Reliability and Validity of the Predicting Health Needs of Seniors Survey

by

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A Thesis

submitted to the Faculty of Graduate Studies in partial fulfillment of the requirement for the degree of

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Department of Community Health Sciences

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Dr. Cornelia van Ineveld

A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University of Manitoba in partial fulfillment of the requirements of the degree

of

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Abstract

Background: The "Predicting Health Needs of Seniors Survey" (PHNSS) is designed as a self-administered questionnaire identifying community dwelling elderly persons at risk of functional decline and high health care utilization. The questionnaire, developed for a low-income population, was adapted for use in Chinese, French, English and Ojibwe. Objectives: To confirm the questionnaire reliability and construct validity in Chinese. French, English and Ojibwe. To test the predictive validity of the PHNSS. Methods: For each cultural group, the PHNSS was administered to well and physically dependant seniors. Demographics and measures of daily functioning, cognition, mood, and physical performance were collected. Test-retest and inter-rater reliability testing were completed. To test predictive validity, responses to items from the 1996 Aging in Manitoba interviews were used to create a "surrogate" PHNSS score. Telephone interviews established functional status 18 months from baseline. Health claims data were used to examine home care use, hospitalization and physician visits at 18 months. Results: There were 52 English, 71 French and 67 Chinese participants for construct validity testing. The PHNSS was highly acceptable and administered in less than 10 minutes. Test-retest reliability for the self-administered survey was high (ICC 0.91). Inter-rater reliability for the total score was acceptable but there were substantive interrater differences on four items. The PHNSS score correlates with functional measures, is higher (worse) in the dependent group, and these associations are consistent across cultural groups. Pre-testing the survey in the Ojibwe population revealed a prolonged administration time and general unacceptability of this type of screening approach.

For predictive validity testing, 338 'surrogate' PHNSS scores were generated. The PHNSS score is positively associated with frequency of physician visits and admissions to hospital over an 18-month period. A higher baseline score is also associated with a greater likelihood of 2 Instrumental Activities of Daily Living (IADL) impairments at 18 months. A score of 15 or higher identifies 46% as being at risk and has moderate sensitivity (64%), specificity (66-72%), positive predictive value (55-69%), negative predictive value (67-74%) for predicting a high frequency of total physician visits and 2 IADL impairments.

Conclusions: The PHNSS can identify a group with greater functional impairment and these findings are consistent across three cultural groups: English, French and Chinese. The PHNSS is able to identify a group of seniors at risk for increased health care utilization and functional decline.

1.0 Introduction and Objectives

Two important themes exist in the literature that surrounds comprehensive geriatric assessment. The first is that mortality, physical function and cost are thought to be the most important outcomes in trials of geriatric care.¹ This emphasis on functional status is reflected in recent trials of in-home preventive assessment programs for older adults where the ability to perform the activities of daily living (ADLs) and instrumental activities of daily living (IADLs) were considered primary outcomes.^{2,3} The second is that using some form of screening, casefinding or referral for assessment to select the people most likely to benefit from an intervention is an important determinant of success in providing health services to the elderly.^{4,5,6} Therefore, there continues to be considerable interest in developing and refining screening tools to identify elderly persons at high risk of functional decline^{7,8,9} as well as in developing programs to prevent functional decline.¹⁰

The strategy of identifying an "at risk" elderly population using some form of a screening questionnaire has been the subject of study for a number of years and formed the basis of a research program entitled "Culturally Sensitive Seniors' High Risk Screening Program" funded by the Seniors Independence Research Program (SIRP) and Canada's Drug Strategy: Community Researcher Award (CRA) (Reference #6606-5567-603). The overall objective of the research program was to develop a "screening protocol" to be implemented by a community health centre to identify community dwelling seniors at risk of functional decline and increased health care utilization. It was intended that the protocol be structured around a self administered questionnaire, that was reliable and valid. The client base for the Health Action Centre (HAC) is a low income population with a high proportion of immigrants. Dominant ethnic groups in its catchment area speak English, Ojibwe, Cree, Chinese and Ukrainian. It is very probable that high proportions of these elderly persons are functionally illiterate. St. Joseph's Community Health Centre is located in a working class neighborhood with a high proportion of Portuguese and Italian immigrants. Because the research program set out to create a screening protocol that was applicable and relevant to both the HCA and the St. Joseph's Community Health Centre it was imperative that the instrument be acceptable and valid in a population with low income, low literacy and diverse ethnic groups. Existing screening instruments are discussed in detail in the literature review. At this time, there are no predictive screening questionnaires that have been adapted or tested for these specific groups. Therefore, as part of the broader SIRP research program, the Predicting Health Needs of Seniors Survey (PHNSS) was developed (Appendix 1).

For the purposes of this thesis, only the research carried out in Winnipeg is discussed. The funded research program included development of the questionnaire, testing the reliability and validity of the PHNSS as well as testing methods of administration. Development of the questionnaire is discussed in the background section of this thesis and was not considered part of the formal thesis project. The thesis focuses on the reliability and validity testing of the PHNSS. Frequently used abbreviations and terms are listed and defined on pages 83-84.

1.1 Objectives

- i. To confirm the reliability and construct validity of the PHNSS in Chinese, English, French, Ojibwe, and Ukrainian.
- ii. To test the predictive validity of the PHNSS.
- iii. To examine the effect of different scoring criteria on the predictive abilities of the PHNSS

2.0 Background and Literature Review

2.1 Functional Status and the Elderly

A white female, aged 85, with 12 or more years of education living in the United States has a remaining average life expectancy of 8.6 years and can expect that for 3.4 of those years (40%) she will be dependent in at least one of the basic ADLs. 11 The prevalence of functional dependence, whether looking at IADLs or ADLs, increases with age for both men and women with women consistently reporting more limitation at all ages. In Manitoba, 13.3% of males aged 75-84 report requiring assistance in at least one basic ADL, this increases to 32.7 % in the 85+ age group. Females report 24.3% and 49.7% ADL dependence, respectively. 12

Dependence in activities of daily living has been documented to be a predictor of hospital admission, prolonged stays in hospital, higher health care utilization, higher mortality rates, home care use and admission to an institution. Using community based prospective studies of four elderly populations in the United States, Gura!nik and colleagues demonstrated that, within each age group of men and women, there was an increase in adverse outcomes (death, nursing home admission and hip fractures) with increasing baseline functional dependence. Dependence in functional activities typically occurs in a hierarchical pattern. Loss of ability to perform IADLs generally occurs first and those who

need help in ADLs are usually the most severely disabled and nearly always require assistance with at least some IADLs.¹⁴ Researchers have been able to demonstrate that items within the measurements of ADLs and IADLs form Guttman scales.^{15,16} This indicates that there is an exact pattern of responses to these items compatible with a consistent loss of IADL and ADL capacities.

Longitudinal cohort data have provided powerful insights into the incidence of new functional impairment in community dwelling elderly. Guralnik and colleagues have described 1363 persons 71 years or older who, at the beginning of the observation period, reported no difficulties in activities of daily living (ADLs) and no difficulty walking 0.8 km. At the end of four years, 15.3% had died, 18.9% reported difficulty walking 0.8 km and 10.0% had difficulty with ADLs.¹⁷ A similar study in New Haven followed 664 subjects who at baseline were cognitively intact and independent in ADLs. Over a one year period, 9% had become dependent in at least one ADL.⁷

However, it has also become evident that physical functioning is a dynamic process, and does not always proceed through this well described gradual loss of autonomy. Hébert and colleagues have recently examined, in detail, changes in physical function in a cohort of representative residents of Sherbrooke, Quebec aged 75+.18 These subjects (n=572) were assessed yearly on three occasions using the Functional Autonomy Measurement System (SMAF) which incorporates abilities in ADLs, IADLs, communication, cognition and mobility. In those subjects that had the same level of function at the beginning and end of the two year period (n=343), there were six that had improved in the first year and then declined, and 38 had declined in the first year and then improved. Of the 115 that declined over the two years only 28 (24.3%) declined consistently. Thirty-eight declined only in the first year, 44 declined only in the second year, and 5 improved in the first year and then declined. Over the 2 year period and within each year, the probability of change (dying, declining or improving) was higher in the older age group (\geq 80 years). Furthermore, Ferrucci and coworkers have made the distinction between catastrophic versus progressive onset of ADL dependence.¹⁹ They analyzed prospective cohort data on 6,640 older persons collected annually over 6 to 7 years. They found similar incidence rates for catastrophic and progressive onset of severe disability (dependence in 3+ ADLs). However, older age (85 +) was associated not only with a higher incidence of disability but a much higher likelihood of a longer disabling process. Though women were no more likely than men to develop severe disability, once present their median survival time was much longer (3.44 vs 2.12 years; p<0.0001). This research group has also been able to show that older persons who develop

catastrophic disability rather than progressive disability differ in their hospitalization rates, principal discharge diagnoses, medicare charges and nursing home admissions.²⁰

While the outcomes associated with functional decline are well described, attempts to develop models which account for ADL status have led to a heterogeneous set of associations. Cognitive function^{14,21,22} depressive symptoms^{14,22,23}, social participation¹⁴, self assessed health status 14,24,25, age25, lower extremity impairment25 and chronic health conditions 14,25,26 have all been identified either individually or in multi-variate models as being predictive of, or associated with, ADL impairment. The role of chronic health conditions and their relationship to mobility impairment and ADL/IADL dependence is starting to become better understood. Thirteen chronic diseases have been consistently associated with physical disability: knee osteoarthritis, hip fracture, diabetes, stroke, myocardial infarction, angina, congestive heart failure, claudication, chronic obstructive pulmonary disease, visual impairment, depression, cancer and cognitive impairment.²⁶ The greater the number of chronic conditions the higher the prevalence of ADL/IADL impairment.²⁶ And in certain conditions, such as cardiovascular disease and arthritis, the combination of these two chronic conditions causes a more prevalent and more significant limitation in mobility related ADLs than either condition alone.²⁷ When ADL/IADL tasks are broken down into domains such as 1) difficulty in mobility/ exercise tolerance demanding tasks 2) upper extremity tasks 3) complex household management tasks and 4) self-care tasks it becomes evident that individual chronic conditions are not necessarily associated with all domains of disability and that patterns of association for specific diseases with different types of disability can be observed.²⁶

2.2 Health Utilization and the Elderly

Older adults, as a group, are disproportionately heavy users of health care resources.²⁸ The costs associated with hospital stays dominate total health care expenditures for older adults.²⁹ It is also well established that the last year of life is the most expensive year of life with respect to health service utilization.^{30,31} Sophisticated data base analysis is allowing researchers to examine numerous areas: health care costs of specific diseases or conditions, cost analyses of specific interventions, small area variations with respect to physician practice patterns and hospital utilization, comparative analyses of health care use across geographic regions are some examples. However, predicting health care utilization at the level of the individual remains difficult. A widely used behavioral model of health utilization, originally proposed by Andersen, suggests that use of health services is based on predisposing, enabling and need characteristics. ^{32,33,34} Of these

three, need, measured as self rated health and ADL, IADL and mobility status, is the largest contributor to models of health services utilization. Unfortunately, even with extensive modeling and the inclusion of such variables as social supports, multigenerational living arrangements, health worries and sense of health control, the amount of variation explained by these models is limited (R²·0.069-0.252).³¹ Furthermore, Wolinsky comments that models of health service utilization are particularly weak with respect to predicting exceptionally high levels of utilization.³¹

2.3 The Impact of Income and Culture

The 1994-95 National Population Health Survey confirmed that low socioeconomic status, measured by adequacy of household income, is associated with greater physical functional dependence (Odds Ratio 1.31).²⁴ When health is defined in broad terms, such as the World Health Organization definition of health as "physical, social well being, and not merely the absence of disease and infirmity"35 it has been well demonstrated that provision of health care alone does not determine the health of a population. Factors such as income, education and employment are also important determinants of health status. Even when health is measured in traditional ways such as mortality rates and prevalence of chronic diseases, socio-economic status is an important predictor of outcomes.³⁶ As a result, comparisons of health status of cultural groups, particularly in circumstances where there may be marked differences in socio-economic status, should try to take into account this potential confounding effect. For example, work in the United States suggests that though the prevalence of specific chronic diseases does differ between cultural groups (for example, Hispanics and African-Americans both report higher rates of hypertension and diabetes than Caucasians), differences in functional status among those with chronic conditions are accounted for mostly by differences in socio-economic status rather than inherent differences in the cultural group.³⁷

There has been some recent effort to compare patterns of functional decline across cultures. Comparing older persons from seven population-based samples in five European countries, Ferrucci and colleagues found that the prevalence of disability in specific ADLs varied across the cultures.³⁸ However, if ADLs/IADLs are classified into domains of disability, a hierarchy of loss of function that meets the criteria for a Guttman scale can be described, and the hierarchy of loss can be replicated across the seven populations.³³ Jylhä and colleagues have described similar findings when they examined self-rated health in population based samples of older persons from Tampere, Finland and Florence, Italy.³⁹ There were cultural differences in ratings of health with

Florentine women and men respectively three times and four times more likely to report good self-rated health than men in Tampere. Yet the correlation of self-rated health with chronic disease, functional ability, symptoms, visual impairment, number of medication and education was no different for the two regions. Also, the ability of self-rated health to predict mortality was similar across genders and cultural groups.

In Canada, immigrants comprise a considerable proportion of our population, even among older persons. There are recent Canadian survey data to suggest that immigrants differ in life expectancy and disability patterns from Canadian-born persons. Using the Health Activity and Limitation Survey data from 1986 and 1991, Chen and co-workers demonstrated that immigrants had lower age-specific mortality rates than the Canadian born population.⁴⁰ The only exception was that after age 70, mortality rates for the European immigrants and Canadian born populations converge. In 1991, 41% of male and 57% of female non-European immigrants could be expected to live to age 85; but in the Canadian born population the proportions were 23% and 45% respectively. The analysis of dependency patterns included all age groups, therefore; overall ADL/IADL dependency rates were relatively low. Nevertheless a gradation of dependency was still observed. Canadian born females reported a 9.3% prevalence of dependence, European immigrants 8.2% and non-European immigrants 5.7%. For basic ADL dependence the rates were 2.0%, 1.7% and 1.4% respectively.

This same group used 1994-95 National Population Health Survey data to examine the effect of length of time in Canada on specific health measures.⁴¹ In general the ageadjusted prevalence rate of chronic conditions, further adjusted for sex, income and educational status, was lower in immigrants than in the Canadian born population, 50% versus 57%. This is especially true of recent non-European immigrants. As the length of time in Canada increases, so does the reporting of chronic conditions. ADL/IADL dependence was less prevalent in recent (less than 10 years) non-European immigrants; however, consistent with the literature, the authors found that lower household income, lower education status and female gender were greater determinants of dependence than immigration status. The differing health characteristics in the immigrant populations are probably accounted for by the "healthy immigrant" effect.^{40,41} The Immigration Act ensures that potential immigrants are screened for serious medical conditions. In addition, a person in good health is more inclined to emigrate than someone in poor health, and employability, although less applicable to the older person, also demands a certain level of health.

These observations argue that it is reasonable to apply the same theoretical constructs with regard to functional decline across cultural groups. However, at the stage of developing screening instruments which rely on measures of functional status, it becomes imperative to validate instruments for each cultural group separately as there is well described variation from group to group on individual items.³⁹ The client base of the HAC is a low income population with a high proportion of immigrants. Dominant ethnic groups in the catchment area speak English, Ojibwe, Cree, Chinese and Ukrainian. It is very probable that a high proportion of the elderly subpopulation is functionally illiterate. Because the research program set out to create a screening protocol that is applicable and relevant to the HAC, it was critical that the PHNSS be acceptable and valid in a population with low income and poor literacy. The additional challenge was to ensure that the PHNSS was adapted and tested for reliability and validity in each of the dominant ethnic communities.

2.4 Screening Questionnaires

Several groups have developed and tested screening questionnaires to identify "at risk" elderly. Prior to describing and comparing the properties of these instruments it is relevant to summarize key attributes of effective screening questionnaires. Before any instrument is considered for clinical or research purposes it is essential that it be tested and proven to be reliable and valid.

Reliability: refers to "the consistency or stability of the measurement process across time, patients or observers."⁴² With reliability testing, the researcher tries to identify potential sources of error and their impact on the consistency of the measurement. For example, subject responses to an instrument that is self-administered may be affected by such factors as the day of the week or fluctuations in chronic diseases (for example, pain and mobility scales in persons with joint disease). The test instrument is administered over several time intervals (test-retest reliability) and the variation in scores analyzed to determine the ratio of the true score variance to the observed score variance. In an interview administered instrument a potential source of error is the influence of the interviewer (rater) on the respondent. There is the possibility that the style or manner of a particular rater will lead to systematically different responses in comparison to other raters. Therefore, subjects are given the same instrument by different raters and scores subsequently analyzed for variance (inter-rater reliability).

- ◆ Validity: in broad terms this refers to "the extent to which a test measures what it is intended to measure".⁴² There are several 'types' of validity, which, though measuring different attributes of the test, are complementary as they all aim to increase the degree of confidence that can be placed in the test.⁴³ Depending on the author there may be an overlap in terms used to describe types of validity i.e. concurrent validity is often used interchangeably with criterion validity.
 - "Content validity" is usually assessed by experts in the field and refers to how adequately the selected items reflect the aim and/ or theoretical construct of the instrument.
 - ◆ "Concurrent validity" correlates the new scale with a criterion or gold standard measure, both of which are given at the same time
 - "Predictive validity" is similar to concurrent validity but the criterion measure or outcome is not available until some time in the future
 - "Construct validity" is tested when there is no easily accessible gold standard against which to test the new instrument. Based on the theoretical construct underlying the structure of the instrument, hypotheses are generated and tested. For example, a hypothesis is generated that a new instrument measuring caregiver stress will correlate highly with symptoms of depression and sleep disturbance but will not correlate with hours of Home Care support. If these findings are obtained then the validity of the new instrument is supported.

If an instrument does not have acceptable reliability and validity then it is usually discarded as the clinician or researcher cannot place any confidence in the interpretation of the results that are obtained.

Screening instruments are then assessed for their ability to accurately classify the population at risk into those with the condition of interest (positive test) and those without (negative test). The most common statistical method used is to calculate the "sensitivity" of the instrument, which refers to the proportion of persons with a particular disease which are correctly classified as diseased and the "specificity" which refers to the proportion of people without the disease who are correctly classified. The ideal screening instrument has high sensitivity so that you minimize the possibility of a person being "missed" who truly has the disease (false negative) and high specificity to minimize the possibility of mislabeling an otherwise well person (false positive). These errors in classification create potential psychological distress as well as incurring costly investigation intervention on an otherwise well person.

There are often situations where the ideal of high sensitivity and high specificity cannot be achieved. In a screening test it is usual to emphasize high sensitivity at the expense of specificity. The rationale is that the goal of a screening test is to capture as many persons who are at risk of the disease being present as possible and to minimize the possibility of missing a person. The screening test can then be followed up by a test with high specificity to remove the false positives. An example is screening for diabetes, the thresholds of fasting and random blood sugars that trigger investigations for diabetes are set relatively low so as increase sensitivity and not miss anyone at risk (false negative), however the specificity (false positive rate) is substantial but easily identified by more rigorous blood sugar testing. Such a strategy is not advisable where a false positive test can lead to psychological distress/ burden particularly in a setting where there is not necessarily an intervention to be offered to those who truly have the "risk" state e.g. prostate cancer screening in men over age 70.

2.4.1 Review of Existing Questionnaires

The existing screening questionnaires to identify "at risk" elderly can be broadly categorized into "casefinding" and "prospective" instruments. The casefinding instruments aim to identify a group of elderly persons who are currently at risk, specifically looking for medical, functional or social problems that may be unreported or unrecognized. 15,44,45,46,47,48,49 Several of the groups have been able to successfully devise a process whereby the questionnaire is mailed out, typically from the family physician's office, self-administered and returned. 44,45,46 The Hebrew Rehabilitation Center for the Aged (HRCA) Vulnerability Index is administered either by phone or in person. 48 The Winchester Disability Rating Scale was originally used by trained volunteers and filled out at a home visit using responses to a semi-structured interview. Typically the casefinding instruments are validated by comparing the categorization of being "at risk" against a clinical assessment. 45,46,47,48 The sensitivities for the validated instruments range from 79% to 95% and specificities from 50% to 87%.

The prospective questionnaires, on the other hand, aim to identify elderly persons who will, at some time in the future, develop an 'at risk' state. Six instruments that fall in this category have undergone thorough evaluation.^{8,9,16,50,51,52} Each differs considerably in its objectives. In addition to the descriptions of the instruments to follow, properties of each instrument are summarized in Appendix 2.

◆ The Older American Resources and Services (OARS) IADL: The OARS IADL questionnaire is interviewer administered and consists of five questions, each

focusing on one IADL task.¹⁶ Fillenbaum administered the questionnaire to a random sample of elderly persons residing in Cleveland (n=1609) and then tested the ability of the OARS IADL to predict mortality at one year. What she identified was a gradation of risk with those able to perform all activities unaided having a relative risk (RR) of mortality of 0.4 and those unable to perform any activity unaided having a RR of 5.4.

- ◆ Sherbrooke Postal Questionnaire (SPQ):8 is a postal questionnaire that predicts functional decline at one year. It consists of six yes/no questions with positive response to two items or non-return of the questionnaire being considered 'at risk'. The investigators have calculated a sensitivity of 68% and specificity of 54% or alternatively a RR of 2.4 for functional decline at one year. While the study drew on a large population (n=607) to test potential questionnaire items, validation of the final version of the questionnaire was tested on a much smaller group (only 45 subjects).
- The Seniors Health and Wellbeing Survey (SHWS):51 was developed by Hay and colleagues as a screening and casefinding instrument for use in a primary care setting.53 It consists of 28 items addressing preventive health measures, lifestyle, medical and psychosocial issues. The ability of the SHWS to predict functional decline has been tested. As part of a larger trial, 445 seniors in a large group practice in Ontario were administered the SHWS and followed prospectively for two years with annual functional, social and resource utilization assessments. Sixty-five percent (n=291) screened positive on one or more items of the questionnaire. Those who screened positive generated significantly higher direct health costs at 1 year (p <0.005) and tended toward higher costs at 2 years (p=0.08). The two groups did not differ in the proportion of patients who experienced deterioration either in activities of daily living (ADL) or in a multidimensional functional assessment.54
- "frailty scale": has been recently described by Rockwood and colleagues.9

 Community dwelling seniors are classified into four levels based on independent mobility, ability to perform basic activities of daily living (eating, bathing, dressing and bath transfers), bowel and bladder continence and cognitive impairment.9 They were able to apply the scale to 9008 randomly selected community dwelling seniors and then follow the cohort prospectively for 5 years. The scale shows a dose-response relationship between grades of frailty and subsequent institutionalization and death. For the most impaired level there is a relative risk of 9.4 (7.7-11.5) and 3.2 (2.7-3.6) for institutionalization and death respectively.

- ◆ P_{ra} Screening Instrument: Boult and colleagues have developed an 8 item, mailed questionnaire which predicts the probability of a person age >70 requiring repeated hospitalization within 4 years.⁵⁰ Items consist of: self-rated health, presence of heart disease or diabetes, hospitalization or >6 physician visits in the past year, presence of a caregiver, gender and age. The P_{ra} value is then generated using a logistic equation. The predictive validity has been tested in both Medicaid⁵⁵ and managed care populations.⁵⁶ The survey can be administered by mail with average response rates of 58-60%. In the Medicaid sample (n=136) a P_{ra} score >0.5 was considered high risk and identified a group with rates of hospitalization and hospital days over a one year period twice that of the low risk group.⁵⁵ There were no differences for death, nursing home admission or emergency room use. In the managed care sample (n=6802), subjects with scores in the highest quartile were considered the high risk responders. Ratios of utilization for high risk compared to low risk respondents were: 2.7:1 for medical claims, 2.5:1 for emergency room use, 3.6:1 for nursing home stays, 3.5:1 for home care days.⁵⁶
- ♦ Health Screening Form: ⁵² is a four item survey predicting hospitalization targeted to seniors at least 81 years of age. The risk variables were derived from a much longer mailed survey. The four risk variables are: presence of heart disease, presence of diabetes, need for help preparing meals, needing help of a person or mechanical aid to get around. These are entered into a logistic regression equation. When applied to a validation cohort (n=1872) the highest decile responders had a hospitalization rate of 23.7% over 4.5 months compared to 4.3% in the lowest decile.⁴⁹

2.4.2 Domains and Predictive Items

In comparing the contents of the questionnaires there are four common domains which emerge:

- ♦ ADLs: especially use of a walking aid;
- ♦ IADLs;
- physical health: especially self-rated health, hospitalization within the past year, four or more medications; and,
- social health: e.g. living alone, help available.

A few authors have used analytic techniques to try to establish which individual questionnaire items are most useful.^{8,16,44,50,53} There is considerable variation in their conclusions; however, in some cases the outcomes these authors sought differed dramatically. For example, Boult was trying to predict hospitalization⁵⁰ and Fillenbaum

mortality¹⁶, thus it is not surprising that their conclusions as to what constitutes the "best" items differ.

Hébert et al. and van Ineveld both examined predictors of functional decline but characterized different risk factors. Hébert identified not living alone (Relative Risk (RR) 1.6), 4 or more medications per day (RR 2.0), problems with hearing (RR 1.5), problems with seeing (RR 2.1), use of ambulatory aid (RR 2.0), problems with memory (RR 1.5) as risk factors. Whereas van Ineveld found that loss of ADL capacity was associated with age greater than 75 years (p=0.01) and worsened health in the past year (p=0.05). Consistent with Hébert's report, van Ineveld did find that the risk of generating higher health costs was greater if the subject reported 4 or more prescription drugs (RR 1.73), use of ambulatory aids (RR 2.37) or a vision concern.

2.5 Development of the Predicting Health Needs of Seniors Survey

In developing the Predicting Health Needs of Seniors Survey (PHNSS), the objective was to have a questionnaire which was reliable, valid and could be self-administered. The questionnaire should have the ability to predict physical functional decline and increased health care utilization over an 18 month interval.

The original proposal submitted for the CRA identified the Seniors Health and Wellbeing Survey (SHWS) as the instrument around which the screening protocol would be based. However, detailed analysis of the properties of the SHWS revealed it did not have adequate discriminatory power for use in a broader setting.

Of the screening instruments targeting community dwelling seniors at risk of medical, social or functional problems, 8,9,15,16,41-50 only the Sherbrooke Postal Questionnaire specifically aims to predict functional decline as the goal of the screening protocol. The authors of the SPQ have indicated that using their criteria, 56% of respondents will be considered at high risk for functional decline, with a sensitivity of 75% and specificity of 52%. Applied to a hypothetical population of 500 community dwelling elderly persons, 280 would screen positive and require a more detailed assessment. Of those screened positive, only 38% (n=106) would go on to develop functional decline. Those screened negative would have had no further intervention but 16% (n=35) would have developed functional decline. Given the investment of health resources required to assess potentially high risk elderly, the SPQ did not appear to have adequate discriminatory power to be useful in a clinical setting. The remaining screening instruments available

either did not target the outcome of interest, were not specific to a low income setting or were too limited with respect to questionnaire domains. For example, the OARS IADL questionnaire contains only functional items but no items regarding health status or medication use.¹⁶

To remain consistent with the objectives of the CRA, which is to use a prospective instrument to predict functional decline and increased health care utilization, it was decided to develop a new instrument, the Predicting Health Needs of Seniors Survey (PHNSS) (Appendix 1).

Items were generated from multiple sources and included SHWS items found to be individually predictive of increased health care utilization, and also associated with functional decline and items identified by other investigators to be individually predictive of functional decline⁸ or hospitalization and mortality.^{9,41,47,51,57} The literature indicates there is considerable overlap between questions that predict health care utilization, hospitalization and mortality⁵⁷e.g. 4 or more medications. Two expert panels consisting of five geriatricians and two gerontologists reviewed the draft instrument for assessment of appropriateness of questions, interpretability, redundancy and face validity. The PHNSS (Appendix 1) consists of 13 items, the majority ask the respondents to self-rate their ability to carry out specific IADL tasks with additional questions on self-rated health, number of medications, recent hospitalization and availability of assistance.

Recommendations for adapting application forms and materials to make them accessible to low-income older adults suggest the addition of graphics as one of a group of changes which include: use of simpler language and sentence structure, simple blocking to clearly designate area for applicant completion, simple and uniform type style and clear color contrast.⁵⁸ Drawings or graphics may be helpful in aiding comprehension of an instrument for those who are functionally illiterate but they also function to enhance written or verbal explanation, rather than replace it.^{48,59,60,61} Preparation of drawings must be given the same attention as the construction of questionnaire items. Essential steps include pre-testing and ensuring they are appropriate to the culture being tested.

In keeping with these suggestions, the following adaptations were made to the PHNSS (Appendix 1):

• increasing font size to 16 point

- addition of graphic images to the response options for self-rated health, medications and functional items. These were developed by the Department of Communication Services of the University of Manitoba.
- simplification of language to ensure readability. Pre-testing took place with clients of the HAC Health Services for the Elderly Program, the participants ranged in literacy levels from functionally illiterate to a high level of literacy.
- to assess the number of prescribed medications a series of graphics of each type of medication is presented with the person being asked to circle the appropriate quantity for each type (see Appendix 1). In pre-testing, the question "do you take more than three different pills" created difficulties for all subjects with considerable ambiguity as to the meaning. Alternative wording was also unsuccessful.

The PHNSS was pre-tested on six clients of the HAC Health Services for the Elderly Program. Also, the original English version has now been administered to over 200 persons, targeted to a low-income, low literacy group where possible. The following observations have been made:

- the content of the items has a high level of acceptability.
- the graphic images have been well received and the majority of participants asked have found them to be helpful.
- for subjects who are functionally illiterate, verbal explanation is still required to allow for completion of the questionnaire.
- administration time generally ranges from 3 to 8 minutes.

2.6 Cross-Cultural Adaptation

Examination of the existing questionnaires suggests the target populations were generally homogeneous in cultural composition. With the exception of Hébert who conducted his work in a Francophone population, the remaining questionnaires have all been developed and validated in the United Kingdom or the United States. It is uncertain whether other cultural groups would participate in a mailed, self-administered screening strategy with the same degree of enthusiasm or, of equal concern, whether the questionnaires retain their validity.

A proportion of the target population of this project was functionally illiterate in English because this was not their first language. One way of ensuring their inclusion in the sample was to translate the questionnaire into the languages most commonly used in the

catchment area of interest. However, there may have been words or concepts in the English version of the questionnaire which remain difficult to communicate in a different language. A question may be meaningless in another culture, or not acceptable because the topic is especially sensitive in that culture. Guillemin and colleagues⁶² have attempted to address these concerns by proposing a set of standardized guidelines for translating a previously validated health-related quality of life measure into another language. The recommended process includes translation, back-translation, committee review, pre-testing and re-examination of the weights for scoring. Using these methods, groups have been successful at adapting commonly used instruments for other cultures.^{63,64} Even so, there remain circumstances where a translated instrument is not adequate and a new scale developed specifically for use in that culture is required.⁶⁵

2.6.1 Defining Cultural Group

Cools has described both aging and ethnicity as variables that "are apparently well known to all (and therefore remain undefined)".66 There are several methods of measuring ethnicity as a research "category" including: personal identity (self-identification), parental or ancestral location of origin, family names or behavioral indicators, e.g. language spoken or membership in an ethnic organization.66 For this project, the approach of self-identification was used. For example, in recruiting the Ukrainian subjects, advertisements for "Ukrainian seniors" were placed in a number of locations, including Ukrainian churches and recreational programs located in parts of Winnipeg with a high concentration of persons of Ukrainian origin. Participants who responded to those advertisements and confirmed that they considered themselves Ukrainian, were considered to be in the Ukrainian group. This did not require that they were born in the Ukraine, belong to a Ukrainian organization or necessarily speak the Ukrainian language fluently.

2.6.2 Cross-Cultural Adaptation of the Predicting Health Needs of Seniors Survey

The English language version of the PHNSS questionnaire was adapted for use in: Chinese, French, Ojibwe and Ukrainian (Appendix 3). The guidelines proposed by Guillemin et. al.⁶² for cross-cultural adaptation of a health-related quality of life measure were followed. The questionnaire was first translated then back-translated by experienced translators. A mix of professional translators and translators who had experience working with community agencies or seniors in the community was used. A committee reviewed all final and source documents, verifying conceptual similarities. The final back-translations are summarized in Appendix 4. This was a valuable process

as discrepancies were frequently identified, particularly around slang expressions (i.e. puffers). Each adapted questionnaire was pre-tested before consensus was reached on the final version of the survey. Throughout this process, particular attention was paid to the maintenance of readability of the questionnaire items, the title and instructions.

