northern areas providers may be "minority language speakers", and the patient and most members of the community may communicate mainly in an Aboriginal language.

It is likely that many centres will use a combination of models, where paid interpreters, volunteers, bilingual staff or telephone interpreters are all used, depending on the type of problem, skill needed, and availability of resources (Durbach, 1994; Carr, 1995). This model (which is based on the premise that health encounters differ in skill level required, time and number of ongoing interactions, and immediacy of response required) attempts to use resources efficiently, by directing scarce or expensive resources towards the situations where they are most required. This model depends both on a high level of coordination, and provider training to accurately assess the level of response needed.

The potential of tele-medicine in addressing language access to health services has not been well explored. This technology, now used in Canada to address distance barriers, appears to be particularly useful where diagnosis is dependent on culture and language, such as in the practice of psychiatry. Video conferencing has received high levels of acceptance from patients in a variety of settings. It may also be useful in certain well-defined situations, where a provider of the same background may be available in another city. This response however, does not rely on interpreters, as it is a strategy that increases the number of language-congruent encounters.

An approach that shows more promise is that of creating roles for bilingual community health workers who could provide interpretation as one of their functions (Bowen, 2000). These roles focus on groups that have traditionally had less access to care, and in many ways play a bridging role between formal health services and communities. These positions may range from "case managers" to "health educators" to "cultural mediators" to "outreach workers". They have been demonstrated to increase access to care, improve quality of care, and reduce costs of care (Witmer et al., 1995; Musser-Granski & Carrillo, 1997), particularly in Aboriginal and immigrant communities (Stevens, 1993b). These more comprehensive strategies may be more cost-effective than a limited interpreter role in some situations (Jackson, 1998), although methods for measuring the benefits of these expanded roles has yet to be developed. This response differs from the use of existing employees as ad hoc interpreters (described earlier in this section), as a principle role of the positions is to provide trained health interpretation. It also differs from strategies designed to increase the number of health professionals who speak non-official languages, as these bilingual workers primarily provide bridging, not direct service, roles and work only with one language community.

It is also important to note that selection of an appropriate model does not in itself result in quality service. Whatever model is chosen, there is also a requirement to establish policy requiring use of trained interpreters (including monitoring and enforcement), and mechanisms for ensuring quality standards. Where standards are implemented, demand for interpreter use rises (Hemlin & Mesa, 1996). A review of provincial reports also indicates that there is consensus that any model should be centrally coordinated, provide 24-hour-a-day service, and obtain adequate and stable funding (Bird & McDonald, 1998).

5.7 Summary

As the following sections will illustrate, there is sufficient evidence on the negative effects of language barriers on health care access and quality of care, that attention should be directed to the practical issues of developing standards of practice and appropriate models of service delivery for the Canadian environment.

While there is continuing debate about how the interpreter role should be defined, there is sufficient consensus on core competencies that these should form the basis for training programs. Although there are many models of interpretation services provision in Canada, both availability and quality of services vary widely. Some initiatives have been developed to address standards of practice, however there is a need for these to be expanded and coordinated at the national level. Training must prepare interpreters to perform a variety of roles and must also be required for providers who work with interpreters. Research is also needed to determine the most appropriate models of interpretation services for the distribution of the Canadian population.

6. Effects of Language Barriers on Patient Access and Care

6.1 Introduction

This section reviews current research on the impact of language barriers and language access programs, under the following headings:

- 6.2 Estimating the need for language access programs;
- 6.3 Effects of language barriers on initial service access;
- 6.4 Effects of language barriers on quality of care; and
- 6.5 How do language barriers affect health and utilization?

Section 3 provided a brief overview of the importance of the sociopolitical environment and its impact on health, health services, and health research. It is important to note that many of the studies discussed in the following sections have been conducted in other countries. Caution is therefore needed in generalizing study results to the Canadian context. Many studies on language access have been conducted in the United States, spurred in part by the interest of managed care organizations in addressing cost-effectiveness issues. Unlike Canada, the United States does not have universal health care insurance. Therefore, any investigation of access will be affected by the fact that many respondents face financial barriers to health care.

In addition, many studies on language access in the United States have focused on the Hispanic population, which is the largest minority language group in that country. This is a highly diverse population, comprised of both native-born Americans, and immigrants from a number of different countries (including significant numbers

of “undocumented” immigrants who face additional barriers to access). English language fluency also differs considerably within this population, including a graduation of language proficiency ranging from monolingual Spanish-speaking individuals to monolingual English speakers (Kikman-Liff & Mondragon, 1991). In many of the regions, Hispanics form a significant percentage of the population, and are gaining increased legal rights as well as service access. Research results may therefore have limited applicability to the situation faced by many minority language speakers in Canada. In addition, it cannot be assumed that research limited to Hispanics can be generalized to other language groups, even within the same country. Barriers to generalizability include the following:

- a) as Spanish is a European language, there is greater likelihood that providers and patients will be able to communicate, even if the patient has limited fluency in the official language (Minkler & Looper, 1978);
- b) the heavy concentration of Hispanics in many areas may result in a broader range of services being available in the client’s first language (including availability of Spanish-speaking health professionals);
- c) professionals may be more familiar with the religious, health, and social beliefs of Hispanics than those of new arrivals from other parts of the world;
- d) there may be other factors specific to Latino populations which may not be shared by other minorities.

Much of the published research has focused on immigrant languages. There has been less attention in North America to speakers of Aboriginal languages, or the Deaf community. This report reflects this emphasis. As acknowledged by the

study authors, many of the studies have limitations – including sample size, possible biases in selection of participants, or failure to collect data on, and control for, potentially confounding variables (e.g. education or socio-economic status). There is also significant variation in how the presence of a language barrier is defined and measured. The presence and/or skill of the interpreter is often not noted. However, there are a number of well-designed studies that provide consistent results.

6.2 Estimating the Need for Language Access Programs

The first step in developing appropriate models for addressing language barriers is to obtain an accurate assessment of need. There are two areas of research that will be discussed here. The first involves estimating the numbers of individuals who require interpretation for health services. The second involves estimating the proportion of those who require health interpretation services who actually receive them.

6.2.1 Need for Interpretation Services

It is estimated that 17% of Canadians have a mother tongue other than English or French. Approximately 10% of the population speaks a “non-official” language at home. On arrival in Canada 42% of immigrants speak neither French nor English (Marmen and Corbell, 1999). This proportion is higher for many refugee populations. One quarter of Aboriginal peoples report a mother tongue other than English or French (Statistics Canada, 1998). This increases to 90% in Nunavut, where 26% of Inuit are monolingual (Penney, 1994). According to the Canadian Association of the Deaf, there are 300,000 Deaf persons who rely on ASL for communication, out of a total of 1.2 million who are deaf or hard of hearing (Wood, 2001). French-speaking individuals living outside Quebec (approximately 3% of the Canadian population

living outside of Quebec report French as the language used at home) and English speakers living in Quebec (10.5% of the Quebec population) may also face similar barriers (Bird and McDonald, 1998).

There has been an increase (approximately 2% in the last decade) in the number of residents who speak neither official language. The shift in source countries of immigration to Asia, Africa and Latin America has contributed to this greater cultural and linguistic diversity. However, this percentage is considered a significant underestimation of the proportion of patients who actually require language access services. Many people with rudimentary knowledge of French or English lack the level of language proficiency required to access services and effectively communicate in a medical encounter. In addition, providers commonly overestimate their patients’ ability to comprehend and communicate in a second language (see, for example Holden & Serrano, 1989; Haffner, 1992; Stevens, 1993b; Jackson, 1998). While we know that the number of Canadians who require an interpreter for health care is at least 1 in 50 (Marmen & Corbell, 1999), the upper limit is much harder to determine. It may be as high as one in ten – the same proportion as Canadians who speak a non-official language at home. The percentage will differ significantly between cities and regions, and will be higher in cities where there are large numbers of immigrants, or in northern areas where Aboriginal peoples comprise a large percentage of the population.

The number of persons requiring language access services will also depend on the specific area of health services. For example, in a region where most Aboriginal young people speak English or French as their first language, access to maternal/child health services may not be hindered by language barriers, although there may still be significant cultural and systemic barriers to equitable care. Within a particular population

however, many older persons may not be proficient in an official language (Tran, 1990). The proportion of seniors who have a mother tongue that is not English or French, for example, ranges from less than 2% (Prince Edward Island) to one third of Manitobans, and over three quarters of those living in the Northwest Territories (Masi & Disman, 1994).

Current research approaches

There appears to be little research that has determined overall need for language access services. While many studies have been at the institutional level, these are often informal estimates and may not be published. Often, a survey of either providers or patients is utilized (McEntee, 1993; Andrea & Renner, 1995; Cross Cultural Health Care Program, 1996; Drennan, 1996; Leman, 1997; Rader, 1998; Bischoff et al., 1999). Many institutional assessments are only disseminated internally or in the local area.

In addition to estimating what proportion of the patient population faces language barriers, some of these studies have also collected information on whether the patient brought his or her own interpreter (Rader, 1988), who was used to interpret (Drennan, 1996; Rader, 1988; Bischoff et al., 1999), the reason an interpreter was needed and the times an interpreter was required (Andrea & Renner, 1995), and waiting time, whether an interpreter was found, and whether data was kept on language proficiency of patients (Bischoff et al., 1999).

It is important to note that whether need is defined as "inability to communicate in an official language" or "lack of language congruence" between patient and provider, may affect assessment of need for language access services. Take for example the situation where a number of minority language speakers are employed in the health professions in a particular community. Although the number of community members who lack

English or French proficiency may be high, the presence of these bilingual health care providers would help increase the number of language-congruent encounters, and decrease the number of encounters for which health interpretation were needed.

Other studies incorporate an estimate of need as one aspect of a larger research project on language access. Many of these also collect demographic information, which provides insight into subgroups that experience higher need. For example, it is generally found that a greater proportion of women, elderly, and less educated persons experience language barriers (Hu & Covell, 1986; David & Rhee, 1998).

Another approach to estimating need is demonstrated by Flores et al. (1998), who undertook a cross-sectional survey of parents of 203 children, with the objective of identifying barriers to health care. Participants attended a Latino inner-city hospital clinic in an American city. Multiple-choice, open-ended and Likert type questions were used, and the questionnaire was made available in both English and Spanish. In this study, parents identified language as the "single greatest barrier" to getting health care for their children, even though many also faced financial barriers to care. Because of this, 11% of the parents reported that they did not seek medical care for their child in the past.

In Canada, perhaps the most common methods of estimating need at the community level are by needs assessments, focus groups, or consultations with community representatives. Such consultations consistently emphasize that immigrant and refugee communities, Deaf persons, and many Aboriginal peoples (particularly First Nations) consider interpretation for health encounters a priority (Stevens, 1993b; Stephenson, 1995; Canadian Nurses Association, 1995; Calgary Multicultural Health Care Initiative, 2000).

However, it is important to note, particularly in the case of immigrant communities, that the proportion of the population that requires services can differ widely both between specific ethno-cultural communities and over time. While there has been a steady need for interpreters for immigrant communities, the actual languages in greatest demand are often linked to current immigration trends (Cross Cultural Health Care Project, 1995).

6.2.2 Proportion of Those Facing Language Barriers Who Receive Service

Estimating the need for an interpreter is based on the experience of one or more of the participants in a health interaction. Estimating the proportion of those patients who require language access services who actually receive them is further complicated by the difficulty of defining what is meant by "interpreter". Only a few studies estimating need have attempted to differentiate between types of interpreters. Often, any form of interpreter is considered equivalent – whether this is a family member, community volunteer, non-medical hospital staff person, or professional interpreter. Although some researchers note the kind of interpretation provided, others do not, and the type of interpreter used may not be a variable in the analysis.

A cross-sectional patient survey, undertaken by Baker et al. (1996), was designed to determine how often interpreters were used to communicate with Spanish-speaking patients; the perceived need for an interpreter as compared to actual interpreter use; the impact of interpreter use on patients' self-perceived knowledge of diagnosis and treatment; and the objective knowledge patients had of discharge instructions. Patients were separated into three groups according to use and need for an interpreter during their visit: a) an interpreter was not used and not thought necessary, b) an interpreter was used, and c) an interpreter was not used, but the patient felt one should have been

used. In addition, language concordance between provider and patient was categorized as a) good concordance (either the patient's English or examiner's Spanish was good), b) fair concordance, or c) poor concordance (the patient spoke little or no English and the examiner spoke little or no Spanish).

The finding that interpreters were frequently not called even when they were needed is consistent with findings in Canadian settings (Stevens, 1993b). Baker et al. (1996) found that interpreters were used in 26% of cases, but in an additional 22% of cases they were not used, even though the patient felt they were needed. When both patient's English, and provider's Spanish was poor, interpreters were not called in 34% of cases. As well, 87% of patients who did not have an interpreter felt that one should have been used. This study also noted the type of interpreter used (nurse 28%; physician 22%; other people in the emergency room 16%; professional interpreter 12%; family members 12%; hospital clerks 11%).

Given what is known about the risks of using untrained interpreters, it is important for future research to differentiate between the types of interpreters used. Interpretation provided by family members, untrained hospital staff, or volunteers is so variable in quality that it cannot be assumed to necessarily be better than no interpretation at all. The effect of professional interpretation therefore cannot be determined.

Hornberger et al. (1997) surveyed primary care physicians in northern California. Respondents were asked how many patients they saw per week, how many encounters were with non English-speaking patients, and how often they used each of six interpretation methods (speaking the patient's language fluently; using a trained health interpreter; using other staff who had no training in interpretation; using a telephone interpretation service; enlisting help of family members or

companions; or “making do”). The survey found that 27% of respondents stated that they spoke the patient’s first language. Trained medical interpreters or telephone interpreters were used in only 6% of cases. In the remaining cases, family members or companions (36%), untrained staff (20%), or no interpreter (11%) were used. It was not possible through this study to determine the quality of communication between patients and providers in the 27% of the cases where the physician claimed to speak the patient’s language.

Studies indicate that sign language interpreters are also underutilized. A survey of physicians in a U.S. university medical centre, for example, found that only 22% of physicians frequently used sign language interpreters when communicating with Deaf patients. Most of the physicians surveyed overestimated the efficiency of lip reading (Ebert & Heckerling, 1995).

6.2.3 Implications for Canadian Health Services

There has been little formal assessment in Canada of the prevalence of language barriers in health care encounters. Attempts to develop estimates are usually based on extrapolations from general population estimates, or of estimates developed by a specific institution. Population-based estimates include reviews of immigration landing statistics, reports from English/French as a Second Language programs or the public school system, local surveys, or consultation with community respondents.

Several institutions have undertaken local assessments, and others are in the process of developing strategies for estimating need. Tracking the language preference of current patients, or collating requests for interpreters are two of the

methods used. A limitation of institution-specific estimates is that in many smaller centres, some model of coordinated service, which can serve the entire community, is likely to be the most cost-effective response. A coordinated review at the regional level would also allow the health system to address needs for language access by all four language constituencies within a coordinated framework, rather than by separate and uncoordinated strategies, which is often currently the case.

