SYMPOSIUM PROCEEDINGS

Patient-Reported Outcomes Measurement in Alberta: Potential of the EQ-5D

October 18 – 19, 2012
Solara Resort and Spa
187 Kananaskis Way
Canmore, AB

HQCA Health Quality Council of Alberta

IHE INSTITUTE OF HEALTH ECONOMICS ALBERTA CANADA

Alberta Health Services

INTRODUCTION

The EQ-5D ("EuroQol-5 dimensions") is a patient-reported outcome measure that captures five dimensions of health-related quality of life: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. It is appealing as a standardized health outcome measure for Alberta because, as a generic measure, it is applicable to a wide range of health conditions and can be used as a research tool at both the population health and program levels, and has potential applications as a clinical monitoring tool. It is designed for completion by the patient, is quick and easy to use and adaptable for use in surveys, face-to-face interviews or the clinic setting. It is commonly used around the world in clinical, population health, health economics and research applications.

The EQ-5D has been developed and supported by an international network of scientists, known collectively as the EuroQol Group (www.euroqol.org). The mission of the group is to undertake research assessing health-related quality of life using the generic measure EQ-5D, and to develop new versions for various applications. For example, a youth version of the instrument (EQ-5D-Y) was introduced a few years ago. The original version of the EQ-5D represented three levels of health across the five dimensions; a newer version with 5 levels has recently been developed which better captures changes or differences in health. A group of EuroQol investigators based in Canada are currently creating a Canadian scoring system for the EQ-5D 5-level version, to reflect Canadian preferences for health outcomes.

In Alberta, the EQ-5D has been used as a research tool in clinical areas (e.g., diabetes care, bone and joint surgery) and in population health surveys for a number of years. Through these applications a considerable amount of experience has accumulated. Moreover, the available data provide population norms for adults and children in the province. The Health Quality Council of Alberta (HQCA) began incorporating it into their large population-based *Satisfaction and Experience with Healthcare Services Survey* in 2010. With the introduction of Strategic Clinical Networks (SCN) in 2012, Alberta Health Services (AHS) recognized that a standardized patient-reported outcome measure was needed that could be used by all SCNs for research and program evaluation purposes.

When the need for greater collaboration around implementation and use of the EQ-5D in Alberta was recognized in early 2012, colleagues from the HQCA, AHS, the School of Public Health, University of Alberta, and the Institute of Health Economics (IHE) met to explore the feasibility of bringing together key stakeholders in Alberta's health system to discuss the potential for adopting the EQ-5D as a standardized health outcome measure in Alberta.

The objectives of the symposium were to:

- Develop a common understanding of what the EQ-5D is and the scope of its application internationally and within Canada
- Identify potential applications for use of the EQ-5D in Alberta as a standardized health outcome measure
- Develop a collaborative research agenda to support broad implementation of the EQ-5D in Alberta

The symposium content was organized around three themes that captured the most common applications of the EQ-5D:

- Clinical health outcomes measurement in research and program evaluation
- Economic analysis of healthcare interventions
- Population health status assessment

On the first day of the symposium, keynote presentations on each theme were followed by a question and answer session. Each theme paired an international or national expert to bring the international perspective with an Alberta speaker who brought a local perspective on the application of the EQ-5D. The second day of the symposium featured small and large group discussions aimed at creating an agenda of activities to support broader implementation of the EQ-5D as a standardized patient-reported outcome measure.

The symposium proved to be an excellent opportunity to network and to explore the integration of EQ-5D in measuring and reporting on patient outcomes which is necessary for assessing quality of care for Albertans. We are pleased to present the symposium proceedings as a resource to support ongoing implementation of the EQ-5D in Alberta.

Symposium Co-Chairs

Tim Cooke (Health Quality Council of Alberta)
Stafford Dean (Alberta Health Services)
Jeff Johnson (University of Alberta)
Andy Chuck (Institute of Health Economics)