During the translation process, the draft questionnaire was reviewed by members of each ethnic community. Members of the Chinese community expressed some concern with the exclusion of traditional medicines from the questionnaire. It is their experience that in these cultures, traditional medicines often take the place of prescription medications. A similar concern was raised by staff at the Health Action Centre about the Ojibwe version. SIRP Community Researcher Award holder Erin Tjam (reference # 6606-5560-603) has developed a questionnaire which measures traditional medicine use in Chinese seniors (Appendix 5). With her permission, her questionnaire was added to the PHNSS validation interview for the Chinese community.

2.7 Potential Strengths and Weaknesses of the Predicting Health Needs of Seniors Survey

As discussed above, longitudinal studies are allowing us to realize that functional decline is a dynamic process. Some elderly move in and out of "frailty", ¹³ others experience catastrophic onset of disability and still others experience the onset of gradual progressive disability. Given the high variability in the outcome, this may significantly limit the ability of any instrument, including the PHNSS, to identify a group at risk of functional decline to an extent that is clinically meaningful.

The PHNSS is limited primarily to IADL items and measures of general health (hospitalization, self-rated health and medications). While all of these items are strongly predictive of functional decline, additional associations have been identified, for example chronic disease, affective and cognitive status. 14,21,22,26,67 One potential weakness of the PHNSS therefore is that in the desire to maintain brevity, critical domains may have been excluded.

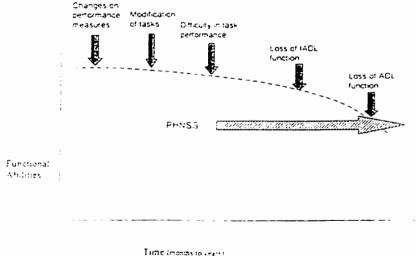
Figure 1 illustrates the progress of gradual functional decline. The PHNSS identifies those individuals who are having difficulty with IADL task performance as well as those with more established impairment. The theoretical construct of focusing on IADL tasks is that those with mild disability 1) are known to be at risk for further decline, 2) are more likely to improve and 3) may have greater potential to benefit from preventive interventions than those with established severe disabilities.²⁵ However, there are subtle

changes that occur even before IADL task become difficult and researchers are currently investigating reliable ways of identifying these groups. Fried et. al. have been exploring an alternative approach of identifying early functional loss by asking persons not only about difficulty in task performance but also task modification and decreased frequency of task performance.⁶⁸ In a cross-sectional study they were able to identify a group of individuals who otherwise would not have been captured by traditional measures and who had an intermediate performance on objectively measured tests and an intermediate number of chronic diseases, compared to those reporting no difficulty or those reporting difficulty.

Another construct that is receiving a great deal of attention is the use of physical performance measures. Two groups have successfully demonstrated that this approach, applied to a group of elderly with no self-reported limitations, can identify a group at higher risk of functional decline.^{7,17} However, because these tests require in-person administration and there is the possibility of significant day-to-day variation in performance among those with chronic diseases, the potential usefulness of performance measures as a screening tool remains under debate.

The potential strength of the PHNSS is that it has been specifically designed and adapted for use in low income settings and across multiple cultural groups. This feature is lacking in existing screening tools. It incorporates the strongest items and domains from several existing instruments. The task of this project was to confirm that the theoretical basis for this instrument was sound, specifically by: examining performance across cultural groups, confirming their reliability, construct validity and predictive validity.

Figure 1: Model of gradual functional decline



3.0 Methods

Streiner and Norman⁴³ outline a general approach to testing of newly designed questionnaires for clinical or research use. This includes:

- item generation
- item reduction
- face validity testing
- reliability testing
- validity testing

This approach was adopted for this project. Reliability and validity testing (construct and predictive) are described in the methods section.

3.1 Construct Validity and Reliability

3.1.1 Subject Recruitment

Inclusion criteria were age 65 years or older and self-identification into one of the targeted cultural groups (English, Chinese, French, Ojibwe, Ukrainian). Exclusion criteria were current residence in a long-term care facility and severe cognitive impairment. All potential study participants were prospectively assigned into either a well or dependent group. Assignment was based on the ability to carry out functional tasks. Those requiring assistance with performance of daily tasks were assigned to the dependent group. Community contacts who recruited participants were familiar with the individuals and made the group assignments.

The recruitment procedure used convenience sampling, targeting inner-city sites with a high proportion of either well or dependent elderly. Organizations and leaders within each of the cultural communities were contacted prior to recruitment of the participants. As a result I developed an extensive database of community contacts. Advisors from each of these cultural groups provided invaluable input into aspects of the recruitment procedure. A number of complementary recruitment strategies were developed. Seniors' centres, elderly persons housing complexes and health service agencies specific to seniors were all helpful in promoting the project and referring the researchers to potential participants. For all cultures, posters and information sheets were distributed or placed in locations frequented by older adults. Informational meetings were held at numerous sites including housing complexes and recreation groups usually by the principal investigator often in conjunction with an interviewer. For the Chinese culture, interviewers were

present at an influenza immunization clinic sponsored by HAC in a non-profit Chinese seniors' housing complex. Shortly after the immunizations were administered, the interviewers approached potential participants by describing to them the purpose and goals of the research project. A list of recruitment sites is included in Appendix 6.

Once a potential participant was identified, they received a mailed summary sheet describing the goals and objectives of the project with a letter thanking them for their interest (Appendix 6). Telephone contact was then made by the interviewer who would answer any questions about the project as well as set up an interview time. Integral to the success of this project was the fact that the interviews were carried out in the participants home and by someone fluent in the language who was sensitive to the differences and characteristics of the culture in which they were interviewing.

3.1.2 Construct validity

Construct validity was tested by administering the PHNSS to community-dwelling elderly persons at two extremes of function: those needing intense formal/informal supports (termed the "dependent" group); and those functioning well and independently without assistance (termed the "well" group). At the same time the following validating measures were obtained (Appendix 7):

- i. socio-economic indicators (marital status, housing, previous occupation, education) by self-report,
- ii. self-report measures of ADL and IADL capacity (Katz et. al. 69, Lawton⁷⁰),
- iii. objective measures of physical function (Physical Performance Test (PPT)⁷¹),
- iv. depression (Geriatric Depression Scale (GDS)⁷²),
- v. cognitive function (Standardized Mini Mental State Exam(SMMSE)⁷³).

This was done as a face to face interview by a trained bilingual interviewer either at home or at the recruitment site. Particular attention was paid to ensuring that the interviewers were fluent in the local preferred languages and dialects, for example Cantonese is the preferred language for the Chinese seniors living in Winnipeg. The a priori hypothesis was that scores on the PHNSS and the additional physical function measures would be consistent with a greater degree of functional impairment in the dependent group compared to the "well" group.

Validation testing was not carried out in the Ojibwe population, in part, due to time constraints. However, pre-testing with the Ojibwe participants also indicated that a questionnaire approach was not acceptable.

The instruments used to validate the PHNSS are well known and widely used within studies of the elderly population. However, with a few exceptions, they have not been specifically adapted or tested for use in other cultures. French and Chinese versions of both the MMSE⁷⁴ and the short form of the GDS ⁷⁵ were identified. For the remaining cultures and for the Katz⁶⁹ and Lawton⁷⁰ measures, items were reviewed and consistent wording agreed upon by the interviewers during training. The following additional steps were undertaken to minimize the impact of the lack of validated adapted versions:

- i. Physical Performance Test⁷¹: Task 1 of the PPT requires the subject, when given the command "go", to write the sentence "whales live in the blue ocean" (Appendix 7). Rather than use the English language version sentence in the non-English cultures or a direct translation of the English sentence, a sentence of similar length was generated for each culture, as listed in Appendix 7.
- ii. SMMSE⁷³ (Appendix 7). Unfortunately, there are items on the MMSE to which respondent scores are known to be influenced by education and ethnicity.⁷⁶
- a) concentration a five letter word was chosen, not necessarily the translation of "world", as listed in Appendix 4. To ensure ability to spell, subjects were asked to spell the word forward and given assistance, as necessary, to learn the task. If they were unable to spell the word forward, backward spelling was not attempted and the total score pro-rated.
- b) repeat "no ifs ands or buts"- the goal of this task is to test repetition of a short phrase with many functor words.⁷⁷ Rather than direct translations, phrases appropriate to each culture were chosen.
- c) write a sentence writing is an important language skill to test, but is very sensitive to education. Years of schooling were determined prior to initiating the SMMSE. Subjects with incomplete primary education were given the option of not answering this item and total scores were pro-rated.

3.1.3 Reliability

Though the PHNSS was intended to be a self-administered instrument, pre-testing indicated that a significant proportion of subjects required some degree of assistance with completion of the questionnaire. Accordingly, both test-retest reliability and inter-rater reliability were measured to quantify sources of measurement error. To assess test-retest reliability, subjects self-administered the PHNSS on two separate occasions within a two week interval. The time interval between the two administrations should have been sufficiently short that the underlying physiological process could be considered stable.

Streiner and Norman suggest that an interval of two days to two weeks is usual.⁴³ Hébert used an interval of one week to test the SPQ⁸ whereas Boult and colleagues used a three-week interval to test their self-administered postal questionnaire.⁷⁸

Inter-rater reliability measures the variation due to interviewer factors on the response of subjects to the test or instrument, in this case the PHNSS. The first administration of the PHNSS occurred during the interview for construct validity. As soon as possible, to a maximum of two weeks later, a second interviewer administered the PHNSS.

3.2 Predictive Validity

Ability to predict functional change and health care utilization was determined by establishing a baseline PHNSS score for a cohort of community dwelling elderly and establishing functional status and health care utilization at 18 months.

Beginning in 1971, the Aging in Manitoba (AIM) study has followed a cohort of Manitobans at several year intervals with assessments of a wide range of demographic, functional and social variables. AIM represents one of the largest population-based longitudinal studies of aging in existence. The latest follow up interviews in 1996 included 1868 survivors, ranging in age from 73-104 residing throughout Manitoba. Within the interview schedule were included all of the items that form the PHNSS except item 2: hospitalization within the past year, item 5: number of medications, item 13: taking out the garbage. Responses to items from the 1996 Aging in Manitoba (AIM) interviews that matched PHNSS items were used to create a "surrogate" baseline PHNSS score (Appendix 8). For the missing items the following methodology was used:

- item 2: hospitalization within the past year. AIM is fully integrated with Manitoba Health administrative data. Hospitalizations for July 1, 1995 to June 30, 1996 were dichotomized into 1+ =yes and 0= no. Admissions of less than 24 hrs, for which the majority were outpatient surgical procedures, were not considered to be a hospitalization episode for the purposes of this study.
- item 5: number of medications. AIM is also linked with computerized Pharmacare data which allowed for the creation of a 'number of medications' item. All prescriptions for January 1, 1996 to June 30, 1996 were reviewed. Excluded were pharmaceutical preparations that did not correspond with the graphics presented in question 5 of the PHNSS (liquids, ointments, patches, suspensions, creams, sprays). Subjects were deemed to be current users of eye drops if the prescription was issued

- on or after April 1, 1996 and current users of antibiotics if the prescription was issued on or after June 1, 1996.
- item 13: taking out the garbage. AIM item A228: "Does anyone help you with doing light housework?" was chosen as the most equivalent item.

Existing prospective screening surveys use time intervals ranging from 4.5 months to 5 years (Appendix 2) to assess outcomes. For the purposes of use as a community based tool, any time interval between 12 and 24 months would have been acceptable. Within this time interval, there would be a high enough proportion of elderly with functional decline to justify initiation of a screening/ intervention program. ^{3,7,17,18,20,80,81} Too short an interval, such as 4-6 months, would likely result in too few persons experiencing decline. Too long an interval, such as 4-5 years would result in an unnecessary high rate of "at risk" persons. Eighteen months was chosen as a relevant time frame after logistics were considered.

Participants in the 1996 AIM interview who had previously consented to participate in further research, who were living in Winnipeg or immediate environs and were community dwelling were considered for inclusion. Subjects were excluded if at the 1996 interview there was significant hearing deficit or the entire interview was completed by a proxy. Participants were contacted by telephone between January and March of 1998 and current functional status was determined using self-reported measures of ADL and IADL capacity (Katz ADL⁶⁹, Lawton⁷⁰) (Appendix 10). For ease of analysis of health utilization data, July 1, 1996 was chosen as the baseline date for all participants and December 31, 1997 as the completion date. Manitoba Health administrative data were used to identify home care use, hospitalization and physician visits in the 18 months from baseline.

3.3 Validation of the Surrogate PHNSS

The PHNSS was specifically developed for use in populations with low literacy. Wording of the questions and responses at times differs from the phrasing used in AIM. In cases where wording or response options differed, a judgement was made as to which AIM response most closely matched PHNSS responses. To measure validity of the interpretation the PHNSS and selected AIM questions were concurrently administered to 10 subjects (Appendix 11). Subjects were recruited from the St. Boniface Geriatric Day Hospital, Stradbrook Age and Opportunity Seniors Centre, Gwen Secter Creative Living Centre. The order in which the questionnaires were administered was randomized.

3.4 Outcome Measures

The primary outcome measures were the ability of the PHNSS to identify:

- i. physical function decline measured using self-report measures (Katz ADL⁶⁹ and Lawton IADL⁷⁰) and a physical performance measure (PPT⁷¹).
- ii. health care utilization measured by Manitoba Health encounter data for physician visits and hospitalizations.

Secondary outcomes were:

- iii. to determine whether the validity of the questionnaire was consistent across cultural groups.
- iv. to examine the effect of different cut points in scoring on the predictive abilities of the questionnaire.

3.5 Sample Size Estimation

3.5.1 Construct Validity

For two of the validating instruments (MMSE and PPT) mean scores with standard deviations in well community dwelling elderly as well as in more impaired, but still community dwelling populations (e.g. Day Hospital, Guest Home), 71,82,83,84 have been established. The estimated sample size needed to be able to demonstrate those expected differences with a one-tailed α of 0.05 and β of 0.20 is 34 per group. 85

3.5.2 Reliability Testing

The measure of reliability for individual questionnaire items was the kappa coefficient. The reliability of the summary score for the PHNSS was tested using the intra-class correlation coefficient (ICC). Boult et. al. have determined a Pearson's correlation coefficient of 0.78 for test-retest reliability at three weeks for an 8 item questionnaire mailed to elderly subjects. The Dartmouth COOP Project has found Pearson's correlation coefficients ranging from 0.42-0.88 for two-week reliability for a questionnaire with 6 items assessing functional domains with the assistance of illustrations. To test a null hypothesis that the ICC of the summary score of the PHNSS is 0.60 and an alternate hypothesis that the ICC is 0.80 requires 35 subjects tested on two separate occasions. This assumes an α of 0.05 and β of 0.20.

3.5.3 Predictive Validity

Sample size estimations are made on the assumption that the PHNSS would identify two discrete groups, low risk and high risk, which will differ in the proportion of subjects with functional decline at 18 months. Based on longitudinal cohort data it was assumed that at 18 months the proportion of subjects in the low risk group with functional decline would be 5% and the high risk group 12%. 3,7,17,18,20,80 It was also assumed that the PHNSS would identify 33% of subjects as high risk. Using $\alpha = 0.05$ and $\beta = 0.20$, 128 and 256 subjects were required in the high risk and low risk groups respectively.88 Allowing for an 8.6% loss of subjects in follow-up required an initial sample size of 420. Of the prospective instruments, the SPQ is the most similar in objective to the PHNSS. When applied to community dwelling elderly aged 70 or older, this instrument identified 53% of subjects as high risk.⁸ It was difficult a priori to predict accurately what proportion of subjects would be screened positive by the PHNSS. Receiver Operating Characteristic (ROC) curves were used to establish the optimum PHNSS cut point for low risk versus high risk.⁷⁵ This technique allows estimation of sensitivity, specificity, positive predictive value, negative predictive value and percent screened positive for a series of cut points. Therefore, there is the ability to select a cut point which results in test characteristics that are as close as possible to those desired by the investigator.

3.6 Statistical Analysis

Data files for study subjects were identified using an alpha-numeric code for confidentiality. Descriptive statistics were used to characterize the participating subjects and to compare groups. Test-retest reliability of the summary score was established using the intra-class correlation coefficient which is derived from an ANOVA. Reliability of individual questionnaire items was tested using the kappa coefficient. ANOVA and correlation coefficients were used to examine the relationships between validating instruments for each cultural group. Internal consistency of the PPT with and without item 1 was tested using item-total correlations.

The association of a high score with the at risk state was tested either with a Chi-square or the Mann-Whitney U test if the at risk state was a continuous measure as the results were heavily skewed (e.g. total Lawton score, total days of Home Care use). Test properties of individual cutoff scores for the prediction of functional dependence and health utilization were generated from 2x2 tables. ROC curves are created by plotting

sensitivity versus 1-specificity for a series of cut points thus allowing choice of the optimal cut-off score.⁴³

4.0 Informed Consent

4.1 Construct Validity and Reliability

Participation in the project was voluntary and all subjects were asked to sign a consent form (Appendix 9) prior to conducting the interview. The following adaptations were made to the consent process:

- i. French: all explanatory materials and consent forms were translated into French.
- ii. Chinese: consent forms were translated into Chinese and provision was made for verbal consent, with the requirement that there be two independent witnesses. This modification occurred because there was considerable reluctance among the Chinese seniors to provide a signature, on any official form, despite verbally consenting to participation.

4.2 Predictive Validity

The principal investigators of the AIM study were approached to give permission to contact 1996 AIM interviewees. During the 1996 AIM interview, subjects were asked to provide written consent if they were willing to be contacted for future studies. Only those subjects who had given consent were considered for inclusion. All contacts with individual AIM participants were made by research staff hired and supervised by AIM. During the initial telephone contact introducing the PHNSS study, consent for participation was sought. If there was agreement to participate, then explicit consent for use of the AIM data and Manitoba Health data was also obtained (Appendix 10).

5.0 Privacy and Confidentiality

All completed data forms were stored in a locked filing cabinet within the offices of the principal investigator. All computer disks containing subject data were maintained in a locked storage container in the offices of the principal investigator. The principal investigator was the only person with access to the filing cabinet and storage containers. To ensure subject confidentiality, each subject was assigned an alpha-numeric identification number and only this identifier was used on each data collection form. Subject names or other identifying information were not included on the data forms or

computer data sets. Subjects are not identified in any reports or written documents summarizing the findings.

AIM has well established and extensive mechanisms in place to ensure security and confidentiality of their data. AIM provided a custom data set for analysis which does not have any personal identifying data for the participating individuals. These data were maintained on computer disks in a locked storage container. All analyses were completed in a protected file on a personal computer which cannot be accessed through the St. Boniface General Hospital or University of Manitoba computer networks.

6.0 Ethics

There were no direct benefits to the subjects in this study. No inducements or compensation were offered to participants.

A summary of committees and institutions from which ethics approval was obtained is included in Appendix 12. Ethics approval was obtained from the University of Manitoba: Faculty Committee on the Use of Human Subjects for the project entitled "Development and Validation of the Predicting Health Needs of Seniors Survey" as well as the project "Predictive Validity of the Instrument: Predicting Health Needs of Seniors Survey". The protocol for this thesis project was contained within these two projects. The status of these two projects as components of an M. Sc. Thesis for the Department of Community Health Sciences was clarified with the University of Manitoba: Faculty Committee on the Use of Human Subjects and the Manitoba Health Access and Confidentiality Committee. Institutional Ethics Approval for access to human subjects was obtained from St. Boniface General Hospital and Seven Oaks General Hospital to allow recruitment of subjects from the Day Hospitals located at those institutions. Not included in Appendix 12 are many of the community agencies that did not have an explicit process in place for involvement in studies (e.g. Manitoba Housing, Age and Opportunity). In those circumstances the agencies were always informed of the status of the project with the University of Manitoba: Faculty Committee on the Use of Human Subjects and a copy of the approval was provided on request. All interviewers were required to sign an oath assuring that any information received from participants would remain confidential. Permission to access Manitoba Health utilization data was obtained from the Access and Confidentiality Committee of Manitoba Health.

7.0 Results

7.1 Construct Validity and Reliability

7.1.1 Study Subjects

For the construct validity testing, 55 English participants (well=33, dependent=22), 71 Chinese participants (well=36, dependent=35), 67 French participants (well=36, dependent=31) and 23 Ukrainian participants (well=18, dependent=5) were recruited. For this study, recruitment was a time intense process and it was not possible to recruit as many Ukrainian participants as planned. A large proportion of the Ukrainian sample was obtained through the Sons of the Ukrainian Pioneers, a male volunteer service organization. This tended to bias several characteristics - with a higher proportion of married persons, higher income levels and higher educational achievement than the other samples. Because of the small and biased sample, the Ukrainian subjects were excluded from further analysis.

Pre-testing of the Ojibwe version of the PHNSS with Ojibwe participants was carried out on 10 seniors recruited from the Health Science Centre or Kekinan, a native Seniors Housing complex. In those subjects that were literate and wished to self-administer the survey, a preference for an English language survey was indicated. When the PHNSS was interviewer-administered because of the number of Ojibwe dialects in Manitoba and the subtle phonetic differences, the interviewers found the Ojibwe version of the PHNSS unwieldy. Administration time was much longer than in the other cultures, averaging 20-25 minutes. The interviewers found the majority of seniors reluctant to provide rapid categorizations of their functional abilities. Finally, in the pre-testing that took place at Kekinan it was evident that a screening questionnaire approach was generally unacceptable. In exploring these sentiments with the Ojibwe participants, the following themes emerged: 1) impatience with the many surveys that have been done without any tangible benefits to their people, and 2) suspiciousness of research by external agencies.

7.1.2 Baseline characteristics

Demographic characteristics for the participating groups are described in detail in Tables 1 to 4. The average age ranged from 76-78 years with the exception of the Chinese dependent group which averaged 83 years. A predominantly female population was recruited. In the English and French groups, the majority lived alone with no differences between the well and dependent groups. In the Chinese participants, though the majority of well participants lived alone, 48% of the dependent seniors lived with two or more adults compared with less than 10% of the French and English participants. The Chinese seniors are a demographically distinct group from the English and French participants with the majority residing in Canada less than 32 years, a much greater proportion with less than 4 years education and much lower economic resources with 88% reporting less than \$1000 per month income.

Table 1: Baseline characteristics of the English participants (percentages unless otherwise indicated)

| Characteristic | Well n=33 | Dependent n=22 |
|---|----------------------|----------------------|
| Mean age (year) Female Married living: | 75.5 69.7 18.2 | 76.5 59.1 18.2 |
| alone | 78.8 | 77.3 |
| with one adult | 21.2 | 13.6 |
| with ≥ 2 adults | | - |
| living in house or apartment | 39.4 | 54.6 |
| living in seniors housing/ guest home | 60.6 | 45.4 |

 $^{- \}le 3$ subjects

Table 2: Baseline characteristics of the French participants (percentages unless otherwise indicated)

| Characteristics | Well | Dependent |
|--|------|-----------|
| | n=36 | n=35 |
| Mean age (years) | 77.6 | 83.2 |
| Female | 66.7 | 80.0 |
| Married | 25.0 | 25.7 |
| living: | | |
| alone | 66.7 | 71.4 |
| with one adult | 28.6 | 25.7 |
| with ≥ 2 adults | - | - |
| living in house or apartment | 38.8 | 22.9 |
| living in seniors housing/ guest home | 61.1 | 77.1 |

^{≤ 3} subjects

Table 3: Baseline characteristics of the Chinese participants (percentages unless otherwise indicated)

| Characteristics | Well | Dependent |
|--|------|-----------|
| | n=36 | n=35 |
| Mean age(years) | 77.1 | 78.1 |
| Female | 72.2 | 71.0 |
| Married | 33.3 | 48.4 |
| living: | | |
| alone | 58.4 | 19.4 |
| with one adult | 19.4 | 32.3 |
| with ≥ 2 adults | 22.3 | 48.4 |
| living in house or apartment | 44.5 | 87.1 |
| living in seniors housing/ guest home | 55.6 | 12.9 |

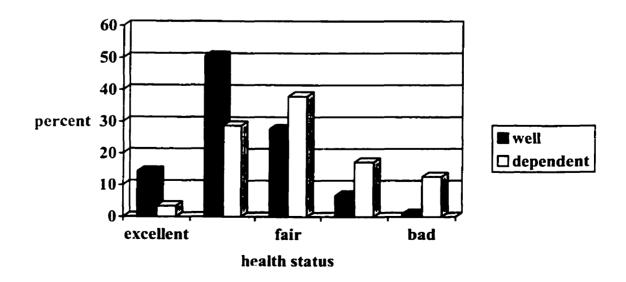
Table 4: Comparison across cultures for selected characteristics (percentages)*

| Characteristic | English (n=52) | French (n=71) | Chinese (n=67) |
|--------------------------|----------------|---------------|-------------------|
| Born in Canada | 76.4 | 95.8 | 0 |
| Immigrated ≤ 32 years | 21.8 | - | 20.9 |
| Income <\$1000 per month | 53.4 | 35.9 | 88.2 |
| Education: | | | |
| ≤ 4 years | 10.8 | 9.8 | 44.8 |
| 5-9 years | 29.1 | 42.1 | 20.9 |
| ≥ 10 years | 54.6 | 46.7 | 32.8 |

^{*} totals do not always equal 100% due to rounding off and missing values

Comparison of the well and dependent participants indicates that the dependent group had lower self-rated health scores, were more likely to have been hospitalized in the previous year and were taking more medications. Figure 2 graphically represents the distribution of responses to the item on self rated health for all the study subjects combined. A greater proportion of the dependent group rated their health as fair, poor or bad.

Figure 2: Self rated health of well and dependent groups



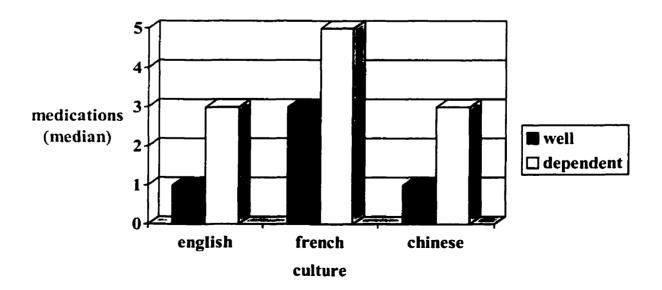
^{≤ 3} subjects

In all three cultural groups, the median response of the well group was "good" and the dependent group "fair". Medication use increased with worsening health status (Table 5), and, as expected, was higher in the dependent group relative to the well group (Figure 3). The greater number of medications taken by the French participants, whether they were well or dependent, is striking. When medication use was dichotomized into less than 4, or 4 or more medications, 68.6 % of the French dependent elderly were taking 4 or more medications compared to 45.5% and 32.3% of English and Chinese dependent

Table 5: Number of medications by self-rated health

| Self-rated health | Median | Mean ± SD | 95% CI for mean |
|-------------------|--------|-----------|-----------------|
| Excellent | 1.50 | 1.90±1.86 | 1.02, 2.87 |
| Good | 2.00 | 2.53±2.08 | 2.06, 3.00 |
| Fair | 3.00 | 2.92±2.19 | 2.36, 3.48 |
| Poor | 5.00 | 4.54±1.76 | 3.76, 5.32 |
| Bad | 4.00 | 4.83±3.59 | 2.55, 7.11 |

Figure 3: Number of medications (median) for well and dependent seniors by cultural groups

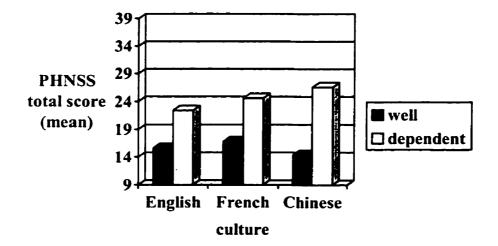


participants, respectively. In the well participants 2.9% of the French were taking 0 medications compared to 21.2% and 38.9% of the English and Chinese participants, respectively. The dependent groups were also more likely to have been hospitalized in the past year (61.5-73.3%) than the well groups (26.7-38.5%).

7.1.3 Construct validity

Figure 4 graphically presents the differences between the PHNSS total score between well and dependent groups for the three cultures. For this portion of the analysis the

Figure 4: PHNSS total score for well and dependent groups of participants



PHNSS score range (which is usually 9-39) was converted to a scale ranging from 0-100 for ease of analysis. As anticipated, dependent groups scored significantly higher (worse) than well groups (p<0.001). These differences are mirrored in the performance on the functional measures (Katz⁶⁹, Lawton⁷⁰ and PPT⁷¹) (Tables 6,7,8) and are statistically significant. These differences are consistent across the three cultures. The findings confirm the construct validity of the PHNSS. There is a less consistent difference between groups for the SMMSE ⁷³ and GDS ⁷². This may reflect small sample size, difficulties with culturally adapting the instruments, may be related to the reliance on volunteers for the sample or some combination of these factors. A group of volunteer participants for a research project can be expected to have fewer difficulties with memory or mood.

Table 6: Group comparisons for the PHNSS total score and validation measures in the English participants, reported as mean and standard deviations

| Instrument | Well (n= 33) | Dependent (n= 22) | P value |
|---|--------------|-------------------|---------|
| PHNSS total score (maximum score 100)^ | 20.2 (14.7) | 44.7 (16.8) | <0.001 |
| Katz ADL (maximum score 6)^ | 0.2 (0.5) | 1.1 (0.9) | <0.001 |
| Lawton IADL (maximum score 8)^ | 0.5 (1.2) | 3.6 (2.3) | <0.001 |
| Physical Performance Test (maximum score 28)* | 22.7 (4.2) | 14.3 (5.2) | <0.001 |
| MMSE (maximum score 30)* | 27.8 (2.7) | 25.4 (4.6) | 0.02 |
| GDS (maximum score 15)^ | 2.7 (2.7) | 5.18 (3.5) | 0.004 |

[^] higher score indicates worse performance

Table 7: Group comparisons for the PHNSS total score and validation measures in the French participants, reported as mean and standard deviations

| Instrument | Well (n=36) | Dependent (n=35) | P value |
|---|-------------|------------------|---------|
| PHNSS total score (maximum score 100)^ | 26.0 (14.6) | 52.1 (16.0) | <0.001 |
| Katz ADL (maximum score 6)^ | 0.3 (0.5) | 1.3 (1.4) | <0.001 |
| Lawton IADL (maximum score 8)^ | 0.9 (1.4) | 4.2 (2.1) | <0.001 |
| Physical Performance Test (maximum score 28)* | 22.3 (3.4) | 14.6 (6.1) | <0.001 |
| MMSE (maximum score 30)* | 27.5 (2.3) | 26.0 (3.6) | 0.04 |
| GDS (maximum score 15)^ | 2.4 (2.0) | 4.6 (3.2) | 0.001 |

[^] higher score indicates worse performance

^{*} lower score indicates worse performance

^{*} lower score indicates worse performance

Table 8: Group comparisons for the PHNSS total score and validation measures in the Chinese participants, reported as mean and standard deviations

| Instrument | Well (n=36) | Dependent (n=31) | P value |
|----------------------------------|----------------|------------------|---------|
| PHNSS total score | 17.9 (8.1) | 58.6 (19.4) | < 0.001 |
| (maximum score 100) [^] | | | |
| Katz ADL | 0.06 (0.2) | 1.6 (2.1) | < 0.001 |
| (maximum score 6) [^] | | | |
| Lawton IADL | 0.9 (1.0) | 5.4 (1.8) | < 0.001 |
| (maximum score 8)^ | | | |
| Physical Performance Test | 20.3 (6.3) | 12.8 (6.2) | < 0.001 |
| (maximum score 28)* | | | |
| MMSE | 23.1 (5.3) | 17.8 (8.8) | 0.003 |
| (maximum score 30)* | | | |
| GDS | 3.8 (2.6) | 5.0 (3.2) | 0.10 |
| (maximum score 15)^ | | | |

[^] higher score indicates worse performance

As a separate measure of construct validity, the correlation coefficient of the PHNSS total score with a measure of ADL status (Katz total score), a measure of IADL status (Lawton total score) and a physical performance measure (PPT total score) (Table 9) was examined. The PHNSS was highly correlated with IADL status across all the cultures examined. This is not surprising as 7 of the 13 items of the PHNSS focus on IADL activities. The PHNSS was moderately correlated with ADL and physical performance across cultures.

Table 9: Pearson correlation coefficients of the PHNSS total score and functional measures

| Culture | PHNSS Total- Katz Total | PHNSS Total- Lawton Total | PHNSS Total- PPT Total |
|----------------|----------------------------|------------------------------|---------------------------|
| English (n=55) | 0.73 * | 0.75* | -0.67* |
| French (n=71) | 0.52 * | 0.77* | -0.72* |
| Chinese (n=67) | 0.72* | 0.88* | -0.59* |

^{*}p<0.001

A number of relevant observations were made during pre-testing and validity testing. Despite the adaptations and addition of graphics, functionally illiterate individuals still required assistance in filling out the survey. This is consistent with the strategy

^{*} lower score indicates worse performance

recommended by Sullivan and colleagues that to obtain high quality health status data, low-income populations should be screened for literacy and appropriate assistance provided.⁸⁹ Not surprisingly, dependent seniors were more likely to ask for assistance filling out the questionnaire than well seniors (31%-80% versus 11% -30% respectively).