In Canada, because neither ethnicity nor language are routinely coded in administrative health data, it is not possible to undertake secondary analysis of this data to determine estimates. While census and household activity surveys collect data on language usage patterns, this data has not yet been used to develop preliminary estimates of unmet needs for health interpretation services. Immigration data may provide some useful information on the numbers of persons arriving in Canada by first language, and ability to speak English or French. However such figures prove less useful over time due to inter-provincial/territorial migration, uncertain rates of second language acquisition, and natural increases in the size of the community.⁶ Figures on numbers and first languages of ESL students may also provide one perspective, but will understate the needs of those who have been in Canada for a longer time and those who, for a number of reasons, may not be attending language classes.

The focus of research in this area should be on assisting health care providers and communities to develop models of service for addressing language access. In addition to obtaining an accurate assessment of numbers of language-disparate

6 While births to parents who do not speak an official language may not increase the number of persons who require interpretation, they will increase the number of interactions for which an interpreter is needed.

encounters, it is also necessary to determine the types of interpreters used in the encounters; reasons why interpretation was not provided; quality control methods for staff interpreters; qualifications of interpreters; training provided; evaluation; presence of language policies; data collection; and service coordination methods (Cross Cultural Health Care Project, 1995).

The first national survey of the need for language access services in the United States included 83 hospitals and was undertaken to identify the demand for interpreters, the ways providers meet the demand, and the models for providing service. The survey found that 11% of patients in these institutions required an interpreter (Ginsberg et al., 1995). A study in Switzerland found that only 14% of medical services surveyed reported using trained interpreters (Bischoff et al., 1999). A similar initiative would provide useful information in Canada.

In many countries where estimates of the need for language access services have been developed, it has been found that a significant proportion of the population faces language barriers to care, and that few patients have access to professional interpretation programs. However, specific population estimates of those with limited official language proficiency, as well as the proportion who have access to interpretation services, can obviously not be generalized from one jurisdiction to another. Canadian-based research is essential. The research approaches developed in other settings, however, can provide guidance to Canadian initiatives in this area.

6.3 Effects of Language Barriers on Initial Service Access

Language 'barriers' have been associated with both higher and lower rates of service utilization. Analysis of utilization patterns associated with language fluency indicate that some of the observed differences may be due to differential effects of: a) language barriers to initial access, and b) communication barriers affecting diagnosis and treatment (Bowen, 2000). The first barriers prevent a person from presenting for assessment and care, while the second affect the quality of care obtained. The research indicates that there is a general pattern of lower use of many preventive and screening programs by those facing language barriers. Higher use has been reported for some emergency department services, and for additional tests ordered to compensate for inadequate communication.

It is important to note that *utilization* may be determined by either the patient or the provider. The patient most often initiates first contact with the health system. However, referral for specialist consultation, diagnostic testing, return visits or prescription of pharmaceuticals is determined by the provider. Even participation in preventive programs may be physician-initiated (rather than patient-initiated) through the course of a routine or other visit.

This section will focus on barriers to *initial* access, and participation in prevention programs, including prevention activities that are physician initiated. Recent arrivals (to the country or to a particular urban centre) usually get information through word of mouth. The process of determining what services are available, how they can be used, how to make an appointment, and, often, finding the location and "checking in", generally requires the services of an interpreter (whether it be friend, family member or bilingual worker), even before first contact is made. Telephone triage or voice mail systems can create additional barriers (Dolman et al., 1996). Many Deaf patients cannot make direct initial contact due to absence of telephone devices for the Deaf (Jones & Tamari, 1997; Witte & Kuzel, 2000). Language barriers to initial access may result in delayed care or avoidance of routine care.

6.3.1 The Issue of Acculturation

A key concept related to research on utilization patterns, particularly of prevention and screening programs, is that of acculturation. This concept describes the process by which individuals entering a new society come to adopt more of its beliefs, values, and practices, and become more similar to others in the host society. It is proposed that as individuals become "acculturated" to North American culture, for example, they are more likely to have health beliefs, practices and utilization patterns similar to those of the general population. In many studies, language has been assumed to be a measure of acculturation rather than the primary variable of interest. However, as the following research indicates, recent studies suggest that language proficiency itself may be the determining factor.

6.3.2 Access to Prevention Programs

Significant differences in utilization of prevention programs by official language proficiency (or language congruence) have been found consistently in the research. This pattern is found for a range of conditions, and is fairly consistent. Most of the research has focused on screening programs (such as mammography or cervical cancer screening). This research emphasis is due at least in part to the availability of data on utilization of these services. Less is known about primary prevention programs, as data on participation is often not maintained.

Many studies have focused on differences in participation by ethnicity or (particularly in the U.S.) by race. Ethnic minorities generally have much lower rates of participation in prevention programs. A variety of reasons have been proposed for this, including: a) differences in insurance coverage, b) cultural beliefs and practices, c) systemic discrimination, or d) ethnicity as a proxy for socio-economic status. Language itself has only recently been studied as a contributory variable. Because of the number of potentially interacting factors that may contribute to reduced participation in preventive care, research in this area must be designed to control for potentially confounding variables.

There are few published North American studies that specifically examine the impact of language on utilization of prevention programs. However, two other categories of research also provide useful perspectives:

- ◆ Research that compares different ethnic groups, where language emerges as a possible or likely factor explaining differences; and

- ◆ Research that compares different ethnic groups, but does not measure or account for language fluency separate from "culture". It is useful to be familiar with the findings in this extensive body of research, as it may often give direction for design of future studies.

Published research on prevention program participation

A number of studies focus on utilization of cancer screening programs. Fox and Stein (1991) examined utilization of screening mammography by racial/ethnic groups in the United States. The method used was a bilingual random digit-dialed interview with over 1,000 women. They found that the most important variable that predicted whether women of all racial groups had a mammogram was whether their doctors had discussed mammography with them. Hispanic women, compared to black or white women, were less likely to have physicians who discussed screening with them. The importance of language as a factor was further explored by distinguishing between Hispanics who spoke English, and those who chose to be interviewed in Spanish. Language preference (English versus Spanish) was strongly correlated with whether the physician discussed mammography with the woman or not.

A British study by Naish et al. (1994) used qualitative methods to investigate reasons for the lower participation rate of minority women in cervical screening programs. The authors found that some reported attitudinal barriers were not, in fact, deterrents, and that women were enthusiastic about screening once they understood the test and the procedures. Language and administration were seen to be barriers to participation by clients, not,

as reported by physicians, lack of interest in prevention programs.

Solis et al. (1991) used data from the Hispanic Health and Nutrition Examination Survey (HHANES) to analyze the relative importance of two predictors of use of preventive screening: access (which in the United States was largely influenced by cost), and acculturation (which includes language). They found that language ability predicted the use of screening services. They suggested that the effect of language on screening practices should not be interpreted as a cultural factor, but as an access factor (i.e. proficiency in English increased access to service).

In a study of health behaviour of older Hispanic women, factor analysis was used to explore four dimensions of cultural assimilation – language preference, country of birth, contact with homeland, and attitudes about children's friends. After controlling for age and education, Marks et al. (1987) found no dimension of acculturation associated strongly with health behaviour. However, use of English language was associated most closely with increased use of screening programs. The authors concluded that cultural factors had little impact on the health behaviour of Hispanics. Access to services and sociodemographic factors were stronger determinants.

6.3.3 Initial Access to Mental Health, Rehabilitation and Counseling Services

Access to mental health and counseling services is a particular area of concern regarding interpreter use. In addition to general barriers to first contact (finding out where to go, making an appointment), there are additional concerns related to cultural differences in service provision, communicating concerns, beliefs about mental illness or emotional

problems, and confidentiality (Canadian Task Force on Mental Health Issues Affecting Immigrants and Refugees, 1988; Li et al., 1999; Mesa, 1997). Many studies indicate that even when patients have contact with the health care system, they may delay seeking care for mental health problems due to language barriers, and underutilize mental health services (Canadian Task Force on Mental Health Issues Affecting Immigrants and Refugees, 1988; Nyman, 1991; Trauer, 1995; Stuart et al., 1996; Roberts & Crockford, 1997). A number of studies have identified barriers to resources for domestic violence and sexual assault victims (McLeod & Shin, 1992; Ontario Department of Justice, 1996; Abraham, 1998; Ozolins, 1998; Bauer et al., 2000) and addictions (Canadian Council on Multicultural Health, 1990; Canada Drug Strategy, 1996). Barriers for Deaf persons are reported to be similar to those of other language minorities, and many Deaf people are not aware of mental health services, turning instead to informal resources (Steinberg et al., 1998).

Counseling program providers (including those in areas such as addictions and family violence) often make no accommodation for language access. Instead they may refer clients to generic "helping" agencies (such as organizations providing general settlement services to immigrants) that do not have specialized expertise. This results in a two-tier level of service (Canadian Task Force on Mental Health Issues Affecting Immigrants and Refugees, 1988; Stevens, 1993b; Canada's Drug Strategy, 1996).

6.3.4 Other Differences in Initial Utilization

One of the earlier studies on the effects of language compared differences in health care usage between Hispanic patients who were a) Spanish-speaking only, b) bilingual with Spanish as a primary language, or c) primarily English-speaking. Hu & Covell (1986) asked a sample of 1,990 patients, selected from five outpatient clinics in San Diego, California, to fill out a questionnaire in Spanish or

English. The survey gathered information on regular use of health care, health insurance, admission to hospital, and frequency of general physical, eye and dental examinations. After controlling for age and income, significant differences in health care utilization were found. The Spanish-speaking only group showed the lowest frequency of general checkups. However, no significant difference was found in the percentage of patients who reported not having seen a health professional when one was necessary. This suggested that it is preventive appointments that were most affected. The authors noted that in this study there was a stronger correlation between primary language and health care levels than between income and health care levels.

Derosé and Baker (2000) examined the independent association of Latinos' self-reported English language proficiency with self-reported use of physician services for patients presenting for care with non-urgent medical problems. In this study four groups were defined for comparative analysis: a) English speaking non-Latinos b) Latinos who were native English speakers, or native Spanish speakers who said their English was good to excellent, c) native Spanish speakers who said their English was fair and d) native Spanish speakers who said their English was poor, or that they did not speak English at all. The study also controlled for the variables of gender, age, literacy level, health status, health insurance status, regular source of care, and indicators of economic status. This study found that among patients who saw a physician at least once in the previous year, Latinos with fair or poor English proficiency reported approximately 22% fewer physician visits than non-Latinos whose native language was English, even after adjusting for other determinants. The authors noted that the effect of limited English proficiency on the number of visits was similar to the effects of having poor health, no health insurance or no regular source of care.

Weinick & Krauss (2000) explored the reasons for racial and ethnic differences in children's usual sources of care. They used logistic regression techniques to analyze data from the 1996 U.S. Medical Expenditure Survey. The authors found that Black and Hispanic children were less likely to have a regular source of care, even after controlling for health insurance and socio-economic status. However, controlling for language eliminated the differences between white and Hispanic children. The authors concluded that the frequently observed finding that Hispanic children are less likely to have a regular source of care is due to language barriers, rather than characteristics attributable to ethnic group membership.

Surveys of patient-reported barriers to care often identify language as the greatest (or one of the greatest) barriers to care, even in countries with explicit financial barriers to care. A survey of Vietnamese immigrants in the U.S. (Davanzo, 1992) revealed that not having an interpreter for health care was the greatest barrier to care for immigrants; and that they tended to seek care only when ill. The greatest difficulties were experienced by recent arrivals, but the author observed that the problems were not of short duration, but continued for many years. The survey participants indicated a willingness to receive health care, and to change providers if necessary to get interpretation help. An Australian survey found that non-English speaking parents reported that language barriers prevented them from taking their child for care (Chak et al., 1984).

While administrators and researchers focus much attention on urgent or emergent needs for care, what may be less evident are the initial barriers to access in many other areas. These include barriers

to health promotion and education resources (Anderson et al., 1993; Stevens, 1993b; Jackson et al., 1997), AIDS/HIV education and counseling (Stevens, 1993; Peinkofer, 1994), participation in First Aid or CPR courses (Flabouris, 1996), access to emergency care (Hick et al., 1998; Kelly & Groff, 2000), out of hours service (Free et al., 1999), pharmacy services (Siganga & Huynh, 1997), support for caregivers of the elderly and disabled (Plunkett & Quine, 1996), and access to a range of mental health, counseling, and rehabilitation services (Canadian Council on Multicultural Health, 1990; Stevens, 1993; Canadian Task Force on Mental Health Issues Affecting Immigrants and Refugees, 1998).

6.3.5 Canadian Research: The Effects of Language Barriers on Initial Access

Canada appears to lag behind the U.S. in research specifically related to language access, and research often includes a loose definition of "language" combined with ethnic and other factors. Many of these studies suggest that language is one factor affecting differences in utilization. More often however, these differences are attributed to differences in cultural beliefs and/or to lower socio-economic status.

Canada's universal system of health care provides a number of advantages for health research. Unlike studies undertaken in the U.S., there is no need to control for insurance status. Universal health coverage also results in centralization of claims data for all residents by province or territory, and there are initiatives to improve consistency in reporting between provinces.

Canadian research indicates that Aboriginal women and some groups of immigrant women are less likely to have had mammography or cervical cancer screening (Hislop et al., 1996; Matuk, 1996a; Gentleman & Lee, 1997; Grunfeld, 1997; Sent et al., 1998; Maxwell et al., 2001), although research by Tudiver and Fuller-Thomson (1999), based on the National Population Health Survey, found that immigrant women had higher rates of mammogram utilization than other Canadian women. However those not proficient in an official language are unlikely to be included in such surveys (Woloshin et al., 1997), and the study did not differentiate between world regions or the length of time women had resided in Canada.

It is recognized that in spite of universal entitlement, participation in prevention programs is linked to socio-economic status. In addition, research has focused on cultural beliefs and practices that may function as barriers to participation and the concept of "acculturation".

Woloshin et al. (1997) analyzed self-reported utilization data on breast examination, mammography and Pap screening from the 1990 Ontario Health Survey. Of the study respondents in one city, 10% were non-English (6% French-speaking and 4% speaking other languages). He found that French speakers were significantly less likely to receive breast examinations or mammography. Women whose first language was neither English nor French were less likely to undergo Pap screening. These results persisted even when adjusted for social and economic factors, contact with the health care system, and measures of culture.

The authors highlighted the difficulties in disentangling the effects of language on medical care from other correlated factors. They observed that language may act in different ways. It may be a barrier to contact with the health care system, a proxy for other factors that affect access (e.g.

poverty), a marker for cultural differences about the value of screening, or a communication barrier. The researchers assessed language by asking what language was spoken most often at home. Two questions were asked related to culture: ethnic self-identification and immigration status (Canadian born, immigrant of more than five years in Canada, immigrant in Canada for less than five years). They found that although language was related to both self-reported ethnicity and years in Canada, there was an important independent relationship between language and the use of preventive services, after controlling for these measures of culture. They concluded that women who spoke a language other than English at home were less likely to receive important preventive services. However, they did not find a relationship between language and contact with the health care system (measured by number of doctor visits in the past year).