7.1.4 Reliability

The PHNSS was self administered on two separate occasions within two weeks of each other with 69 subjects. It had high test-retest reliability with kappa coefficients for individual items ranging from 0.41-0.93 and an intra-class correlation coefficient of 0.91 for the total score (Table 10). Inter-rater reliability testing was completed with two pairs of raters, 5 subjects for Pair 1, 10 subjects for Pair 2. Pair 1 were French and Pair 2 were Chinese. This limited testing demonstrated that the rater has an effect on the scoring of the PHNSS (Table 10). Though the ICC was acceptable for both rater pairs (Pair 1= 0.83, Pair 2= 0.67), there were specific questionnaire items that demonstrated significant variability between the raters:

- Item 3: Do you have someone you can count on if you need help around the house?
- Item 4: How would you rate your current health?
- ♦ Item 6: How easy or hard is it to get out of a chair?
- Item 10: How easy or hard is it for you to prepare meals?

Table 10: Kappa reliability coefficients for individual PHNSS questionnaire items and Intra-class correlation coefficients for the PHNSS total score

| PHNSS Items | Test-retest Self-administered (n= 69 pairs) | Inter-rater Reliability Pair 1 (n=5) | Inter-rater reliability Pair 2 (n=10) |
|-----------------------|---|--|---|
| 1. 75 years or older | 0.93 | 1.00 | 1.00 |
| 2. hospital past year | 0.87 | 0.62 | 1.00 |
| 3. help around house | 0.69 | 0.29 | -0.43 |
| 4. current health | 0.68 | (60%) | (10%) |
| 5. medications | 0.78 | (60%) | 0.51 |
| 6. out of a chair | 0.65 | (40%) | (90%) |
| 7. walk inside | 0.78 | 1.00 | (100%) |
| 8. cut toenails | 0.86 | 1.00 | (100%) |
| 9. buy groceries | 0.77 | 0.54 | (80%) |
| 10. prepare meals | 0.77 | 0.76 | -0.19 |
| 11. use telephone | 0.41 | 1.00 | (100%) |
| 12. banking | 0.89 | 0.54 | 1.00 |
| 13. take out garbage | 0.73 | 1.00 | (90%) |
| Total score | 0.91 | 0.83 | 0.67 |

⁻⁻ Kappa could not be computed because the two-way table was asymmetric, % agreement is in parentheses

7.1.5 Impact of Culture on the Measurement Tools

As mentioned above, only in a few instances were cross culturally adapted and tested validating instruments available. Therefore, it is particularly important to look at the possible impact of participant culture on the performance of each instrument within a particular group and how it compared between groups.

PHNSS: On ANOVA, culture had an independent effect on the PHNSS total score (p=0.030). This effect was most pronounced with the dependent sample (Figure 4, p.41). In the French group this reflected primarily the greater rate of medication use (Figure 3, p. 40). In the Chinese population there was a greater degree of reliance on others for IADL tasks that rely heavily on use of language (telephone, grocery shopping, banking). The finding that dependent Chinese elderly were much more likely to be living with one

or more adults (Tables 1, 2, 3, pp.37-8) is reflected in the fact that they were more likely to have someone to call on for help, and a higher proportion reported someone else taking out their garbage. Therefore, out of the 13 items in the PHNSS, 6 appear to be particularly sensitive to the impact of the culture of the participant:

• item 3: help around the house

• item 5: number of medications

• item 9: grocery shopping

• item 11: using the telephone

• item 12: banking

• item 13: taking out garbage

MMSE:⁷³ Despite the ability to obtain adapted, validated instruments administered by interpreters, performance on the MMSE was uniformly worse for the Chinese seniors (p<0.05) (Tables 6,7,8, pp. 42-3). Well Chinese seniors scored on average 23.1 compared to 27.8 and 27.5 for English and French groups respectively. The differences were even more dramatic for dependent Chinese seniors who scored 17.8 compared to 25.4 and 26.0 for English and French. Review of responses to individual items indicated that the participants were attempting to answer questions with high error rates rather than simply refusing to undertake a task with which they were unfamiliar (Table 11). Error rates were high across all items.

Table 11: Selected Items on the MMSE

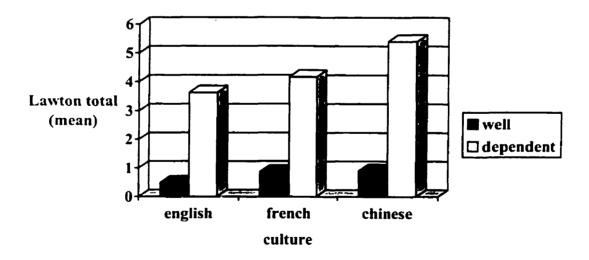
| Item | English | | English Chinese | | |
|-------------------|---------------|-------------|-----------------|-------------|--|
| | Incorrect (%) | Refused (%) | Incorrect (%) | Refused (%) | |
| Province | 5.5 | | 34.3 | 3.0 | |
| City | | | 23.9 | 3.0 | |
| Concentration (1) | 5.5 | 9.1 | 37.3 | 3.0 | |
| Concentration (2) | 7.3 | 9.1 | 52.2 | 3.0 | |
| Repeat | 25.5 | 5.5 | 23.9 | 3.0 | |
| Sentence | 12.7 | 9.1 | 52.2 | 6.0 | |

GDS⁷²: There was no significant impact of culture on performance on the GDS. However, there was variation in the mean total score in the well participants with the Chinese participants generating higher mean scores (3.77) than the English (2.67) and French (2.44) participants with a trend towards statistical significance (p=0.055). Of note there were 7 Chinese participants who refused or were unable to answer the majority

of questions on the survey. This did not occur with any participant in the other groups. Of the 7 non-completers, 4 had no formal schooling, but 3 had achieved grade 10 education or higher. There were interesting differences in how questions were answered. Well Chinese seniors were more likely to report satisfaction with their life (p<0.01), both well and dependent Chinese seniors were more likely to report not being in good spirits (p<0.01), a desire to stay at home rather than going out and doing new things (p<0.05) and problems with memory (P<0.01). Dependent English seniors were more likely to report a feeling of helplessness (p<0.05).

Katz⁶⁹ and Lawton⁷⁰: There was a low prevalence of dependence in ADLs as reflected in low Katz scores. The culture of the participant did not have an impact on this. As expected the pattern of dependency in the Lawton (Figure 5) was very similar to the PHNSS (Figure 4, p. 41), and had an independent effect on the ANOVA (p=0.001). Similar to the experience with the PHNSS, dependent Chinese seniors required substantially more assistance with language dependent IADLs: shopping, finances and transportation. This group did require greater assistance with telephoning, as well, but it did not reach statistical significance.

Figure 5: Lawton score (mean) in well and dependent participants by cultural group



PPT⁷¹: There was no significant impact of culture on performance on the PPT. Mean scores for well and dependent groups were similar across cultures (Tables 6,7,8, pp. 42-3). The item most sensitive to culture was item 1: write a sentence..... (Appendix

7). The proportion of participants who were unable, did not try or refused this item were 18.2%, 12.1% and 43.3% in the English, French and Chinese groups respectively. The low education levels in the Chinese seniors likely account for some of these differences. Of the Chinese participants who were unable, did not try or refused this item, 62% had no formal schooling. Expressed in a different way, of the Chinese participants with no formal schooling, 75% did not complete item 1 of the PPT.

Dropping Item 1 from the PPT did not appear to have an impact on the overall performance of the instrument. The correlation between the total score for the original PPT and the modified PPT is extremely high: English 0.982 and Chinese 0.984. To further test this hypothesis two analyses were performed. First, individual PPT items were correlated with the total and a modified total score with item 1 withdrawn (Table 12). All correlations remain statistically significant and there were no substantive changes on withdrawal of item 1. The second analysis compared correlations of the PPT total score and modified score to the functional measures (Table 13). Withdrawal of item 1 did not lead to any changes in the correlation of the PPT with the Katz, Lawton or the PHNSS in the English participants. In the Chinese participants, there was an overall improvement in the association of the PPT with functional measures when item 1 is removed, though the changes are not statistically significant.

Table 12: Item-total correlations for the PPT total and modified PPT total (totalitem 1)

| PPT Item | English | English | | |
|----------|-----------|-----------------------|-----------|-----------------------|
| | PPT Total | Modified PPT Total | PPT Total | Modified PPT Total |
| Item 2 | 0.573 | 0.546 | 0.803 | 0.793 |
| Item 3 | 0.634 | 0.610 | 0.599 | 0.635 |
| Item 4 | 0.860 | 0.884 | 0.696 | 0.700 |
| Item 5 | 0.795 | 0.799 | 0.736 | 0.776 |
| Item 6 | 0.568 | 0.629 | 0.824 | 0.826 |
| Item 7 | 0.816 | 0.808 | 0.749 | 0.747 |

Table 13: Correlations of PPT and modified PPT (PPT-item 1) with functional measures

| | English | | Chinese | |
|--------------|-----------|--------------------|-----------|--------------------|
| | PPT Total | Modified PPT Total | PPT Total | Modified PPT Total |
| Katz | -0.669 | -0.656 | -0.075 | -0.168 |
| Lawton | -0.716 | -0.712 | -0.530 | -0.560 |
| PHNSS | -0.678 | -0.678 | -0.589 | -0.638 |
| Modified PPT | 0.982 | 1.000 | 0.984 | 1.000 |

7.1.6 Traditional Chinese Medicines

The Traditional Chinese Medicine (TCM) use survey was developed by Dr. Erin Tjam and has been used in Waterloo, Ontario and China. Within the survey there are measures of acculturation, belief systems with regard to illnesses, questions on use of TCM and how TCM is accessed (Appendix 5). There is no specific quantification of the amount or frequency of TCM use.

The supplement to the PHNSS survey was administered by trained Chinese interviewers, with Chinese cue cards to assist in rating items. The survey results indicated that the sample had remained immersed in the Chinese culture. Seventy nine percent described themselves as non-fluent in written English and 78% as non-fluent in spoken English. Over 90% spoke only Chinese at home, preferred Chinese food, thought in Chinese only and read in Chinese only. Despite that, there was strong preference for the use of Western medicine only, for a variety of diseases and symptoms (Table 14).

Select individuals preferred TCM only for symptoms such as headaches, dizziness and pain. A small proportion of subjects, 9.6% to 17% of those with the relevant symptom, indicated a desire for both types of medicines. The only symptom where Western medicine only was not clearly preferred was "memory", when 48% of the sample preferred

Table 14: Preference for type of medicine for select diseases and symptoms

| Disease/ | Present | TCM only | Both | Western | Do nothing |
|--------------|---------|----------|------|---------|------------|
| symptom | | | | only | |
| Hypertension | 50.0 | | 4.8 | 43.5 | 1.6 |
| Diabetes | 15.3 | | | 13.6 | 1.7 |
| Allergies | 16.9 | 1.7 | | 8.5 | 6.8 |
| Arthritis | 50.9 | | 10.2 | 28.8 | 11.9 |
| Headaches | 22.8 | 3.5 | 5.3 | 10.5 | 3.5 |
| Dizziness | 26.4 | 1.8 | 7.0 | 12.3 | 5.3 |
| Pain | 15.8 | 3.5 | - | 8.8 | 3.5 |
| Constipation | 16.1 | | 1.8 | 8.9 | 5.4 |
| Метогу | 61.4 | | 15.8 | 15.8 | 29.8 |
| Sleep | 25.0 | | 3.6 | 5.4 | 16.1 |

to do nothing. Forty six percent of the participants did indicate that they would use TCM for reasons other than medical treatment i.e. health tonic, health promotion.

When asked about beliefs towards TCM and Western medicine, the respondents were ambivalent towards most belief statements such as: TCM is less harmful, TCM should be used for incurable illness, combining is the most effective treatment (70.6%, 70.0% and 64.0% ambivalent respectively). The majority (64.7%) felt Western medicine should be used for major problems and they were divided on the use of TCM for chronic illness (49.9% ambivalent, 45.1% disagree).

7.2 Predictive Validity

7.2.1 Study Subjects

A list of 521 participants was generated by AIM personnel of whom 368 (70.7%) were able to be contacted by telephone and were willing to continue with the interview. Reasons for not establishing contact included:

• n=52 (9.9%): telephone not in service, unlisted or wrong phone number

• n=31 (6.0%): no answer despite multiple attempts

• n=28 (5.4%): refused to be interviewed

♦ n=24 (4.6%): deceased

• n=18 (3.5%): person requested to be called back but unable to establish second

contact

Of those consenting to the interview, 30 (8.2%) refused access to Manitoba Health claims data, therefore there were 338 participants for whom there was complete data and for whom a surrogate PHNSS could be generated. For 22 (6.5%) of the 338 participants, information was provided by a proxy. In these instances, the most common circumstance was that the original AIM participant had been admitted to a personal care home.

Comparison of baseline AIM data on participants, and those had died, could be not be contacted or refused use of Manitoba Health claims data (excluding those who refused to be interviewed at the time of phone contact) indicated that the non-participants were older, had lower educational achievement, were more likely to have poor self-rated health and were more likely to report heart problems (Table 15).

Table 15: Comparison of study participants and non-participants on selected characteristics (percentages unless otherwise indicated)

| Characteristics | Participants (n=338) | Non-participants (n=152) | Statistical significance |
|------------------------------|----------------------|--------------------------|--------------------------|
| Female | 63.3 | 56.6 | NS |
| Mean age (years) | 79.3 | 82.0 | P<0.001 |
| Living alone | 47.0 | 43.7 | NS |
| Education grade 8 | 27.1 | 38.2 | P=0.01 |
| General health Fair/poor/bad | 32.5 | 49.7 | P<0.001 |
| Heart problems last year | 34.0 | 45.6 | P=0.01 |
| Hypertension last year | 35.2 | 36.0 | NS |
| Cancer last year | 10.7 | 12.0 | NS |

NS= not significant

7.2.2 Surrogate PHNSS

The PHNSS has a minimum score of 9 and maximum of 39. The higher the score the greater the risk. When the "surrogate" PHNSS (sPHNSS) was applied to the AIM derived sample, there was a mean score of 15 (SD 3.8) and median of 14, the range of values was 9-28 (Figure 6). There was only a small ceiling effect, with 4% of participants obtaining the lowest (least risk/best health status) score and there was no observed floor effect (highest risk/worst health status).

The "surrogate" PHNSS (sPHNSS) was tested against the individual AIM questions from which it was derived in a distinct sample of elderly persons (validation cohort). The range of PHNSS scores was 11-23 for this group with a mean score of 16 (SD 4.6). Raw agreement between individual PHNSS items and AIM derived items ranged from 78-100%.

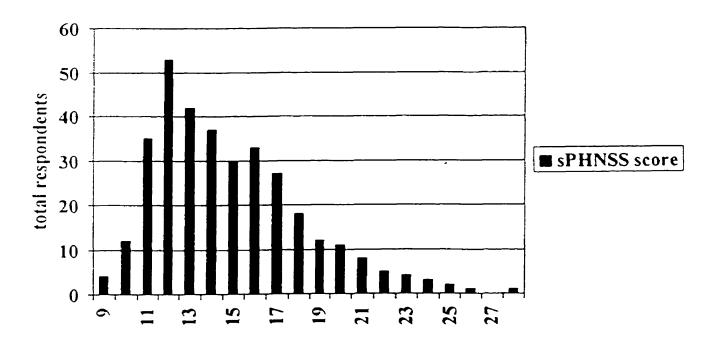


Figure 6: Distribution of "surrogate" PHNSS scores

The main limitation was that in items where the PHNSS has a "hard" or "difficult" option there were no similar response options in the AIM derived surrogate items. Four surrogate questionnaires were initially created each with slight variations in how the AIM derived items were interpreted. This did not result in large variations in total score

ranges, means or medians. The sPHNSS used in this study was chosen as it had the highest agreement with original AIM questions in the validation cohort.

From the sPHNSS, four potential "cutoff" scores were tested for the ability to predict functional impairment and health utilization. Each cutoff point identifies a different proportion of the population as being "at risk" (Table 16). A higher baseline score on the sPHNSS was significantly associated with increasing age, a greater likelihood of living in designated seniors housing and an increased prevalence of self-reported chronic diseases: cardiovascular disease, hypertension, stroke, previous heart attack, chronic pain, arthritis, ear problems and eye problems. These findings were consistent across all four cutoff scores of the sPHNSS. Of note, a higher baseline score was not associated with gender, living alone or loneliness.

Table 16: sPHNSS cutoff scores

| Cutoff score | Percent at risk |
|--------------|-----------------|
| 13/14 | 57 |
| 14/15 | 46 |
| 15/16 | 37 |
| 16/17 | 27 |

7.2.3 Predicting Functional Dependence

Overall, the prevalence of dependence in at least one ADL at 18 months was 18.9%. The prevalence of dependence as measured by the Katz⁶⁹ was low (<2%) for dressing, feeding, toileting or transfers. Six percent reported dependence in bathing and 15% in continence, which more specifically can be broken down into occasional accidents in 13.6% and supervision or use of a catheter in 1.5%. Of those at 18 months, who required assistance with bathing, 76.2% required mechanical support to walk around the neighborhood and 4.8% had difficulty getting in and out of bed at baseline.

A higher baseline score on the sPHNSS was significantly associated with dependence in bathing and continence at 18 months and dependence in at least 1 ADL. As Table 17 and 18 demonstrate the sensitivity and specificity of the sPHNSS for these outcomes were only moderate. The exception is the high sensitivity for bathing at 18 months. However,

the low prevalence of dependence in bathing and high false positive rate result in a very low positive predictive value.

Table 17: Dependence in bathing at 18 months

| Score cutoff | Percent at | Sensitivity | Specificity | Positive | Negative |
|--------------|------------|-------------|-------------|------------|------------|
| | risk | | | Predictive | Predictive |
| | | | | Value | Value |
| 13/14 | 57 | 0.90 | 0.45 | 0.10 | 0.99 |
| 14/15 | 46 | 0.90 | 0.67 | 0.12 | 0.99 |
| 15/16 | 37 | 0.90 | 0.67 | 0.15 | 0.99 |
| 16/17 | 27 | 0.76 | 0.76 | 0.17 | 0.98 |

Table 18: Dependence in one or more ADLs at 18 months

| Score cutoff | Percent at risk | Sensitivity | Specificity | Positive Predictive Value | Negative Predictive Value |
|--------------|-----------------|-------------|-------------|---------------------------------|---------------------------------|
| 13/14 | 57 | 0.75 | 0.47 | 0.25 | 0.89 |
| 14/15 | 46 | 0.62 | 0.59 | 0.28 | 0.89 |
| 15/16 | 37 | 0.61 | 0.69 | 0.31 | 0.88 |
| 16/17 | 27 | 0.50 | 0.78 | 0.35 | 0.87 |

As expected, there was a higher prevalence of IADL dependence than ADL dependence in this population; at 18 months half the participants were dependent in more than one IADL as defined by the Lawton Index.⁷⁰ The prevalence of dependence for housekeeping appeared very low, but was a reflection of the scoring system devised by Lawton. Table 19 summarizes the prealence of dependence for tasks as defined by the Lawton Index. In fact, only 37.3% of respondents reported maintaining their residence alone. Also of interest is that some male respondents had difficulty answering IADL questions as they were not expected to perform them within their households and therefore "don't do" the tasks (n=40 laundry, n=29 meal preparation). These responses were ultimately classified as dependent responses.

Table 19: Dependence in specific IADL tasks at 18 months follow-up

| Lawton Item | Percent dependent |
|-----------------------|-------------------|
| Shopping | 43.2 |
| Laundry | 29.3 |
| Transportation | 27.5 |
| Meal preparation | 24.6 |
| Medication management | 6.2 |
| Banking | 5.6 |
| Housekeeping | 5.0 |
| Use of telephone | 1.8 |

For each cutoff score the higher risk group had a higher prevalence of IADL dependence (p<0.0001). The ability to predict dependence in 2 or more IADLs was modest (Table 20) though with the higher prevalence of IADL impairment, the positive predictive value improves.

Table 20: Dependence in two or more IADLs at 18 months

| Score cutoff | Percent at risk | Sensitivity | Specificity | Positive Predictive Value | Negative Predictive Value |
|--------------|-----------------|-------------|-------------|---------------------------------|---------------------------------|
| 13/14 | 57 | 0.75 | 0.55 | 0.52 | 0.77 |
| 14/15 | 46 | 0.64 | 0.66 | 0.55 | 0.74 |
| 15/16 | 37 | 0.57 | 0.76 | 0.61 | 0.73 |
| 16/17 | 27 | 0.47 | 0.86 | 0.68 | 0.71 |

It was possible to look at change in function for two specific IADL tasks as not all IADL dependencies at 18 months were necessarily new dependencies (Table 21). In both of the selected tasks, for 20% of dependent participants this represented an ongoing functional impairment. Only a very small group, 0.6%, gained independence in these tasks over the 18 month period.

Table 21: Change in selected IADLs: AIM interview to 18 month follow up

| IADL | Became independent | Remained independent | Became dependent | Remained dependent |
|----------------------|--------------------|----------------------|---------------------|-----------------------|
| Shopping | 2 (0.6%) | 189 (56.1%) | 117 (34.7%) | 29 (8.6%) |
| Hot meal preparation | 2 (0.6%) | 253 (74.9%) | 66 (19.5%) | 17 (5.0%) |

A higher score on the sPHNSS, regardless of the cutoff value, identified a group with a higher proportion of new dependence in shopping or meal preparation (Table 22).

Table 22: sPHNSS scores and new dependence in IADLs

| Score | Proportion in each group with new dependence in shopping | Proportion in each group with new dependence in hot meal preparation |
|-------|--|--|
| ≤ 13 | 25.3^ | 14.4* |
| ≥ 14 | 41.9 | 23.4 |
| ≤ 14 | 27.5^ | 14.8* |
| ≥ 15 | 43.2 | 25.2 |
| ≤ 15 | 29.2^ | 15.5* |
| ≥ 16 | 44.0 | 26.4 |
| ≤ 16 | 31.4* | 16.7* |
| ≥ 17 | 43.5 | 27.2 |

^{*} p ≤ 0.05 , ^ p ≤ 0.01

7.2.4 Predicting Health Utilization

Over the 18 month period there were 127 hospital admissions in 23.7% of the sample when ER visits and day surgery was excluded. Sixty-six percent of persons with admissions had only one such event and only 8% had 3 or more. The maximum number of admissions over the study period was 8. As Figure 7 (p. 57) illustrates, the incidence of hospital admissions rose with higher baseline sPHNSS scores. The small numbers of persons with higher baseline scores contributed to high variability in admission rates in that range, however the overall trend is easily discernible. The sensitivity and specificity for predicting hospitalization is reported in Table 23, and the values were modest.

Figure 7: Relationship of hospital admissions over 18 months to baseline sPHNSS scores

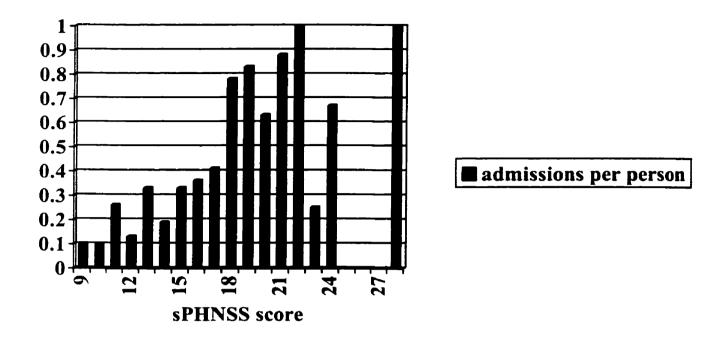


Table 23: sPHNSS properties for one or more hospital admissions over 18 months

| Score cutoff | Percent at risk | Sensitivity | Specificity | Positive Predictive Value | Negative Predictive Value |
|--------------|-----------------|-------------|-------------|---------------------------------|---------------------------------|
| 13/14 | 57 | 0.66 | 0.46 | 0.28 | 0.81 |
| 14/15 | 46 | 0.59 | 0.58 | 0.30 | 0.82 |
| 15/16 | 37 | 0.49 | 0.66 | 0.31 | 0.80 |
| 16/17 | 27 | 0.38 | 0.76 | 0.33 | 0.80 |

There were a total of 5962 physician visits over the 18 months, of which 57% were general practitioner (gp) visits and 43% were specialist visits. The median number of physician visits was 14 with a range of 0-98 (Table 24). As with most health utilization data, the physician visit data are heavily skewed with relatively few participants representing extremely heavy users of health services. For example, the 10 most frequent visitors to physicians represent 10.6% of all physician visits. A cutoff score of 13/14 or 14/15 identified respectively 100% and 90% of these individuals (Table 25).

Table 24: Physician visits over 18 months

| Physician type | median | mean | range | total |
|----------------------|--------|------|-------|-------|
| general practitioner | 8.0 | 9.9 | 0-53 | 3357 |
| specialist | 5.5 | 7.6 | 0-52 | 2591 |
| all physicians | 14.0 | 17.7 | 0-98 | 5962 |

Table 25: Ability of sPHNSS to identify "highest users" of medical services

| Cut-off scores | Percent of general | Percent of "highest users" |
|----------------|--------------------|----------------------------|
| | population at risk | identified |
| 13/14 | 57 | 100 |
| 14/15 | 46 | 90 |
| 15/16 | 37 | 70 |
| 16/17 | 27 | 50 |

An important qualifier with respect to physician visits is that the data provided did not distinguish where the visits took place i.e. office versus hospital. Therefore, physician visits reflect use of both inpatient and community based services. For the high frequency users, physician assessments and follow up visits at the time of hospitalization likely account for a substantial proportion of the visits.

Table 26 summarizes the predictive properties of the sPHNSS for physician visits. They were stronger than for hospitalization, particularly for positive predictive value, but remained in the modest range. The predictive properties for either general practitioner or specialist visits were less robust than for total physician visits.

Table 26: sPHNSS properties for prediction of 14 or more physician visits over 18 months

| Score cutoff | Percent at risk | Sensitivity | Specificity | Positive Predictive Value | Negative Predictive Value |
|--------------|-----------------|-------------|-------------|---------------------------------|---------------------------------|
| 13/14 | 57 | 0.71 | 0.58 | 0.67 | 0.67 |
| 14/15 | 46 | 0.64 | 0.72 | 0.69 | 0.67 |
| 15/16 | 37 | 0.54 | 0.80 | 0.73 | 0.64 |
| 16/17 | 27 | 0.40 | 0.85 | 0.73 | 0.59 |

Figures 8, 9 and 10 illustrate the relationship between the sPHNSS scores and physician visits. There was an easily discernible positive association between higher sPHNSS scores and total physician visits. A similar trend existed for sPHNSS scores and general practitioner visits, but not for specialist visits. The visual associations in Figures 8 and 9 were confirmed with correlation coefficients of 0.79 and 0.68 for the sPHNSS and total physician and general practitioner visits respectively (p≤0.001). The correlation of the sPHNSS with specialist visits was 0.35 and not significant.

Figure 8: Relationship of total physician visits over 18 months to the baseline sPHNSS score

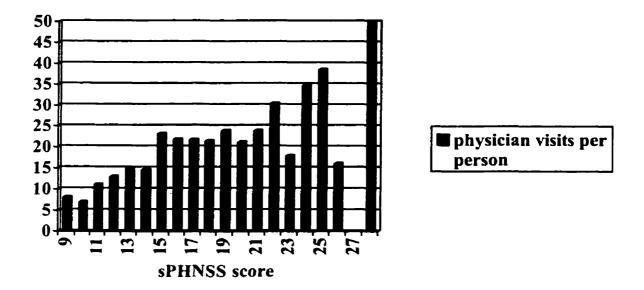


Figure 9: Relationship of general practitioner visits over 18 months to the baseline sPHNSS score

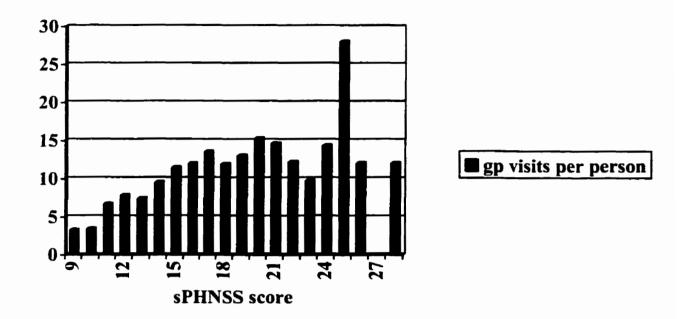
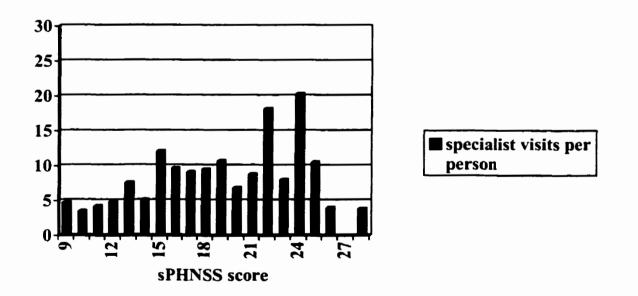


Figure 10: Relationship of specialist visits over 18 months to the baseline sPHNSS score



7.2.5 Cutoff Score

Figures 11-14 represent Receiver Operating Characteristic (ROC) curves for the four test cutoff scores of the PHNSS. A non-discriminating test follows a diagonal line from point (0,0) to (1,1). The better a test is in dividing cases from non-cases, the closer the line connecting the points approaches the upper left hand corner. The cut point which minimizes the overall number of errors is the score which is closest to the upper left hand corner.⁴³ For the four domains: ADL impairment, IADL impairment, hospital admission and total physician visits, examining the character of the curves reveals that the PHNSS was strongest at predicting IADL impairment (Figure 12) and total physician visits (Figure 14). The curve for hospital admission (Figure 13) was close to the diagonal suggesting poor discriminating ability for this domain.

Using the ROC curves the optimal cutoff point for prediction of IADL impairment and physician visits was 14/15. For ADL impairment the optimal cutoff point was 15/16, however the utility of the PHNSS for this domain was not as strong as evidenced by the poor positive predictive value (Table 18, p. 54). With a 14/15 cutoff, 46% of the survey population could be identified as being "at risk."

Figure 11: ROC curve for ADL dependence

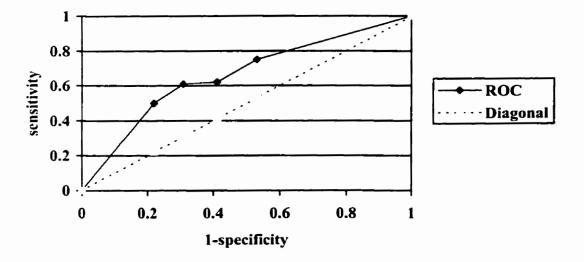


Figure 12: ROC curve for IADL dependence

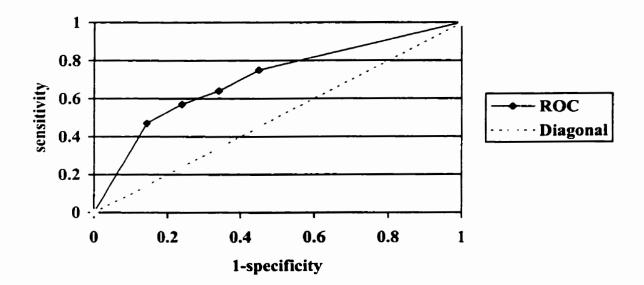


Figure 13: ROC curve for hospitalization

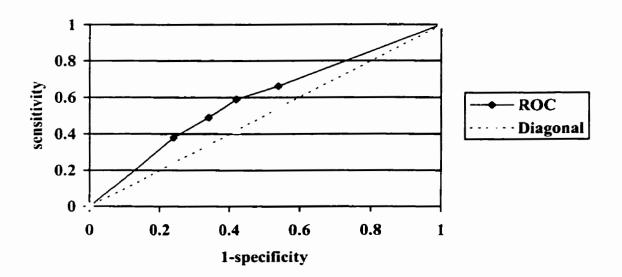
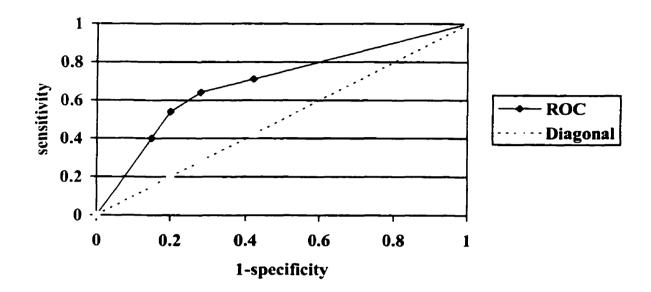


Figure 14: ROC curve for physician visits



7.2.6 Comparison with the Sherbrooke Postal Questionnaire

As discussed earlier, the Sherbrooke Postal Questionnaire (SPQ) is a screening tool developed in Canada to predict functional decline in community dwelling elderly. Of the prospective surveys, it is closest in intent to the PHNSS as its goal is to predict functional decline. It consists of 6 yes-no items each weighted equally, each with a maximum score of 1. It is designed as a mailed survey and non-response to the survey is automatically considered an at risk state. Using the same AIM derived sample as was used for the predictive validity study, a surrogate SPQ (sSPQ) was developed (Table 27). A score of 2 or higher was considered positive. Applying these criteria to the AIM derived sample identified 52% of the population as screening positive on the sSPQ. This mirrored closely the original work by Hébert where 56% of the community dwelling population screened positive.

Table 27: Development of the "surrogate" SPQ

| SPQ Item | Surrogate Item |
|---------------------------|--|
| 1. living alone | A53: How many persons live in this household |
| 2. >3 medication | DPIN database as for PHNSS item 5 |
| 3. require cane or walker | A324: Do you require mechanical supportto walk around the neighborhood |
| 4. trouble with vision | A289: eye trouble in the last year |
| 5. trouble with hearing | A290: ear trouble in the last year |
| 6. trouble with memory | A35-44: Mental Statue Questionnaire 7/10 or less |

Table 28 compares the sensitivity and specificity of the sPHNSS and sSPQ for the prediction of IADL impairment at 18 months and 14 or more total physician visits. The sPHNSS had a stronger performance than the sSPQ especially with respect to predicting physician visits. The instruments both had moderate predictive abilities with similar sensitivities (0.64-0.67) and negative predictive values (0.71-0.74). However, the sPHNSS had superior specificity for both. Better specificity means there are fewer false positive cases and stronger positive predictive values.

Table 28: Comparison of properties of the sPHNSS and sSPQ

| Domain | Instrument | Sensitivity | Specificity | Positive Predictive Value | Negative Predictive Value |
|-----------|------------|-------------|-------------|---------------------------------|---------------------------------|
| IADL | sPHNSS | 0.64 | 0.66 | 0.55 | 0.74 |
| | sSPQ | 0.67 | 0.55 | 0.50 | 0.72 |
| Physician | sPHNSS | 0.64 | 0.72 | 0.69 | 0.67 |
| visits | sSPQ | 0.64 | 0.57 | 0.59 | 0.61 |

If these instruments were both applied to a hypothetical population of 500 community dwelling elderly (Table 29) the sPHNSS would identify 30 less persons as being "at risk". Because the sPHNSS has a stronger positive predictive value, even though it identified fewer persons as positive, a greater proportion are true positives with 20% fewer false positives for IADL impairment and 33% fewer false positives for physician visits. Of the persons screened as not being "at risk", both instruments had substantial

false negative rates; that is, persons who were truly high risk but were classified as low risk by the instruments. The sPHNSS was consistently lower than the sSPQ in terms of the proportion of low risk responders that were improperly classified: For IADLs 26% and 28% for the sPHNSS and the sSPQ respectively; for physician visits, 34% and 39% for the sPHNSS and the sSPQ respectively. However, in absolute terms the sPHNSS would "miss" 3 persons more than the sSPQ for predicting IADL impairment and 5 persons less than the sSPQ for total physician visits.

Table 29: Outcomes of the application of the sPHNSS and sSPQ to a population of 500 community dwelling elderly

| Domain | Instrument | Screened Positive | True Positive | False Positive | True Negative | False Negative |
|-----------|------------|----------------------|------------------|-------------------|------------------|-------------------|
| IADL | sPHNSS | 230 | 126 | 104 | 200 | 70 |
| | sSPQ | 260_ | 130 | 130 | 173 | 67 |
| Physician | sPHNSS | 230 | 159 | 71 | 181 | 89 |
| visits | sSPQ | 260 | 153 | 107 | 146 | 94 |

8.0 Discussion

This project set out to validate a screening instrument that predicts functional decline and health care utilization. As outcome measures these two variables dominate the current geriatric literature. They are considered highly relevant outcomes as functional abilities are a measure of independence and therefore to a certain extent, quality of life. As well they are predictors of future hospitalization, nursing home use and mortality. Identifying a group at risk for high health expenditures has more pragmatic implications. Once applied at a population level, screening programs require the expenditure of resources for implementation. In the competition for scarce health resources funding agencies such as governments or Health Maintenance Organizations in the United States wish to see that the new expenditure is offset by a cost-saving or demonstrable health gains for the target group to justify the infusion of new funds.

However, focusing on measurable risk factors and outcomes does require recognition that what may be risk factors at a population level may not always have relevance at the level of the individual. Concerns have been raised that during the administration of standardized assessment instruments the individual being surveyed has no opportunity to contribute his/her perception of what constitutes successful functioning⁹⁰ or, for that matter, to identify to surveyors what is perceived as his/her primary problem or challenge.

8.1 Construct Validity

Convenience sampling was used to recruit the study subjects for construct validity testing and reliability testing. It was the only practical method by which to establish contact with potential subjects, as there are no regional or provincial databases that can identify a person by culture. Recruitment efforts were intense and relied heavily on establishing contact and credibility with key members and agencies in the community. The ability to offer bilingual interviews in the persons' home was also instrumental to the positive response to the study. The sampling methods were successful in recruiting two distinct groups. Participants prospectively identified as "dependent" did have lower self rated health, higher medication use, were more likely to have been hospitalized and had a higher prevalence of chronic diseases.

The original hypothesis, that there would be a higher PHNSS score in a functionally impaired population is strongly supported by the study results (Fig. 4, p.41). That the dependent groups also had more impaired scores on the three functional measures are to be expected as recruitment targeted functionally independent and dependent seniors. As a separate measure of construct validity the correlation coefficients for the PHNSS with functional measures were similar and statistically significant for each cultural group (Table 9, p.43). The PHNSS contains within it questions on multiple domains. It is dominated by questions on IADLs (6) but also has ADL items (2), medication use (1), general health (1), hospitalization (1), age (1) and access to help (1). Because of the multiple domains correlations of the PHNSS with the Katz ADL scale⁶⁹ and the PPT⁷¹ were modest though statistically significant. As expected, the PHNSS is most closely correlated with the Lawton IADL (r=0.75-0.88).⁷⁰ There are important differences between the two instruments that would preclude much higher correlation. They are both measures of actual function ("does do") as opposed to perceived ability ("can do"). However, the PHNSS contains within most of its items the option of the task being "easy" or "hard" whereas the Lawton, as it was applied to this study, is limited to dependence or independence. And, as mentioned previously, the PHNSS includes domains beyond IADL function whereas the Lawton is exclusively a measure of "instrumental" functioning.

There were patterns of response to the PHNSS items and to the Lawton that differed subtly by cultural groups, this was particularly evident in the dependent sample. However, the overall performance of the PHNSS was acceptable and comparable in each cultural group. This instrument is successful in measuring similar constructs across three different cultural groups.

The weakness of using groups at extremes of function to assess validity of instrument is that it does not reflect how the instrument will function in real life. This is particularly true of an instrument being tested for use in a clinical context. For example, a scale designed to measure function in persons with arthritis may easily distinguish between normal subjects and those with advanced disease presenting to a specialty clinic. However, this does not reflect how the instrument will perform when applied to a broad spectrum of patients presenting to a general practice with various stages of disease. While this phase of the thesis project confirms that the PHNSS can distinguish between well and dependent seniors and this ability is consistent across three cultural groups, the tests of predictive validity are critical to determining whether the PHNSS is appropriate for broader use.

8.2 Reliability

While the PHNSS was intended for use as a self-administered instrument, a substantial proportion of participants required the survey to be interview administered. Therefore, both test-retest and inter-rater reliability were examined. There are also implications from these findings for use of the PHNSS in clinical or research practice. For example, Chinese elderly participants clearly preferred to have the PHNSS interview administered. This immediately increases the resources required to administer the instrument to this particular population. Implementation of a screening program which requires face to face contact with the target population necessitates different strategies than a screening program based on a mailed survey.

The PHNSS had high test-retest reliability whether the overall score or individual items were examined (Table 10, p.45). It did not perform as well for inter-rater reliability. Though the ICC for the total score was acceptable for both pairs of raters, there were four items for which there was substantive disagreement between raters indicating that for these four items, differences between raters strongly influenced how the individual responded. These discrepancies were not limited to one rater pair so there is no reason to believe that one cultural group or one interviewer was particularly problematic.

Item 3 (help around the house) was the most difficult for both rater pairs. The current wording "Do you have someone you can count on if you need help around the house" has the possibility of being interpreted as availability of assistance in times of crisis or alternatively the availability of assistance with daily tasks on an ongoing basis. How an individual interprets this remains consistent over time (κ =0.69 of test-retest). The markedly poor performance on inter-rater reliability indicated how strong the influence of the rater was on this item, as it appeared the raters had different personal interpretations. An alternative wording used by Boult et. al. is "Is there a friend, relative or neighbor who would take care of you for a few days if necessary?" This wording is much clearer with respect to the intent of the question. They have only examined test-retest reliability of this item which is κ =0.57, however it is probable that in an interview administered-setting, the raters would be less able to influence the response. Future versions of the PHNSS will adopt the wording suggested by Boult.

Item 4 (current health) created a problem only for one pair of raters. The wording, response options and graphics are very similar to Chart 6 of the 'Dartmouth COOP Functional Assessment Charts/ WONCA (COOP/WONCA).91,92 The COOP/WONCA

Charts are a quality of life instrument used in general practice that consist of 6 items measuring physical, social, emotional functioning and general health. Each item is accompanied by simple graphics. Test-retest reliability for overall health, which is identical to Item 4 with respect to response options and graphic images, is $\kappa=0.65$. identical to the reliability coefficient obtained in this study (Table 10 p. 45).93 There is little information available about inter-rater reliability as the COOP/WONCA Charts are intended to be self-administered. Fortunately, there is a group who has specifically examined this question in Chinese elderly persons using an interview-administered Chinese version of the COOP/WONCA Charts.⁹⁴ One important difference from the thesis project is that the re-test interval was short, on average 57 minutes, as opposed to 1-2 weeks as in the current trial. In the project conducted in China, researchers were able to recruit a population similar to that of this study, predominately female with little formal education. There was 59% raw agreement for current health with an ICC of 0.56.94 In this thesis project Pair 1 (French) also had raw agreement of 60%, however Pair 2 (Chinese) was much lower at 10%. This is unlikely to be just an effect of the time between testing, as responses were stable in the other participants but rather reflects the sensitivity of this item to the influence of the interviewer.

Item 6 (out of a chair) was a problem for one rater pair. Items on ability to rise from a chair appear infrequently in instruments assessing function. Briefer instruments generally limit themselves to mobility within a house/ apartment, ability to toilet and ability to transfer out of bed. Jette has developed the Functional Status Index (FSI) for use in rheumatology patients, which incorporates a very detailed self-assessment of functional abilities as well as a separate assessment of pain and difficulty associated with these tasks. Fearly work on inter-rater reliability found that agreement for the assessment of ability to rise from a chair was much higher (81% agreement) than agreement on assessment of difficulty rising from a chair (53% agreement). It was his experience that subjects had a hard time using the fixed responses to classify their degree of difficulty. The PHNSS requires the participant to identify if rising from a chair is "difficult". Extrapolating from the work by Jette, it is this item response that likely introduces the variance.

Item 10 (meal preparation) presented a problem for one pair of raters. The wording of this particular item is unique to the PHNSS. The intent was to build into the responses a gradation of loss of function. Persons who relied on services or families for their main meal but could still prepare light food would be scored as having higher functioning than those who relied on others for all aspects of meal preparation. To simplify language,

words such as "big meal" and "small meals" were incorporated as well as pictographs. The lack of specificity of these terms i.e. "small meal" rather than " sandwich, soup and tea" may have been the factor that created the discordance. An alternative possibility is that the meal presentation in the graphics created a particular difficulty for Chinese seniors. Pair 2 interviewed Chinese seniors who reported greatly preferring Chinese food and dietary habits. It may be that because the graphics represent typical Western food items and there is lack of specificity to the item wording, it was difficult for this group of seniors to understand the distinction between response options. The graphics were previewed by members of the Chinese community and by the Chinese interviewers and no specific concerns were raised prior to starting the project, however this possibility needs to be examined prior to widespread use of the PHNSS in a Chinese population.

The noted difficulties in inter-rater reliability should be able to be overcome by alternative wording (item 3), use of a single trained interviewer where possible and closer attention to the interpretation of items 4, 6 and 10 during interviewer training, especially if multiple interviewers are to be used.

The original premise behind incorporation of graphics was that they would enhance reliability, especially in those who were marginally literate. While there was no way of assessing this directly within this study design, the hypothesis is supported by current literature. The only other health assessment instruments in general use that incorporate graphics are the COOP/ WONCA charts. 91,92 The graphics are very similar in nature to the PHNSS graphics. A study using the pain COOP chart suggests that the presence of graphics does not lead to a difference in distribution of responses between similar groups 97 and therefore does not lead to a systematic bias in responses. Though not specific to the COOP charts, work by Hadorn et. al. did find that the addition of cartoons improved one-week test-retest reliability for questions on self-assessment of health status. 98

When asked, participants in this project found the graphics to be helpful. The COOP/WONCA Charts have been adapted and used in several cultures. When subjects were asked directly about the helpfulness of the graphics in the COOP/WONCA charts, poorly educated participants were more likely to indicate usefulness.⁹⁹ In educated, North American subjects used to filling out health assessment surveys, the COOP/WONCA had lower item completion rate than the lengthier SF-36.¹⁰⁰ Extrapolation of these findings suggests that the PHNSS with its simplified wording, relatively few items

and simple graphics is best suited to a population sample with relatively low educational achievement.

8.3 Cultural Differences

One striking finding of this project was the inability to adapt and use the PHNSS in a manner that was acceptable to the Ojibwe population. Review of the survey by members of the aboriginal community did not identify any concerns about the content of the questionnaire; it was only in the field that the interviewers provided the feedback on the impracticality of this approach. This occurred despite having the survey documents presented in Ojibwe by Ojibwe speaking interviewers, there appeared to be barriers at several levels 1) choice of language/dialect of the survey instrument; 2) discomfort with an approach that demands rapid responses and rapid categorization; 3) a general reluctance to participate in a "test" situation; 4) distrust of external agencies.

The First Nations and Inuit Regional Health Survey National Steering Committee published the Final Report of the First Nations and Inuit Regional Health Survey (FNIRHS) in 1999.¹⁰¹ They were able to complete surveys on 9870 First Nation and Inuit adults focusing on: children's health, health services, tobacco, medical conditions, activity limitations, residential schools, wellness and dental health. In implementation of the FNIRHS, the same barriers that occurred in this thesis project were met. For example: all surveys had to be interview administered, it was a significant challenge to standardize wording across all the communities and initiation of the FNIRHS required overcoming a very long history of distrust of external agencies especially those with a relationship to government. Achieving this task required among other things: having a National Steering Committee directly under First Nation and Aboriginal control, a Letter of Understanding defining issues of governance and ownership of the process, accepting that wording of "core questions" were subject to variation depending on the priority of the community. Reviewing the experiences of the FNIRHS National Steering Committee provides some explanation for the reactions observed as part of this project. To the credit of advocates for aboriginal peoples there is now a greater emphasis on the outcome of research and health surveys being relevant to a community's immediate needs.

A fascinating aspect of this project was the search for appropriate validating instruments. Only in the last ten years have techniques of cross-cultural adaptation of instruments become the standard in the field. Prior to that language adaptation without an emphasis on psychometric equivalence was common. The most notable finding was

that despite the use of an MMSE that had been adapted for use in Chinese seniors and was being administered by trained interviewers in Chinese, the study participants performed poorly on this test. Katzman et. al., the group who developed the adapted Chinese MMSE (CMMS) that was used in this project, reported a similar experience.⁷⁴ To accommodate for this they recommended that for Chinese seniors with middle school or higher education the cutoff score on the CMMS be lowered to 21. For Chinese seniors with no formal education they also reported low test scores and went so far as to suggest that an altogether different approach to screening needs to be considered. Kaufert and Shapiro described a similar experience observing the administration of an adapted mental status questionnaire with Cree elders. 104 They contrasted the experience of administering a brief mental status screen translated for use with Cree elderly with the development and administration of a culturally and educationally adapted and harmonized mental status survey. Routinely used questions in the translated screening test such as asking respondents to state their age resulted in 49% being unable to complete the item. Fieldwork revealed that most native elders do not have a copy of their birth certificate and that recall of birth date and age was not a measure of cognitive impairment. In this circumstance, recall of local historical events in their childhood was a more appropriate measure of date recall. In their observations Kaufert and Shapiro emphasize the importance of systematically examining the impact of linguistic, cultural and structural factors on survey instruments even when validity and reliability have been established. 104

The different patterns of impairments between cultures were identified and measured by both the Lawton and the PHNSS. These insights into cultural differences are to be expected and fascinating. The French elderly respondents, whether categorized as well or dependent, used the most medications of all the three cultural groups. Not surprisingly, the Chinese elderly participants were dependent in language-based functions such as banking, shopping, telephone use. It is possible that these observed differences reflect sampling biases. Arguments against this are the similar self-rated health ratings for all of the groups, similar age distribution and similar performance on the PPT.

This study was not designed to provide an explanation for these observed differences. However, the observations are not new. There is little information in the English language literature on comparative medication consumption between Francophone seniors and other groups. However, there has been one very interesting study comparing the use of psychotropic medications (anxiolytics, hypnotics, anti-depressants) for complaints of insomnia and anxiety between population based samples of residents of

France and French-speaking Montréalers. While rates of insomnia were similar between the two populations, medication use was much higher in the French population with females and the elderly being the primary consumers of medications in both samples. For example, for women 65 years of age or older 29.0% of the French sample and 14.5% of the Montréal sample used sleep promoting medications (p <0.005). 105

Overall, there is less prescription medication usage among the Chinese seniors in this study especially when compared to French seniors. However, concerns that this group is using Traditional Chinese Medicines (TCM) as a substitute for prescription (Western) medicine appears to be unfounded for Chinese seniors in downtown Winnipeg. Although this group remained absorbed in the Chinese culture, they endorsed the use of Western medicines over TCM for a variety of acute and chronic symptoms (Table 14, p. 50). Therefore, at this time there is no need to alter the construction of question 5 on medications.

A large multi-centre international project currently underway examines the measurement of functional status and quality of life across cultures. The SF-36 Health Survey is a 36 item generic measure of health comprised of eight domains. The International Quality of Life Assessment Project (IQOLA), has been translating the SF-36 which is followed by validating and developing norms of the surveys for international use. ¹⁰⁶ To date this project has reported on the translation, adaptation and validation of the SF-36 into 11 languages. In each case the SF-36 has been found to be acceptable for general use, though within each culture there may be unique characteristics. ¹⁰⁷ For example, in the Italian version, the General Health scale performs poorly although this does not affect the performance of the overall scale. ¹⁰⁸ In the Japanese version of the SF-36, the Role-Emotional scale does not associate with the Mental Health scale as it does in other cultures, nor can it discriminate between groups with and without serious physical and mental conditions. ¹⁰⁹

The findings in this project are consistent with the IQOLA experiences. There were subtle differences in the performance of the PHNSS and the Lawton between cultures but both instruments were still easily able to discriminate between well and dependent groups. However, when applying these instruments at the level of the individual or comparing data between cultural groups it is imperative that researchers and clinicians be aware of differing response patterns. For example, setting threshold levels or cutoff levels for "risk" based on either scale will need to be assessed for each culture

individually. Similarly, approaches that rely on identifying one or two key IADLs as key indicators for "risk" will need to be validated in each cultural group to which it is applied.

The PPT was included as a validating instrument to offset a circumstance where the self-report instruments were found to have cultural biases. However, even within the PPT, item 1 (write a sentence) clearly created greater difficulty for the Chinese population than for the English or French. Removal of Item 1 did not have a significant impact on the overall performance of the PPT. Therefore, if the PPT is to be adapted and applied to a population where there is a high prevalence of illiteracy, results from this study support modifying the test by dropping item 1.

8.4 Predictive Validity

The population used to test predictive validity was similar in characteristics to the well participants of the construct validity samples with respect to age, percent living alone, and self-reported health status. For example, of the well participants in the construct validity sample 35% reported fair, poor or bad health compared to 32.5% of participants in the predictive validity component. While the original 1996 AIM study participants were randomly selected and can be said to be representative of community dwelling elderly persons, the participants in this project were a higher functioning sample of the AIM population. Twenty four percent of the original sample could not be contacted or had died and 5% refused to be interviewed. Non-participants differed substantially from participants with respect to age, health status and educational achievement (Table 15, p. 51). It is probable that several of those who could not be contacted had moved to more supportive environments or died. Theoretically, using a population with a potentially lower incidence of functional decline and/or health utilization could lead to underestimation of the discriminative power of the PHNSS. This likely did not have a significant impact on the results as there was a high prevalence of IADL impairment, with half the sample having two or more IADL impairments at 18 months as well as substantial use of the health care system (Table 24, p. 58).

The advantage of generating a surrogate PHNSS from baseline AIM data was the relative simplicity and low cost with which this project could be completed. Applying the original instrument to a population of 350 randomly selected elderly persons and following this sample over 18 months would have required substantial research funding. The major disadvantage of this method, however, was that the sPHNSS was not a perfect replication of the PHNSS. Most notable is the loss of the response option "hard" from 5

items as this is meant to identify individuals with self-perceived difficulty but who are still managing tasks independently. In these situation the sPHNSS was most likely to underestimate the true score, as the person would still be rated as independent for the task. Given an overall score range for 9-39 at most this could potentially cause a 16.7% variance of the true PHNSS score from the sPHNSS score and only if the respondent would have used the "hard" option on all five affected items, an unlikely occurrence. It is reassuring that validation of the sPHNSS confirmed a high concordance between responses to the wording of the AIM derived items used in the sPHNSS and the wording of the PHNSS items.

Applied to the AIM sample, the sPHNSS is normally distributed, albeit skewed (Figure 6, p. 52). The small ceiling effect and lack of observed floor compares favorably with common well-studied general health surveys such as the Nottingham Health Profile, COOP/WONCA charts, Duke Health Profiles and SF-36 Health Surveys where there are often significant ceiling effects (12-78%).110 Chronic diseases, especially cardiovascular disease, arthritis, visual impairment and hearing impairment are established risk factors for functional decline. The association of higher sPHNSS scores with increased prevalence of these diseases was expected and supports the hypothesis that the sPHNSS was able to identify a population at risk for functional impairment. The association of higher sPHNSS scores with increased age and greater likelihood of living in seniors housing was also consistent with the theoretical construct of the sPHNSS. The lack of association of higher sPHNSS with gender, living alone and loneliness is equally important and also supported by literature. Living alone has been controversial as a risk factor for functional decline to the point where Hébert argues it is protective for functional decline.⁸ Finally, depression and lack of social contact have both been associated with functional decline⁶⁴ but not loneliness specifically, and though there is considerable overlap between these three domains they are not identical.

The sPHNSS was strongest at predicting IADL dependence and total physician visits at 18 months. The original intent was to identify a group at risk for ADL dependence. For the 14/15 cutoff, 5.9% of the low risk group and 13% of the high risk group had one or more ADL impairment respectively. However, the overall low prevalence of ADL dependence results in an unacceptably high false positive rate and at this time the PHNSS can not be recommended for screening for ADL impairment. The instrument was able to identify a group with a high prevalence of IADL impairment at 18 months and analysis of selected IADL tasks confirmed that the majority of subjects were experiencing new IADL impairment rather than ongoing dependence. In retrospect, administration of the

PHNSS at 18 months in concert with the Katz and Lawton would have been useful to document changes in dependence across a spectrum of domains including self-rated health.

In this study, total physician visits represents a composite of primary and specialty care provided as an outpatient, in the emergency room and in hospital. It does not include physician services that are secondarily generated i.e. pathologists, radiologists. anesthetists. The sPHNSS was best at predicting high use of a composite measure rather than any one component of health utilization e.g. hospitalization or primary care physician services. Hospital use, general practitioner visits and total physician visits rose steadily with higher sPHNSS scores (Figures 7, 8, 9 pp.57, 59, 60) supporting the hypothesis that the sPHNSS identified a higher risk group. Also, 9 of the 10 highest users were captured with the proposed 14/15 cut-off. It is very interesting that sPHNSS scores correlated with general practitioner visits and not with specialist visits. In Canada, specialist services can only be engaged at the request of the primary care physician in response to the presence of a particular disease state. The events triggering the use of primary care health services versus specialty care services are often quite different. Persons with functional impairments are more likely to present, in the first instance, to a primary care physician and then be referred on for specialty care only if a specific disease state is detected. Since the PHNSS focuses on functional abilities rather than specific diseases or symptoms the positive relationship with general practitioner visits and lack of relationship with specialist physicians reinforces the construct validity of the PHNSS.

The predictive abilities of the sPHNSS were modest but comparable to other screening instruments used with the elderly population. The instrument closest in design to the PHNSS is the SPQ⁸ and a detailed comparison is presented in Table 28 (p. 64). However, it is important to appreciate that all prospective screening instruments to identify "at risk" elderly persons tested to date, have limited discriminative properties. In the Literature Review, six instruments are reviewed. Direct comparisons are limited by the fact that each instrument is designed and tested for a different outcome and has a different statistical measure of predictive ability. While each can identify a high-risk group, relative risks are modest generally, ranging from ratios of 2-4.

Physical function, mortality and health utilization are each determined by complex factors to the point where modeling any one of these outcomes perfectly may be an unattainable task. Functional decline, as an example, is difficult to predict accurately because it is not a uniform, predictable process affecting all elderly persons in the same

manner. The PHNSS attempts to select a population that will experience gradual decline over several months to years. However, the measured outcome - functional impairment - did not discriminate between those who experience catastrophic medical events versus the target group, those with gradual change. A similar argument exists for predicting health utilization. Mukamel and colleagues described developing a survey trying specifically to predict the top 5% of users of services in a Health Maintenance Organization (HMO). They started with 69 items, each correlated with factors influencing health utilization. Despite this, at best they achieved a positive predictive value of 17%.¹¹¹ Having reviewed the literature extensively, while there may be opportunities to refine existing instruments, given the complex and dynamic nature of function and health utilization it is unlikely there will ever be screening tools with dramatically better properties.

8.5 Application

The practical question becomes whether there is any role for the application of the PHNSS or similar instruments at the level of the individual senior in a medical practice. There is a spectrum of opinion in the medical literature. Academics such as McHorney and Tarlov¹¹⁰, in their review of five widely used health status surveys, argue that deficiencies in basic test properties such as reliability, floor and ceiling effects and risk of false-negative case-finding would normally preclude use of these surveys for individual patients. At the other end of the spectrum, Mukamel and colleagues¹¹¹ have modeled the practical application of screening tools such as the Pra Questionnaire⁵⁰ to an elderly population attending an HMO. They argue that as long as the tool can identify high users of health care and application of an intervention (such as case management) offsets the costs of the intervention, an imperfect tool with a low positive predictive value can still be a useful clinical tool. In their example, they modeled the application of a screening tool that identified the top 5% of health care users over the age of 65 in an HMO. Despite the fact that the positive predictive value of their instrument was low (17%) in a model where case-management reduces the hospitalization costs of true high-cost utilizers, they were able to effect net savings. Based on similar arguments, the Pra Ouestionnaire⁵⁰ is already in regular use as a screening instrument for HMOs in the United States.

Between the extremes of this discussion there is a potential role for the PHNSS in a clinical setting. Comprehensive Geriatric Assessment (CGA), particularly offered in the home, has consistently demonstrated positive benefits if targeted to the right population.⁴

Usually this consists of a comprehensive review of physical, social and cognitive functioning and an assessment of general medical status and the environment. Recommendations are then made with regard to environmental changes, medical follow-up and potential resources in the community. This intervention may be one time only or consist of regular follow-up contact and generally is more successful if there is follow-up contact. Clinical trials have shown this type of approach to be most successful when there is targeting of a high risk population.^{6,45} In those at highest risk, for example, already frequently attending emergency departments or already experiencing significant functional impairment, a more intensive approach such as ongoing case management and ongoing multi-disciplinary team management is usually required.

Figure 15 illustrates a two-phase model for incorporating the PHNSS into a community based screening program. Phase 1 consists of the administration of a screening instrument. Phase 2 involves CGA and then a range in intensity of interventions could be offered. This is a slightly different approach from clinical trials to date where the intensity of intervention is pre-determined and not necessarily flexible. For example, trial A will have all recommendations forwarded to the family physician and trial B four times yearly in-home follow-up. However, there would be no opportunity for clinical judgement as to which may be the most appropriate given the particular clinical scenario. The phase 2 screen would then take those who had screened positive and separate them into 4 levels of intervention. As Figure 1 (p.26) illustrates, the PHNSS will identify not only those with early IADL impairment but also those persons with more established impairments who are already dependent and using high amounts of health services. However, it is beyond the ability of any simple screening tool to differentiate those who need ongoing case management from those who need only environmental modification and meals-on-wheels, for example. Discussion of cost-effectiveness and feasibility of such a model is beyond the scope of this research. However, the concepts are not new and in varying degrees, have been instituted. There are many clinical trials of varying success but limited by the fact that they have provided only one pre-determined intensity of intervention.

The PHNSS is an appropriate tool for use as the phase 1 instrument. It is brief, uses simple language and has high reliability when it is self-administered making it appropriate for use in an office setting. The scoring is straightforward and can be done immediately on completion of the survey. This allows clinicians to act quickly on the survey results. There is only a small ceiling effect and no observed floor effect. Construct validity was found to be consistent across three cultural groups. It offers



Community dwelling elderly, aged 70 and over Score ≤ 14 Screened Phase 1 Apply PHN88 in **Negative** primary care setting No further intervention Score ≥ 15 Screened Positive Phase 2 No further Geriatric intervention Assessment Environmental modification Exercise programs Environmental modification • Home care services Medication changes OT/PT assessments Short term follow-up Above + • Long term case management Long term multi-disciplinary team management 79a

Figure 15: A model for implementation of the PHNSS in the primary care setting

advantages over existing instruments. The instrument closest in objective is the SPQ however the PHNSS does have better specificity than the SPQ, ultimately leading to a lower false negative rate. While the P_{ra} Questionnaire⁵⁰ is in widespread use, the scoring is cumbersome and it has not been tested to identify functional decline.

A cut-off score of 14/15 on the PHNSS maximizes sensitivity, specificity and performs optimally on the ROC curves. However, if this instrument were to be generally applied in a screening, program factors beyond specificity and sensitivity need to be considered. A cut-off score of 14/15 identifies 46% of all persons over the age of 70 in a region as "high risk". Efficiency in the CGA component of phase 2 may compensate for this high positive rate. However, there may not be the resources to perform a CGA on all of the "high risk" population. Higher cut-off scores identify fewer persons as "high risk". However, the instrument becomes less efficacious at higher scores. The true positive rate remains relatively unchanged, but, because fewer persons are screened, fewer high risk persons are identified. Also, because sensitivity decreases markedly at higher scores, the percentage of persons identified as false negative (persons at risk who are not identified) increases markedly. If resources allow, 14/15 should remain as the cut-off score on the PHNSS.

This type of approach may not be feasible or appropriate for all communities of elderly persons. Experience in this project would indicate that a different approach would be desirable for a predominately aboriginal community. In a community where there is a high proportion of Chinese elderly, for example, the need to have the PHNSS interviewer administered would greatly increase resource requirements. At the other extreme, an affluent community where there is already excellent use of available medical and social resources would see little added benefit from such an approach.⁵³

9.0 Conclusions

There were many lessons learned from this project that go beyond the assessment of reliability and validity of the PHNSS. The experience of trying to involve four diverse cultural groups was challenging. Based on this work the following conclusions and recommendations can be made:

- Cross-cultural adaptation of health-related quality of life instruments should follow a standardized, methodologically rigorous approach.
- Instruments that are commonly used to measure health status in the elderly, both in clinical and research sites, should be adapted and validated for use in dominant ethnic groups in Canada. Great caution should be used when interpreting scores or responses from unadapted or non-validated instruments.
- Ethnically diverse, dependent seniors can and will participate in research if culturally sensitive, bilingual interviewers are used, home visits are offered, and community agencies assist in developing the recruitment process.
- Screening approaches must be individualized to the cultural group. For example, while a self administered screening instrument is acceptable to English and French seniors, it must be interview administered with Chinese elderly persons and may be entirely unacceptable to Ojibwe seniors.