The authors emphasized the importance of doing research in Canada where health insurance cannot confound analyses. Of note was the observation that households where no one spoke English or French (the two languages of the interview) were excluded from the study (2.4%) and that the actual difference between other language speakers and English/French speakers may be understated because of this. This study also identified differences in utilization between English and French language speakers in a primarily English-speaking province.

Less research is available related to effect of language barriers on access to health promotion and disease prevention information. Many of these initiatives occur outside the formal health system and are heavily dependent on language as they are "education" based. However, the research undertaken in this area provides evidence of significant barriers in the areas of health education.

A study by Fitch et al. (1997) surveyed 513 older adults using the Cancer Knowledge Survey for Elders. Of the respondents, 349 were born outside Canada, and 243 of these completed the survey translated into their native language. Responses were analyzed in two categories, based on whether they had completed the survey in English or in another language. The authors found that the proportion of non-English language respondents with incorrect answers was higher than for English language respondents on all items. In all but three of the items, the differences were significant. These results suggest that non-English speaking groups have less access to information on cancer and cancer prevention. The survey did not control for other potentially confounding demographic factors, such as educational background. However, as one of the few Canadian studies where the primary analysis was on differences related to language use, it provided important information on the ways in which language proficiency may, through affecting access to health information, result in delayed diagnosis of serious disease.

An exploratory study interviewed 57 South Asian women in Toronto regarding breast cancer detection practices (Choudry et al., 1998). A network sampling technique was used. All of the participants were first generation immigrants of Indian or Pakistani background, and spoke Hindi, Punjabi, Urdu or Gujarati. A questionnaire was designed and translated into these four languages, and then back-translated into English for verification purposes. The questionnaire was pre-tested with 11 women. The study found that a lower percentage of the sample practiced breast self-examination than the general population. Of the 60% who were aware of the procedure, only 10% could describe it accurately. Regression analysis was used to identify factors that were significant predictors of breast health practices. Age, education and mother tongue showed no statistically significant relationship with breast health practice scores. However, both proficiency in English and

the number of years in Canada had a significant relationship with breast health practices. The authors also noted that language and unfamiliarity with Western culture, rather than negative attitudes towards practices (such as touching the breasts), appear to act as barriers. Lack of knowledge was suggested by the women as a reason for lower rate of breast health practices; language barriers result in difficulties in accessing health information.

A prospective longitudinal survey by Edwards (1994) explored the predictors of prenatal class attendance among immigrant women. It found that a strong predictor of prenatal class attendance was official language ability. All women who were eligible for inclusion in the study had immigrated from Eastern Europe or a developing country. A number of factors hypothesized to be predictors of prenatal class attendance were included: level of acculturation; current immigration status; ethnic identity; official language comprehension; length of time in Canada; experience as a refugee; marital status; age; education; and whether or not the pregnancy was planned. Following logistic regression analysis, two variables were found to be significant predictors of attendance for first-time mothers: self-rated English/French language ability and maternal age. Women who rated their official language ability as excellent or very good were 7.36 times more likely to report attending prenatal classes than those who rated their language ability as poor or fair. The author concluded that among primiparas, lack of language ability was an important barrier to prenatal class attendance.

There have also been other Canadian studies that suggest that language may have a role in facilitating or impeding access to services. Many of these studies used smaller samples, and have not measured (or controlled for) language directly. In an Ontario study, Majumdar et al. (1995) compared use of in-home services by clients that they grouped into several "ethnic" categories (white English speaking, white non-English speaking,

visible minority, Francophone, indigenous and Hispanic). Of all the clients, 88.3% were found to be white English speaking, and 11.7% were from "multicultural groups". Based on estimates indicating that multicultural groups make up 24% of the population in the region, the authors concluded that these groups were under-represented as clients of home care services. Language and cultural barriers were proposed as one potential factor contributing to this. There were, however, a number of limitations to this study. The study did not analyze differences in utilization controlling for language, and estimates were based on provider recall. It can also not be assumed that the proportion of persons requiring home care within the local population is similar to the proportion of "multicultural" sub-populations within the overall population. Canadian studies indicate that in many areas immigrant populations tend to be younger than the population average, and have lower rates of disability.

A similar approach compared psychiatric admissions to an adolescent inpatient unit of Asian Canadians and their white peers (Roberts & Crockford, 1997). A retrospective case review was undertaken of all Asian Canadian adolescent admissions to one Calgary hospital. The authors note that as the hospital database did not track ethnocultural factors, a manual search based on patients names was required. Only 11 cases were found, and small numbers did not allow for statistical analysis. Expected admission rates were calculated based on the proportion of Asian Canadians in Calgary according to the Canada Census. These admission rates were found to be approximately 1/3 of those found for white Canadians. It was also found that the study population, compared to the white Canadian group, was predominantly admitted on an emergency basis. This study is an example of one where ethnic differences in utilization are indicated but there is insufficient evidence to conclude the underlying causes of such differences.

A 1991 newcomer health survey, based on the Ontario Health Survey questionnaire, was conducted by Matuk (1996b) in Windsor, Ontario. Questionnaires were completed by 548 individuals from 297 families. Of the respondents, 7% stated that they faced language barriers, and 3% did not know a doctor or where to go. However, there were a number of limitations to this study. Participants were selected by non-random sampling and were identified by community contacts. A variety of data collection methods were used and the authors found that the participants had little knowledge of the purpose or value of health promotion and research. Specific examples described in the study indicated that lack of confidence could have resulted in social acceptability response bias (e.g. one person declined to be interviewed based on fears of deportation).

More compelling are the consistent reports from health care users themselves, based on community consultations and direct assessment (interviews, focus groups or surveys). Qualitative methods are particularly useful for this type of research, as they allow exploration of the differences in use patterns of health services from the clients' perspective. Language barriers are consistently raised as one of, if not the most, important barrier to care, both in Canada (Stevens, 1993b; Stephenson, 1995; Calgary Multicultural Health Care Initiative, 2000) and in other countries (Davanzo, 1992; Watt et al., 1993; Dolman et al., 1996).

6.3.6 Implications for Canadian Providers: Research on Barriers to Access

There is good evidence that Canadians who do not speak an official language face important barriers to initial access to health care. However, because of universal health coverage, it is unlikely that these barriers have a significant effect on access for those who are acutely ill or injured. Canada provides a unique environment for assessing the relative importance of financial compared to other

barriers to access, and it cannot be assumed that language barriers will have the same effect on access as in countries without universal health insurance. It is important that future studies investigate the effects of official language proficiency, while also controlling for factors related to ethnicity, immigration status, socio-economic status and education.

Strategies for facilitating access must also recognize that barriers to access are not limited to physician and hospital care. Greater attention should be given to the barriers to prevention programs, particularly health promotion programs, which are aimed at providing health information and avoiding future health problems.

6.4 The Effect of Language Barriers on Quality of Care

While the previous section focused on evidence of the effects of language barriers on initial access to care, this section focuses on the impact of language barriers to quality of care. This includes research related to a number of different dimensions:

- 6.4.1 the case study literature;
- 6.4.2 differences in treatment of clients due to language barriers;
- 6.4.3 health outcomes;
- 6.4.4 patient satisfaction;
- 6.4.5 patient understanding and "compliance";
- 6.4.6 standards of ethical care.

Few studies were identified that have focused specifically on language barriers as the major factor affecting care. However, a greater number of studies suggest that language may be an important factor that results in different patterns of care experienced by various ethnic groups.

6.4.1 The Case Study Literature

Case studies are the most comprehensive source of information on the range of problems related to quality of care that may result from language barriers. While this literature will not be reviewed here, it should be noted that it is this body of research that first identified problems resulting from language barriers, and provided direction for future research. These reports not only illustrate, through concrete examples, the effects of language barriers on quality of care; but also present the context of service provision, and provide insight into the mechanisms through which care is impaired. Numerous examples of delayed diagnosis, misdiagnosis, inappropriate referral, failure to explain the patient's condition or recommended care, or failure to ensure confidentiality or obtain informed consent have been documented (Bowen & Kaufert, 2000a; Haffner, 1992; Holden & Serrano, 1992; Stevens, 1993b; Flores et al., 2000). These case studies may also demonstrate the health effects of language barriers or inappropriate interpreter use on the health of other family members (Jacobs et al., 1995).

6.4.2 Differences in Treatment Due to Language Barriers

In the United States, increasing attention has been given to the question of inequities in health care provision and health status by ethnicity and race. A comprehensive review by Mayberry et al. (1999), supported by the Henry B. Kaiser Foundation, found that there were significant differences in quality of care and health status between ethnic/racial groups, that could not be explained by income, education, lifestyle, insurance status or other factors. This leads to the conclusion that there are inequities based on ethnicity within the U.S. health system. These findings cannot be assumed to apply to Canada, as provision of a universal, publicly-funded health care system address many sources of inequities, and the

cultural and political climate is distinct. However, there has also been almost no Canadian research in this area, so it cannot be assumed that inequities based on ethnicity do not exist.

While the research suggests that there may be patterns of lower utilization of physician-initiated services related to ethnicity (Mayberry et al., 1999), the evidence of the relationship of language barriers to quality of care is not so consistent. There is some evidence that in many cases, service utilization increases where there is language discordance between patient and provider.

Hospital admissions

Lee et al. (1998) undertook an observational prospective study to determine whether physician-patient language disparity would increase the probability of admission to hospital after presentation to a hospital emergency department (ED). A convenience sample of 1,000 patients was evaluated as to whether the patient's preferred language of communication was different from that of their primary physician. English was preferred by 85.3% of patients. More than half of the non-English speakers spoke Spanish. Data was also collected on age, gender, acuity level of the patient, and whether an interpreter was present. Physicians involved in the study were blinded as to its purpose, and told only that the emergency department was doing a "needs assessment" for translation services. Initial analysis found that language disparity significantly increased the risk of hospital admission for adult, but not pediatric, patients. Multivariate analysis was undertaken to control for possible confounding variables (such as acuity or age). This resulted in a relative risk of hospital admission (disparate vs. matching language) of 1.7. In other words, adults who did not speak the same language as their provider had a 70% greater chance of being admitted to hospital than patients who did. The authors proposed that a provider, when treating patients with whom s/he could not

communicate effectively, would be more likely to admit them to hospital as a precautionary measure. This study also found that when an interpreter was used, the risk of admission decreased. It should be noted however that in this study other possible confounding variables (such as patient socio-economic status) were not controlled for, and could have been a factor influencing admission rates.

Diagnostic testing

Hampers et al. (1999) undertook a prospective cohort study to determine whether language barriers between families and the emergency department (ED) physician were associated with a difference in diagnostic testing and length of stay in the ED. The clinical status of, and care provided to, patients who presented to a pediatric ED was prospectively assessed. The treating physician was asked whether the patient spoke English, and if so, whether this created a language barrier. If a language barrier was identified, it was noted whether or not an interpreter was used. Of the 2,467 patients who were included in the study, 12% of the families did not speak English. This created a language barrier for the physician in 8.5% of the cases (although an interpreter was used in only 6.4% of the cases). The study included a limited number of conditions, and focused on generally healthy children. In cases where a language barrier existed, patients were more likely to be given intravenous fluids and admitted to hospital. The overall mean charge for tests was also significantly higher (\$145 vs. \$104). Employing an analysis of covariance model, which included race/ethnicity, insurance status, physician training, attending physician, urgent care setting, triage category, age, and vital signs, the presence of a language barrier accounted for a \$38 increase in charges for testing, and a 20 minute longer hospital stay.

The investigators also noted a number of limitations to the study. The physician, rather than family, did an assessment of language barriers, and more complicated cases were excluded. All families who faced a language barrier were analyzed in the same group – those who used no interpreter, those who used a professional interpreter, and those who used an ad hoc interpreter. It was suggested that as interpreters may have facilitated understanding in many cases, the study results probably underestimated the effects of language barriers.

Patient follow-up

Other studies suggest that language barriers result in lower physician-directed utilization. In a cohort study, Sarver and Baker (2000) explored the association between language barriers and 1) rates of referral for follow-up appointments, 2) patient knowledge that a follow-up appointment had been scheduled, and 3) actual compliance with follow-up appointments. This study controlled for a number of potentially confounding variables, including age, gender, socio-economic status, reading ability, health insurance and regular source of care. Attention was also given to categorizing the discharge diagnoses in order to control for the type of presenting medical problem. Three language groups were created. Group 1 consisted of native English speakers (white, black and Latino) and Spanish-speaking Latinos who said they communicated with their provider (either in Spanish or English) without the aid of an interpreter, and who did not think an interpreter was needed. Approximately half of this group spoke English, and half Spanish. Group 2 consisted of native Spanish-speaking Latinos who communicated with their provider through an interpreter. (It was noted that a hospital interpreter was used for only 12% of these patients – family members or ad hoc interpreters were used for the others). Group 3 consisted of native Spanish-speaking Latinos who said that an interpreter was

not used, but should have been. In reviewing demographic information, patients who reported a language barrier were more likely to be female, with less education, less likely to own a car (the measure of socio-economic status), and more likely to report overall health as poor.

The investigators found that both patients who used an interpreter, and those who did not use an interpreter but felt one was needed, were significantly more likely to be discharged without a follow-up appointment. However, there was no association between the groups and either their knowledge of appointments or compliance with the follow-up appointment. This challenged the commonly held belief that some clients are culturally less compliant in their care, and points instead to the importance of communication.

Pain management

Other studies have focused on pain management. Although most have studied differences according to “ethnicity” and not language ability, they do, however, suggest areas for further research.

Cleeland et al. (1997) conducted a prospective clinical trial aimed at evaluating the adequacy of prescribed analgesics of minority patients with cancer. They found that only 35% of minority patients, compared to 50% of non-minority patients, received guideline-recommended analgesic prescriptions. Difficulties in assessing pain due to language and culture were one of the potential factors cited by the authors to explain these findings. More Hispanic patients than black patients were inadequately medicated (69% vs. 54%). This suggested that English language fluency may have played a role. However, a number of other factors were proposed, including cultural differences in willingness to use analgesics. As language was not directly assessed, there was no information available on whether interpreters were available. In another study, Todd et al. (1993)

explored the role of Hispanic ethnicity in predicting Emergency Department analgesia for long bone fractures. Ethnicity was a strong predictor of analgesic administration, with Hispanics twice as likely to receive no pain medication. Primary language attained borderline significance. However, the presence of interpreters was not measured in this study.

Another study (Chan & Woodruff, 1999) examined whether patients who are not fluent in English receive less than optimal palliative care. The subjects were 130 consecutive patients with advanced malignancies (106 English speakers and 24 non-English speakers). Of patients who were unaware of their diagnosis, 92% were non-English speaking. During their last two months, control of non-pain symptoms was poorer for these patients than for English-speaking patients. The author suggests that these results indicate that patients not fluent in English received less than optimal palliative care.

Prescription of medication

Other studies have found differences in other prescribing patterns by ethnicity. Some of these also suggest that language may be a factor. A study of prescription patterns of hormone replacement therapy (HRT) among African-American, Asian, Latina, Soviet, and white women in the United States found significant differences by self-identified ethnicity (Brown et al., 1999). Soviet women, many of whom did not speak English, were the group least likely to be prescribed HRT (6.6% compared to 33.1% of other white women). The large disparity between Soviet immigrants and the other white women in the study may reflect communication difficulties, although there is also a possibility of differences in cultural beliefs. In addition, for some of the Asian and Latina women,

language may have also been a factor, but the authors were not able to address this in the research design.

In a British study, Gill et al. (1995) found that Pakistanis and Indians, when compared to white and West Indian groups, were significantly more likely to receive a prescription from their general practitioner. As Pakistanis or Indians are more likely to face a language barrier than the other groups, communication barriers may be one factor contributing to increased prescribing.

Diabetes management

One study found evidence that more non-English-speaking patients were receiving care that met the American Diabetes guidelines on testing, number of clinic visits a year, and dietary consultations, than were English-speaking patients. In other words, there was some evidence that their quality of care was better (Tocher & Larson, 1998). The authors suggest that these results could be a reflection of the tendency of physicians to be less certain of the medical history of non-English-speaking patients, and that time constraints involved in working with interpreters could result in more compensatory test ordering and visits.

This is one of the few studies where professional interpreters were provided to all non-English-speaking patients. While the authors identify a number of limitations to the study (including the fact that the training and qualifications of the interpreters are not described), the results suggest that interpreters can have an important effect on addressing language barriers to care. It was also noted that, compared to other studies, the cohort was drawn from a list of established patients, which indicates that initial barriers to care had already been addressed.

Special concerns

Canadian researchers have identified language as the most ubiquitous barrier to accessing appropriate mental health services (Canadian Task Force on Mental Health Issues Affecting Immigrants and Refugees, 1988). There is perhaps no other health area where diagnosis and treatment is as dependent on language and culture, and the risks of inadequate interpretation have been raised by a number of authors. It is also the area where providers have the most concerns about using interpreters (Sabin, 1975; Marcos, 1979; Putch, 1985; Canadian Task Force on Mental Health Issues Affecting Immigrants and Refugees, 1988). It has been observed that patients give different responses to questions depending on the language of the interview (Marcos, 1979; Oquendo, 1996). Assessment is dependent not only on language but also on non-verbal cues that may differ between cultural groups. The presence of an untrained interpreter may create additional distortions, and any breakdown in confidentiality may have devastating effects. Drop-out rates may be higher, attributed to services that are culturally or linguistically inappropriate (Flaskerud, 1986). Lower utilization of such programs is also determined by providers who may feel that therapy is not of use to those with limited official language proficiency. Providers may therefore be less likely to initiate or continue treatment (Marcos, 1979).

Similar risks are faced when dealing with many sexuality and reproductive health issues, HIV/AIDS counseling and testing (Stevens, 1993b), or counseling for a number of issues including addictions and family violence (Canadian Council on Multicultural Health; 1990; Ontario Department of Justice, 1996; Abraham, 1998). Fear of losing confidentiality when professional interpreters are not available may result in both avoidance of care and reluctance to disclose information that may be embarrassing or stigmatizing (Stevens, 1993b; Li et al., 1999).

Another area of particular challenge relates to rehabilitation services, and services for persons with disabilities (Smart & Smart, 1995; Wardin, 1996; Shah, 1997; Choi & Wynnem, 2000). Barriers to initial access may result in delayed use of services. Difficulties in appropriate assessment and therapy due to language barriers may result in additional delays in treatment. Language barriers may present almost insurmountable problems for services such as speech therapy or assessment of developmental delay (Jackson, 1998). Communication with family members is also important for many rehabilitation and home care services (Plunkett & Quine, 1996).

Canadian research on differences in treatment

Although differences between ethnic groups in health status and patient-initiated utilization have received research attention in Canada, historically there has been little research directed towards determining whether there are any differences in *treatment* based on ethnicity. The focus of equity in Canadian research has been on differences in health status and utilization according to socio-economic indicators.

One large study (Blais & Maiga., 1999) comparing ethnic groups with native-born Canadians, found evidence that physician-initiated utilization tended to be higher among ethnic groups. This study of health service utilization in Quebec used data from the 1987 Quebec Health Survey along with administrative data (Quebec physician claims data). It compared service use of members of ethnic groups (defined as persons born outside Canada, or whose mother tongue was neither English nor French) and native Quebecers. Data linkage methods were used to link the two data sources. Members of ethnic groups were matched with native Quebecers having the same level on six control variables: age, gender, income, access to health care, perceived health, and overall health. Data analysis indicated that

after controlling for a number of potentially confounding variables, the average number of medical services used in a year did not differ from that of native Quebecers. However, members of ethnic groups made more visits to specialists in private offices.

The authors cite a number of potential explanations for this higher utilization rate. One is that communication problems may result in a tendency for physicians to refer to specialists for further investigation. This interpretation is consistent with another finding of the study – that ethnic groups also used more diagnostic radiology than other Quebecers. However, there are other possible explanations for the differences in utilization. Language congruence/disparity was not assessed in the survey, so no conclusions can be drawn as to underlying causes. Another major limitation is that aggregate data on immigrant status was used. This did not allow analysis of differences between country of origin or between new arrivals (who are less likely to speak an official language) and established immigrants.

6.4.3 Specific Health Outcomes

Only a few studies have investigated differences in health outcomes related to language barriers. However, the literature suggests that there are many intermediate effects, such as delays in seeking care, misdiagnosis, inappropriate treatment, reduced comprehension and compliance, and malpractice injury that could affect health outcomes.

A recent U.S. study of outpatient drug complications by Ghandi et al. (2000) included language (English, Spanish or other) as one of the non-clinical correlates that were analyzed. A random sample of 2,248 English- or Spanish-speaking patients from 11 ambulatory care clinics was drawn for a telephone survey. Multiple logistic regression demonstrated that a primary language

other than English or Spanish was significantly correlated to reported drug complications. However no significant differences were found by race, gender or education. The failure of providers to explain side effects before treatment was associated with increased reporting of drug complications. This may be a major contributing factor in the differences found.

A U.S. study by Perez-Stable et al. (1997) investigated the effects of ethnicity and language on the medical outcomes of patients with hypertension and diabetes. Researchers found that language concordance with the physician did not significantly affect health outcomes, although these patients did report better health-related quality of life. This study randomly selected Latino or Caucasian patients to complete a questionnaire (either self, or interviewer-administered) in English or Spanish. The questionnaire included scales on physical functioning, psychological well-being, health perceptions, and pain. Latino patients who completed the questionnaire in Spanish were classified as Spanish-speaking. In addition, record reviews were undertaken for the preceding year. After adjusting for confounding variables, having a language-concordant physician was found to be associated with 10 of 14 health status measures. The authors identified a number of limitations with the study: a completion rate of only 53% was achieved, which risked generalizability of findings; lack of validation of the instruments in their Spanish language form; limitations inherent in retrospective chart review methods; and difficulties in adjusting for pre-existing conditions. There is also a possibility that Latinos with higher levels of well-being sought out language-concordant physicians. It was proposed that the failure to identify intermediate health outcomes may have been a reflection of sample size and clinical situation (Perez Stable & Napoles-Springer, 2000).

One of the most striking indications of the possible health outcomes of language barriers was described in a study by LeSon & Gershwin (1996) of young adults, aged 20-34, with asthma. The purpose of this study (and a companion study focusing on pediatric patients) was to determine the risk factors for intubation. Intubation was used as a marker predicting death. This was a retrospective cohort study of hospitalized young adults, including all asthmatics aged 20-34 admitted over a 10-year period to a university medical centre in California. Of the 550 admissions, 209 were black, 180 were white, 118 were Hispanic, 27 American Indian; and 16 were Asian. Of all the patients, 34 required intubation. Severity of asthma was estimated as severe, moderate, or mild according to National Heart, Lung and Blood Institute guidelines. A large number of potential risk factors were included, including socioeconomic variables and a variety of factors related to psychosocial functioning. Multivariate analysis was undertaken to determine the effects of each of these variables while holding the effects of the other variables constant. A number of covariates were found to be statistically significant. Patients with language barriers (defined as an inability to speak English) were over 17 times more likely to be intubated than patients with the same characteristics who were fluent in English. In contrast, patients with low formal education were only 5.7 times more likely, and active smokers 7.1 times more likely, to be intubated. A similar study of pediatric patients also found that a language barrier was a significant predictor, but the odds ratio fell to 3.3 (in other words, those with a language barrier were only 3.3 times more likely to be intubated than other patients) (LeSon & Gershwin, 1995). The study did not attempt to explain the link between a language barrier and greater risk of intubation. However, management of this chronic disease requires significant patient education and compliance with medication. Research on differences in asthma management by ethnicity has also found differences in patient

understanding of the disease and self-management (Moudgil & Honeybourne, 1998). As discussed in this section, there is strong evidence that patient education is impaired by the presence of a language barrier.

Surveys of patients also provide insight on outcomes. For example, Flores et al. (1998) surveyed parents of all 203 children who were brought to a pediatric Latino clinic over a 13-month period. Researchers wanted to know about their experiences prior to their first visit with the clinic. The parents reported that language barriers had caused their child to receive poor medical care (8%), misdiagnoses (6%), inappropriate medications (5%), and inappropriate hospitalization (1%).

6.4.4 Patient Satisfaction

Patient satisfaction is the most recognized and widely used measure of effectiveness of provider-patient communication (Kaplan et al., 1989). It is also an outcome of care, and has been suggested as highly correlated with quality of care. One would expect that individuals who do not share a common language with their providers would be less satisfied with their care: most research on the topic confirms that this is indeed the case.

A number of studies have examined different aspects of patient satisfaction with care. Carasquillo et al. (1999) studied non-English-speaking patients in the northeastern United States. They used a cross-sectional survey and follow-up interview to examine patient satisfaction and willingness to return to an emergency department (ED). Over 2,300 patients were included in the study. Fifteen percent reported that English was not their first language. In multivariate analysis, non-English speakers were more likely to report problems with testing, communication, and overall problems. Only half of them reported satisfaction with their care. Even when results were adjusted for other confounding variables, they were still less

satisfied and less likely to return to the same ED than were English-speaking patients. It should be noted that this study dichotomized English language ability, and included all those for whom English was not the first language in the non-English-speaking group. This likely underestimated the actual differences attributable to language barriers, due to the range of language abilities in the "non-English-speaking" group. In addition, interviews were only held in English or Spanish. Whether an interpreter was included in the interview was not indicated in the data.

Other studies have examined satisfaction with care related to interpreter use. In one cross-sectional study, Baker, Hayes & Fortier (1998) surveyed patient satisfaction with providers' friendliness, respectfulness, concern, ability to make the patient comfortable, and time spent in the exam. Patients were analyzed in three groups: those who communicated adequately without an interpreter; those who used an interpreter; and those who communicated directly with the provider but felt an interpreter should have been used. Analysis of the data found differences in perceptions of provider friendliness, respectfulness and concern between the three groups. For example, only 34% of those who did not need an interpreter stated that they wished the examiner had explained better. This figure was 90% for those where an interpreter was not used, but the patient felt one was needed. On the measures of understanding, those who used an interpreter were less satisfied than those where no interpreter was needed.

Another study (Morles et al., 1999) distinguished between Latinos responding in Spanish (Latino/Spanish), Latinos responding in English (Latino/English), and non-Latino whites in measurements of satisfaction with provider communication. The method used was an English and Spanish language questionnaire, sent to a random sample of patients receiving care from one physician group. Over 7,000 questionnaires were returned, for a response

rate of 59%. Five aspects of provider communication were rated: a) "medical staff listen to what you have to say", b) "answers to your questions", c) "explanations about prescribed medications", d) "explanations about tests and procedures", and e) "reassurance and support from your doctor and support staff". Latino Spanish respondents were significantly more dissatisfied with communication than either Latino English or white respondents, even after multivariate analyses controlled for potentially confounding factors such as age, gender, education or insurance status. The size of disparities in ratings by interview language was 5.4 points. This compared with 2.5 points for age, 2.5 points for insurance status, 0.4 points for gender, and 0.2 points for income. This indicates that language congruence had a much greater effect on satisfaction than any of these variables. However, use of interpreters was not included in this study.

Language barriers have also been found to be associated with increased time spent in the emergency department (Hampers et al., 1999), decreased general satisfaction with care (David & Rhee, 1998), and lower satisfaction with a number of non-clinical aspects of care (Madhok et al., 1992). Hu and Covell (1986) found that the percentage of patients describing their care as more than adequate was almost twice as high for English-speaking than non-English-speaking patients.

6.4.5 Patient Understanding and Compliance

Patient "compliance" is another issue that emerges from the literature as affected by language access. One would anticipate that patients who had more difficulty understanding their physician would be less likely to follow treatment directions. This appears to be the case. This is not only due to the obvious difficulties in obtaining accurate information, but also because good communication can be a source of motivation, reassurance and support, as well as an opportunity to clarify expectations

(Kaplan et al., 1989). As will be illustrated in this section, what is often termed "compliance" in the medical literature may perhaps be better understood as a patient's comprehension of his or her condition and of the prescribed treatment.

A review of the literature reveals consistent and significant differences in understanding and compliance when a language barrier is present. David & Rhee (1998) investigated general access to ambulatory primary care in a major teaching hospital. They designed a five-minute survey in English and Spanish, which asked patients to rate their Spanish and English verbal skills and whether or not they used an interpreter to communicate with their physician. Patients were asked whether, and from whom, they received information on medications; and if receiving this information affected compliance with therapy. In this study cases were defined as patients who reported using a translator or having poor English skills. Those who reported not using a translator and having good English skills served as controls. Both groups were primarily made up of Hispanic patients. Patient satisfaction was also assessed as an indicator of clinical outcome. Of the 272 patients approached consecutively over a 3-week period, 261 participated. Only 53% of cases, compared to 84% of controls felt that side effects of medications were explained. When only Hispanic patients were compared, the percentage was 53% for cases and 88% for controls, indicating that differences were due to a language barrier, not cultural factors. In addition, a significantly higher percentage of controls reported satisfaction with medical care. While this study made an attempt to control for ethnicity by analyzing the subset of Hispanic patients, it did not gather information on education, and the cases were also somewhat older than controls. It should also be noted that the interpreters used for this study were medical office assistants who had no formal training in interpretation.