As with any research, this project raises new questions for exploration:

- Do the graphics add to reliability in the interview-administered PHNSS?
- How do medication consumption patterns in Francophone Manitoban seniors compare to Quebecois seniors? Are the differences consistent across all classes of medications?
- Are patterns of IADL impairment similar in Canadian born Chinese elderly persons and non-Canadian born Chinese elderly persons?
- Does the addition of questionnaire domains such as cognition and mood substantially change performance of the PHNSS?

The PHNSS is able to identify a group at high risk for future IADL impairment and high rates of physician visits. As with other predictive instruments, instrument properties are modest. However the sensitivity, specificity, positive predictive value and negative predictive value are marginally stronger than the Sherbrooke Postal Questionnaire⁸ which is also meant to predict functional decline. Strengths of the PHNSS are its simple wording and use of graphics. It is valid in a sample of mixed educational achievement and three cultural groups. The PHNSS could have a role as an initial screening instrument in a community-based strategy to identify elderly persons at risk for functional decline. The setting for which it has been developed and for which it is most appropriate is an inner city or other low income, low literacy neighborhoods. There is still work to be done before the PHNSS is ready for clinical or research use. Specifically, improving the inter-rater reliability and establishing cutoff scores for individual cultures. However, it is an instrument that has the potential for filling a need; that is, as a validated measure of function and future risk of functional decline in a culturally diverse lowincome, low literacy setting.

List of Definitions and Abbreviations

ADLs: Activities of Daily Living, referring to activities related to the

basic capacity of persons to care for themselves. Usually this encompasses: eating, dressing, toileting, transferring, walking

CGA: Comprehensive Geriatric Assessment

CRA: Community Research Award

Disability: Restriction or lack of ability to perform certain activities as a result

of an impairment. For example, being unable to dress

independently as a consequence of left sided weakness secondary

to a stroke is a disability

GDS: Geriatric Depression Scale

HAC: Health Action Centre

HMO: Health Maintenance Organization

IADLs: Instrumental Activities of Daily Living, refers to the ability to

perform functions generally required to live in the community. This usually includes: shopping, banking, meal preparation,

housekeeping, transportation, medication management, telephone

use and banking

Impairment: A reduction in physical or mental capacity usually as a

consequence of disease, anatomical structure or injury. For example, left sided weakness secondary to a stroke is an

impairment.

PHNSS: Predicting Health Needs of Seniors Survey

Physical Function: The broader term "functional assessment" usually incorporates

ADL assessment, IADL assessment, measurements of mental

status, mood, social and economic resources. The term *physical* function is used to specify physical problems as the source of functional limitations are being examined. Measures of ADL and IADL capacity, pain and mobility are usually considered components of physical function.

PPT: Physical Performance Test

SIRP: Seniors' Independence Research Program

SMMSE: Standardized Mini Mental State Exam

SPQ: Sherbrooke Postal Questionnaire

sPHNSS: Surrogate Predicting Health Needs of Seniors Survey

sSPQ: Surrogate Sherbrooke Postal Questionnaire

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Appendix 1:

The Predicting Health Needs of Seniors Survey

Predicting Health Needs of Seniors Survey

| | you for taking the time to fill out this survey. For all of the questions, e mark the box with a for the best answer. |
|----|--|
| Ι. | Are you 75 years or older? |
| | Yes |
| | No |
| 2. | Have you been in hospital in the past year? |
| | Yes |
| | No . |
| 3. | Do you have someone you can count on if you need help around the house? |
| | Yes |
| | No 🗌 |
| | |
| | |
| | |
| | |
| | For office use only ID No |

4. How would you rate your current health?

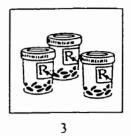
| Excellent | |
|-----------|-------------|
| Good | 2 |
| Fair | (OO) - |
| Poor | (00) |
| Bad | <u>(QQ)</u> |

5. How many different medications do you take?

Pills





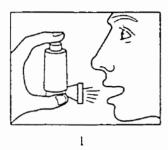


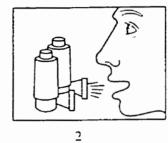


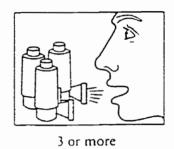


5 or more

Puffers or inhalers





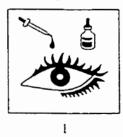


Needles



I or more

Eyedrops







3 or more

6. How easy or hard is it for you to get out of a chair?

| Easy | |
|------------------------------------|---|
| Hard | 2 |
| Need the help of another person | 3 |
| Unable even with help | |

7. How easy or hard is it for you to walk inside your house or apartment?

| Easy | |
|------------------------------------|---|
| Hard | |
| With the help of a cane or walker | 3 |
| Need the help of another person | 4 |
| Unable even with help | 5 |

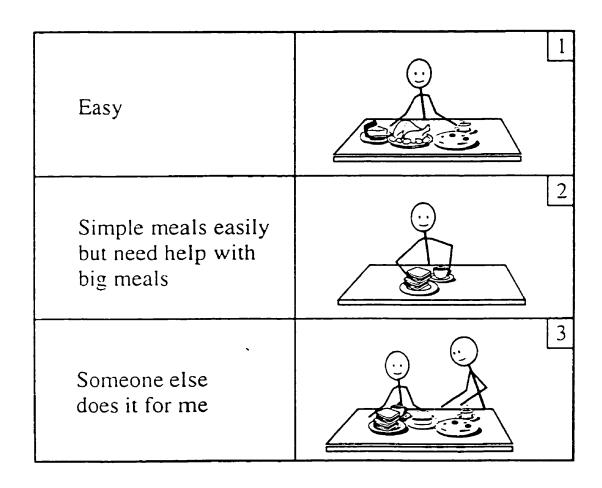
8. How easy or hard is it for you to cut your own toenails?

| Easy | |
|------------------------------------|---|
| Hard | 2 |
| Need the help of another person | 3 |

9. How easy or hard is it for you to get out to buy groceries or other shopping?

| Easy | |
|------------------------------------|---|
| Need the help of another person | 2 |
| Someone else does it for me | 3 |

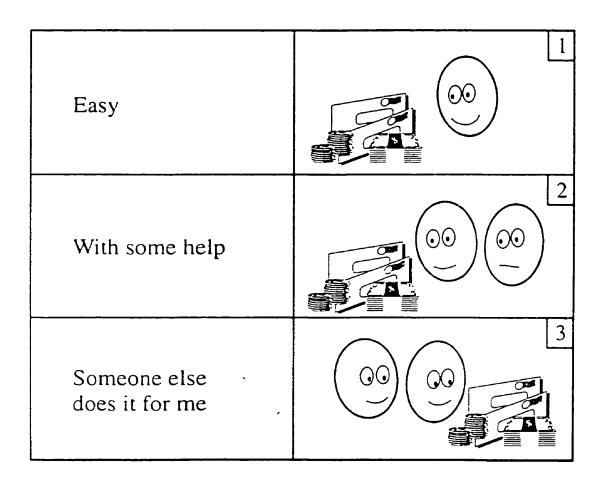
10. How easy or hard is it for you to prepare meals?



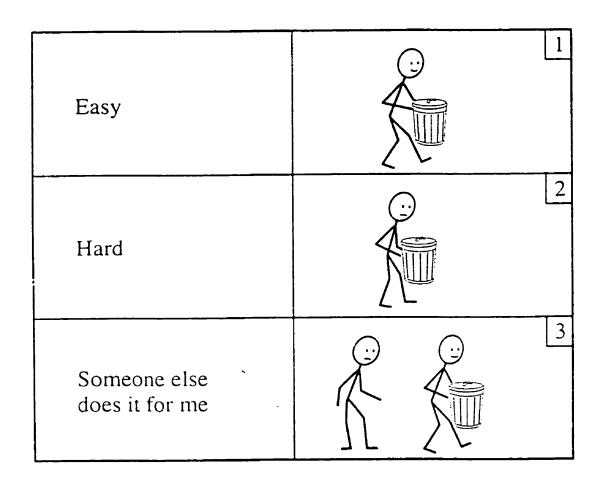
11. How easy or hard is it for you to use the telephone?

| Easy | |
|-----------------------------|---|
| Hard | 2 |
| Someone else does it for me | 3 |

12. How easy or hard is it for you to do your own banking and paying bills?



13. How easy or hard is it for you to take out your own garbage?



Appendix 2:

Summary of Screening Instruments

Comparison of Characteristics of Prospective Screening Surveys

| Reliability | Test-retest total score Pearson r= 0.71 | Test-retest Individual items | N R | ≅ Z |
|----------------------|---|---|---|---|
| Predictive Ability | Unable to perform any activity unaided RR=5.4 Able to perform all activities unaided RR=0.4 | Sensitivity 68% Specificity 54% RR2.4 of functional decline if positive | OARS total score Sensitivity 75% Specificity 45% Health costs Positive 28.9% high cost Negative 15.5% high cost | Institutionalization: 1 RR=1.7 2 RR=3.6 3 RR=9.4 Mortality 1 RR=1.2 2 RR=2.0 3 RR=3.1 |
| Percent screened | 6.4% can do no activity | 53 | 74 | Class 1 12% Class 2 16% Class 3 5% |
| Follow Outcome up | Mortality | Functional decline (includes mortality, nursing home) | OARS: total score/ subscore Health costs | Institutionalization death |
| Follow up | l year | l year | l year | 5 years |
| Age group | 65+ | 75+ | 65+ | 65 + |
| Subjects | 1609 | 607 derivation 45 validation | 445 validation | 9008 validation |
| Trial Design | Prospective cohort | Prospective cohort | Prospective cohort | Prospective cohort |
| Instrument | OARS IADL 16 | Sherbrooke Postal Questionnaire ⁸ | Seniors Health and Well- being Survey ^{51,53,54} | "frailty scale" ⁹ |

Comparison of Characteristics of Prospective Screening Surveys contd.

| Instrument | Trial Design | Subjects | Age grou p | Follow up | Outcome | Percent screened positive | Predictive Ability | Reliability |
|---|--------------------|--|------------------|--------------|---|--|--|---|
| P _{ra} screening instrument ⁵⁰ , 55,56,79 | Prospective cohort | 2942 derivation 9299 validation | 70+ | 2 years | Hospitalization Emergency room use Nursing Home stays Home care days | Top quartile (25%) $P_{ra} \ge 0.5 = 20.6\%$ | Medical claims RR=2.7 Emergency use RR=2.5 Nursing home stays RR=3.6 Home care days RR=3.5 Hospital days/ person year Low risk 2.4 High risk 4.5 | Test-retest Individual items κ=0.50-1.00 Test-retest P _{ra} score r=0.78 |
| Health Screening Form ⁵² | Prospective cohort | 1873 derivation 1872 validation | 81+ | 4.5 months | Hospitalization | 10 | Hospitalization rate: Lowest decile 6.2% Highest decile 19.0% RR=3.1 | NR |

NR=not reported

Appendix 3:

Chinese, French, Ojibwe, Ukrainian versions of the PHNSS

預測者英保健需求調查

謝謝您推出實責時間填妥這份調查。請在所有問題的答案图上最適合您的回答。

1. 您是否已七十五歲或以上?

是

不是

2. 在遇去的一年中您曾否住遇醫院?

有

沒有

3. 當您在家裡需要協助時,有沒有 可靠的人能協助您?

有

沒有

| For office use only |
|---------------------|
| ID No |

I

4. 您認為您的健康現狀如何?

| 極好 | |
|-----|------|
| 好 | 2 |
| 達可以 | (OD) |
| 差 | (OO) |
| 很差 | (S) |

5. 您服用幾種不同的藥物?



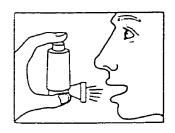


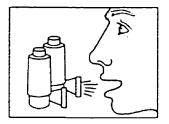


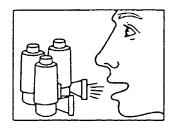




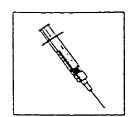
您使用幾種噴劑或吸劑助您呼吸?







幾種針劑?



幾種眼藥水?







6.對您從座椅上起身是否容易或困難?

| 容易 | |
|------------|---|
| · 维 | 2 |
| 需要別人協助 | 3 |
| 即使有人協助也起不來 | |

7. 您在屋內或公寓內行走是否容易或困難?

| 容易 | | 1 |
|-----------------|----|---|
| 日難 | | 2 |
| 需借助拐杖或助行架 | AM | 3 |
| 需要別人扶持 | | 4 |
| 即使有人協助也 不能行走 | | 5 |

8. 您自己剪腳趾甲是否容易或困難?

| 容易 | |
|--------|---|
| 凝粒 | 2 |
| 需要別人幫助 | 3 |

9.出去購物對您是否容易或困難?

| 容易 | |
|--------|---|
| 需要別人協助 | 2 |
| 別人替我購物 | 3 |

10. 一天煮三餐對您是否容易或困難?

| 容易 | |
|--------------------------------|---|
| 可烹煮简单的餐食, 较複雜的餐食則需 要別人幫手 | 2 |
| 別人替我烹煮 | 3 |

11.使用電話對您是否容易或困難?

| 容易 | |
|----------|-------------|
| 田難 | |
| 有別人替我打電話 | 3 A A |

12.到銀行解理存款,提款或交水電费等,對您是否容易或困難?

| 容易 | |
|--------|---|
| 需要幫助 | 2 |
| 別人替我解理 | 3 |

13.将垃圾拿出屋外,對您是否容易或困難?

| 容易 | |
|-------|---|
| 需要幫助 | 2 |
| 別人替我做 | 3 |

Sondage d'Évaluation des Besoins de Santé pour les Personnes Âgées

Merci de prendre le temps de répondre à ce sondage. Pour toutes les questions, veuillez encercler la réponse qui convient le plus.

| 1 | Avez-vous 75 ans ou plus? |
|----|--|
| | Oui |
| | Non |
| 2 | Étes-vous allé(e) à l'hôpital pendant l'année qui vient de s'écouler? |
| | Oui |
| | Non |
| 3. | Y a-t-il quelqu'un sur qui vous pouvez compter si vous avez besoin d'aide à la maison? |
| | Oui |
| | Non |

4. Comment evaluerrez-vous l'état général de votre santé?

| Excellent | |
|----------------------|---------|
| Assez bien | <u></u> |
| Bien - | 3 |
| l [:] aıble | (OO) 4 |
| Mauvais | 5 |

5 : Combien de sortes de médicaments prenez-vous?

Pilales





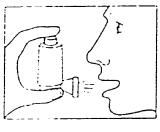




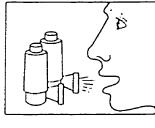


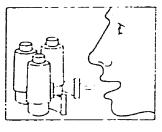
1 2 3 4

l'ompe respiratoire (pour les problèmes respiratoires et l'asthme)



l





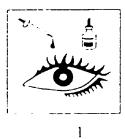
2 3 ou plus

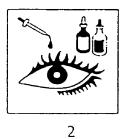
Piqures



I ou plus

Couttes pour les yeux







3 ou plus

6. Comment facile ou difficile est-ce pour vous de vous lever d'une chaise?

| Facile | |
|---------------------------------------|---|
| Difficile | 2 |
| Besoin d'aide d'une autre personne | 3 |
| Incapable même avec de l'aide | 4 |

7 Comment facile ou difficile est-ce pour vous de vous déplacer dans votre maison ou dans votre appartement?

| Facilement | |
|-------------------------------------|---|
| Difficilement | 2 |
| Avec une canne ou un marchette | 3 |
| Avec l'aide d'une autre personne | 4 |
| Incapable même avec de l'aide | 5 |

Sociomment facile ou difficile est-ce pour vous de couper vos ongles d'orteils?

| Facile | |
|-------------------------------------|---|
| Difficile | 2 |
| Avec l'aide d'une autre personne | 3 |

9 Comment facile ou difficile est-ce pour vous de faire votre épicerie?

| Facile | |
|-------------------------------------|---|
| Avec l'aide d'une autre personne | 2 |
| Quelqu'un le fait pour moi | 3 |

10. Comment facile ou difficile est ce pour vous de faire à manger?

| Facile | I |
|---|---|
| Facile pour les repas simples, mais besoin d'aide pour les repas consistants | 2 |
| Quelqu'un le fait pour moi | 3 |

11 Comment facile ou difficile est-ce pour vous d'utiliser le téléphone?

| Facile | |
|-------------------------------|--|
| Difficile | |
| Quelqu'un le fait pour moi | |

12. Comment facile ou difficile est-ce pour vous de faire vos comptes et de paver vos factures?

| Facile | |
|-------------------------------|---|
| Avec de l'aide | 2 |
| Quelqu'un le fait pour moi | 3 |

13. Comment facile ou difficile est-ce pour vous de sortir la poubelle?

| Facile | |
|-------------------------------|---|
| Avec de l'aide | 2 |
| Quelqu'un le fait pour moi | 3 |

Gaa-wii-gikenjigaadeg Izhi-ayaawin Ogitaadiziing Onji

Milgwech emooshkinebil'aman owe ozhibil'igan gakina gegoonan gaa-gagwejimigooyan behzig.

| 1 | Niizhwaaso-midana-shi-naanan na gidasibibone, gemaa nawaj na gi-gitaadiz? |
|---|---|
| | Eya |
| | Gaawin |
| 2 | Gi-gii-ayaa na aakoziiwigamigong noongom gaa-akiiwang? |
| | Eya |
| | Gaawin |
| 3 | Gi-dayaawaa na awiiya ge-debwewagenimad ji-wiiji'ik endaayan? |
| | Eya . |
| | Gaawin |
| | |
| | |
| | |
| | |
| | |
| | |
| | Office Use Only II) |
| | |

4. Aaniin enenindizowin epiichi-mino-ayaayin?

| Wiinge ni-minomanjiw | |
|------------------------------------|--------|
| Ni-minomanjiw | (OD) |
| Eniweg ni-minomanjiw | 3 |
| Gaawiinaapiji ni-minomanji'osii | (OO) - |
| Ni-maanzhimanjiw | 5 |

5. Aaniin minik(a)ko dinoo'ikaanan mashkikiwan wedaa pinaman?

Mashkikiwan



1-behzig



2-niizh



3-niswi

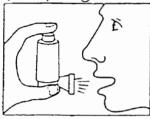


4-niiwan

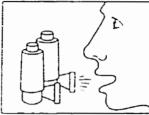


5 naanan gemaa awashime

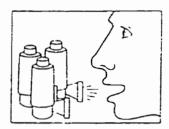
Ji-onji-bagidanaamoyan



1-behzig



2-niizh



3-niswi gemaa awashime

Badaka'on gemaa



1-aabading gemaa awashime aabiding

Oshkiinzhigo-mashkiki



1-behzig



2-nuzh



3-niswi gemaa awashime

6. Aaniin ezhi-zanagag gemaa ezhi-wendag ji-onji-bazigwiiyan, desabiwining onji?

| Wendan | |
|--|---|
| Zanagan | 2 |
| Awiiya ji-wiiji'id | 3 |
| Gaawiin ngashki'osii aanawi awiya e'wiiji'id | 4 |

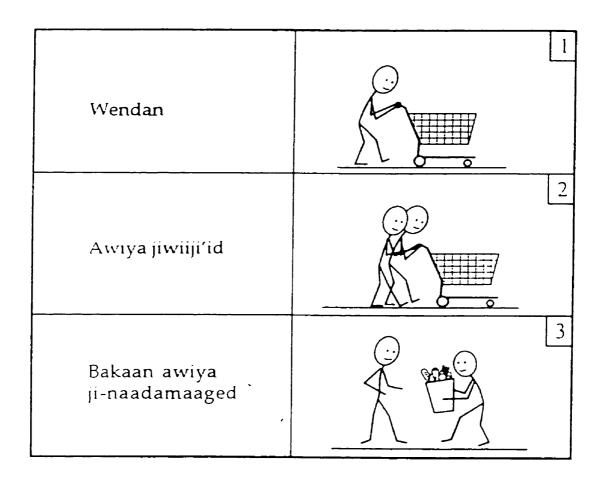
7. Aaniin ezhi-wendag gemaa ezhi-zanagag e-bimoseyan biindig endaayan?

| Wendan | 1 |
|--|---|
| Zanagan | 2 |
| Niwiiji'igon nzaka'on gemaa - bimosekaan | 3 |
| Awiya ji wiiji'id | 4 |
| Gaawiin ngashkitoosiin aanawi awiya e-wiiji'id | 5 |

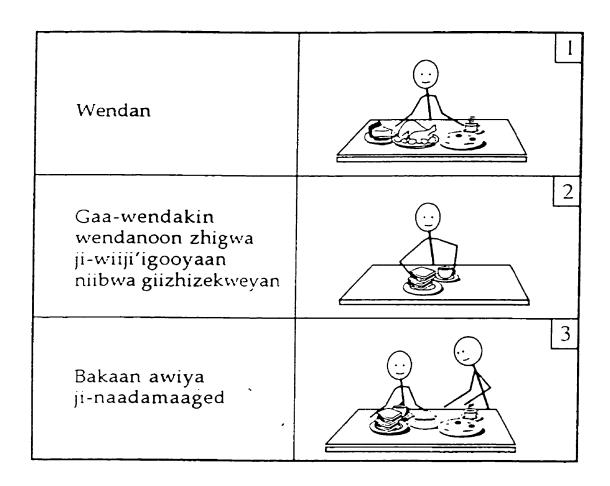
8. Aaniin ezhi-wendag gemaa ezhi-zanagag ji-giishkizhondwaa gishkazhiig giniisiigizidaaning onji?

| Wendan | |
|------------------|---|
| Zanagan | 2 |
| Awiya jiwiiji'id | 3 |

9. Aaniin ezhi-wendag gemaa ezhi-zanagag ji-naazikaman ji-ando-adaaweyan gi-miijim gemaa ji-ando-adaaweyan bakaan gegoon?



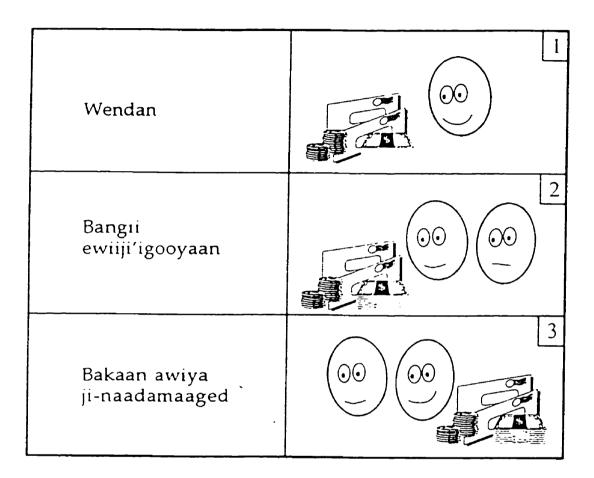
10. Aaniin ezhi-wendag gemaa ezhi zanagag ji-giizizikweyan?



11. Aaniin ezhi-wendag gemaa zanagag e-aabajitooyan gugidowin?

| Wendan | |
|----------------------------------|---|
| Zanagan | 2 |
| Bakaan awiya ji-naadamaaged ` | 3 |

12. Aaniin ezhi-wendag gemaa ezhi zanagag zhooniyaawigamigong e ji-asad gizhooniyaam zhigwa ji-diba'aman gimazina'igewinan?



13. Aaniin ezhi-wendag gemaa ezhi zanagag ezaagijiwidooyan gaa-webinaman gegoon?

| | |
|---------------------------------|-------------|
| Wendan | |
| Zanagan | 2 |
| Bakaan awiiya ji-naadamaaged | 3 |

Так

Hi

Звіт щодо оздопровчих потреб старших громадян

Дякую за те, що Ви призначили час виповнити цей звіт. На всі питання обведіть колом найкращу відповідь.

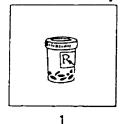
Чи Вам 75 років чи більше? Так
Ні
 Чи Ви перебували в госпіталі в минулому році?
Так
Ні
 Чи ви маєте якусь одну людину на яку ви можете полягати коли ви потребуєте допомоги довколо хати?

4. Як би Ви оцінили загальний стан свого здоров'я тепер?

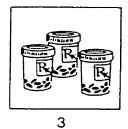
| Дуже добрий | (00) | 1 |
|-------------|------|---|
| Добрий | (00) | 2 |
| Задовільний | (OO) | 3 |
| Не добрий | (OO) | 4 |
| Поганий | | 5 |

5. Скільки різник ліків ви заживаєте?

Пілюлі / Пігулки





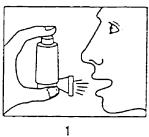


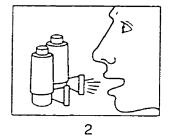




5 або більше

Інгалятори (для астми або проблем з диханням)







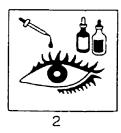
Застрики / голки



1 або більше

Краплі для очей







3 або більше

6. До якої міри Вам легко або важко вставати з крісла.

| Легко | |
|--|---|
| Важко | 2 |
| Потребую допомогу іншої людини , | 3 |
| Не можу, навіть з допомогою | 4 |

7. До якої міри Вам легко або важко ходити по вашій хаті або помешканні?

| , , , , , , , , , , , , , , , , , , , | |
|---|---|
| Легко | |
| Важко | 2 |
| 3 допомогою палки або ходака | 3 |
| Потребую допомоги іншої людини | 4 |
| Не можу, навіть з допомогою | 5 |

8. До якої міри Вам легко або важко обтинати нігті на своїх ногах?

| Легко | |
|--|---|
| Важко | 2 |
| Потребую допомоги іншої людини , | 3 |

9. До якої міри Вам легко або важко вийти з хати щоб купувати харчі або ходити на закупки?



10. До якої міри Вам легко або важко готувати їжу?



11. До якої міри Вам легко або важко користуватися телефоном?



12. До якої міри Вам легко або важко ходити до банку і платити свої рахунки?



13. До якої міри Вам легко або важко виносити своє сміття?



Appendix 4:

Summary of Back Translations

PHNSS Back-Translations

E=English F=French C=Chinese O=Ojibwe

U=Ukrainian

E. Predicting Health Needs of Seniors Survey

- F. Survey to determine health needs of the elderly
- C. Predicting Seniors' Health Needs Survey (Questionnaire)
- O. The knowledge about Elders that is being searched
- U. Survey as to Health Needs of Senior Citizens

E. Thank you for taking the time to fill out this survey. For all of the questions, please circle the best answer.

- F. Thank you for taking the time to answer this survey. Please circle your answer for each question.
- C. Thank you for taking the time to complete this questionnaire. Please answer all questions by circling the most suitable choice.
- O. Thank you for filling out this paper, all things you are being asked, circle one.
- U. Thank you for your participation in this survey. Please circle the appropriate answer, for all questions.

Question 1.

- E. Are you 75 years or older?
- F. Are you 75 years or older?
- C. Are you 75 years of age or over?
- O. Are you 75 years old or are you older?
- U. Are you 75 years or older?

Question 2.

- E. Have you been in hospital in the past year?
- F. Have you been to the hospital during the past year?
- C. During the past year, have you been a patient at the hospital?
- O. Were you at a hospital this year?
- U. Were you hospitalized in the past year?

Question 3.

- E. Do you have someone you can count on if you need help around the house?
- F. Is there someone you can count on if you need help around the house
- C. When you need help at home is there a person who you can rely on to help/assist you?
- O. Do you have someone that you can rely on to help you at your home?
- U. Do you have someone if you need help around the house?

Question 4.

E. How would you rate your current health?

- F. How do you define your state of health?
- C. How would you rate your current health?
- O. How do you think you are in your health?
- U. How would you rate your health now?

E. Excellent

- F. Excellent
- C. Very good
- O. I'm very well
- U. Very good

E. Good

- F. Good
- C. Good
- O. Good
- U. I'm feeling well

E. Fair

- F. Average
- C. Satisfactory
- O. I'm feeling fairly well
- U. Average

E. Poor

- F. Poor
- C. Bad
- O. I'm not feeling very well
- U. Poor

E. Bad

- F. Bad
- C. Very Bad
- O. I'm feeling badly
- U. very poor

Question 5

E. How many different medications do you take?

- F. How many different medications do you take?
- C.
- O. How many kinds of medicines do you usually take?
- U. How many medications do you use?

E. Pills

- F. Pills
- C. How many different types of medications are you presently taking?
- O. Medicines
- U. Pills

E. Puffers or inhalers (for breathing problems or asthma)

- F. Inhaler (for respiratory and asthma problems)
- C. How many types of puffers are you using to help you with your breathing?
- O. So that you can breathe
- U. Inhalators (for asthma or other respiratory problems)

E. Needles

- F. Needles or injections
- C. How many types of shots do you require?
- O. Needle (sewing and injection)- depends on the dialect
- U. Syringes (needles)

E. Eyedrops

- F. Eyedrops
- C. How many types of eyedrops are you using?
- O. Eye medicine
- U. Eyedrops

Question 6.

E. Please easy or hard is it for you to get out of a chair.

- F. How easy or difficult is it for you to get out from a chair?
- C. Is it easy or hard for you to get up from a chair?
- O. How is it hard or easy to get up from a chair?
- U. To what extent is it easy or difficult for you to get out of a chair?

E. Easy

- F. Easy
- C. Very easy
- O. It's Easy
- U. Easy

E. Hard

- F. Difficult
- C. Not easy
- O. It's hard
- U. With some difficulty

E. Need the help of another person

- F. Need someone to help me
- C. Needs assistance
- O. Someone to help me
- U. Require someone's assistance

E. Unable even with help

- F. Impossible even with assistance
- C. Cannot get up even with assistance
- O. I can't get up even if someone helps me
- U. Not at all, regardless if assistance was available

Ouestion 7.

E. How easy or hard is it for you to walk inside your house or apartment?

- F. How easy or difficult is it for you to get around your house or apartment?
- C. Is it easy or hard for you to walk in the house or apartment?
- O. How is it easy or hard for you to walk inside your home?
- U. To what extent is it easy or difficult for you towalk about your house or apartment?

E. Easy

- F. Easily
- C. Easy
- O. It's easy
- U. Easy

E. Hard

- F. With difficulty
- C. Difficult
- O. It's hard
- U. With some difficulty

E. With the help of cane or walker

- F. With a cane or a walker
- C. Require a cane or walker
- O. My cane or walker helps me
- U. With the use of a cane or a walker

E. Need the help of another person

- F. Need someone to help me
- C. Need to hold onto someone
- O. For someone to help me
- U. Only with the assistance of someone else

E. Unable even with help

- F. Impossible even with assistance
- C. Cannot get up and walk even with assistance
- O. I can't get up even is someone helps me
- U. Not al all, regardless if someone's assistance was available

Question 8.

E. How easy or hard is it for you to cut your own toenails?

- F. How easy or difficult is it for you to cut your own toenails?
- C. Is it easy or hard for you to cut your toenails?
- O. How is it easy or hard for you to cut your nails from your toes?
- U. To what extent is it easy or difficult for you to trim the nails on your feet?

E. Easy

- F. Easy
- C. Easy
- O. It's easy
- U. Easy

E. Hard

- F. Difficult
- C. Have difficulty
- O. It's hard
- U. With some difficulty

E. Need the help of another person

- F. With some assistance
- C. Require someone else to cut them
- O. Someone to help me
- U. Someone else must trim them

Question 9.

E. How easy or hard is it for you to get out to buy groceries or other shopping

- F. How easy or diffcult is it for you to run your errands?
- C. Is it easy or hard for you to go out shopping?
- O. How is it easy or hard for you to fetch, to go buy your food or go buy other things
- U. To what extent is it easy or dfficult for you to go shopping or buy groceries?

E. Easy

- F. Easily
- C. Easy
- O. It's easy
- U. Easy

E. Need the help of another person

- F. With some assistance
- C. Require someone's assistance
- O. Someone to help me
- U. Require someone's assistance

- F. Someone does it for me
- C. Require someone else to do the shopping
- F. A different person to help out
- U. My shopping is done by someone else

Question 10.

E. How easy or hard is it for you to prepare meals

- F. How easy or difficult is it for you to prepare your meals?
- C. Is it easy or hard for you to cook three meals a day?
- O. How is it easy or how is it hard for you to cook?
- U. To what extent is it easy or difficult for you to prepare food?

E. Easy

- F. Easily
- C. Easy
- O. It's easy
- U. Easy

E. Simple meals easily but need help with big meals

- F. Easy for simple meals, but need some help for substantial meals
- C. Can prepare simple meals, require assistance to cook difficult to prepare meals
- O. The easy ones are easy and I have helped with cooking big meals
- U. Small amounts of food are not difficult but I require assistance when preparing greater amounts

- F. Someone does it for me
- C. Require someone else to prepare meals
- O. A different person to help out
- U. Food preparation is done by someone else

Question 11.

E. How easy or hard is it for you to use the telephone?

- F. How easy or hard is it for you to use the phone?
- C. Is it easy or hard for you to use the telephone?
- O. How is it easy or hard to use a telephone?
- U. To what extent is it easy or difficult for you to use a phone?