Crane (1997) conducted an exit interview of a convenience sample of 314 patients seen in a hospital emergency department. Of these, 69% were English-speaking and 31% were Spanish-speaking. A questionnaire was administered to each of the patients by trained bilingual research assistants. It tested the patients' ability to recall their diagnosis and discharge instructions, follow-up instructions, and proper use of prescribed medicines. The average overall number of correct responses was 59%. However, Spanish-speaking patients performed significantly worse than English-speaking patients. They provided an average of only 46% correct answers, compared to 65% for English-speaking patients. It was noted that few of the treating physicians were bilingual, though about half of the discharge clerks were. Analyses were based on the language of the patients (Spanish or English), not by language congruence/disparity between patient and physician. In this study there was no professional interpreter available.

Karter et al. (2000) provided an example of how language barriers may effect management of chronic diseases. Through a cross-sectional survey, they explored patterns of self-monitoring of blood glucose (SMBG) by diabetic patients in a U.S. managed care population, Kaiser Permanente. As all patients were in the same Health Maintenance Organization, they all had similar access to care. Self-monitoring is considered one of the cornerstones of diabetes care, and is widely recommended. The cover letter accompanying the survey included text in several languages, allowing for requests for surveys in other languages. Those who requested a survey or health education materials in a non-English language, or who used a Spanish-speaking interviewer were categorized as having difficulty communicating in English, as were those who the interviewer assessed as lacking in English language fluency. American Diabetes Association Clinical Practice Guidelines were used to determine adequate utilization. The investigators found that

60% of patients with Type 1 diabetes, and 67% of those with Type 2 diabetes reported practicing SMBG at less than recommended levels. Multivariate analysis revealed that having language difficulties was a significant predictor of less than optimal frequency of SMBG. The authors proposed that this likely happened because patients with language difficulties had difficulty in benefiting from English language diabetes education literature, and may have had more difficulty negotiating the automated telephone systems associated with managed care systems.

Manson (1988) examined the effect of language concordance on patient compliance and emergency room use for patients with asthma. Only monolingual Spanish speakers were included. Patients were considered monolingual if chart notes or the physician explicitly stated that patients spoke only Spanish. Patients whose physicians spoke fluent or nearly fluent Spanish (language concordant group = 65) were compared with patients whose physician spoke little or no Spanish (language discordant group = 31). Patients in both groups were similar in age, gender, employment status and disease severity.

Compliance was measured by serum levels of bronchodilator medication, and by kept appointments. Both emergency room visits and hospital admissions were used as a measure of medical outcome. Patients with a language-discordant physician were less likely to have therapeutic blood levels of bronchodilator medication, and more likely both to miss office appointments, and to make an emergency room visit. This study demonstrated a pathway through which language barriers may affect health outcomes. Poor communication may result in poorer understanding and compliance with medication regimes. This increases the probability that less than optimal levels of medication will be maintained, resulting in poorer symptom control and higher risk of acute episodes.

Evidence is not consistent on the effects of language barriers on appointment keeping behaviour. Gruzd et al. (1986) conducted a multivariate analysis of 25 independent predictors of "no-show" appointment behaviour. They found that language was one of six variables significantly associated with appointment keeping, while race/ethnicity was not. This confirms Manson's findings (1988). In a smaller study, Enguidanos & Rosen (1997) found no significant association between language and appointment keeping. However the small sample size, and lack of control for the type of patient condition and severity of symptoms may have affected results. Sarver & Baker (2000) also found that while there were differences in the number of follow-up appointments given by physicians based on language proficiency, there were no differences in compliance.

Baker et al. (1996) collected information on both patient assessment of their language skills, and physician ability to speak Spanish. Patients were categorized into three groups: those who used an interpreter; those who felt an interpreter was not needed; and those who did not use an interpreter but felt one was needed. A total of 467 Spanish-speaking and 63 English-speaking Latinos were surveyed as to both their self-perceived understanding of diagnosis and treatment, and their objective knowledge of discharge instructions. Patients who said an interpreter was not necessary rated their understanding of their disease as good to excellent 67% of the time. This compared to 57% of those where an interpreter was used, and 38% of those who felt an interpreter should have been used. For understanding of treatment these figures were 86%, 82% and 58% respectively, also a significant difference. However, while there were differences between the groups in objective measures of understanding, these differences were not statistically significant. A limitation of this study was that a variety of different types of interpreters were used, and in only 12% of the time

were these professional interpreters. This results in potentially important differences in quality of communication within the group using interpreters.

A review of North American pediatric burn units found that 41% of facilities reported language and sociocultural barriers to patient education (Jenkins & Stanwick, 1991). Given the complexities of care for burn patients, this lack of patient information may well be associated with poorer outcomes. Difficulties in understanding and compliance in rehabilitation settings has also been highlighted (Smart & Smart, 1995). One study of mental health services found that 40% of patients had a negative experience seeking mental health services, mostly because they did not understand the diagnosis and found treatment to be ineffective (Li et al., 1999).

6.4.6 Ethical Standards of Care

There is also compelling evidence that quality of care for those who are not fluent in an official language is affected through failure of health care providers to meet ethical standards. Three ways that ethical care is compromised are through a) failure to provide care to the same standard as received by other patients, b) failure to protect patients' confidentiality, and c) failure to adequately ensure patients' informed consent to treatment.

Equitable access to quality of care

Government reports have indicated that patients who do not speak an official language do not receive the same standard of care in Canada (Tang, 1999). While the most dramatic examples are those where misdiagnosis has resulted in injury or death, the research indicates that in spite of the best intentions of providers, patients who do not speak an official language are likely, on a day to day basis, to receive less protection in terms of ethical standards than English- or French-speaking patients.

Both the case study literature and recent prospective studies indicate that absence of accessible services often results in failure to utilize preventive care, and delayed presentation for care (Li et al., 1999; Stevens, 1993b). Flores et al. (2000), in an analysis of three pediatric cases, explored: the ways in which language barriers resulted in delayed diagnosis, and then in complications; the inappropriate apprehension of children based on an inaccurate diagnosis of child abuse; and failure to communicate to parents the severity of a critically-ill newborn's condition. Interpreters who are family members may also withhold crucial evidence necessary for diagnosis and care (Affiliation of Multicultural Societies and Services Agencies of BC, 2000).

Informed consent and confidentiality

Obtaining informed consent and maintaining confidentiality are both critical standards in the delivery of ethical care. However, open and frequent communication is essential for informed consent to occur. When patient and provider do not share the same language there is an immediate barrier to informing the patient of his/her situation and the choices available (Barnes et al., 1998). In many cases where consent is given, the patient does not understand all the implications of the procedure. For example, cases have been reported of women agreeing to be sterilized, not realizing that this is a permanent procedure (Stevens, 1993b), or scheduled for abortions that they did not want (Affiliation of Multicultural Societies and Services Agencies of BC, 2000). Family members or untrained interpreters not only risk misinterpreting key concepts, but may also distort the message by omission or by direct intervention in the process. This fundamental barrier to consent may also be complicated by an increased risk of misunderstanding due to differences between the cultures of the provider and patient.

"Consent" also has different meanings in different societies. Those facing language barriers may be more likely to hold beliefs related to sharing of bad news, and individual versus family decision making, that do not neatly fit medical perspectives of the consent process (Marshall & While, 1994; Solomon, 1997; Kaufert et al., 1999; Ellerby et al., 2000). Kaufert & Putsch (1997) have used case studies of interpreter mediated communication in ethical decision making to understand the limitations of professional codes of ethics and roles of interpreter advocates in consent and decisions at the end of life.

One of the greatest risks of using untrained, ad hoc interpreters (the most common response to language barriers in Canada) is the risk to confidentiality. This is of particular concern in sensitive areas such as mental health or reproductive health (Stevens, 1993b; Betancourt & Jacobs, 2000). The case study literature provides many examples of the ways that communication barriers result in breakdown of confidentiality and failure to obtain consent for treatment, and describes the potentially devastating effects on the patient or family (Haffner, 1992; Stevens, 1993).

While concern over use of family members or volunteers as interpreters has focused on the risks to the patient and provider, there are also ethical issues involved in placing volunteers or family members in these situations. Often volunteers do not want to interpret, but feel that there is no other option. They often report stress and discomfort (Affiliation of Multicultural Societies and Services Agencies of BC, 2000). Using children to interpret for often sensitive or traumatic topics is a particular concern, as this practice can disrupt normal family relationships and expose children to psychological risk. The case study literature includes examples where a child has been asked to communicate to her mother that the fetus she was carrying was dead (Haffner, 1992), has experienced severe psychiatric disturbance after being asked to

interpret, over an extended period of time, for a dying sibling (Jacobs et al., 1995), or has been asked to interpret information related to sexual activity of a parent (Stevens, 1993b).

6.5 How Do Language Barriers Affect Health and Utilization?

The research described above has identified differences in treatment, outcomes, satisfaction and "compliance" between patients who face linguistic barriers to care, and those who do not. But how exactly do language barriers result in these effects?

6.5.1 Analysis of Provider-Interpreter-Patient Interactions

One approach to investigating how the effects described above are accomplished involves presentation of narrative text showing the actual process of interpretation.

Marcos (1979) undertook a study of Chinese- and Spanish-speaking psychiatric patients and their providers. He attempted to identify the patterns of distortions associated with the interpreter-interviewer procedure with three different types of interpreters: psychiatric nurses with experience in clinical psychiatry; nurse's aides; and patient's relatives. While the author states that all were fluently bilingual, other qualifications were not identified. Content analysis of audio taped interviews were conducted by an English-speaking psychiatrist with the help of an interpreter. Marcos found three major types of distortions: a) distortions associated with the interpreter's language competence and translation skills, b) distortions associated with the interpreter's lack of psychiatric knowledge, and c) distortions associated with the interpreter's attitudes. He provided specific examples of each of the three types. An example of the type of distortion that can arise in the

interpretation process is illustrated through the interpreter's transmission of a patient's response to the question about whether there was anything that bothered him:

Patient: *"I know...I know that God is with me. I'm not afraid, they cannot get me. [pause]. I'm wearing these new pants and I feel protected, I feel good, I don't get headaches anymore."*

Interpreter: *"He says that he is not afraid, he feels good, he doesn't have headaches any more." (p. 173)*

The study concluded that clinicians evaluating non-English patients through an interpreter are confronted with consistent, clinically relevant, interpreter-related distortions that may give rise to important misconceptions about the patient's mental status.

Ebden et al. (1988) examined four bilingual (Gujarati/English) interviews where family members were used as interpreters. Gujarati sections of videotaped interviews were independently translated into English. From these transcripts, 143 questions and answers were analyzed according to question structure, translation of terminology, and family interactions that may have hampered communication. Analysis of question structure showed that complex and serial questions resulted in the greatest number of interpretation errors. Even simple questions resulted in an average of over 25% of all questions being either mis-translated or not translated at all. In the 143 exchanges, 80 words or phrases were mis-translated or not translated by at least one interpreter. Errors were found in anatomical terms (e.g. leg used for ankle, back teeth for jaw, neck for tonsil, and chest for ribs). Interpretation of symptoms caused more difficulties (e.g. interpreters used the terms laxative for diarrhea, watery feces for passing water, and getting fat for swelling).

Technical terms (e.g. breathlessness for asthma, being mad for epileptic fit) were often mis-translated, and words such as gynecological, gallstones, or waterworks, were not translated at all. It was also found that questions about body functions (e.g. menstruation or bowel movements) were often ignored. Children found it embarrassing to translate these types of questions for parents. Of interest was the authors' observation that the interviews appeared reasonably normal to the physician.

Downing, a professor and researcher in linguistics at the University of Minnesota, in his analysis of interpreted health encounters (1992) also demonstrated the risks in using untrained/ volunteer interpreters. In one example, an encounter between a nurse practitioner, a patient, and the patient's son acting as an interpreter identified several kinds of miscommunication. In a conversation of only 25 exchanges, the following were identified:

- ◆ the interpreter failed to understand the provider's question and did not seek clarification (4 times);
- ◆ the interpreter interfered with the flow of the interview by asking for a paraphrase or explanation of particular words (4 times);
- ◆ the interpreter misinterpreted because of lack of understanding of particular words and idioms (5 times);
- ◆ the interpreter responded to a question himself without any attempt to interpret the question or his English response to the patient (6 times);
- ◆ the interpreter volunteered his own opinions or information regarding the patient (5 times);
- ◆ the interpreter's failure to interpret the question led the patient to try to guess what the question was and attempt an answer (4 times);

- ◆ the interpreter failed to interpret an answer offered by the patient (6 times);
- ◆ the interpreter seriously distorted the message in the process of interpreting it by adding information (2 times), omitting information (4 times), or changing the meaning (7 times);
- ◆ the reply that the practitioner received from the patient was the answer to a different question than the one she asked, but did not know it (2 times) .

Flores et al. also report on a study in a pediatric primary care clinic where an average of 29 interpretation errors were made per encounter, and 63% of the errors had definite or potential clinical consequences (Flores et al., 1999 as cited by Flores et al., 2000).

These analyses demonstrate both the frequency of errors and the types of errors made in the interpretation process. They highlight the risks of using untrained, ad hoc interpreters or family members, and alert providers to the potential effects of mis-translation. Analyses can also identify differences in communication where no interpreter is available.

A study from British Columbia by Jones & Amelsoort Jones (1986) on communication with elderly patients in long-term care facilities, demonstrated how a language barrier can result in different "quality of care". Patients were divided into three groups: those born in Canada, those born in the United Kingdom, and those born in other countries (Jones, 1986). All in the third group were born in non-English, non-French-speaking countries (mostly European), and only one was fluent in English. Tape recordings of interactions with nurse resident contacts were collected in two one-hour blocks each weekday. Tapes were transcribed and utterances coded as "words", "commands", "statements", and "questions". Significant differences were found between the

three groups, with the "ethnic" elderly being communicated with less than the other two groups. Limitations of the study included the small sample size (36), the fact that only certain hours in the day were chosen for analysis, and the lack of data on both language congruence between staff and patient, and non-verbal behaviour between patients and staff.

6.5.2 Making the Links: Research on Patient-Provider Communication

A broader perspective on the potential impact of language barriers on health outcomes can be obtained by reviewing the research related to patient-provider communication. It is generally accepted that the provider-patient relationship is built through the effective use of language. Communication is central to the practice of medicine (Woloshin, 1995). Reviews of the literature (Kaplan et al., 1989; Stewart, 1995; Stewart et al., 1999, 2000) indicate that there is a relationship between the quality of patient-provider communication and the patient's health outcomes. In addition to the more obvious effects on satisfaction and adherence to treatment regimens, the quality of communication has been found to have a generally positive effect on actual patient health outcomes, such as pain, recovery from symptoms, anxiety, functional status, and physiologic measures of blood pressure and blood glucose levels. Kaplan et al. (1989) describe three basic communication processes associated with improved health outcomes: a) the amount of information exchanged, b) the patient's control of the dialogue, and c) rapport established. All of these processes are jeopardized in language discordant encounters (Betancourt et al., 1999).

These processes can also be affected when an interpreter is used. Rivadeneyra et al. (2000) explored dimensions of communication in encounters requiring an interpreter. Video-taped interviews with Spanish-speaking and matched

English-speaking patients were coded using Henbest and Stewart's Patient Centeredness Measure, which assesses how a physician responds to a patient's verbal "offers". Offers were coded into six categories: symptoms, expectations, thoughts, feelings, prompts and specific cues. Physicians' responses to these offers were coded as ignoring, closed, open, or facilitating. English- and Spanish-speaking patients differed significantly on all categories of offers except prompts. English-speaking patients (where no interpreter was used) made an average of 20 offers, compared to an average of seven offers for Spanish-speaking patients. English-speaking patients were also more likely to receive a response to their comments from the physician, and less likely to have their comments ignored than were Spanish-speaking patients. Interpreters were all clinic nurses, however, there was no description of their training in interpretation. While there were highly significant differences in provider-patient communication related to language, there were no significant differences by ethnicity (that is, English-speaking Latinos had similar offers and responses as non-Latinos). The authors note that they found no evidence that Latino cultural norms about behaviour in a health encounter exacerbated the differences.

While the research on provider-patient communication suggests the ways in which language barriers may effect health outcomes, satisfaction and compliance; patients who lack proficiency in an official language are often excluded from participation in research related to patient-provider communication. Therefore the specific effects of language barriers on the provider-patient relationship have not been well explored. In addition, the exclusion of these patients from research means that studies are not describing the experience of all patients in the society. More research is needed in this area.

6.5.3 Making the Links: Research Related to Health Literacy

Another source of insight into the possible impacts of language on health outcomes is the literature on health literacy. Recent research has highlighted the correlation between literacy and health status and health outcomes (Sarginson, 1997; Perrin, 1998). Low literacy has been linked to lower health status, increased rates of hospitalization (Baker et al., 1997; Baker et al., 1998), and poor understanding of health conditions and diseases (Williams et al., 1998; 1998a). Patients with low health literacy are less likely to understand discharge instructions, and more frequently report medication errors due to inability to read prescription labels (Baker, 1999). Literacy is also a factor affecting ability to benefit from health promotion or disease prevention information (Sarginson, 1997).

It is important to note that while low literacy is correlated with low education levels, low health literacy is also found among individuals with higher levels of education who lack fluency in an official language. It is estimated that 29% of those who are foreign born and claim some university education actually test as functionally illiterate in an official language, compared to 6% of the Canadian born population with the same level of education (Calamai, 1987). Deaf persons are also likely to have significantly lower literacy rates in official languages (Witte & Kuzel, 2000).

Provision of materials in non-official languages

While use of print or audio-visual materials is not the focus of this report, provision of materials in non-official languages is one way to address certain types of language barriers (e.g. patient health education material, or discharge instructions). Persons who do not speak an official language are much less likely to pick up ambient information (e.g. from the media, or even from conversations). Research on knowledge of specific health topics such as AIDS has found that those who do not speak an official language (including Deaf persons) tend to have much lower rates of understanding of the disease and are subsequently less likely to adequately protect themselves (Stevens, 1991; Peinkofer, 1994).

There are two general approaches to provision of resources in other languages: translation from the original, or development of resources based on community needs and interests (Stevens, 1993b). Specialized expertise is required for either of these methods, and both face issues of limited funding and quality control. Few translated materials are available, and many are developed independently by specific institutions, resulting in duplication and inefficiency. One response to this has been the Translated Health Materials Project, which aims to provide coordination, reduce duplication, and establish standards for resource development, translation and evaluation (Wilson & Ibanez-Carrasco, 2000).

However, many who lack proficiency in an official language may also have lower literacy in their first language. Written materials must therefore be supplemented with other approaches. Provision of a greater variety of plain language materials in English or French is another strategy for increasing access to health information, for both those who have limited proficiency in an official language, and official language speakers with low literacy skills.

6.5.4 Making the Links: Time Needed for Consultation

A recent time-motion study comparing physician time spent with non-English-speaking and English-speaking patients in an American hospital found that there were no significant differences in the time physicians spent providing care to the two groups. However, a significant number of physicians believed that they spent more time during a visit with non-English-speaking patients (Tocher & Larson, 1999). In this study, certified interpreters were available to all patients. A small survey of occupational therapists in the U.S. found that therapists reported taking more time with patients who were not proficient in English. However the size and design of the study may have led to bias (Wardin, 1996). In a more recent U.S. study (Kravitz et al., 2000), both Spanish- and Russian-speaking patients were found to take more time than proficient English speakers, and encounters with professional interpreters took more time than those using friends and family. However, this study was small and non-randomized, and the three language groups differed in many ways. Other studies have found that patients using a hospital interpreter spend less time in the clinic between evaluation and discharge, than those who bring their own interpreter (Cashman, 1992).

These studies suggest another route through which quality of care (resulting in poorer outcomes, satisfaction and compliance) is affected. Additional time is required for communication when an interpreter is utilized. Equal time for appointments is unlikely to translate into equal care when patients cannot communicate directly with physicians (Taira, 1999). However, as they are not reimbursed for this additional time, providers may "skip" verbally based evaluation. This may result in greater reliance on diagnostic testing. In the absence of any compensatory testing, there may be a lower likelihood of correctly identifying and

treating the underlying condition. Additional research is needed on the effects of both language barriers and various types of interpreters on the time necessary for effective provider-patient communication.

6.5.5 Making the Links: Provider Continuity and Regular Source of Care

An issue of growing concern in many countries, including Canada, relates to the effects on health of not having a regular source of care (such as a family physician). Lack of a regular physician is associated with both lower health status and differences in utilization patterns. In a recent Canadian study, bivariate analysis and logistic regression were used to undertake secondary data analysis of the National Population Health Survey. A total of 15,777 respondents were included in the study. Being a recent immigrant was one of the characteristics associated with not having a regular physician. Those who had lived in Canada less than four years (the group most likely to face language barriers) were twice as likely to have no regular doctor (Talbot et al., 2001). While language proficiency was not included as a variable in the analysis, findings in other countries have identified language as a barrier to having a regular source of care (Weinick & Krauss, 2000). This study also found that immigrants who had lived in the country more than 10 years were significantly more likely than the Canadian born to have a regular doctor. These findings suggest a complex interaction between immigrant status and health service utilization that requires further research.

6.5.6 “Ethnic Matching” Between Client and Provider

It has been suggested that patients may have more confidence in care by providers from their own ethnic background (Health Canada, 1998; Saha et al., 2000). A number of studies have identified higher levels of utilization and satisfaction where

there has been ethnic matching between patient and provider (Flaskerud, 1986; 1990; Ahmad et al., 1989; 1991; Snowden et al., 1995; Silgrove et al., 1997; Jerrell, 1998). Language congruence has been proposed as one explanation for this. For example, Ahmad et al. (1989) found that for South Asian women language was more important in their choice of a physician than was gender. A recent U.S. study found that language was one of the reasons that minority patients sought physicians of their own race (Saha et al., 2000). To what extent “ethnic matching” is important as a marker of language congruence requires additional research (Flaskerud, 1990; Flaskerud & Lui, 1990).

6.6 Summary

This section reviewed evidence of the impact of language barriers on quality of care from a number of perspectives:

- ◆ the treatment clients receive after presenting for care;
- ◆ the health of the client;
- ◆ patient understanding and compliance;
- ◆ patient satisfaction; and
- ◆ ethical standards of care.

In Canada, although there has been significant research on differences in treatment based on socio-economic status (Dunlop et al., 2000) there has been almost no research on differences in treatment by ethnicity or language proficiency. While research from other countries suggests that there may be inequities in treatment based on ethnicity (Todd et al., 1993; Cleeland et al., 1997; Mayberry et al., 1999), similar research has not been undertaken in Canada. It is also unclear to what extent language barriers may account for observed differences in treatment between ethnic groups.

There is some suggestion that in Canada, those who lack official language proficiency may be more likely to receive specialist referrals or diagnostic testing (Blais & Maiga, 1999). This is consistent with some research in other countries that indicates that in some situations providers may “compensate” for language barriers by relying more heavily on laboratory or specialist assessment (Tocher & Larson, 1998; Karter et al., 2000). There is however, strong evidence that in Canada, as in other countries, those facing language barriers receive different services and quality of treatment in the areas of mental health and counseling (Canadian Task Force on Mental Health Issues Affecting Immigrants and Refugees, 1988).

The question of whether treatment provided to patients is affected by language barriers requires significantly more research. In the absence of research focusing on questions of equitable treatment, it cannot be assumed that inequities do not exist. Until specific Canadian research is undertaken, findings of differences in treatment in other countries should be interpreted with caution. Research from one country often cannot be generalized to another because of differences in culture, history, and systems of health care provision.

There is also little direct evidence related to the effects of language barriers on health status. However, it is useful to make the links between the research on language barriers and the literature on provider-patient communication and health literacy; two closely related research areas. There is strong evidence from this body of research that poor provider-patient communication and lower literacy in the official language(s) is linked with poorer health outcomes. Effects on health outcomes due to differences in communication can be expected to be similar between countries.

There has been more research related to patient satisfaction. Language barriers are consistently associated with lower patient satisfaction with care. It is not clear to what extent findings from other countries related to patient satisfaction can be generalized to Canada, again because of differences between health systems. Many programs report that immigrants are often extremely positive about the health care system in Canada, and express high levels of satisfaction. Differences in satisfaction appear most closely correlated with social class, with those from less privileged backgrounds expressing the highest satisfaction (Bowen, 1999).

At the same time, most studies of immigrants in Canada, like those done in other countries, find that one of, if not the greatest, barrier to access reported by newcomers is that of lack of interpreters or bilingual providers (Stevens, 1993b; Stephenson, 1995; Calgary Multicultural Health Care Initiative, 2000). Canadian research also indicates that there is much higher satisfaction with professional compared to volunteer interpreters. A survey by the Montreal Inter-regional Interpreters Bank of 68 clients found that 76% of clients preferred dealing with a professional interpreter when consulting medical personnel; 88% had more confidence in the accuracy of interpretation provided by professional interpreters, and 83% had more confidence in the discretion of a professional interpreter (Mesa, 1997). This indicates that even if many arrivals are appreciative of health services in general, their satisfaction with specific encounters may be low. Research on this topic, therefore, requires careful assessment of these two aspects of satisfaction.

Satisfaction with care by Aboriginal peoples is often low, however, there is greater evidence that there are differences in access and care related to geographical barriers, confusion over provincial/federal jurisdiction for Aboriginal health coverage, and distrust of health services based on historical

and personal experience of discrimination (Canadian Nurses Association, 1995; Aboriginal Health and Wellness Center, 1997; O'Neil et al., 1988; O'Neil et al., 1999). While language barriers are expected to increase dissatisfaction, the importance of language barriers in contributing to dissatisfaction is unclear.

The research indicates that language barriers have a negative effect on patients' understanding of their condition and the prescribed treatment, and therefore on patient "compliance". This is consistent with the general literature on provider-patient communication, that provides strong evidence that communication affects patient adherence (Stewart et al., 1999). There is no reason to suggest that findings related to compliance and communication would be significantly different in Canada than in other countries. It may, however, be expected that adherence to treatment may be higher in Canada on some measures, as universal coverage removes many financial barriers to adherence to prescribed treatment.

There is solid evidence from Canadian programs that patients who do not speak an official language do not receive the same standard of ethical care as other Canadians. Case studies from across the country, found in both the published and grey literature, emphasize the failure of Canadian health services to ensure informed consent, and protect the confidentiality and privacy of patients who face language barriers.

In addition to research on provider-patient communication and health literacy, three other research areas are related to that of language access. Research related to ethnic matching of provider and client; research on the importance of a regular provider; and research related to time allocated to the patient-provider interaction may also provide useful insights on the importance of language barriers to health.

It cannot be assumed that the barriers to quality of care experienced by Deaf, immigrant or Aboriginal patients is equivalent. Most studies identified for this review have focused on immigrant communities. Research is needed to explore whether the effects of language barriers experienced by one language constituency can be generalized to others.

7. Other Effects of Language Barriers

Language barriers, and the absence of programs to address them, have other indirect but important effects. These include:

- 7.1 Effects on health research and development of knowledge;
- 7.2 Effects on health care providers; and
- 7.3 Effects on costs of service provision.

7.1 Effects on Health Research and Development of Knowledge

A less obvious effect of language barriers is the exclusion of those who are not proficient in an official language from participation in health research. Over the past several years, the recruitment of diverse populations has emerged as an important challenge to health researchers (Lovato et al., 1997; Hodge et al., 2000). It is recognized that both clinical and health services research tends to under-represent ethnic minorities, especially those who are not proficient in an official language (Hazuda, 1996; Ren & Amick, 1998).

There are a number of reasons for this exclusion. Since the Second World War, the participation of vulnerable persons in health research has been approached with caution. This has been in response to medical abuses in the late nineteenth and early twentieth century in Europe and North America. However, it is increasingly acknowledged that exclusion from research results in discrimination and injustice towards minorities.

“Members of society should neither bear an unfair share of the direct burdens of participating in research, nor should they be unfairly excluded from the potential

benefits of research participation.”
(Medical Research Council of Canada, 1998)

Reviews have confirmed that ethnic minorities are often deliberately excluded from biomedical research. Larson (1994) reviewed 754 approved research protocols from one tertiary care centre over a two-year period, and found that the number of minority persons enrolled in clinical trials was disproportionately small. The author noted that an important limitation of the study was that only exclusionary criteria specifically mentioned in the written protocols were evaluated, and that much more non-stated exclusion occurred in practice. For example, while only 0.3% of studies reported deliberately excluding patients on the basis of language, many more failed to include them. Exclusion is often attributed to difficulties in recruitment, and obtaining informed consent (Guilano et al., 2000). Patients are expected to give *informed* consent to participation in research activities. This is not possible if there are significant language barriers. Another reason for exclusion is that researchers may not have the financial or human resources to include non-English or non-French speakers. Not only is it necessary to identify research assistants with the appropriate background and language skills, but research instruments may need translation and validation – activities that are expensive and time consuming. Clinical trials may also deliberately exclude specific ethnocultural or racial groups in order to ensure similarity of research subjects. However, in other cases, the option of including minority language speakers is simply not considered.

Those who do not speak an official language are excluded from other forms of research as well. Exclusion from survey research may perhaps be the most obvious example. Few surveys have the resources for either questionnaire translation/validation or trained bilingual interviewers. Woloshin et al. (1997) noted that approximately

2.4% of those eligible could not be included in an Ontario health survey because they could not communicate in one of the official languages. As indicated in an earlier section, even when minority language speakers are included, (by means of a translated instrument, for example) there remain concerns about the quality of the information obtained.

One study by Frayne et al. (1996) focused specifically on exclusion of non-English-speaking persons from research. A total of 172 original investigations on provider-patient relations, involving direct interaction between researcher and subject, were identified through a Medline search. The authors of these studies were then surveyed. The researchers found that non-English-speaking persons were included in only 22% of these studies, and that the studies that included them often appeared to do so incidentally rather than systematically. They found that half had no operational definition of "non-English-speaking" (NES), 8% used 'informal interpreters', and only 26% stated in their methods section that they had included NES persons. In addition, nearly 1/3 of studies that included NES persons included some groups but not others. The authors also identified evidence that non-English-speaking persons were an "invisible group" to researchers. Many researchers stated that there were no NES persons in their area, even though almost all studies took place in large metropolitan areas. Over half of those who excluded NES persons stated that they hadn't thought about the issue.