E. Easy

- F. Easy
- C. Easy
- O. It's easy
- U. Easy

E. Hard

- F. Difficult
- C. Have difficulty
- O. It's hard
- U. With some difficulty

- F. Someone does it for me
- C. Require someone else to do the phoning
- 15. A different person to help out
- U. Someone else must operate the telephone for me

Question 12.

E. How easy or hard is it for you to do your own banking and paying bills?

- F. How easy or difficult is it for you to do your own banking and pay your bills?
- C. Is it easy or hard for you to deposit money, withdraw money or pay your utility bills?
- O. How is it easy or hard to put your money in the bank and to pay your bills?
- U. To what extent is it easy or difficult for you to go to your bank and pay your bills?

E. Easy

- F. Easily
- C. Easy
- O. It's easy
- U. Easy

E. With some help

- F. With some assistance
- C. Require assistance
- O. For me to be helped a little
- U. Require some assistance

- F. Someone does it for me
- C. Require someone else to do the banking
- O. A different person to help me
- U. Someone else does my banking and pays my bills

Question 13.

E. How easy or hard is for you to take out your own garbage?

- F. How easy or difficult is it for you to take out the garbage?
- C. Is it easy or hard for you to take out the garbage?
- O. How is it easy or hard to take out what you're throwing away?
- U. To what extent is it easy or dfficult for you to carry out your own garbage?

E. Easy

- F. Easily
- C. Easy
- O. It's easy
- U. Easily

E. With some help

- F. With some assistance
- C. Require assistance
- O. For me to be helped a little
- U. With some assistance

- F. Someone does it for me
- C. Require someone else to take out the garbage
- O. A different person to help out
- U. Someone else must do this for me

Appendix 5:

Supplementary Questionnaire to Chinese PHNSS:

Traditional Chinese Medicine Use in Chinese Seniors

Supplementary Questionnaire

| (Please Check the reporting Self Report- [[] [| | | • | • | | |
|--|------------|---------------|---------------|----------------------|--|--|
| I. Which one of the following English Language? | ; categori | es accurately | describes you | r ability to use the | | |
| | Fluent | Know Som | e Non-fluent | | | |
| | I | 2 | 3 | | | |
| a. Written Englishb. Spoken English | <u>-</u> | 0.0 | <u> </u> | | | |
| II. How long have you been living in Canada or other primarily English speaking countries? | | | | | | |
| Number of years: y Left home country in 19 | | months | | | | |

[II.] I would like to discuss your general lifestyle, the language that you prefer to speak, your interests and reading habits. For each of the following statement, which category best describes you. The categories are

(Please provide a cue card for the categories)

7. Your friends today are.....

8. Your music preference is...
9. Your movie preference is...
10. Your food preference is...
11. You prefer to think in...
12. You prefer to write in...
13. You prefer to read in ...

| Chinese Only | Mostly Chinese Some English | Both Chinese And English | Mostly Some (| _ | | Eng On | glish Iy |
|--|--------------------------------|-----------------------------|------------------|--------------|--------|---------------|-----------------|
| 3 | 5 | In Equal Amount | | 2 | | = | ; |
| I | 2 | 3 | | 4 | | 5 | |
| In general | | | | inese ily | Both | | English Only |
| | | | I | 2 | 3 | 4 | 5 |
| 1. If you are | at home, you speak | | 0 | \Box | \Box | Ξ | _ |
| 2. If you are | at work, you speak | | 🖸 | \Box | 3 | $\overline{}$ | _ |
| • | choose, you prefer to | | | J | | _ | _ |
| • | | - | | _ | _ | _ | Ξ |
| 4. When your parents talk to each other, they speak.5. When your children talk to each other, they speak. | | | | | _ | _ | _ |
| • | | | . – | | _ | _ | - |
| 6. Before age | : 18, your friends were | e | _ | Ξ | _ | _ | _ |

000000

00111100

CONTRACTOR

IV. I would like to ask if you have or have had any of the following health conditions or symptoms in the past year? For the conditions or symptoms you have experienced I would like to ask what type of health care you have used or relied on? Choose ONE category that best describes your preferences for treatment.

The categories are

(Please provide a cue card for the categories)

| TCM | Mostly TCM | Both TCM & | Mostly | Western | Do |
|------|--------------|-------------------|-----------|-----------|---------|
| Only | Some Western | Western Treatment | Western & | treatment | >otpruñ |
| • | Treatment | in Equal Amount | Some TCM | Only | |
| _ | - | · - | <u>.</u> | _ | - |
| _ | _ | _ | <u>-</u> | _ | _ |
| I | 2 | 3 | 4 | 5 | 6 |

Traditional Chinese Medicine (TCM) and Western medicine treatments can include home remedies, over-the-counter medicines, western prescription drugs, or doctor's visit Traditional Chinese Medicines can be in two forms: HERBAL FORM (including tonics and animal products), or PROPRIETARY FORM (including pills, tablets, capsules, powder, drinks, oil, ointment, or plasters).

| | | | ſF | TCN Only | | Both | | Vestern Only | Do Nothing |
|-----|---|-----------|---------|--------------|--|--------------|------------------------|-----------------|---------------|
| | | NO | YES | I | 2 | 3 | 4 | 5 | 6 |
| Di | seases Conditions | | | | | | | | |
| 1. | High blood pressure | C | _ | 2 | - | _ | - | ₽. | _ |
| 2. | Coronary artery disease | \Box | _ | <u> </u> | = | _ | Ξ | _ | _ |
| 3 | Stroke | | | _ | o contration of | _ | HILL TO THE CONTRACTOR | _ | - |
| 4. | Diabetes | - | _ | _ | = | | = | _ | = |
| 5. | Chronic lung disease | | _ | = | | | - | _ | _ |
| 6. | Chronic Kidney /Gall Stone disease | | Ξ | - | _ | _ | _ | = | = |
| 7 | Allergies | | _ | _ | = | _ | _ | Ξ | _ |
| 8 | Arthritis | | = | _ | _ | _ | _ | = | _ |
| 9 | Bone fractures | | = | <u>-</u> | <u>-</u> | _ | _ | _ | <u>-</u> |
| 10 | Osteoporosis | _ | = | _ | _ | _ | _ | = | _ |
| | Skin disease | _ | = | - | _ | _ | _ | _ | - |
| | Dementia | _ | _ | - | _ | _ | _ | _ | = |
| | Peptic ulcer | Ξ | _ | _ | _ | _ | _ | _ | - |
| | Glaucoma/ Cataracts | Ξ | _ | <u> </u> | - | _ | _ | _ | - |
| | Gladcoma Camaco | _ | _ | _ | _ | _ | _ | = | _ |
| Syı | mptoms | | | | | | | | |
| 15. | Stomachache | \square | _ | _ | _ | Ξ | \subseteq | _ | = |
| 16 | Poor appetite | _ | _ | - | _ | _ | _ | _ | - |
| 17. | Tooth & gum problem | _ | _ | E. | _ | .= | \Box | _ | = |
| 18 | Headaches | <u>-</u> | = | _ | _ | - | - | _ | - |
| 19 | Dizziness | ē | ETOTOTO | попрыва | 000000 | reduction of | anganga | | = |
| 20. | Pain | ò | Ξ | <u>-</u> | _ | _ | Ξ | Ē | _ |
| 21. | Cold /Cough or Sore Throat | ָרָר ב | ָרָר וּ | | | _ | _ | Ē | = |
| | Constipation | | רו כ | 0 | C | | | _ | _ |
| | Fatigue | | Ē | 0 | | | | C | Ξ |
| | Loss of memory | | 0 | | | Ü | | | |
| | Nervousness | _ | | | | | | Ξ | - |
| | Sleeping problems | | G | C | | C | : : | | = |
| | t ··· · · · · · · · · · · · · · · · · · | \Box | 2 | ت | <u>. </u> | _ | Ē | <u>'_</u> | <u>-</u> |

V. Do you take TCM for reasons other than as a treatment (e.g. use it as a tonic or other health promoting purposes)?

| Yes | | 0 |
|-----|--|-----|
| No | | : 7 |

VI. How much do you agree or disagree with all of the following sentences. Choose the category that best corresponds to your feelings. The categories are

(Please provide a cue card for the categories)

| Strongly | Moderately | Neither Agree | Moderately | Strongly |
|----------|------------|---------------|------------|----------|
| Disagree | Disagree | Nor Disagree | Agree | Agree |
| ď | | C. | G | = |
| ī | 2 | 3 | 4 | 5 |

In general

| | | | sब्रह् | - | S | Y ह्या Guon | • |
|-----|---|---|--------|---|---|----------------|---|
| | | i | 2 | 3 | 4 | 5 | |
| i | Illnesses are caused by internal yin-yang imbalance | - | _ | _ | - | - | |
| | Illnesses are caused by external imbalance (e.g. infectious | _ | _ | _ | _ | - | |
| | bacteria) | - | - | - | - | - | |
| _ | | _ | _ | _ | _ | _ | |
| 3 | Going out in cold wind results in headache/cold | _ | - | _ | - | - | |
| 4. | Strong anger/ rage poisons one's blood | _ | _ | _ | _ | _ | |
| 5 | A cold or flu should be treated with a hot liquid, not | | | | | | |
| | medicine | _ | - | G | - | - | |
| 6 | Taking vitamins or supplements is essential to good health | _ | | = | | _ | |
| | • | _ | - | - | - | - | |
| | I use TCM, not Western medicine for minor health problems | _ | _ | - | _ | _ | |
| 8. | I use Western medicine/ services, not TCM for major health | | | | | | |
| | problems | _ | | - | - | _ | |
| 9. | • | _ | _ | _ | - | _ | |
| | · | | _ | | _ | _ | |
| 10. | I use Western medicine, not TCM for my acute illnesses | _ | _ | _ | _ | - | |
| 11. | Combining Western medicine and TCM can get most | - | _ | _ | _ | _ | |
| | effective treatment results | | | _ | - | _ | |
| | | _ | _ | - | = | _ | |
| | TCM is less harmful to one's body than Western medicine | _ | _ | _ | - | _ | |
| 13 | I would try TCM for incurable illnesses | | Ξ. | _ | _ | _ | |

| VII. | Where do | vou obtain | the knowledge | on TCM | properties |
|------|----------|------------|---------------|--------|------------|
|------|----------|------------|---------------|--------|------------|

| a TCM doctor b Chinese Western doctor c non-Chinese Western doctor d. TCM herbal store retailer e. general /grocery store retailer f. families or friends g. others | | YES | |
|---|------------|--------------|------------|
| (If the respondent does not use any forms of TCM, to continue with the questions) | hen tern | ninate here. | Otherwise, |
| VIII How often do you consult a TCM doctor before | s nzruតិ : | any TCM | |
| a. always | | | |
| IX Where do you get your TCM | | | |
| a TCM doctors b. TCM herbal stores c. health food stores d. general /grocery stores e. family or friends f. overseas g. others | | YES | |

□自答-I□□IVVVIVI □助答-I□□IVVVIVII

1.以下那一項正確地描述你的英語能力?

: . ·

| | 流利 1 | 稍懂 2 | 不流利 3 |
|---|---------|---------|----------|
| a. 書寫 · · · · · · · · · · · · · · · · · · | 0 | | |
| b. 食話 · · · · · | C | ۵ | ū |

11。你在加拿大或其他主用英語國家共住了多少年?

總年數:___年___月· 19___年版開原生地

[1]。以下的問題是有關你日常生活形態,慣用語言,你的嗜好及閱讀習慣等問題。在以下五個小項目中,請選出最適合你的一項。五個小項目詳列如下。。

| 全是中文 | 大部份是中文 小部份是英文 | 中英文並用 雨者一樣多 | 大部份是英文 小部份是中文 | 全是英文 |
|------|------------------|----------------|------------------|------|
| 0 | G | | | 0 |
| 1 | 2 | 3 | 4 | 5 |

| 大致上・・・・・・・ | 全是 中文 1 | | 中英 並用 3 | 4 | 全是 英文 5 |
|---|---------------|--------|---------------|---|-------------------|
| 你在在比较深入時間 你你你你你你你你你你你你你你你你你你你你你你你你你你你你你你你你你你你你 | 0000000 | 000000 | 000000 | | 00000000 |

IV。以下的問題,答案分馬兩部分。第一部分,我將會問你有否在過去一年內有過以下的疾病或症狀。如有,第二部分將問你所使用過的治療方法。

· . ·

在第二项,以下的小项目是用於描述不同的治療方法。請選擇最適合你的一项目。項目詳列如下:

| 只用中醫 | 中醫療法為主西醫療法為副 | 中醫療法與西 醫療法並用 | 西醫療法為主 中醫療法為副 | 只用西督 | 什麼都不用 |
|---------|--------------|-----------------|------------------|------|-------|
| ī. 1 | □ 2 | ົ່ມ 3 | [] 4 | □5 | 6 C.1 |

中唇支西唇治療包括家傳秘方,藥房自購,西藥配方支醫生看病。 中藥可分爲兩類:草藥類(包括補藥及動物產品)支成藥類(包括丸、片、囊、粉、露、油、膏或貼)。

| | | | 只用中醫 | | 中西 並用 3 | | 只用 西醫 | 不用 |
|--|---|---|------|---|---------------|---|-----------------|----|
| 疾病 : | 否 | 有 | 1 | 2 | 3 | 4 | 5 | 6 |
| 1·高应整 2·心中糖 3·中糖 4·糖 4·糖 4·糖 4·糖 4·糖 5·慢性 5·慢性 5·慢性 8· 8· 8· 8· 8· 9· 8· 11· 10· 12· 4 11· 12· 13· 13· 13· 13· 13· 13· 13· 13· 13· 13 | 0 | 0 | | | | 0 | | 0 |
| 14·青 - 青 - 青 | | | | | - | | | |

V·请表示你同意以下各問題與否·選擇最能描述你的看法的一項·項目詳列如下:

| 坚决不同意 | 有些不同意 | 整不同意 也不贊成 | 有些同意 | 坚决同意 |
|-------|-------|--------------|------|------|
| 0 | 0 | | 0 | 0 |
| 1 | 2 | 3 | 4 | 5 |

| | 整決 整決 不同意 同意 1 2 3 4 5 |
|--|------------------------------|
| 1·疾病是因體內陰陽失調而造成 2·疾病是因外在因素失調而造成(如病毒、细菌) 3·出外吹冷風會引起頭痛感冒 4·動怒發脾氣易引起體內血中毒 5·总冒應以喝熱飲料治療,不是吃西藥 | |
| 6·吃维他命或補品是保健基本之道 7· 富我生小病時,我是用中藥療法,不是用西藥療法 8· 富我生大病時,我是用西藥療法,不是用中藥療法 | |
| 9· 當我有慢性疾病時,我是用中無療法,不是用西藥療法 10· 當我有急性疾病時,我是用西藥療法,不是用中藥療法 11·合並使用中西式療法可以截長補短,得到最好的治療效果 12·中藥療法對身體的傷害比西藥療法少 13·對不治之病我會使用中藥療法 | |

VI·除了治病以外,你有沒有用中藥於其他的用途(例:補身壯體)

有・・・[□] 没有・・[□]

. : .

VII·你對中無的認識是從那裏來的?

| | | | | | | | | | <u> </u> | ـــــ |
|-----|---------|--------------|---------------------------------------|---|---------------------------------------|---|---|---|---|---|
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| 唇• | • | • | • | • | • | • | • | • | • 🗆 | 0 |
| | • | • | • | • | • | • | • | • | • 🗆 | |
| | • | • | • | • | • | • | • | • | • 🛭 | 0 |
| | • | • | • | • | • | • | • | • | • 🗆 | 0 |
| | | | | | • | • | • | • | • 🛘 | 0 |
| | 各 · · · | 各 · · | 各···································· | 各 · · · · · · · · · · · · · · · · · · · | 各···································· | 各 · · · · · · · · · · · · · · · · · · · | 各 · · · · · · · · · · · · · · · · · · · | 各 · · · · · · · · · · · · · · · · · · · | 各 · · · · · · · · · · · · · · · · · · · | 各 · · · · · · · · · · · · · · · · · · · |

(如被访者不用中藥,請在此终止。如用中藥請繼續)

VIII。你用中藥前有否詢問中醫的意見

| a. 每次· | • • | • • | | • • | • • | _ |
|--------|-----|-----|-----|-----|-----|---|
| b.通常· | | • • | • • | | • • | _ |
| c.有時。 | | | | | • • | = |
| d.不曾· | | | | | • • | = |
| - | | | | | | |

IX·你在那裏得獲中無

| | | を | 是 |
|-------|---------------------------------------|-----|---|
| a • | 中長 | • 🗇 | 0 |
| b • | · · · · · · · · · · · · · · · · · · · | • - | ٥ |
| C • | 西式健康食品店・・・・・ | • 🗆 | |
| d • - | 普通商店・・・・・・・ | •] | C |
| e • | 家庭或朋友・・・・・・ | • 🖯 | G |
| | · 海外 · · · · · · · · · · | | 9 |
| g • . | 其他••••• | • 🗓 | |

Appendix 6:

Community Contacts and Recruiting Material:

General Cross-Cultural Contacts

French Community Contacts

Chinese Community Contacts

Ukrainian Community Contacts

Aboriginal Community Contacts

Recruiting Material

General Cross-Cultural Community Contacts (PHNSS)

| Name | Title | Address | Phone Number |
|----------------------------|--|---|--|
| Tina Alto | Executive Director | Manitoba Society of Seniors Suite 330-1700 Portage Ave. Wpg., MB R3C 0C4 | 942-3147 |
| Vanessa Coniglio | Tenant Relation Worker | Manitoba Housing Authority 100-185 Smith St. Winnipeg, MB R3C 3G4 | 945-0712 |
| Judy Fijal | Outreach Coordinator | Health Action Centre 425 Elgin Avenue Wpg., MB R3A 1P2 | 947-1626 Fax: 942-7828 |
| Madelyn Hall | Research Associate | Department of Community Health Sciences Room S110 - 750 Bannatyne Ave. Wpg., Manitoba R3E 0W3 | 789-3831 Fax:789-3905 |
| Arlene Jones | Nurse Coordinator | | 987-8853 |
| Heather McCaine- Davies | Publisher | Seniors Today 232 Henderson Hwy. Wpg., MB R2L 1L9 | 982-4000 |
| Irene Nordwich | President of Resident Council and Former professor of Nursing (U of M) | Fred Douglas Place 805-333 Vaughan Street Wpg., MB R3B 3J9 | 989-2297 |
| Maria Rogers | Centre Director | Smith Street Senior Centre 2nd Floor, 185 Smith Street Winnipeg, MB R3C 3G4 | 943-3463 |
| Karen Shore | Property Manager | Suite 116-411 Cumberland Wpg., MB R3B 1T7 | 942-3654 or 947-2242 Ext. 175 |

| Anne Skuba | National Council on Aging Member and Retired Nurse | Fred Douglas Place 1101-333 Vaughan Street Wpg., MB R3B 3J9 | 94-9785 |
|---------------------|--|---|---------------------------|
| Roberta Verch | Manager of Volunteer Services | Lions Manor 320 Sherbrook St. Winnipeg, MB R3B 2W6 | 784-1254 Fax: 784-1241 |
| Maria Wasykewycz | Counsellor of Elder Abuse Resource Centre | Age and Opportunity 400 Stradbrook Wpg., MB R3L 2P8 | 475-9150 Fax: 943-3463 |
| Mavis Webb | Coordinator | Age and Opportunity 283 Portage Avenue Wpg., MB R3B 2B5 | 956-6440 Fax: 956-6447 |
| John Zacharuk | Recreation Worker | SAM Management St. Andrews Place 425 Elgin Avenue Winnipeg, MB R3A 1P2 | 253-1842 |
| Marjorie Woods | Executive Manager | Creative Retirement 811-294 Portage Ave Wpg., Manitoba R3C 0B9 | 949-2553 Fax: 957-7839 |

French Community Contacts (PHNSS)

| Name | Title | Address | Phone Number |
|-----------------------------|--|---|--|
| Aime Barnabe | President Residents' Association | 404-200 Masson St. Winnipeg, MB R2H 3G1 | 237-3652 |
| Lorette Beaudry- Ferland | French Services Res. Unit | Room 609 Sante en Francaise 400 Tache Ave. St. Boniface Hospital | Ext. 3293 Fax: 237-0984 |
| Kevin Bettens | Student | St. Bernadette Parish 820 Cottonwood Wpg., MB R2J 1G1 | 255-1951 |
| Ann Camus | Ph.D Student | Department of French University of Manitoba 430 Fletcher Argue Bldg. Wpg., MB R3T 2N2 | 474-9313 Home:255-4029 Fax: 474-7578 |
| Rebecca Colburn | Ph.D. Student | Department of French University of Manitoba 430 Fletcher Argue Bldg. Wpg., MB R3T 2N2 | Home: 284-3024 |
| Tess Coss | President Manor Club | President Manor Club 211 - 266 Enfield Crescent Wpg, MB R2H 1B7 | 235-0679 |
| Josee T. Desjardins | Coordinator | La Federation Des Aines Franco- Manitobains 383-212 Provencher Blvd. Wpg, MB R2H 0G9 | 235-0670 Fax: 233-1017 |
| Father Gerard Dionne | | Ste. Marie Paroisse 29 DesMeurons Wpg., MB | 237-6097 |

| Mgr. Albert Frechette | Pastor | St. Boniface Cathedral Basillica 190 Cathedrale Wpg, MB | 233-7304 Fax: 231-1205 |
|--------------------------|---|--|---|
| Diane Frost | Senior Centre Director | St. Vital Seniors Centre 613 St. Mary=s Road Wpg., MB R2M 3L8 | 253-1842 |
| Terry Gagnon | Day Care Program Coordinator | Tache Centre 185 Despins | 233-3692 Ext. 231 |
| Greg Girardin | Receptionist | Holy Cross Parish 252 Dubuc Wpg., MB R2H 1E3 | 233-7367 |
| Mary-Anne Gribben | Language Bank Manager | International Centre 406 Edmonton St. Wpg., MB R3B 2M2 | 943-9158 Fax: 949-0734 |
| Pat Hope | Tennant Resource Worker | Manitoba Housing 100-185 Smith Street Wpg, MB R2C 3G4 | 237-1386 945-8762 pager 196 Cell: 792-0317 |
| Leanne Johnson | Community Resource Coordinator | Boni-Vital Council for Seniors Unit 6 - 845 Dakota St. Wpg., MB R2M 5M3 | 255-2061 |
| Lise G. Lacombe | Coordinator of French Language Services | Manitoba Health 1200-447 Portage Ave. Wpg., MB R3B 3H5 | 945-6731 |
| Father Ron Leger | | Holy Family Church 778 Dubuc Wpg., MB R2J 0Y4 | 237-3068 |
| Sandra Loewen | Director of Social Work | Tache Centre 185 Despins Wpg, MB R2H 2B3 | 233-3692 ext. 267 Fax: 233-6803 |

| Guy Mao | Manager | Accueil Colombien Inc. 10-200 Masson Street Wpg MB R2H 3G1 | 233-0501 |
|---------------------------------------|---|---|---------------------------|
| Suzette Pare | Secretary | St. Martyrs- Canadiens Paroisse 289 Dussault Winnipeg, Man. R2J 1N5 | 982-4400 |
| Leo Remillard | President (Residents Association) | Place Des Meurons 403-400 Des Meurons Winnipeg, Manitoba | 237-6220 |
| Robert Ronceray | Manager | Columbus Manor 266 Enfield Crescent Wpg, MB R2H 1B7 | 233-7080 Fax: 237-3453 |
| Warren Smith | Manager | St. Phillips Court 234 Tache Ave. Wpg., MB R2H 1Z7 | 237-3650 |
| Carol Tessier Replace by Agathe | Secretary | Precieux Sang Paroisse 200 Kenny Wpg., MB R2H 2E4 | 233-2874 |
| Joan Yewchyn | Manager | Chateau Guay 107-231 Goulet St. Wpg., MB R2H 0S1 | 233-7271 |

Chinese Community Contacts (PHNSS)

| Name | Title | Address | Phone Number |
|----------------------|--|---|----------------------------|
| Dorothy Choy | Coordinator | (Manitoba Chinese Historical Society) Home: 469 Queenston Street Wpg., MB R3N 0X1 | 489-8919 Fax: 942-3221 |
| Lan Doan | Director | Winnipeg Chinese Culture and Community Centre 2nd Floor - 180 King St. Wpg., MB R3B 3G8 | 943-2627 |
| Michelle Fu | Lecturer | Asian Studies University of Manitoba 327 Fletcher Argue Bldg. Wpg., MB R3T 2N2 | 474-8958 Home: 452-0872 |
| Mary-Anne Gribben | Language Bank Manager | International Centre 406 Edmonton St. Wpg., MB R3B 2M2 | 943-9158 Fax: 949-0734 |
| H.C. Lim | President of the Chinese Community Council of Manitoba | Chinese Community Council of Manitoba 948 Beaverhill Blvd. Wpg., MB R2J 3B7 | 253-2313 |

| Dr. Terence Russel | Professor | 411 Isbister Building Department of Asian Studies University of Manitoba Winnipeg., MB R3T 2N2 | 474-8964 Fax: 474-7601 |
|-----------------------|--|--|------------------------------------|
| Boon Su | Outreach Worker also: (Vice - President/Indo- Chinese Assoc.) | Health Action Centre 425 Elgin Ave. Wpg., MB R3A 1P2 | 947-1626 Fax: 947-7828 |
| Anita Suen | Centre Facilitator | Age and Opportunity West-End Seniors Centre 644 Burnell Street Wpg., MB R3G 2B7 | Phone: 772-9581 Fax: 946-5667 |
| Betty Wong | Management Staff | Harmony Mansion 100 - 201 Princess Street Wpg., MB R3B 3E9 | 947-1705 |
| Grace Wong | Secretary | Winnipeg Chinese Cultural Centre 2nd Floor 180 King St. Wpg., MB R3B 3G8 | 943-1197 Fax: 944-8308 |
| Mabel Yee | UCW Chair | (Chinese United Church of Winnipeg) Home Address: 112 Brittany Drive Wpg., MB R3R 3G9 | Church: 943-3052 Home: 896-1400 |

Ukrainian Community Contacts (PHNSS)

| Name | Title | Address | Phone Number |
|------------------------|--|--|---------------------------------------|
| Oksana Bondarchuk | Coordinator of Volunteers | Holy Family Home 165 Aberdeen Ave. Wpg., MB R2W 1T9 | 589-7381 |
| Ernie Cicierski | Executive Director | Ukrainian Cultural and Educational Centre | 942-0218 Fax: 943-2857 |
| Stella Hryniuk | Professor | St. John's College University of Winnipeg Winnipeg, Manitoba R3T 2M5 | 474-8101 |
| Martha Korbutiak | Former Ukrainian Seniors Social Service Worker (?) | 1011 Polson Bay Wpg., MB R2X 1M7 | Home: 582-3812 |
| Stefania Myhaluk | Manager | St. Mary's The Protectress Millenium Villa Inc. 800 Burrows Avenue Wpg., MB R2X 3A9 | 586-5816 |
| Alexandra Pawlowsky | Professor | Centre for Ukrainian Canadian Studies 29 Dysart Rd. Wpg., MB R3T 2M7 | 474-8905 589-7501 Fax: 275-0803 |
| Barbara Russel | Director | Selkirk Avenue Seniors Centre 472 Selkirk Ave. Wpg., MB R2W 2M7 | 582-2329 |

| Lydia Shawarsky. Lesia Szwaluk | Executive Director Executive Assistant | Ukrainian Canadian Congress 456 Main St. Winnipeg, Manitoba R3B 1B6 | 942-4627 |
|--------------------------------------|---|---|--|
| Rose Skavinski | Executive Assistant | St. Andrews College 29 Dysart Road Winnipeg, Manitoba R3T 2M7 | 474-8895 Home: 284-4657 Fax:275-0803 |
| Edith Toews | Housing Coordinator | Donwood South 1245 Henderson Highway Winnipeg, Manitoba R2G 1M1 | 338-8688 Fax:339-3554 |
| John Zahark | Centre Worker | Age and Opportunity St. Vital Senior's Centre 613 St. Mary's Rd. Wpg., MB R2M 3L8 | 253-1842 |

Aboriginal Community Contacts (PHNSS)

| Name | Title | Address | Phone Number |
|-----------------------|--|--|--|
| Carol Beaulieu | Researcher Writer (soon to be Conciliator) | Manitoba Association of Native Languages 211 - 181 Higgins Ave. Wpg., MB R3B 3G1 | 989-6392 Fax: 989-6396 |
| Gerald Berthelette | Director/Aboriginal Services Department | Health Sciences Centre CN403 - 840 Sherbrook St. Wpg., MB R3A 1S1 | 787-2457 787-3427 Pager: 3436 Fax: 787-1680 |
| Loretta Byer | Aboriginal Health Strategist | Manitoba Health P.O. Box 925 599 Empress St. Wpg., MB R3C 2TC | 786-7294 Fax:772-2943 |
| Doreen Fines | Administrator | Metis Cultural Resource Centre 506 - 63 Albert St. Wpg., Manitoba R3B 1G4 | 956-7767 |
| Darlene Hall | Director/Childrens Programs | Aboriginal Health and Wellness Centre 215 - 181 Higgins Ave. Wpg., MB R3B 3G1 | 925-3700 |
| Joan Harris | Office Manager | Aboriginal Council 112 - 181 Higgins Ave. Wpg., MB R3B 3G1 | 989-6380 Fax: 942-5795 |
| Thelma Meade | Executive Director | Kikinamawin Centre 202 - 228 Notre Dame Ave. Wpg., MB R3B 1N7 | 943-0207 Fax: 956-5829 |

| Pat Ningewance | Lecturer (U of M) | 474 Craig St. Winnipeg, Manitoba R3G 3C1 | 774-8007 774-1160 |
|----------------|-------------------|--|----------------------|
| Mary Richard | President | Aboriginal Council of Wpg. 181 Higgins Ave. Wpg., MB R3B 3G1 | 989-6390 |

Subject Recruitment Locations

| Culture | Location |
|-----------|---|
| English | Ellice Place |
| | Health Action Centre: Health Services for the |
| | Elderly |
| | Seven Oaks Hospital- Day Hospital |
| | Jack's Place |
| | The Friendly Neighbour Council |
| | Age and Opportunity-Seniors Centres |
| | All Things New |
| | Willow Centre |
| French | Manor Club |
| | La Fédération des Aînés Franco-Manitobains |
| | St. Vital Seniors' Centre |
| | Taché Centre |
| | Manitoba Housing Authority |
| | Boni-Vital Council for Seniors |
| | Age and Opportunity-Seniors Centres |
| | Acceuil Colombien |
| | Place Des Meurons |
| | Columbus Manor |
| Chinese | Manitoba Chinese Historical Society |
| | Winnipeg Chinese Culture and Community |
| | Centre |
| | Chinese Community Council of Manitoba |
| | Health Action Centre |
| | Age and Opportunity-Seniors Centres |
| | Harmony Mansion |
| | Sek on Toi- Seniors Housing |
| Ukrainian | Sons of the Ukrainian Pioneers |
| | Seven Oaks Hospital- Day Hospital |
| | Holy Family Church |
| | Age and Opportunity-Seniors Centres |

English Speaking Seniors Required

for a study on day to day activities

Involves answering questions about:

- health and day to day activities
- personal background
- memory
- mood

And a few tests that show us how well your arms and legs are working.

Amount of time required:

Approximately 45 minutes to 1 hour

Interviewers are willing to come to your home.

All responses will be kept confidential.

Contact:

Bev Wirth

Willow Centre (632-5940)

or

Jennifer Nguyen or Dr. Kristel van Inveveld St. Boniface General Hospital Phone: 237-2443





'ection of Geriatric Medicine Department of Medicine University of Manitoba



409 Taché, Winnipeg, Manitoba, Canada R2H 2A6 Tel (204) 233-8563 Fax (204) 231-0640

Dear Participant:

Thank you for your interest is our research project entitled the Predicting Health Needs of Seniors Survey. With this short letter is a description of the project and what is involved. We are eager to have you participate. One of our interviewers will contact you shortly to arrange a time to come and talk with you. The answers that you provide us will remain completely confidential.

If you have any questions, please call Jennifer Nguyen, the research assistant, at 237-2443. We hope that you continue to agree to participate.

Sincerely yours.

Cornelia (Kristel) van Ineveld MD, FREP(C)

Lecturer, Geriatric Medicine

Phone: 237-2443 Fax: 237-2697

Phone: 237-2443

Jennifer A. Nguyen

Research Assistant

Fax: 237-2697

NOUS AVONS BESOIN DE VOUS!

Aîné(e)s francophones âgées de 65 ans et plus pour une étude concernant vos activités quotidiennes

Des questions concernant votre:

- santé et vos activités quotidiennes
- vie personnelle
- mémoire
- humeur

Nous vous demanderons de passer un test pour évaluer l'usage de vos bras, et de vos jambes.