The authors concluded that this exclusion limited the generalizability of the research, which affected both efficacy and effectiveness of treatment. This study is of particular interest as it focused on a research area (patient-provider communication) where there is clear evidence that language discordance has a major effect.

Exclusion from research has both health and economic effects. The risk of certain diseases and conditions, and the response to specific drugs are only two of the areas where there may be ethnic/racial differences. Exclusion of certain ethnic groups from biomedical research may therefore mean that study results cannot be generalized to the entire population (Harrison, 1994; Cotton, 1990). Exclusion specific to language fluency may also prevent accurate assessment of the actual effectiveness of treatments (as opposed to efficacy) by not including the effects of language difficulties on treatment comprehension and compliance. In addition, members of language minority groups are prevented from benefiting from participation in cutting edge treatment for diseases such as cancer (Kaluzny et al., 1993; Roberson, 1994; Guilano et al., 2000).

7.2 Effects on Health Care Providers

While the focus of this report has been the effect of language barriers on patients, language barriers also pose problems for providers.

Communication barriers result in stress and lower job satisfaction. The presence of an interpreter poses difficulties in establishing the same quality of communication and rapport (Rivadeneira et al., 2000). Working with an interpreter can be frustrating. Providers may have less confidence that the work they are doing with patients is helpful, and express discomfort in seeing patients when there is a language barrier (Kline et al., 1980; Hoyt et al., 1981). Using an interpreter takes more time than direct communication, and often this is not time for which fee for service providers (e.g. physicians) are reimbursed.

Language barriers may also present challenges to learning for medical students and residents. A survey of medical residents by Chalabian and Dunnington (1997) found that 97% of residents

believed that quality of care was affected to some degree; 44% felt that language barriers had a significant or very significant impact on quality of patient care; and 80% felt that language barriers had significant or very significant impacts on communication with the family. Respondents reported that they shifted their focus of care in bedside encounters to issues not requiring patient participation. Language barriers were also identified as a key source of stress for residents. Reports indicated that language barriers lengthened the workday by 52 minutes. They also reported that language barriers affected the quality of the learning experience, as role modeling by teachers could not demonstrate certain skills.

Providers may also experience stress in attempting to meet ethical standards in providing health care, including the Codes of Ethics for their professions. Language barriers affect several key ethical areas: medical decision making, confidentiality, patient vulnerability, equity among patients, and cultural representation – which includes the obligation to address language barriers (Emmanuel, 1996).

Linguistic barriers to accurate diagnosis and informed consent may also place a provider at greater risk of liability (Schneiderman, 1995). Two British Columbia cases illustrate these risks. The B.C. Supreme Court found a doctor negligent in his examination and diagnosis of a man whose leg was amputated as the result of this misdiagnosis. The ruling stated that the patient's language difficulty should have made the doctor especially careful in conducting his physical examination. The patient was awarded \$1.3 million (Needham & Wolff, 1990). In another case, language barriers were identified as a contributing factor in the death of a pregnant Vietnamese woman. The coroner in the case recommended that the College of Physicians and Surgeons assess the need for interpreters for patients who speak little or no English (Walton, 1996). The issue of the interpreter's role in

obtaining consent was also raised in the recent inquiry into pediatric cardiac deaths in Manitoba (Sinclair, 2001).

It has been predicted that litigation in the health field will remain a dominant force. Providers are advised to take particular care in ensuring appropriate consent, and in recording the basis for their actions (which includes noting the role of an interpreter in obtaining consent) (Shneiderman, 1995; Champion, 2000).

General studies about patient satisfaction or dissatisfaction related to patient-doctor communication indicate that complaints about doctors are usually due to communication problems and not technical competency issues (Rozovsky & Rozovsky, 1982; Stewart et al., 1999). The Canadian Medical Protective Association identifies communication as the major source of lawsuits against its members (McKerrow, 1997). Other issues related to malpractice claims are delays and diagnostic errors, which are also more likely when a language barrier is present.

To date, there have been relatively few lawsuits related to language barriers in Canada. This may in part be due to the fact that satisfaction is linked with patient expectations (Stewart et al., 1999). For example, many new arrivals may have different expectations of the health care system than the Canadian born, especially if in their country of origin they had less access to care (Bowen, 1999). Communication barriers may also prevent or discourage patients from making a complaint. They may be unfamiliar with their rights and the appropriate process for lodging complaints. It has also been identified that many newcomers, particularly refugees, may be afraid of making complaints, as they are unsure what repercussions this may have on their future care (Stevens, 1993b).

7.2.1 Differences Between Provider and Patient Assessment of Barriers

There is evidence that providers and their clients have different perspectives on the importance of various barriers to access. Many differences in utilization have been attributed to differences in cultural beliefs and practices. Where language has been studied, it has often been as a measure of "acculturation". However, while ethnic groups have been found to have differing health beliefs and practices than the general population, specific research controlling for both language and culture does not support the hypothesis that these traditional beliefs and practices act as barriers to access to health care or utilization of preventive services (Jenkins et al., 1996). Guo (2000), in discussing health behaviours of older Chinese in the U.S., observed that they did not resist something simply because it was "culturally different", and that much of their resistance to Western medicine was due to costs, the complexities of access, language problems and other pragmatic reasons. These findings are confirmed by many program reports where it is found that patients are often enthusiastic about "western" medicine, even when it differs significantly from their traditional practice (Stevens, 1993b).

There have been a number of Canadian studies comparing barriers to access and care from the perspective of providers and patients. A qualitative study by Cave et al. (1995), using focus groups of family physicians and immigrant patients, found that physicians tended to see patients as "norms" who behave in expected ways, rather than individuals of a given background with their own stories. Physicians appeared to think that understanding a patients' culture would help achieve better diagnosis and more effective management. They were often frustrated and anxious about using interpreters. Patients tended to think that culture was unimportant, and did not expect culturally

sensitive care. They were happier with using interpreters.

Chugh et al. (1993) undertook phone interviews of physicians and immigrant clients. They found that language barriers were perceived by both physicians and patients. However, only physicians found that patients' belief in traditional practices or compliance with treatment to be a barrier. Only patients reported that racial discrimination was a barrier. Similar differences between providers and clients were found in a Quebec study (Gravel & Legault, 1996) of social workers and immigrant families. Families tended to look to health professionals for help with problems, and when they did not, language was determined to be the major problem with accessibility. Workers, on the other hand, placed more emphasis on the importance of cultural compatibility of service provision.

While these studies were small and risked selection bias, this review of the research on language access suggests that there is relatively weak evidence for "culture" as the determining factor in patient-initiated utilization, once differences in health insurance, socio-economic factors and language are taken into account. For immigrants in particular, there is increasing evidence that "ethnicity" (and differences attributed to country of origin or immigration status) may often be a marker for language discordance between patient and provider. In studies where language access has been the focus of research, the ability to communicate with providers, and not ethnicity, has emerged as the determining factor.

There continues to be a need for development of culturally appropriate programs, particularly in health promotion, and for greater emphasis on increasing the cultural competence of providers. However, the research suggests that greater efforts should be directed at facilitating language access between clients and providers.

7.3 Effects on Costs of Service Provision

As indicated throughout this and the previous section, there is evidence that language barriers may have important effects on health care costs, through their impact on service utilization and health outcomes. However, the potential cost savings of skilled interpretation have never been adequately assessed (Jackson, 1998).

"Costing studies" related to language access services are often not full economic evaluations. Instead, they undertake a partial evaluation by estimating only costs, or only consequences; or by documenting the costs of only one alternative. Many institutions do not accurately track costs on services provided. Methods for estimating costs vary depending on whether professional interpreters are used (whether paid a salary or by session), whether there is reliance on interpretation by telephone, or whether estimates of volunteer or redirected staff time are used. For example, a 1996 report in British Columbia found that the nine hospitals surveyed reported costs using different definitions for interpretation, and there was difficulty in identifying total costs (Berman, 1996).

Rader (1988) used a simple method to compare the *costs* of two alternatives to language access. In this study, costs to the specific institution were examined – costs to other systems or patients were not included. After determining the percentage of persons who required interpretation who did not come with their own interpreter, she then analyzed who was being used for interpretation. It was found in this case that over 50% of interpretation was provided by nurses and doctors in the clinic, with additional services provided by other clinic staff. Using the estimates developed from a survey of

average interpretation time, the total number of hours per month of staff "interpreter" time was calculated, and this figure multiplied by the average nurse's salary. This study was successful in demonstrating the 'cost effectiveness' of hiring additional interpreters.

Other studies evaluated only consequences. Hampers et al. (1999) measured the charges⁷ made for testing that were ordered for two groups of patients (those with and without a language barrier to care). It was determined that significantly higher charges were incurred for patients where a language barrier was present. Based on the differences between the two groups, the authors identified a 32% "premium" for work-up of patients facing a language barrier. The authors observed that to determine cost-effectiveness of professional health interpreters, it would be necessary to determine a) the volume of patients with a language barrier for whose language the interpreter had been hired, b) the precise size of the "language barrier premium" (incremental costs associated with absence of a program), and c) the extent to which the interpreter could reduce that premium.

While many providers are concerned about the costs of professional interpretation programs compared to no program at all (in other words the costs of language barriers compared to costs of some intervention), another approach is to compare the costs of two different methods of addressing language barriers.

Hornberger (1998) developed an analytical framework for estimating costs of alternative methods of bridging language barriers to optimal health care. He summarized key principles of cost accounting directly relevant to costing studies in

7 "Charges" refers to the price charged by the institution, whereas "costs" refers to the actual costs to the institution of providing the service. Charges and costs may differ substantially, particularly in a private health care system.

health interpretation, with the aim of assisting consumer groups, health care administrators, and public health officials in determining the optimal method for bridging language barriers.

He then compared remote-simultaneous interpretation (by phone service), and proximate-consecutive (in-person) interpretation, in the well baby clinic of a medical centre. The two alternatives had been previously evaluated through a randomized clinical trial. This study had found that the new, remote system was associated with a high level of acceptance, more utterances, and fewer interpretation errors. Then the cost of implementing the new, remote system was assessed. Costs were identified as the telecommunications system necessary to link with the interpreter; headsets for interpreter, patient and clinician; dedicated phone lines; and training in simultaneous interpretation. The salary costs were considered to be equivalent. By varying the assumptions in the model, an estimation was made of the number of interpretation encounters per day. The study found that the average cost per proximate-consecutive encounter was \$11.25, and the added (or incremental) cost of remote-simultaneous interpretation was \$1.10. It would be necessary for the new program to increase the number of interpretation sessions from 15 (the average number of in-person sessions) to 17 (at which time the new program would begin to be cost effective).

A comprehensive approach to cost-benefit analysis was undertaken in one U.S. hospital by Nazneen (1997). This study involved the application of cost-benefit analysis to evaluating interpretation services as a mechanism for overcoming access barriers to health care. Nazneen hypothesized that providing interpretation services, as an input variable for limited English-speaking patients, would save money by avoiding delayed care. This would result in reduced complications; reduced hospitalizations and hospital

emergency department utilization; reductions in lab work; and reductions in the number of unnecessary tests. Consumer benefits were measured in terms of reducing the probability of death related to medical complications and reducing suffering from incorrect treatments and incorrect diagnoses.

The mechanism for increasing producer surplus was hypothesized to be that of providing interpretation services for limited English-speaking patients. Nazneen proposed that this would avoid duplication of services, help avoid unnecessary complications, save physician time and improve patient compliance with treatment procedures and scheduled appointments. However she also recognized that the high level of unmet need for health care could produce a situation in which the provision of interpretation services might actually increase utilization of services.

This analysis utilized data on the experience of patients with selected admission criteria, in selected hospitals in Massachusetts, before and after the introduction of interpretation services. The investigator examined inpatient costs for Spanish-speaking patients, adding the cost of interpretation services for patients on six units. She examined children's health status, evaluated through calculating the average number of outpatient visits, and apparently controlling for the influence of case mix by using Diagnosis Related Groups. Her longitudinal analysis of discounted costs of treatment appeared to reflect a slight, but continuous decrease in discounted costs of care over a four-year time period.

Nazneen's creative use of data to model and assess the cost and effectiveness of interpretation services, applied a social utility model to demonstrate the consequences of using trained and untrained interpreters. However the analysis faced some fundamental limitations. These included limitations on a) availability of data on the

actual provision of interpretation services, b) the outcome measures used to reflect changes in health status, c) meaningful measures of continuity of care, and d) level of control over other potentially confounding variables (particularly due to the 'before and after' design of the study). The assignment of costs is also open to question.

7.4 Summary

The exclusion of those with limited proficiency in an official language from health research does not appear to differ significantly between countries. This is also one area where changes in Canadian practice will have limited effect. Reliance on international research to guide Canadian practice means that the failure of other countries to include language minorities will also have an effect on the information available in Canada. For this reason, along with explicit policy and resource allocation designed to increase research participation, there is also a need for strategies to increase researcher and clinician awareness of the effects of research exclusion.

While the effects of language barriers on providers are also similar between countries, a specific Canadian strategy is required. Providers must be made aware of the effects of language barriers and the different perspectives of patients and providers.

In spite of limited research on costs and benefits of health interpretation, some hospitals have concluded that, based on a partial analysis, provision of paid interpreters will save money (Zimmerman, 1996). It is likely that as more research is undertaken, the "evidence" of various costs of language barriers (e.g. reallocated staff time, use of diagnostics, missed appointments, drug complications, hospitalizations, physiological health outcomes) will increase, making provision of interpretation programs more attractive to administrators. Because of differences in financing between health systems, it is not evident to what extent findings in one country can be generalized to another. Specific Canadian research is needed in this area.

8. Conclusion and Recommendations

8.1 Effects of Language Barriers

There is compelling evidence that language barriers have an adverse effect on access to health services. Patients face significant barriers to health promotion/prevention programs. There is also evidence that they face significant barriers to first contact for care in a number of settings. Although limited research has been undertaken in Canada, research findings in this area are consistent with studies undertaken in other countries.

With the exception of access to mental health and counseling services, there is not at this point evidence that patients in Canada who face language barriers have reduced access to physician-initiated care. There is limited evidence that in some cases, Canadians who have lower official language proficiency may have higher utilization of specialist and diagnostic services. However, both initial access to, and quality of care provided for, psychosocial issues appears to be impaired by the presence of language barriers. More research is needed.

In many cases the rights to confidentiality and informed consent are not protected for patients who do not speak an official language, and they do not receive the same standards of ethical care as other patients. There is a paucity of research in Canada related to differences in treatment based on race/ethnicity. Based on the information currently available, there is some suggestion that in this country, for immigrants, language, rather than ethnicity, may be a more important factor in *initial health care access*, if not in health status. This is an area in which significant research is needed.

In addition to the direct effects on patient access and care, language barriers have a negative effect on provider effectiveness and satisfaction. Exclusion of non-official language speakers from clinical and health services research affects the generalizability of research findings and the development of knowledge.

There is evidence that providing language access services may result in benefits to a number of stakeholders:

- ◆ patients/clients (improved diagnosis, avoidance of unnecessary interventions, better health outcomes and satisfaction);
- ◆ providers (less frustration, less risk of malpractice);
- ◆ administrators (decreased liability and increased efficiency);
- ◆ health system (more appropriate use of services, and improved health outcomes); and
- ◆ society in general (increased health and productivity of all citizens).

In spite of the risks of language barriers to access and quality of care, and the potential benefits of language access services to patients and providers, little responsibility for ensuring language access has been assumed by the health care system. It has been observed that while providers may intuitively or explicitly realize the risks of language barriers to patients and providers, they may find it inconvenient to address the issue of language access without externally articulated requirements and obligations (U.S. Office of Minority Health, 1999). While accessibility is a fundamental principle of Canada's health care system, to date *access* has been defined most often as the absence of explicit financial barriers to care. With the exception of interpretation services for Deaf patients, there are no specific requirements that professional interpreters be used.

While the designation of health as a provincial/territorial responsibility makes the development of a national response more difficult, there is a need for the development of national standards, and coordination of research and training. Strategies to increase language access must also be coordinated with other initiatives aimed at addressing the inequities in access to health services.

8.2 Current Challenges

8.2.1 Promoting Cultural Competence and Social Responsiveness

Provision of professional health interpreters is essential if equitable access to care is to be ensured. However, it is not a sufficient response. Provision of interpreters does not remove the obligation of health services to promote a range of initiatives to increase language and cultural diversity within the health professions. Relying solely on interpreters to provide a communication bridge to services that may be culturally uninformed or unresponsive, will not provide true access (Stevens, 1993a; James, 1998; Doyle & Visano, 1987).

Continuing effort is needed to increase the social responsiveness of health services, and the cultural competence of providers (Capon & Watson, 1999). Too often, differences in communication and culture are viewed as problems belonging to minority communities, which health interpreters can help "overcome". Difficulties in access then are attributed to characteristics of communities, rather than to systemic barriers within the health care system. The assumption that failure to participate in prevention activities arises from "cultural beliefs", rather than structural barriers, is one example of this. The lack of health system response to the needs of clients for language access is an indication that there is continuing need for systemic change. Without addressing the larger

issues of inequity, provision of language services will not have the desired effect. However, unless language access is obtained, this larger agenda will be hindered.

Greater effort is needed to develop roles that provide cultural interpretation and advocacy, and to develop specific health initiatives that respond to community needs (Stevens, 1993b; Vissandjee et al. 1998b). To ensure appropriate utilization of interpreters within institutions, policy requiring the use of interpreters is needed, along with provision for monitoring and evaluation. Training of service providers in working with interpreters is an essential component of cultural competence training, and should be a part of all health curricula. Interpreters must be viewed as members of the health care team, not simply as "language decoders". The relative "invisibility" of interpreters' needs and perspectives in the interpretation research highlights the marginal role to which they have been assigned to date.

It is also clear that not all barriers to language access can be best addressed by the provision of health interpreters. In particular, health promotion initiatives can probably best be provided through bilingual providers – whether in a professional or paraprofessional role. Greater attention also needs to be given to the development of multilingual resources in a number of areas – health promotion, health service orientation, information on diseases and conditions, and patient care instructions. Development of a greater variety of quality plain language resources in English and French would also increase accessibility to health promotion and patient care information of many with limited official language fluency (Robinson & Miller, 1996; Gordon, 1996). This response would also improve communication for all clients.

8.2.2 Research Needs

Much research from other countries can be useful to Canadian policymakers and researchers. However, there are a number of areas where caution is needed in generalizing results. Different mechanisms may affect access to specialist or other more intensive care in a country with universal health coverage, compared to countries where there are significant disparities in insurance coverage. While a review of the U.S. literature related to ethnicity concludes that ethnic minorities receive less needed care (Mayberry et al., 1999), there is not evidence that these results can be generalized to Canada. Other factors related to the history, culture, organization of health services, and population density within a particular country may also affect results. While there is good evidence that the general findings on provider-patient communication, initial access to care, patient compliance and knowledge, and research participation may be similar between countries, additional Canadian-based research is required related to differences in treatment following assessment, and general satisfaction with the health care encounter.

An important limitation of much U.S. research is the focus on the Hispanic (Spanish-speaking) population. Sufficient research has not been undertaken on other, smaller language minority groups. Although there is no evidence that language barriers would be less for other language groups (and in many cases may be higher), the *response* to such barriers may differ between communities. Challenges related to validation of instruments for use with culturally diverse groups are of particular concern for research which attempts to measure patient satisfaction or self-reported health status and health needs.

It is also essential to build on Canadian research that has highlighted the role of socio-economic status in health status and patterns of utilization.

Research in other countries often finds that non-English speakers are poorer than official language speakers. Canadian data suggests the same – persons with disabilities (including Deaf persons), new (though not established) immigrants, and Aboriginal peoples tend to be poorer than other Canadians. Recent research has emphasized the complex interaction between ethnicity, socio-economic status and health. Socio-economic status does not explain all differences in health between ethnic groups (Krieger, 1999; Mayberry et al., 1999). As indicated in this report, the research also suggests that official language proficiency is itself a determinant of health, and may interact with ethnicity and socio-economic status. It is a variable that should be included in future research.

While in general immigrants do not identify any more unmet health needs than the general population, twice as many lower income immigrants report unmet health needs as compared to those with higher incomes (Chen, Ng & Wilkins, 1996). As lower income is linked to a decreased likelihood of fluency in one or more official language, more research is needed to determine whether language barriers to access, not simply income, might contribute to lower health status. Kinnon (1999) also notes that access is an area in which the distinction between recent and more settled immigrant populations is critical, and urged further research to explore the lack of access and need for appropriate services.

8.2.3 Models of Interpretation Services

While there are a number of interpretation programs operating in Canada, they vary in size, resources, model of service delivery and capacity to ensure quality. Additional research is needed to develop models appropriate for the distribution of Canada's population. Some of these models must be appropriate for regions with lower density, and high diversity, of non-official language speakers.

Strategies to increase language access to health services should not be limited to addressing access to physician and hospital appointments. Investment in the long-term health of the population must recognize that access to health promotion and preventive programs is also important, and that strategies must meet the needs of clients and providers who work in a variety of professions and settings. Strategies should also be developed around the needs of clients, not of institutions.

Research has identified negative effects of language barriers not only on physician and hospital care, but also on long-term care, speech and occupational therapy, counseling and rehabilitation, community health nursing, pharmacy services, emergency and ambulance services, participation in CPR classes, access to out-of-hours services, abuse prevention and intervention services, home care, and health promotion and prevention (e.g. childbirth preparation, cancer awareness and prevention, HIV/AIDS education and counseling), and support for caregivers of the elderly and disabled. Therefore, a comprehensive strategy for addressing language barriers must take into account barriers to a variety of services, and match the form of service to the need. This may, for example, result in telephone interpretation for emergency services, in-person interpretation for a pre-booked appointment, use of bilingual providers for health promotion, and increased development of multilingual and plain language patient information materials.

8.2.4 Development of National Standards

A crucial issue is the development of standards for institutions, providers, and interpreters. These should include standards for interpreter training and for providers working with interpreters; the requirement for policy outlining situations where professional interpreters must be used; and development and coordination of accreditation processes for interpreters and institutions. A

coordinated response to developing models of interpretation services appropriate for the distribution of the Canadian population is also needed.

8.2.5 Economic Evaluation

There are two forces currently promoting provision of health interpretation services in Canada. The first is based on patient rights and a commitment to ensuring quality of care for all patients. There is evidence that failure to address language barriers has an adverse effect on the health and satisfaction of patients and their rights to equitable standards of care. This, some argue, is sufficient reason to provide language access services, and cost-benefit analysis should not be applied to issues of ethics and rights to care.

The second argument, that of cost-effectiveness, has in the past been viewed as a constraint to provision of language access programs. Programs, such as interpretation services, were understood simply to involve additional costs to the health care system, without significant economic benefits. As evidence related to costs and benefits has mounted however, there is a realization that provision of language access services may result in cost savings to both the health system and the larger society. The focus on reducing health care costs may therefore also serve as an impetus for developing strategies to address language barriers. In one U.S. hospital, a review of the effects of language barriers combined with requirements for cost reduction promoted creative restructuring which resulted in the reallocation of some existing positions to a new multilingual advocate model (Corso, 1997). In Canada too, there is increasing interest in undertaking cost-benefit analysis of language access programs.

Economic evaluation of health interpretation services raises two challenges. The first is that economic evaluation of health care is in its infancy. The methodology has not yet been adequately

developed to accurately assess the “costs” of various health interventions. The other relates to the complexity of the task of defining and measuring both the inputs, and the outputs, of various interventions, including defining the “interpretation function” itself.

While it usually appears feasible to measure costs (inputs) of programs, (or absence of programs), measuring the effects (“benefits” or “outputs”) is much more complex. There are a variety of possible outcomes, and many interventions may have delayed effects. There is often insufficient awareness of the potential costs to the patient and family, to the society in general or even to the larger health care system (community-based, continuing care, or preventive services, for example) over the long term. In addition, the data available through current collection systems does not provide the necessary information to provide cost estimates. Collaboration between researchers and providers of language access services is required.

It is however necessary that economic evaluation of interpretation programs be undertaken as one component of a complete evaluation and planning process. Determining the effectiveness of the interventions, and analyzing ethical responsibilities are other necessary components of such an evaluation.

8.3 Recommendations

Based on this review of the literature the following recommendations are proposed by the author:

- ◆ Examine the feasibility of incorporating, as part of health system data collection, information on patient proficiency in official languages.
- ◆ Include, wherever possible, proficiency in an official language as a variable for analysis in health services research. This should always

occur when ethnicity is one of the factors to be considered.

- ◆ Include in the review of health research proposals an assessment of whether those who are not fluent in an official language are eligible to participate, and promote inclusion of language minorities in both clinical and health services research.
- ◆ Develop strategies to increase health researcher awareness of the effects of exclusion of language minorities from health research, and methodological and ethical issues related to conducting health research with participants who have limited official language fluency.
- ◆ Develop initiatives to promote awareness of the importance of provider-patient communication, and the profession of interpretation within the health professions. Promote training on the effects of language barriers and working with interpreters as a required component of pre-service professional preparation.
- ◆ Develop strategies to promote dissemination of research on language access to policymakers and health service planners.
- ◆ Develop strategies to assist communities and institutions to develop models of service delivery appropriate for the variety of settings where interpretation is needed.
- ◆ Develop a coordinated national research strategy to further understanding of the impact of language barriers on health service utilization and health status of Canadians.
- ◆ Establish a centralized “clearinghouse” capacity for information and research on language barriers and language access programs in Canada.
- ◆ Develop a national strategy for health interpreter training, interpreter accreditation and standards of service provision.
 - ◆ Develop national standards of practice and appropriate models of service for the Canadian environment.

- ◆ Coordinate strategies for training and accreditation of interpreters.
- ◆ Include and coordinate strategies for official language, Aboriginal, visual, and immigrant languages.

8.4 Summary

Language barriers have been demonstrated to have adverse effects on access to health care, quality of care, rights of patients, patient and provider satisfaction, and most importantly, on patient health outcomes. In spite of universal health coverage, patients who lack proficiency in English

or French may not have access to the same quality of care as other Canadians. There is also evidence that language barriers contribute to inefficiencies within the health system

This document is intended to serve as the starting point for further dialogue among providers of language access programs, health administrators and policymakers, and researchers in Canada. It is hoped that it will promote further collaboration, program development and Canadian-based research related to language access to health care services.

9. Glossary

Aboriginal:

All indigenous persons of Canada who are of North American Indian, Inuit, or Metis ancestry, including those in the Indian Register. **First Nations** refers to those whose names appear on Indian Register maintained by the Department of Indian Affairs and Northern Development.

Back-translation:

A process by which original material is translated into a second language and subsequently translated back into the original language by a second translator. This method is used to monitor the accuracy of translation where the researcher cannot speak the two languages involved.

Deaf:

The word deaf, when the d is capitalized, as in *Deaf*, refers to those who belong to the cultural community of Deaf people. Many of these persons are pre-lingually deaf, and while they may learn to read and write English or French, learn these as second languages. In contrast, the words *deaf*, or deafened (with a lower case "d") refers to lack of hearing. Not all those who are deaf are members of the Deaf community or use sign language, the focus of our discussion here.

Immigrants:

"People who are, or have been at one time, landed immigrants to Canada" (Statistics Canada). **A landed immigrant** has been granted the right to live in Canada permanently by immigration authorities. Landed immigrants include both those who voluntarily immigrate to Canada, and **refugees** who are forced to flee their home countries.

Interpretation:

For the purpose of this report, **interpretation** refers to the process by which a spoken or signed message in one language is relayed, with the same meaning, in another language.

Translation refers to the written conversion of one language into another. Two common forms of interpretation are simultaneous interpretation, and consecutive interpretation. In **simultaneous interpretation** the interpreted message is delivered nearly instantaneously after the original. This is the common form of conference interpreting.

Consecutive interpretation involves interpretation of segments of a conversation, with a lag between the original message and its interpreted form. Interpretation may also be categorized as **proximate**, meaning the interpreter is present in the encounter, or **remote** (e.g. by using telecommunication technology). American Sign Language (ASL) interpretation is most often proximate and simultaneous, while most other health interpretation is consecutive and proximate, although the development of communications technology has increased the availability of remote, and simultaneous interpretation.

Institutionally complete communities:

Those cultural communities that can provide a wide range of social, educational, economic and cultural services through providers of the same cultural background. In institutionally complete communities, individuals can obtain all or most services needed in their first language.

Multivariate analysis:

A set of techniques used when the effects of several variables are to be studied at the same time.

Odds Ratio:

The ratio of two odds. **Odds** refers to the ratio of the probability of the occurrence of an event to that of the non-occurrence of the event.

Plain language:

Language that is simple, clear, direct and uses common words. The intent of plain language is to make information accessible, especially to those who have low literacy skills, or low proficiency in a second language.

Self-rated health:

How individuals describe their own physical and mental health.

Underservice:

The increased likelihood that individuals will, because of their membership in a certain population, experience difficulties in obtaining needed care; receive less, or a lower standard of care; experience differences in treatment by health personnel; receive treatment that does not adequately recognize their needs; or be less satisfied with health care services.

Validity:

The degree to which conclusions reached in a study are warranted.

Visible minorities:

Persons other than Aboriginal peoples who are non-Caucasian in race or non-white in color. (Employment Equity Act, Canada).

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