Combien de temps prendra-t-il?

Environ 45 minutes, une heure tout au plus.

Des gens sont prêts à venir chez vous.

Toutes les réponses que vous donnerez resteront confidentielles.

Personne contact: Anita au 233-4111

Pour plus d'amples renseignements veuillez contacter:

Jennifer Nguyen et Dr. Kristel van Ineveld Gérontologie Hôpital Général St. Boniface au 237-2443







ection of Geriatric Medicine Jepartment of Medicine University of Hanitoba



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Cher participant, Chère participante,

Nous vous remercions pour l'intérêt que vous portez à notre projet d'étude intitulé « Sondage d'évaluation des besoins de santé pour les personnes âgées ». Cijoint vous trouverez un aperçu du projet et qu'est-ce que ça implique. Nous sommes anxieux de votre participation. Un ou une de nos interviewers va communiquer avec vous prochainement afin de fixer un rendez-vous pour vous rencontrer. Les réponses que vous donnerez seront complètement confidentielles.

Si vous avez des questions, n'hésitez pas communiquer avec l'adjointe du projet de recherche, Madame Jennifer Nguyen au 237-2443. Nous espérons que votre intérêt se continue dans notre projet.

Veuillez agréer, cher participant, chère participante, nos sentiments les meilleurs.

Comelia (Kristel) van Ineveld MD, FRCP(C) Conférencière en Gérontologie

Téléphone: 237-2443 Télécopieur: 237-2697 Jennifer A. Nguyen Adjointe du projet de recherche

Téléphone: 237-2443 Télécopieur: 237-2697

誠徵華裔者英參與日常活動之研究

包括回答以下之有關問題:

- ·健康與日常活動 ·個人背景

以及一些有關手足功能的測驗。

所需時間:

·大約45分鍾至一個鍾頭。

訪問人員願意登門造訪。,

所有回應將以保密。

請和王女士聯絡

電話: 269-0847

英語請電: Jenniser Nguyen or Dr. Kristel van Ineveld

Geriatric Medicine

St. Boniface General Hospital

Phone: 237-2443

Appendix 7:

Interview Schedule for Construct Validity

English: complete schedule
French: MMSE, GDS, PPT
Chinese: MMSE, GDS, PPT
Ukrainian: MMSE, GDS, PPT

| #; Date: Interviewer#: | | | |
|------------------------------|--|------------------------------|-----------------------|
| interviewer #. | Pred | licting Health Needs of S | Seniors Survey |
| 1. | Indicate gender: | | |
| | Female | | |
| | Male | | |
| 2. | What is your date of birth? | (month) (day) | (year) |
| 3. | Your marital status: (Please | e check one) | |
| | Married or common law Divorced or separated Widowed Never been married | | |
| 4a). | Do you live alone? (Please | check one) | |
| | yes no | | |
| 4b). | If no, how many adults live | with you? | |
| 4c). | We would like to know v following people live with | | to you. Do any of the |
| | Spouse Sibling/in law Child/in law | Please check if <u>yes</u> F | How many people? |

Friend/unrelated person

Parent/in law Grandchild/in law

| 6. | How long have you been living in your pre | sent household? |
|----|--|-----------------|
| | Less than six months | |
| | Over six months but less than a year | |
| | One year to three years | |
| | Three to five years | |
| | Over five years | |
| 7. | Where do your nearest relatives live? (Plea | se check one) |
| | In same household | |
| | In same building | |
| | In same neighbourhood | |
| | Less than I day journey by land travel | |
| | More than 1 day journey by land travel or outside Canada | |
| 8. | What type of housing do you live in? | |
| | Whole house or self-contained** house | |
| | In multiple dwelling (eg. condominium) | |
| | self contained** suite (excluding seniors' housing units and condominiums) | |
| | Suite in senior citizens' housing unit | |
| | Board and room (hotel, foster home, commercial boarding home) | |
| | Personal care home (nursing home) | |
| | Other specify | |
| | ** A self-contained unit is one which i sleeping, and bathroom facilities for use of | |

| 9a). | Were you born | in Canada? |
|--------|---|--|
| | yes no | |
| 9b). | If no, when did | you come to Canada? |
| | year of 19 | |
| 9c). | What nationalit | y/descent do you consider yourself? |
| 10. | What language | do you speak most often? |
| 11. | How many year | rs or grades did you complete in school? |
| | (Specify number | r of years) |
| Use to | he occupation co | odes shown below to answer items 12 and 13. |
| 12. | What was/is yo | ur occupation? |
| 13. | What was/is yo | ur spouse's occupation? |
| | Codes 01 02 03 04 05 06 07 08 09 10 11 12 13 14 | Occupation Fishing Trapping Prospecting, Guiding Mining Forestry Logging Farming Housewife Unskilled labour (Manufactoring, Industrial, Construction) Skilled labour (Manufacturing, Industrial, Construction) Crafts Management Professional Clerical Sales & Service (including domestic service) Trapportation Communication Recreation (Tourism) |
| | 16 17 | Transportation, Communication, Recreation (Tourism) Never employed |

| 14. | Are you presently retired? | |
|-----|------------------------------------|------------|
| | yes no | |
| 15. | If yes, what age were you when yo | u retired? |
| | years old | |
| 16. | What was your income in the past t | month? |
| | \$ | |

End of Demographics

STANDARDIZED MINI-MENTAL STATE EXAMINATION 0 1991 Malloy, Alemoyeks, Roberts



| Orientation to Time (Allow 10 seconds) | Score |
|--|-------|
| Year | |
| Season | |
| Month | |
| Today's date | |
| Day of the week | |

| Orientation to Place (Allow 10 seconds) | Score |
|---|-------|
| Country | |
| Province | |
| City | |
| Name of Building | |
| Floor of Building | |

| Immediate Recall of Three Words | Score |
|---------------------------------|-------|
| Ball | |
| Car | |
| Man | |

| Concentration: Spell "WORLD" Backwards Spell the word WORLD (may assist), now spell it backwards allow 30 seconds | Score |
|---|-------|
| D | |
| L | |
| R | |
| 0 | |
| W | |

| Delayed Recall of Three Words What were the three objects that I asked you to remember | Score |
|--|-------|
| Ball | |
| Car | |
| Man | |

| Language | Score |
|------------------------------|-------|
| Name a wristwatch | |
| Name a pencil | |
| Repeat "NO IFS ANDS OR BUTS" | |

| Visual - Verbal Recognition | Score |
|-----------------------------|-------|
| CLOSE YOUR EYES | |

| Score |
|----------|
| |
| <u> </u> |
| |
| |

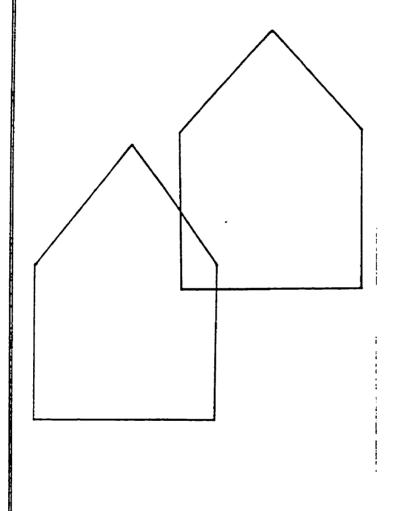
| Writing Ability (Allow 30 seconds) | Score |
|------------------------------------|-------|
| Write a complete sentence | |

| Visual - Motor Integration Copy this design please, allow multiple tries | Score |
|--|-------|
| Copy a design | |

Key 24-30 N, 20-24 MildCL, 10-20 ModCL, 0-10 SCI

| Total Score | /30 |
|-------------|-----|
| Date | |

CLOSE YOUR EYES



DEPRESSION SCALE © 1986 Shelkh, Yearvage



| | se the best answer for how you have felt over the past week. le responses count one point) | YES | NO |
|------|---|---------------|-----|
| ١. | Are you basically satisfied with your life? | | 0 |
| 2. | Have you dropped many of your activities and interests? | 0 | |
| 3. | Do you feel that your life is empty? | 0 | |
| 4. | Do you often get bored? | 0 | |
| 5. | Are you in good spirits most of the time? | | 0 |
| 6. | Are you afraid that something bad is going to happen to you? | 0 | |
| 7. | Do you feel happy most of the time? | | 0 |
| 8. | Do you often feel helpless? | 0 | |
| 9. | Do you prefer to stay at home rather than going out and doing new things? | 0 | |
| 10. | Do you feel you have more problems with memory than most? | 0 | |
| i 1. | Do you think it is wonderful to be alive now? | | 0 |
| 12. | Do you feel pretty worthless the way you are now? | 0 | |
| 13. | Do you feel full of energy? | | 0 |
| 14. | Do you feel that your situation is hopeless? | 0 | |
| 15. | Do you think that most people are better off than you are? | 0 | |
| | | Total score _ | /15 |

Other Information:

LAWTON - INSTRUMENTAL ACTIVITIES OF DAILY LIVING



With regard to the following functions, which statements best describe how this patient has functioned in the last week. Please circle the most appropriate number beside the statement.

A. Ability to use telephone

- Operates the telephone on own initiative looks up and dials numbers etc.
- 1 Dials a few well known numbers.
- 1 Answers telephone but does not dial.
- 0 Does not use telephone at all.

B. Shopping

- Takes care of all shopping needs independently.
- O Shops independently for small purchases.
- 0 Needs to be accompanied on any shopping trip.
- 0 Completely unable to shop.

C. Food Preparation

- 1 Plans, prepares and serves adequate meals independently.
- O Prepare adequate meals if supplied with ingredients.
- 0 Heats and serves prepared meals or prepares meals but does not maintain adequate diet.
- 0 Needs to have meals prepared and served.

D. Housekeeping

- 1 Maintains house alone or with occasional assistance (eg. "heavy work-domestic help").
- 1 Performs light daily tasks such as dishwashing, bedmaking.
- Performs light daily tasks but cannot maintain acceptable level of cleanliness.
- 1 Needs help with all home maintenance tasks.
- O Does not participate in any housekeeping tasks.

E. Laundry

- 1 Does personal laundry completely.
- 1 Launders small items rinses socks, stockings etc.
- 0 All laundry must be done by others.

F. Mode of transportation

- 1 Travels independently on public transportation or drives own car.
- Arranges own travel via taxi, but does not otherwise use public transportation.
- 1 Travels on public transportation when assisted or accompanied by another.
- Travel limited to taxi or automobile with assistance of another.
- 0 Does not travel at all.

G. Responsibility for own medications

- Is responsible for taking medication in correct dosages at correct time.
- Takes responsibility if medication is prepared in advance in separate dosages.
- 0 Is not capable of dispensing own medication.

H. Ability to handle finances

- 1 Manages financial matters independently (budgets, writes checks, pays rent, bills, goes to bank) collects and keeps track of income.
- 1 Manages day-to-day purchases, but needs help with banking, major purchases, etc.
- 0 Incapable of handling money.

| Total Score: | |
|--------------|---------|
| | - 3 |

KATZ ACTIVITIES OF DAILY LIVING (ADL)



For each new area of functioning listed below, check the description that applies. (The word "assistance" means supervision, direction or personal assistance.)

| assistance means supervision, direction or person | iai assistance | =-) |
|--|----------------|----------------------------------|
| BATHING - either sponge bath, tub bath or show | er. | |
| Receives no assistance (gets in and out of tub by self if tub is usual means of bathing) | | INDEPENDENT |
| Receives assistance in bathing only one part of the body (such as back or leg) | | |
| Receives assistance in bathing more than one part of the body (or not bathed) | | DEPENDENT 🗖 |
| DRESSING - gets clothes from closets or drawers using fasterner (including braces if worn) | - including | underclothes, outer garments and |
| Gets clothes and gets completely dressed without assistance | | INDEPENDENT 🗖 |
| Gets clothes and gets dressed without assistance except for assistance in typing shoes | | |
| Receives assistance in getting clothes or in getting dressed, or stays partly or completely undressed | | DEPENDENT 🚨 |
| TOILETING - going to the "toilet room" for bowe elimination, and arranging clothes | el and urine | elimination; cleaning self after |
| Goes to the "toilet room" cleans self, and arranges clothes without assistance (many use object for support such as cane, walker, or wheel chair and may manage night bedpan or commode, emptying same in morning) | | INDEPENDENT |
| Receives assistance in going to "toilet room" or | | |
| in cleaning self or in arranging clothes after elimination or in use of night bedpan or commode | | DEPENDENT \square |
| Doesn't go to the room termed "toilet room" for the elimination process | | |

| TRANSFER | | |
|--|----------|-------------|
| Moves in and out of bed as well as in and out for the following object or support such as cane, walker or rails) | | INDEPENDENT |
| foves in and out of bed or chair with assistance | | DEPENDENT 🔲 |
| Poesn't get out of bed | | |
| CONTINENCE | | |
| ontrols urination and bowel movment completely by self | | INDEPENDENT |
| as occasional "accidents" | | DEPENDENT 🔲 |
| upervision helps keep urine or bowel control; atheter is used, or is incontinent | | |
| EEDING | | |
| eeds self without assistance | | INDEPENDENT |
| eed self except for getting assistance in atting meat or buttering bread | | |
| eceives assistance in feeding or is fed partly completely by using tubes or intravenous fluids | | DEPENDENT 🚨 |
| OTAL NUMBER OF ITEMS RATED AS DE | EPENDENT | |
| | | |
| | | |
| | | |

PHYSICAL PERFORMANCE TEST



| Instruction | Scoring | Time (Seconds) |
|--|--|-------------------|
| Write a sentence (whales live in the blue ocean) | \$ 10 sec = 4 10.5-15 sec = 3 15.5-20 sec = 2 >20 sec = 1 unable = 0 | |
| Simulated eating | \$ 10 sec = 4 10.5-15 sec = 3 15.5-20 sec = 2 >20 sec = 1 unable = 0 | |
| Lift a book and put it on a shelf | ≤2 sec = 4 2.5-4 sec = 3 4.5-6 sec = 2 >6 sec = 1 | |
| Put on and remove a jacket | \$ 10 sec = 4 10.5-15 sec = 3 15.5-20 sec = 2 >20 sec = 1 umable = 0 | |
| Pick up penny from floor | \$2 sec = 4 2.5-4 sec = 3 4.5-6 sec = 2 >6 sec = 1 | |
| Turn 360 degrees | discontinuous steps = 0 continuous steps = 2 unsteady (grabs, staggers) = 0 steady = 2 | |
| 50-foot walk test | ≤15 sec = 4 15.5-20 sec = 3 20.5-25 sec = 2 >25 sec = 1 | |

MINI-EXAMEN DE L'ÉTAT MENTAL © 1975 Febricka, Febricka, McElagh

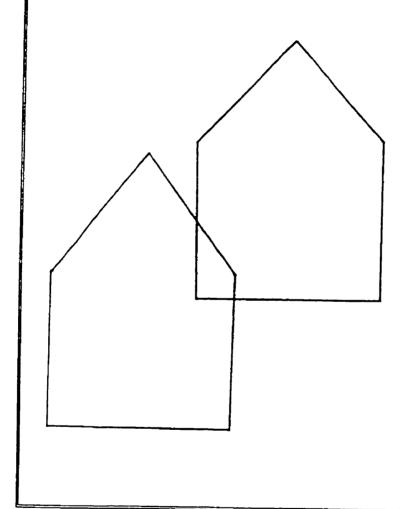
| Orientation | Cote |
|---------------------------------------|------|
| En quelle année sommes-nous? | |
| En quelle saison sommes-nous? | |
| Quelle est la date? | |
| Quel jour sommes-nous? | |
| En quel mois sommes-nous? | |
| En quelle province sommes-nous? | |
| En quel pays sommes-nous? | |
| En quelle ville sommes-nous? | |
| En quel hôpital/bâtiment sommes-nous? | |
| En quelle étage/bureau sommes-nous? | |

| Fixation: Nommez trois mots | Cote |
|-----------------------------|------|
| Balle | |
| Voiture | |
| Homme | |

| Attention et calcul: Épeler le mot "monde" à l'envers | Cote |
|---|------|
| E | |
| D | |
| N | |
| 0 | |
| М | |

| Retention mnésique | | Cote |
|---|--------------|------|
| Balle | | |
| Voiture | | |
| Homme | | |
| | | |
| Langage | | Cote |
| Nommer une montre | | |
| Nommer un crayon | | |
| Répéter "PAS DE SI, NI DE ÇA" | | |
| | | |
| Lire et faire ce qui suite | | Cote |
| FERMEZ VOS YEUX | | |
| | | |
| | | |
| Executer une commande en trois étapes | | Cote |
| Executer une commande en trois étapes Prenez cette feuille de papier dans votre main d | roite/gauche | Cote |
| | roite/gauche | Cote |
| Prenez cette feuille de papier dans votre main d | roite/gauche | Cote |
| Prenez cette feuille de papier dans votre main d Pliez-la en deux | roîte/gauche | Cote |
| Prenez cette feuille de papier dans votre main d Pliez-la en deux | roîte/gauche | Cote |
| Prenez cette feuille de papier dans votre main de Pliez-la en deux Posez-la par terre | roîte/gauche | |
| Prenez cette feuille de papier dans votre main de Pliez-la en deux Posez-la par terre Capacité d'écrire | roite/gauche | |
| Prenez cette feuille de papier dans votre main de Pliez-la en deux Posez-la par terre Capacité d'écrire | roite/gauche | |
| Prenez cette feuille de papier dans votre main de Pliez-la en deux Posez-la par terre Capacité d'écrire Ecrire une phrase | roite/gauche | Cote |
| Prenez cette feuille de papier dans votre main de Pliez-la en deux Posez-la par terre Capacité d'écrire Ecrire une phrase Visuel-Intégration Motrice | roite/gauche | Cote |
| Prenez cette feuille de papier dans votre main de Pliez-la en deux Posez-la par terre Capacité d'écrire Ecrire une phrase Visuel-Intégration Motrice | Total/30 | Cote |

FERMEZ VOS YEUX



ECHELLE GERIATRIQUE DE DEPRESSION 0 1962 Brisk, Ymerrage of sk



| Choisir la meilleure réponse pour décrire la façon dont vous vous OUI NON sentez depuis une semaine: | | | |
|--|---|----------|---|
| 1. | Êtes-vous essentiellement satisfait de votre vie? | | 0 |
| 2. | Avez-vous abandonné plusieurs de vos activités et intérêts? | 0 | 0 |
| 3. | Est-ce que vous sentez que votre vie est vide? | 0 | |
| 4. | Vous ennuyez-vous souvent? | 0 | |
| 5. | Avez-vous un bon moral la plupart de temps? | <u> </u> | 0 |
| 6. | Avez-vous peur qu'une chose terrible va vous arriver? | 0 | |
| 7. | Vous sentez-vous heureux la plupart de temps? | | 0 |
| 8. | Vous sentez-vous souvent abandonné ou sans recours? | 0 | |
| 9. | Préfèrez-vous rester à la maison plutôt que de sortir et faire de nouvelles choses? | 0 | |
| 10. | Sentez-vous que vous avez plus de problème de mémoire que la plupart de gens? | 0 | |
| 11. | Pensez-vous qu'il est bien agréable d'être vivant maintenant? | | 0 |
| 12. | Vous sentez-vous bien inutile tel que vous êtes présentement? | 0 | |
| 13. | Vous sentez-vous plein d'énergie? | 0 | 0 |
| 14. | Pensez-vous que votre situation est sans espoir? | 0 | |
| 15. | Pensez-vous que la plupart des gens sont plus favorisés que vous? | 0 | |
| | | | |
| | | Total/15 | |

PHYSICAL PERFORMANCE TEST

| 1 | • | 14 | 77 | 7 |
|------|---|----|----|---|
| 1990 | • | | ~ | |

| Instruction | Scoring | Time (Seconds) |
|---|--|-------------------|
| Write a sentence (le poisson rouge nage dans l'eau) | <pre>\$ 10 sec = 4 10.5-15 sec = 3 15.5-20 sec = 2 >20 sec = 1 unable = 0</pre> | |
| Simulated eating | s 10 sec = 4 10.5-15 sec = 3 15.5-20 sec = 2 >20 sec = 1 unable = 0 | |
| Lift a book and put it on a shelf | s2 sec = 4 2.5-4 sec = 3 4.5-6 sec = 2 >6 sec = 1 | |
| Put on and remove a jacket | \$ 10 sec = 4 10.5-15 sec = 3 15.5-20 sec = 2 >20 sec = 1 unable = 0 | |
| Pick up penny from floor | \$2 sec = 4 2.5-4 sec = 3 4.5-6 sec = 2 >6 sec = 1 | |
| Turn 360 degrees | discontinuous steps = 0 continuous steps = 2 unsteady (grabs, staggers) = 0 steady = 2 | |
| 50-foot walk test | \$15 sec = 4 15.5-20 sec = 3 20.5-25 sec = 2 >25 sec = 1 | |

STANDARDIZED MINI-MENTAL STATE EXAMINATION



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| Orientation to Time (Allow 10 seconds) | Score |
|--|-------|
| Year | |
| Season | |
| Month | |
| Today's date | |
| Day of the week | |

| Orientation to Place (Allow 10 seconds) | Score |
|---|-------|
| Country | |
| Province | |
| City | |
| Name of Building | |
| Floor of Building | |

| Immediate Recall of Three Words | "皮球" | "国旗" | "树林" | Score |
|---------------------------------|------|------|------|-------|
| 皮球 | | | | |
| 国旗 | | | | |
| 树木 | | | | |

| Concentration: Spell "WORLD" Backwards Spell the word "天上有月亮"。(may assist), now spell it backwards allow 30 seconds | Score |
|---|-------|
| 尧 | |
| 月. | |
| 有 | |
| 上 | |
| 天 | |

| Delayed Recall of Three Words What were the three objects that I asked you to remember | |
|--|--|
| 皮球· | |
| 国旗 | |
| 树木 | |

| Language | Score |
|-------------------|-------|
| Name a wristwatch | |
| Name a pencil | |
| Repeat "四十四只石獅子"。 | |

| Visual - Verbal Recognition | Score |
|-----------------------------|-------|
| 请闭上您的眼睛 | |

| Ability to Follow Directions | Score |
|---------------------------------------|-------|
| Take a piece of paper in correct hand | |
| Fold it in half once | |
| Put it on the floor | |

| Writing Ability (Allow 30 seconds) | Score |
|------------------------------------|-------|
| Write a complete sentence | |

| Visual - Motor Integration Copy this design please, allow multiple tries | |
|--|--|
| Copy a design | |

Key 24-30 N. 20-24 MildCL 10-20 ModCL 0-10 SCI

| Total Score _ | /30 | |
|---------------|-----|--|
| Date | | |

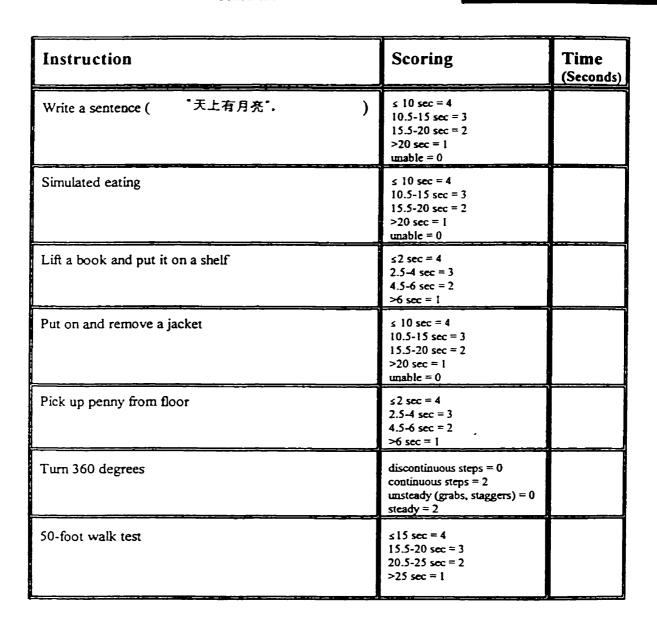
请闭上您的眼睛

DEPRESSION SCALE 0 1984 Shells, Yearrage

| Choose the best answer for how you have felt ove ("2" responses count 1 point) | er the past week. | - |
|---|---|---|
| B. 老人即 聲狀況 | | |
| 1. 你大致上橫暗橫塞你自己戰生活! | U 2=引送息 U 1=減息 | |
| 2.你保唔保放低咗好多你嘅活動問理與歷呢! | ? [] [=昭 (A) [] 2=(A) | |
| 3. 你會唔會覺得你嘅生活好無聊! | □ 1=昭曾 □ 2=曾 | |
| 4.你會唔會經常都覺得好問! | □ 1=昭曾 □ 2=曾 | |
| 5.你係唔係經常都覺得精神好好! | □ 2=唔係 □ 1=係 | |
| 6.你合唔會推心有口唔好嘅嗎会略你身上發 生 1 | □ 1= 符合 □ 2=會 | |
| 7.你保唔保時時都覺得好閒心! | □ 2=唔保 □ 1=保 | |
| 8. 你集唔係成日都覺得有也人幫餌你! | □ 1=1 日 保 □ 2=保 | |
| 9. 你保唔保健意留啡屋企多遇出街! | □ 1=唔保 □ 2=保 | |
| 10.你覺唔覺得有記性傑你好多麻煩! | □ 1=唔 觉得□ 2=觉得 | |
| 11.略!你而家仲在生吗,你覺得閒唔閒心呀! | 「 □ 2=唔覺得 □ 1=覺得 | |
| 12. 你覺唔覺得自己好有用 1 | □ 1=唔 复得 □ 2=覺 得 | |
| 13. 你覺唔覺得自己充裝活力 1 | □ 2=唔 覺得 □ 1=覺得 | |
| 14.你覺唔覺得而家嘅處境有也希望! | □ 1=唔 党 得 □ 2=党得 | |
| 15. 你係唔係覺得大部份人嘅生活都好過你! | □ 1=唔係 □ 2=係 | |
| | | |

Other Information:

PHYSICAL PERFORMANCE TEST



STANDARDIZED MINI-MENTAL STATE EXAMINATION

| ID#: | |
|-------|-----|
| Date: | |
| | • . |
| * | |

C 1991 Mailoy, Alemeyehu, Robert

| Orientation to Time (Allow 10 seconds) | Score |
|--|-------|
| Year | |
| Season | |
| Month | |
| Today's date | |
| Day of the week | |

| Orientation to Place (Allow 10 seconds) | Score |
|---|-------|
| Country | |
| Province | |
| City | |
| Name of Building | |
| Floor of Building | |

| Imme | diate Recall of Three Words | Score |
|-------|-----------------------------|-------|
| Apple | яблуко | |
| Chair | крісло | |
| Key | ключ | |

| Concentration: Spell "BIKHO" Backwards Spell the word BIKHO (may assist), now spell it backwards allow 30 seconds | Score |
|---|-------|
| 0 | |
| н | |
| K | |
| I | |
| В | |

| Delayed Recall of Three Words What were the three objects that I asked you to remember | | Score |
|--|--------|-------|
| Apple | яблуко | |
| Chair | крісло | |
| Key | ключ | |

| Language | Score |
|---------------------------------------|-------|
| Name a wristwatch | |
| Name a pencil | |
| Repeat " Баба з возить коням лекшем " | |

| Visual - Verbal Recognition | Score |
|-----------------------------|-------|
| | |

| Ability to Follow Directions | Score |
|---------------------------------------|-------|
| Take a piece of paper in correct hand | |
| Fold it in half once | |
| Put it on the floor | |

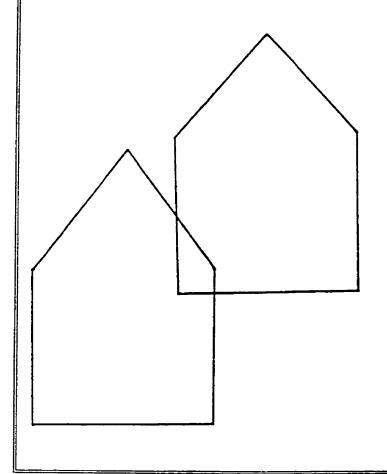
| Writing Ability (Allow 30 seconds) | Score |
|------------------------------------|-------|
| Write a complete sentence | |

| Visual - Motor Integration Copy this design please, allow multiple tries | Score |
|--|-------|
| Copy a design | |

Kes. 24-30 N; 20-24 MidCl; 10-20 ModCl; 0-10 SCI

| Total Score _ | /30 |
|---------------|-----|
| Date | |

CLOSE YOUR EYES ЗАКРЕЙТИ ВАШІ ОЧІ



DEPRESSION SCALE

C 1986 Sheikh, Yesavage

| | | | | |
|-------|-----|------|---------|--|
| ID#: | • . | | . • | |
| Date: | | | | |

| H | ose the best answer for how you have felt over the past week. cle responses count one point) | YES | NO |
|-----|--|-----|----|
| 1. | Are you basically satisfied with your life? Чи ви задоволені своїм життям? | | 0 |
| 2. | Have you dropped many of your activities and interests? Чи ви покинули багато ваших інтересів і занять? | 0 | |
| 3 | Do you feel that your life is empty? Чи ви відчуваєте що ваше життя порожнє? | 0 | |
| 4 | Do you often get bored? Чи вам часто скучно? | 0 | |
| 5 | Are you in good spirits most of the time? Чи ви переважно в доброму настрої? | | 0 |
| 6 | Are you afraid that something bad is going to happen to you? Чи ви боїтеся що вам щось погане станеться? | 0 | |
| 7 | Do you feel happy most of the time? Чи ви найбільший час відчуваєте себе щасливі? | | 0 |
| 8 | Do you often feel helpless? Чи ви часто почуваєтеся безпорадні? | 0 | |
| 9. | Do you prefer to stay at home rather than going out and doing new things? Чи ви волієти бути вдома замість кудесь ходити або чимось новим займатися? | 0 | |
| 10. | Do you feel you have more problems with memory than most? Чи ви відчуваєте що у вас більше проблем з пам'ятт'ю ніж інших людей? | 0 | |
| 11 | Do you think it is wonderful to be alive now? Чи ви радієте життям? | | 0 |

| 12 | Do you feel pretty worthless the way you are now? Чи ви почуваєтеся безвартісні? | 0 | |
|-----|---|-----------|--------|
| 13. | Do you feel full of energy? Чи ви вічуваєтеся повні енергії? | | 0 |
| 14. | Do you feel that your situation is hopeless? Чи ви почуваєтеся безнадійні? | 0 | 0 |
| 15. | Do you think that most people are better off than you are? Чи ви думаєте що життя для інших людей краще ніж ваше? | 0 | |
| | | Total sco | ore/15 |

Other Information:

PHYSICAL PERFORMANCE TEST

| ID#: | | |
|-------|------|--|
| Date: | | |
| | | |

| Instruction | Scoring | Time (Seconds) |
|--|--|-------------------|
| Write a sentence (whales live in the blue ocean) Риби живуть в синьому морі. | ≤ 10 sec = 4 10.5-15 sec = 3 15.5-20 sec = 2 >20 sec = 1 unable = 0 | |
| Simulated eating | £ 10 sec = 4 10.5-15 sec = 3 15 5-20 sec = 2 >20 sec = 1 unable = 0 | |
| Lift a book and put it on a shelf | £2 sec = 4 2 5-4 sec = 3 4.5-6 sec = 2 >6 sec = 1 | |
| Put on and remove a jacket | ≤ 10 sec = 4 10 5-15 sec = 3 15.5-20 sec = 2 >20 sec = 1 unable = 0 | |
| Pick up penny from floor | \$2 sec = 4 2 5-4 sec = 3 4 5-6 sec = 2 >6 sec = 1 | |
| Tum 360 degrees | discontinuous steps = 0 continuous steps = 2 unsteady (grabs, staggers) = 0 steady = 2 | |
| 50-foot walk test | ≤15 sec = 4 15.5-20 sec = 3 20.5-25 sec = 2 >25 sec = 1 | |

Appendix 8:

Surrogate PHNSS

Source of 'Surrogate' PHNSS Items

| PHNSS | SURROGATE ITEM |
|--------------------------------------|--|
| 1. Are you 75 years or older | AIM: Age at time of 1996 Interview |
| 2. Have you been in hospital in | MHSC hospitalization data June 30 1995- June 30 |
| the past year | 1996, admitted at least once: yes/no |
| 3. Do you have someone you can | AIM A105: Is there anyone on who you can call, if |
| count on if you need help around | you need help |
| the house | |
| 4. How would you rate your | AIM A251: For your age, would you say in |
| current health | general your health is good, fair, poor |
| 5. How many different | DPIN medications prescribed Jan-June 1996. |
| medications do you take | Only pills, puffers, injections, eye drops included. |
| | One time prescriptions only if April or later, |
| | antibiotics only if in June, eye drops only if April |
| | 15 or later. |
| 6. How easy or hard is it for you | AIM A376: Because of any long-term condition or |
| to get out of a chair | health problem do you need the help of another |
| | person in getting out of a chair |
| | no= easy/ hard yes= another person/ unable |
| 7. How hard or easy is it for you to | AIM A380: Are you capable of getting about the |
| walk inside your house or | house without any help from anyone? |
| apartment | yes=easy/ hard |
| | no= need the help of another person, unable even |
| | with help |
| 8. How easy or hard is it for you | AIM A393: Does anyone usually help you with |
| to cut your own toenails? | cutting your toenails? |
| | Do it= easy |
| | Person out of home = hard |
| | person in home/service/ staff = another person |
| 9. How easy or hard is it for you | AIM A238: Does anyone usually help you with the |
| to get out to buy groceries or | shopping |
| other shopping? | do it= easy |
| | person in home= need the help of another person |
| | person out of home/ service/ staff= someone else |
| | does it for me |
| 10. How easy or hard is it for you | A234: Does anyone usually help you preparing a |
| to prepare meals? | hot meal |
| | A232: Does anyone usually help you with making |
| | a cup of tea or coffee |
| | do it meal= easy |
| | yes meal, do it tea/coffee= simple meals easily but |
| | need help with big meals |
| | yes both= someone else does it for me |

| 11. How easy or hard is it for you to use the telephone? | A405: Does anyone usually help you with using the phone do it= easy person in home= hard person out of home/service/staff=someone else |
|---|--|
| 12. How easy or hard is it for you to do your own banking and paying bills? | A240: Does anyone usually help you with managing financial matters do it= easy person in home= with some help person out pf home/ service/ staff = someone else does it for me |
| 13. How easy or hard is it for you to take out your own garbage? | A228: Does anyone help you with doing light housework do it= easy person in home= hard person out of home/service/staff= someone else does it for me |

Item Response Rates for the 'Surrogate' PHNSS

Item 1: Are you 75 years or older?

| Score | Response | : | Frequency | Percent |
|-------|----------|-------|-----------|---------|
| 0 | <75 | | 77 | 22.8 |
| 1 | 75+ | | 261 | 77.2 |
| | | Total | 338 | 100.0 |

Item 2: Have you been in hospital in the past year?

| Score | Response | | Frequency | Percent |
|-------|----------|------|-----------|---------|
| 0 | no | | 285 | 84.3 |
| 1 | yes | | 52 | 15.4 |
| | missing | | 1 | .3 |
| | | | ***** | |
| | Т | otal | 338 | 100.0 |

Item 3: Do you have someone you can count on if you need help around the house?

| Score | Response |] | Frequency | Percent |
|-------|----------|------|-----------|---------|
| 0 | yes | | 334 | 98.8 |
| 1 | no | | 4 | 1.2 |
| | Т | otal | 338 | 100.0 |

Item 4: How would you rate your current health?

| Score | Response | Frequency | Percent |
|-----------------------|---|----------------------------|--|
| 1 2 3 4 5 | excellent good fair poor bad missing | 27 199 95 13 1 | 8.0 58.9 28.1 3.8 0.3 0.9 |
| | - | | |
| | Total | 338 | 100.0 |

Item 5: How many different medications do you take?

| Score | Fr | equency | Percent |
|-------|-------|---------|---------|
| 0 | | 91 | 26.9 |
| 1 | | 58 | 17.2 |
| 2 | | 58 | 17.2 |
| 3 | | 43 | 12.7 |
| 4+ | | 88 | 26.0 |
| | | ***** | |
| | Total | 338 | 100.0 |

Item 6: How easy or hard is it for you to get out of a chair?

| Score | Response | Frequency | Percent |
|-------|---|-----------|-------------|
| 1 3 | easy/difficult another person/ unable | 323 15 | 95.6 4.4 |
| | Total | 338 | 100.0 |

Item 7: How easy or hard is it for you to get out of a chair?

| Score | Response | Frequency | Percent |
|-------|-----------------------|-----------|---------|
| 1 | easy/difficult/ | 336 | 99.4 |
| 4 | another person/unable | 2 | 0.6 |
| | | | |
| | Total | 338 | 100.0 |

Item 8: How easy is it for you to cut your own toenails?

| Score | Response | Frequency | Percent |
|-------|-----------------------|-----------|---------|
| 1 | easy | 252 | 74.6 |
| 2 | difficult | 22 | 6.5 |
| 3 | another person/unable | 64 | 18.9 |
| | | | |
| | Total | 338 | 100.0 |

Item 9: How easy is it for you to get out to buy groceries or other shopping?

| Score | Response | Frequency | Percent |
|-------|---------------------------------|-----------|---------|
| 1 | easy | 273 | 80.8 |
| 3 | another person/ someone else | 65 | 19.2 |
| | | | |
| | Total | 338 | 100.0 |

Item 10: How easy is it for you to prepare meals?

| Score | Response | Frequency | Percent |
|-------|--------------|-----------|---------|
| 1 | easy | 274 | 81.1 |
| 2 | simple meals | 54 | 16.0 |
| 3 | someone else | 10 | 3.0 |
| | | ****** | |
| | Total | 338 | 100.0 |

Item 11: How easy is it for you to use the telephone?

| Score | Response | Frequency | Percent |
|-------|---------------------------------|---------------|--------------------|
| 1 2 | easy someone else missing | 332 5 1 | 98.2 1.5 0.3 |
| | | | |
| | Total | 338 | 100.0 |

Item 12: How easy is it for you to do your own banking and paying bills?

| Score | Response | Frequency | Percent |
|-------|---------------------------------|-----------|--------------|
| 1 3 | easy/ some help someone else | 292 46 | 86.4 13.6 |
| | | | |
| | Total | 338 | 100.0 |

Item 13: How easy is it for you to take out your own garbage?

| Score | Response | Frequency | Percent |
|-------|--------------|-----------|---------|
| 1 | easy | 297 | 87.9 |
| 2 | hard | 22 | 6.5 |
| 3 | someone else | 19 | 5.6 |
| | | | ****** |
| | Total | 338 | 100.0 |

Appendix 9:

Paraphrase and Consent for Construct Validity

English: Paraphrase, Consent Form

French: Paraphrase, Consent Form

Chinese: Consent Form

Oath of Confidentiality for Interviewers

The Predicting Health Needs of Seniors Survey

What is the Reason for Doing This Research Project?

Most seniors live at home and are doing just fine. But, there are also some seniors who are having more and more trouble managing at home. They are okay right now but in the next year or so might need help coping day to day. We want to find a simple way to pick out seniors who are having trouble or might have trouble soon. We think we can do this by having people answer a few questions on paper. We have called these questions the "Predicting Health Needs of Seniors Survey" (PHNSS). We have added drawings to the questions to make it easier to answer. Also, we plan to translate the questions into different languages.

We need to see if these questions really work. One way of doing this is to ask the questions to different groups of people. The first group are seniors who are well, busy and getting out of the house without problems. The second group are seniors who are going to programs for therapy to help them manage day to day activities. People in the first group should have different answers to the questions than people in the second group.

What is expected of people taking part?

A person can choose to whether to take part or not. Nothing will happen if you decide not to be part of the study. Taking part means answering the PHNSS which is made up of questions about health and day to day activities. Answering it should take 5-10 minutes. At the same time or later one of our assistants will interview you at home or a place of your choosing. He or she will ask you more detailed questions about your day to day activities. There will also be questions about your personal background, your memory and your mood. Finally, you will be asked to do a simple test of how your arms and legs are working. It includes a few things like picking up a penny from the floor. This part will be timed. Altogether this should take about one (1) hour of your time. Some people might find the time it takes to answer all the questions tiring. About two weeks later, some people will be asked to fill out the PHNSS again. If, during the questions, you

decided you no longer want to be part of the study you can stop at any time without any problems.

Who is doing the research?

This is a joint project between the Health Action Centre and researchers at the University of Manitoba. If there are any questions about the study, what is involved in taking part or the results you can call Jennifer Nguyen or Dr. Kristel van Ineveld at 237-2443. If you see a doctor or nurse at Health Action Centre, this project does not affect the care you receive there. If you decide you don't want to take part or want to stop at some point, nothing will happen to your medical care.

What about privacy?

All information about you will be kept confidential. The results if this study will talk only about differences between groups of people. There will be no way to identify a specific person.

When will the results be known?

The results should be available by May 1998. If you want information at that time you can call Dr. Kristel van Ineveld at 237-2443.

Consent Form

I have read and understand the reasons for the study. I will be asked to fill out a short survey which asks questions about my general health and how I manage day to day. To see how accurate the survey is, I will then be interviewed to describe my current health and abilities in much more detail. I will also be asked to carry out a few physical tasks (like pick up a penny from the floor). Altogether, this may take up to an hour of my time.

I understand my participation is voluntary and I may ask to stop at any time, even after starting the study. Whether I take part or not does not affect any medical care I might receive at the Health Action Centre. I understand the above explanation and agree to take part in this study.

| I,(please print) | , agree to ta | ake part in this study |
|--|---------------|----------------------------|
| " Predicting Health explained to me by | | Survey" which has been |
| Signature | | Date |
| Witness | | Date |

Sondage d'évaluation des besoins de santé des personnes âgées

Pourquoi ce projet de recherche?

La plupart des personnes âgées vivent à la maison et font assez bien. Mais il y a des personnes âgées qui ont plus en plus de problème à fonctionner à la maison. Elles font assez bien aujourd'hui mais dans la prochaine année elles pourront avoir besoin de l'aide avec leurs activités quotidiennes. Nous voulons trouver une simple solution d'identifier ces personnes qui ont de la misère ou qu'elles vont en avoir bientôt. Nous pensons pouvoir faire cela en demandant diverses questions sur papier. Nous avons appelé ces questions le «Sondage d'évaluation des besoins de santé des personnes âgées» (SEBSPA). Les questions incluront des dessins pour faciliter les réponses. Nous avons aussi traduit les questions en diverses langues.

Il faut y voir si ces questions fonctionnent. Une façon de faire cela est de les demander à divers groupes. Le premier groupe contient des personnes âgées qui sont en santé, occupées et qui sortent de la maison sans problèmes. Le deuxième groupe vise à des personnes âgées qui suivent un programme de thérapie qui les aide avec leurs activités quotidiennes. Les personnes du premier groupe devraient avoir des réponses aux questions différentes de ceux du deuxième groupe.

Qu'est-ce que nous attendons de ceux qui participent?

Une personne peut choisir d'y participer ou non. Rien va se passer si vous décidez ne pas faire part à l'étude. Y faire part veut tout simplement dire de répondre au SEBSPA qui consiste en questions sur la santé et les activités quotidiennes. Cela devrait prendre 5 à 10 minutes. Au même moment ou plus tard, un ou une de nos assistant(e)s va vous interviewer chez vous ou à un endroit de votre choix. Il ou elle vous demandera des questions plus détaillées au sujet de vos activités quotidiennes. Il y aurait aussi des questions sur votre vie personnelle, votre mémoire et votre humeur. Finalement, nous allons procéder à un petit test sur la condition de vos bras et vos jambes. Cela inclut certains exercices tel que ramasser une cent du plancher. Le temps de ces exercices sera calculé. Au total, ça devrait prendre une (1) heure de votre temps. Certains gens pourront trouver fatiguant de répondre à toutes les questions. À peu près deux semaines plus tard, certaines personnes pourraient être approchées pour encore répondre au SEBSPA. Si durant le sondage vous décidiez que vous ne vouliez plus faire part à l'étude vous n'avez qu'arrêter à n'importe quel temps sans problèmes.

Oui fait la recherche?

Ce projet est donné conjointement avec le Centre d'action de santé et des rechercheurs à l'Université du Manitoba. Si vous avez des questions en ce qui a trait à l'étude, qu'est-ce que ça demande de vous ou les résultats, veuillez communiquer avec Jennifer Nguyen ou le docteur Kristel van Ineveld au 237-2443. Si vous voyez un médecin ou une garde-malade au Centre d'action de santé, cette étude n'affecte pas les soins que vous recevez au Centre. Si vous décidez de ne pas y faire part ou d'arrêter à un certain moment, rien ne va arriver aux soins que vous recevez.

La confidentialité

Toute information sera confidentielle. Les résultats de l'étude consisteront en groupe de personnes. Aucun individu ne sera spécifiquement identifié.

Quand est-ce que les résultats seront connus ?

Les résultats devront être publics par le mois de mai 1998. Si vous voulez d'information à ce temps vous pourrez communiquer avec le docteur Kristel van Ineveld au 237-2443.

Consentement

J'ai bien lu et je comprends les raisons pour cette étude. Je serai demandé de remplir un court sondage qui consiste en questions sur ma santé en générale et comment je vis de jour en jour. Pour voir comment le sondage est exact je serai interviewé en détail pour décrire ma santé actuelle et mes habilités. Je serai aussi demandé de faire part à certaines exercices physiques (tel que ramasser une cent du plancher). Au total cela prendre à peu près une (1) heur de mon temps.

Je comprends que ma participation est volontaire et je peux demander d'arrêter à n'importe quel temps même après avoir commencé l'étude. Que j'y fais part ou non n'affecte pas mes soins de santé que je pourrais peut-être recevoir du Centre d'action de santé. Je comprends l'explication ci-haut mentionnée et je consente de faire part à l'étude.

| Je | , consente de faire part de l'étude «Sondage |
|---|--|
| (Lettre moulées s.v.p.) d'évaluation des besoins de santé des personnes âgées» qui m'a été expliqué p | |
| | |
| Signature | Date |
| Témoin | Date |

同意書

我曾閱讀而且明白這一研究的緣由,我將 被要求填寫一份有關一般健康及如何處理日常 事務的問券。為確保研究的正確性,我將會見 訪問員,提供有關我的健康現狀及體能的詳細 資料。我還會被要求進行一些功能測驗(如:

| 從地 | 上 | 檢 | 起 | _ | 枚 | 銅 | 幣 |) | , | 這 | 些 | 豣 | 究 | 花 | 費 | 的 | 時 | 間 |
|--------|---|----|----|-----|---|---------------|---|----------------|------------------|----------|---|----|---|---|-----|-----|---|----|
| 大約 | / | 個 | 鐘. | 頭 | 0 | | | | | | | | | | | | | |
| | 我 | 明 | 白 | 参 | 與 | 這 | 個 | 研 | 究 | 是 | 屬 | 自 | 愿 | 的 | , | 即 | 使 | 研 |
| 究已 | 經 | 開: | 始 | , | 我 | 也 | 可 | 以 | 隨 | 時 | 要 | 求 | 中 | 止 | . • | 不 | 論 | 我 |
| 是否 | 冬 | 與 | 言 | 項 | 研 | 究 | , | 將 | 不 | 會 | 影 | 響 | 我 | 可 | 能 | 在 | | |
| | | | - | | | | | | | | 接 | 受 | 的 | 醫 | 療 | 服 | 務 | 0 |
| 我明 | 白 | 以。 | 上 | 的 | 説 | 明 | , | 並 | 同 | 意 | 参 | 與 | 這 | 項 | 研 | 究 | o | |
| | 本 | 人 | | | | - | | | - | | | | 同 | 意 | 多 | - 與 | 這 | 項 |
| 《預 | 測 | 耆. | 英 | 健 | 康 | 要 | 求 | 調 | 查 | 》 | 研 | 究 | 0 | | 這 | 項 | 調 | 查 |
| 研究 | 的 | 過 | 程 | , | 己 | 由 | | | · - · | | - | | | | | | | - |
| 向我 | 解 | 釋: | 清 | 楚 | 0 | | | | | | | | | | | | - | •• |
| | | | | | | | | | | | | | | | | | | |
| | 簽 | , | 名 | • . | | | | - - | | | 日 | 期 | • | - | | | | |
| | 目 | 这 | Z | • | | | | | | | | 甘口 | • | | | | | |

| 簽 | 名: | 日期: | |
|----|-----|-----|--|
| 見證 | 圣人: | 日期: | |

OATH OF CONFIDENTIALITY

| This is to certify that I, |
|--|
| (print name) |
| take an oath of confidentiality regarding all data related to the study: |
| Culturally Sensitive High Risk Screening Program. I understand that such confidentiality refers to any information collected as part of this study and that the penalty for violation of this oath is subject to university discipline and dismissal procedures. |
| · |
| |
| |
| |
| Signature |
| • |
| |
| Date |

Appendix 10:

Introduction, Consent and Interview Schedule Predictive Validity

To be reviewed at the beginning of the telephone conversation. Pause after each paragraph to allow for replies, questions or any indications of uncertainty.

| Introduction | |
|-----------------------------------|---|
| Hello, is Mr. or Mrs. | _ there? |
| future studies with us. At the ti | and I am calling from the Aging in Manitoba study. e asked you if you would be willing to become involved in ime you told us that you might be willing to do that. I o explain what we are doing, and if you agree to be ons |

Paraphrase

There is a researcher, Dr. van Ineveld, working with the University of Manitoba and the Health Action Centre, Dr. van Ineveld is a geriatrician working at St. Boniface Hospital. Her research team has developed a short questionnaire which tries to pick out seniors who are currently living at home and doing fine but may develop trouble coping day to day over the next year or two. At this stage, we are trying to find out if these questions really work.

[if more information needed read this]

"Most seniors live at home and are doing just fine. But, there are also some seniors who are having trouble managing at home. Some are okay right now but in the next year or so might need help coping day to day. We are trying to find a simple way to pick out seniors who are having trouble or might have trouble soon. We think we can do this by having people answer a few questions. What we are doing now is trying to find out if the questions we have put together really work...."

[READ THIS]

If you do agree to be part of this study, we will look at the answers you gave to certain questions that you were asked a year and a half ago in the Aging in Manitoba study. We then want to compare those answers to how you are managing day to day now,. We also want to look at how much help from the health care system you've needed over last while.

So, to find out how you are managing day to day I would like to ask you a few questions, which will take 5 or 10 minutes of your time. But just because you agreed to be in the Aging in Manitoba study doesn't mean you have to agree to be involved in this one."

Consent

"So I am asking your permission for three things. The first is permission to use in our new study the information you gave to the Aging in Manitoba study..."

"The second thing is that Aging in Manitoba has information from Manitoba Health on how much help from the health care system that you've needed over last while. With your permission we would like to use the information that Aging in Manitoba has...."

"The third thing is to answer some more questions now about how you are managing at home. All the information you give me and any information that we get from the Aging in Manitoba study will be kept confidential...."

"If at any point you would like to stop then you should tell me right away."

"Do I have your permission to go ahead and use the Aging in Manitoba information?..."

yes

no

"Are you willing to answer a few more questions at this time?..."

yes n

[if NO to either of these thank and end survey] [if YES then continue]

"that is great, and ..."

"Do we also have your permission to use your health care information that Aging in Manitoba has?..."

yes no

"Thank you very much for your help."

"Would you like us to send you a written explanation of this study?..."

yes no

Administer questionnaire

Okay, to begin with:

I have some questions about your ability to carry on different activities:

(Lawton)

- 1. When you use the phone do you:
 - A. use the phone on your own initiative, look up and dial numbers on your own. (I)
 - B. only phone a few well known numbers.(I)
 - C. or, only answer the phone but do not dial out.(I)
 - D. Do not use the telephone at all.(0)
- 2. When thinking about shopping:
 - A. Do you take care of all shopping needs by yourself (I)
 - B. Shop independently for small purchases. (0)
 - C. Have someone accompany you for all shopping trips (but you go along).(0)
 - D. Or, Does someone else shop for you, you are unable to shop.(0)
- 3. Now thinking about food preparation; Do you:
 - A. Plan, prepare and serve meals independently that are adequate in nutrition. (I)
 - B. Prepare adequate meals if you are supplied with ingredients. (0)
 - C. Do you heat and serve prepared meals or prepare your own meals but You are not maintaining an adequate diet?(0)
 - D. Do you need to have meals prepared and served.(0)
- 4. Housekeeping:
 - A Do you maintain your house alone (with occasional assistance for heavy work.) (I)
 - B Do light daily tasks such as dishwashing and bed making(I)
 - C Do light daily tasks but cannot maintain acceptable level of cleanliness(I)
 - D Do you get help with all home maintenance tasks.(I)
 - E. Do you not participate in any housekeeping tasks.(0)
- 5. When it comes to personal and household laundry:
 - A Do you do your own laundry personally.(I)
 - B Do you do the Landry of small items, like rinsing socks, stockings etc.(I)
 - C or, Do you have all laundry done by others.(0)

- 6. Thinking about modes of transportation for your self:
 - A. Do you travel independently on public transportation or your own vehicle.(I)
 - B. Arrange for your own travel, via taxi, but don't use public transportation.(I)
 - C. Travel by public transportation when assisted or accompanies by another.(I)
 - D. Do you limit travel by taxi or automobile with assistance of another.(0)
 - E. Or, do you not travel at all. (0)
- 7. In regards to responsibility for medications:
 - A. Are you responsible for taking medication and take them in correct dosage and correct time. (I)
 - B. Do you take responsibility if medication is prepared in advance in separate dosages.(0)
 - C. Or, are you not capable of dispensing own medication.(0)
- 8. Thinking about managing your finances:
 - A. Are you able to manage financial matters independently (budgets, writes checks, pays rent, bills, goes to bank) collects and keeps track of income. (I)
 - B. Manage day to day purchases, but get help with banking, major purchases etc.(I)
 - C. Or are you incapable of handling money.(0)

(Katz)

- 9. When bathing either sponge bath, tub bath or showers
- I A. Do you bath independently, receiving no assistance and get in and out of tub by self.
- B. Do you receive only some assistance, one part of the body (like back or leg) when bathing.
- D C. Or, do you receive assistance with more than one part of the body (or not bathed).
- 10. When dressing:
- A. Do you dress yourself completely without assistance including shoes.
- I B. Do you get dressed without assistance except for assistance in tying shoes.
- D C. Do you receive assistance in getting clothes or in getting dressed (or does not dress, stays partly or completely undressed).
- 11. When using the toilet:
- A. Do you go to the "toilet room", cleans self and arrange clothes without assistance (many use object for support such as cane, walker, or wheel chair and may manage night bedpan or commode, emptying same in morning).
- D B. Do you receive assistance when going to the "toilet room" or in cleaning self or in arranging clothes after elimination or in use of night bedpan or commode.
- D C. Or do you not go to the "toilet room" for the elimination process.

- 12. When getting about in your house:
- I A. Do you move in and out of bed as well as in and out of chair without assistance (May be using object for support such as cane, walker or rails).
- D B. Do you move in and out of bed or chair with assistance
- D C. Doesn't get out of bed.

13. Continence

- I A. Do you control your urination and bowel movement completely by self
- D B. Do you have occasional accidents?
- D C. Supervision helps keep urine or bowel control: catheter is used, or is incontinent

14. When you eat:

- I A. Do you feed yourself without assistance
- I B. Feed self except for getting some assistance in cutting meat or buttering bread.
- D C. Or, do you receive assistance in eating, or use tubes or intravenous fluids.

Appendix 11: Validation of Surrogate PHNSS

Dear Participant,

Thank you for taking a few minutes of your time to help us. We are trying to find out how the wording of questions about how you manage day to day affects your answers. It may take about 10-15 minutes to fill out the questionnaires. You are not required to answer these questions but we would greatly appreciate your help.

Please take your time filling out the questionnaire and place a check mark in each box that has an appropriate response for you. There are no right or wrong answers. If you do not want to answer a question that is okay, just go on to the next question. Please be patient with us. It may seem that the questions are repetitive, but it is important that we get your answers. We assure you that all your answers are confidential and will be used for research purposes only. If you have any questions feel free to ask either Anneke Bertens or Dr. Kristel vanIneveld at 237-2443.

Once again, thank you for taking the time out to fill in your answers. Your assistance is an important part of this study and we appreciate your help.

Sincerely,

Dr. Kristel van Ineveld Dept. of Geriatric Medicine Anneke Bertens Research Assistant

Predicting Health Needs of Seniors Survey - Aging in Manitoba

| Thank you for taking the time to fill out this survey. | | |
|--|---|--|
| 1. | How old are you? | |
| For all remaining questions, please mark the box with a $\sqrt{\ }$ for the best answer. | | |
| 2. | What gender are you? Male \square or Female \square | |
| 3. | Is there anyone on whom you can call, if you need help? | |
| | YES □ | |
| | NO \square | |
| 4. | For your age, would you say in general your health is? | |
| | ☐ Excellent (Never prevents you from doing activities). | |
| | ☐ Good (Rarely prevents you from doing activities). | |
| | Fair (Occasionally prevents you from doing some activities). | |
| | Poor (Very often prevents you from doing many activities). | |
| | ☐ Bad (Health troubles prevent you from doing most activities, or requires confinement to bed). | |

The following questions are about your ability to carry out different activities. We would like to know whether or not you are able to do these activities and whether or not you usually get help with these activities.

| 5a. | Are you capable of getting in and out of bed without any help from anyone? |
|--------------|---|
| | ☐ YES |
| | □ NO |
| 5b. | Does anyone usually help you with getting in and out of bed? |
| | ☐ YES |
| | □NO |
| 6 a . | Are you capable of getting in and out of a chair without any help from anyone? |
| | ☐ YES |
| | □ NO |
| бb. | Because of any long-term condition or health problem do you need the help of another person in getting in and out of a chair? |
| | ☐ YES |
| | |
| 7a. | Are you capable of getting about the house without any help from anyone? |
| | ☐ YES |
| | |

| 7b. | Does anyone usually help you with getting about the house? |
|--------------|--|
| | ☐ YES |
| | □ NO |
| 8a. | Are you capable of making a cup of tea or coffee? |
| | ☐ YES |
| | □ NO |
| 8b. | Does anyone usually help you with making a cup of tea or coffee? |
| | ☐ YES |
| | □ NO |
| 9 a . | Are you capable of preparing a hot meal without any help from anyone else? |
| | ☐ YES |
| | \square NO |
| 9b. | Does anyone usually help you with preparing a hot meal? |
| | ☐ YES |
| | □ NO |
| 10a. | Are you capable of using the telephone without any help from anyone? |
| | ☐ YES |
| | \square NO |

| 10 b . | Does anyone usually help you with using the telephone? |
|---------------|---|
| | ☐ YES |
| | □ NO |
| 11a. | Are you capable of shopping without any help from anyone? |
| | ☐ YES |
| | □ NO |
| 11b. | Does anyone usually help you with shopping? U YES |
| | \square NO |
| 12a. | Are you capable of managing financial matters (Banking, Paying Rent, Handling money)? |
| | ☐ YES |
| | □ NO |
| 12b. | Does anyone usually help you with managing financial matters? |
| | ☐ YES |
| | □ NO |
| 13a. | Are you capable of cutting your toenails without any help from anyone? |
| | ☐ YES |
| | \square NO |

| 13b. | Does anyone usually help you with cutting your toenails? |
|------|---|
| | ☐ YES |
| | ∐ NO |
| 14a. | Are you capable of doing light housework (Washing up, dusting, etc.)? |
| | ☐ YES |
| | □ NO |
| | |
| 14b. | Does anyone usually help you with doing light housework? |
| | ☐ YES |
| | |
| 15a. | Are you capable of doing heavy housework (Cleaning floors, windows, heating, etc.)? |
| | |
| | □ NO |
| 15b. | Does anyone usually help you with doing heavy housework? |
| | ☐ YES |
| | |
| 16a. | Are you capable of going out of doors in good weather? |
| | ☐ YES |
| | |

| 16b. | Does anyone usually help you with going out of doors in good weather? |
|------|---|
| | YES |
| | □ NO |
| 17. | Do you require mechanical support such as braces, a cane or crutches to be able to walk around the neighbourhood? |
| | ☐ YES |
| | □ NO |

Appendix 12:

Ethics Approval

UNIVERSITY OF MANITOBA

FACULTY COMMITTEE ON THE USE OF HUMAN SUBJECTS IN RESEARCH

NAME: Dr. C. van Ineveld REFERENCE: E96:304

DATE: February 18, 1997

YOUR PROJECT ENTITLED:

Protocol Title: Development and Adaptation of the Predicting Health Needs of Seniors Survey

Approval of Study Paraphrase and Consent Form undated but received with letter of January 14, 1997

HAS BEEN APPROVED BY THE COMMITTEE AT THEIR MEETING OF:

Approval by Dr. Grahame on behalf of the committee on January 21, 1997

COMMITTEE PROVISOS OF LIMITATIONS:

Approved as per your letter of January 14, 1997

You may be asked at intervals for a status report. Any significant changes of the protocol should be reported to the Chairman for the Committee's consideration, in advance of implementation of such changes.

**THIS IS FOR THE ETHICS OF HUMAN USE ONLY. FOR THE LOGISTICS OF PERFORMING THE STUDY, APPROVAL SHOULD BE SOUGHT FROM THE RELEVANT INSTITUTION, IF REQUIRED.

Sincerely yours,

Gordon R. Grahame, M.D.

Chairman,

Faculty Committee on the Use of Human Subjects in Research

GRG/tk

TELEPHONE INQUIRIES-Theresa Kennedy:

789-3255 or e-mail: kennedy@bldghsc.lanl.umanitoba.ca

June 4, 1997

Dr. Cornelia van Ineveld Department of Geriatric Medicine St. Boniface General Hospital 409 Tache Avenue Winnipeg, MB R2H 2A6

Dear Dr. van Ineveld:

Re: Development and Adaptation of the Predicting Health Needs of Seniors Survey

As we communicated to you previously, the aboye named study has been approved for conduct at the St. Boniface Geriatric Day Hospital, provided there are no additional cost implications for the hospital. Please provide our office with a copy of the results of this study following its completion.

Yours truly,

John Foerster, MD, FRCPC

Judisto

Director of Research

JF/ds

351 Taché Avenue, Winnipeg, Manitoba R2H 2A6; Telephone: (204) 235-3206



September 15, 1997

Dr C van Ineveld, Dept of Geriatric Medicine, 409 Tache Ave, Winnipeg, Manitoba R2H 2A6

Dear Dr van Ineveld,

Re: Research proposal entitled "Development and Adaptation of the Predicting Health Needs of Seniors Survey"

At its September 11 meeting, the Therapeutics, Ethics and Research Committee ratified its expedited approval of your research proposal submitted over the summer Mary Woloski, Patient Care Manager for the Day Hospital, will serve as your contact on our staff

A copy of your proposal will be kept on file in the office of the Vice-President, Medical If any changes are made to the approved version, you are required to resubmit the proposal for further consideration

Please inform the Secretary of the Pharmacy, Therapeutics, Ethics and Research Committee, Ms S Bettess, when your research has been completed. We request that you provide the Committee with a copy of your completed research report.

Sincerely,

Norman R Kasian,

President

cc Ms S Bettess

Ms M Woloski

UNIVERSITY OF MANITOBA

FACULTY COMMITTEE ON THE USE OF HUMAN SUBJECTS IN RESEARCH

NAME: Dr. C. van Ineveld REFERENCE: E97:258

DATE: September 29/97

YOUR PROJECT ENTITLED:

Protocol Title: Predictive Validity of the Instrument:

Predicting Health Needs of Seniors Survey

Approval of Study

HAS BEEN APPROVED BY THE COMMITTEE AT THEIR MEETING OF:

September 22, 1997

COMMITTEE PROVISOS OR LIMITATIONS:

Approved as per your letter dated September 8, 1997 and our letter of September 29, 1997

You may be asked at intervals for a status report. Any significant changes of the protocol should be reported to the Chairman for the Committee's consideration, in advance of implementation of such changes.

**THIS IS FOR THE ETHICS OF HUMAN USE ONLY. FOR THE LOGISTICS OF PERFORMING THE STUDY, APPROVAL SHOULD BE SOUGHT FROM THE RELEVANT INSTITUTION, IF REQUIRED.

Sincerely yours,

THE UNIVERSITY OF MANITOBA

Gordon R. Grahame, M.D.,

Chairman,

Faculty Committee on the Use of Human Subjects in Research

GRG/tk

Inquiries should be directed to Theresa Kennedy

Telephone: 789-3255 Fax: 789-3942

E-mail: kennedy@bldghsc.lanl.umanitoba.ca



Health

Health Information Systems Branch P.O. Box 925 599 Empress Street Winnipeg, MB R3C 2T6

December 17, 1997

Cornelia van Ineveld, MD, FRCP(C) Geriatric Medicine St. Boniface General Hospital 409 Tache Avenue Winnipeg MB R2H 2A6

Dear Dr. van Ineveld:

Re; Predictive Validity of the Instrument: Predicting Health Needs of Seniors Survey

The Access and Confidentiality Committee reviewed your letter of November 19, 1997 to Dr. R. Walker addressing the concerns raised at the October 7, 1997 meeting

The Committee agreed to recommend to Manitoba Health that the alternative process, as you have suggested, be followed to generate the list of participants in your study from the 1996 Aging in Manitoba study participants whose particulars were provided by Manitoba Health I am pleased to advise that we have accepted the recommendation.

Yours truly,

G. K. Neill, Director.

Health Information Services.

GKN/bsg

c c Dr. Robert D. Walker