March 2013

PROGRAM AGENDA

Thursday, October 18

8:00 am	Continental Breakfast/Registration
8:45 am	**Welcome/Opening Remarks** ■ Charlene McBrien-Morrison, Executive Director, Health Quality Council of Alberta ■ Steve Buick, Director of Policy and Communications, Institute of Health Economics ■ Kathryn Todd, Senior Vice President, Research, Alberta Health Services
9:00 am	**EQ-5D – Building Common Understanding** ■ Jeff Johnson, University of Alberta and Alberta Health Services
9:30 am	**Theme 1: Patient-Reported Outcome Measure (PROM) Applications** **Host: Alberta Heath Services – Stafford Dean**
9:35 am	**NHS Experience with the EQ-5D as an Outcome Measure** ■ Nancy Devlin, Office of Health Economics, London
10:10 am	Break
10:30 am	**Application of the EQ-5D in the Alberta's Caring for Diabetes (ABCD) Project** ■ Jeff Johnson, University of Alberta and Alberta Health Services
11:05 am	Panel Discussion: PROM Applications
11:35 am	Lunch
12:15 pm	**Theme 2: Economic Analysis Applications** **Host: Institute of Health Economics – Steve Buick**
12:20 pm	**National Institute for Health and Clinical Excellence (NICE) Experience with Using the EQ-5D in Economic Analysis** ■ Stirling Bryan, Vancouver Coastal Health Research Institute and University of British Columbia
12:55 pm	**Using the EQ-5D to Inform Choice of Dialysis Modality in Patients with Kidney Failure** ■ Braden Manns, University of Calgary
1:30 pm	Panel Discussion: Economic Analysis
2:00 pm	Break
2:15 pm	**Theme 3: Population Health Applications** **Host: Health Quality Council of Alberta – Tim Cooke**
2:20 pm	**Understanding the Impact of Smoking and Obesity on Population Health in the United States** ■ Erica Lubetkin, City University of New York

Thursday, October 18 – *continued*

2:55 pm	**Incorporating the EQ-5D into Population Level Surveys in Alberta** ■ Markus Lahtinen and Emmanuel Ngwakongnwi, Health Quality Council of Alberta
3:30 pm	Panel Discussion: Population Health Applications
4:00 pm	**Wrap-up: What We Heard** ■ Stafford Dean, Alberta Health Services

Friday, October 19

8:15 am	Breakfast and networking
9:00 am	**Theme 4: Working Towards Implementation of the EQ-5D in Alberta** **Host: Alberta Health Services – Stafford Dean**
9:05 am	**Question 1: What do you see as potential applications of the EQ-5D in your area?** ■ Small group discussions (30 min) ■ Report back/large group discussion (40 min)
10:15 am	Break
10:30 am	**Question 2: What resources would be required to implement or integrate the EQ-5D in your area?** ■ Small group discussions (30 min) ■ Report back/large group discussion (40 min)
11:40 am	Lunch
12:30 pm	**Question 3: To move implementation of the EQ-5D forward in Alberta, what 3 specific actions (next steps) are required at the academic, research, program and clinical levels?** ■ Small group discussions (30 min) ■ Report back/large group discussion (40 min)
1:40 pm	**Wrap-up – What we heard, where do we go from here** ■ Stafford Dean, Alberta Health Services
2:00 pm	**Adjournment**

PROGRAM DETAILS

Day One: Thursday, October 18, 2012

Speaker slides and videos of the presentations and discussions related to each theme on Day 1 can be viewed at the website of the Institute of Health Economics: http://www.ihe.ca/research/knowledge-transfer-initiatives/--methodology-forum/patient-reported-outcome-measurement-in-alberta-potential-of-the-eq-5d-symposium/

8:45 – 9:00 am Opening Remarks

- **Charlene McBrien-Morrison, Executive Director, Health Quality Council of Alberta**
  Charlene McBrien-Morrison gave some background to the meeting, noting that planning for the symposium began in March 2012 as a collaborative effort between the three groups: Institute of Health Economics (IHE), Health Quality Council of Alberta (HQCA) and Alberta Health Services (AHS). The objectives of the symposium were to: 1) develop a common understanding of the EQ-5D and its applications 2) support its application and implementation in Alberta.
- **Steve Buick, Director of Policy and Communications, Institute of Health Economics**
  Steve Buick addressed the room optimistically and opened saying that, "good things happen when you put smart people in a room!" He touched on the importance of this meeting, acknowledging that many individuals with different backgrounds were present. He stated that there is a need for systems change to address current healthcare challenges and the importance of knowledge sharing and knowledge translation.
- **Kathryn Todd, Senior Vice President Research, Alberta Health Services**
  Kathryn Todd provided the AHS perspective. This meeting was important in that it provided: 1) a learning opportunity 2) expertise and 3) constructive feedback. She set the background for the meeting stating that healthcare costs have been increasing and are predicted to continue to increase and [AHS] does not know how Albertans are gaining value with the increasing government healthcare spending. There is a need to measure health outcomes, to get more value for money, to inform decisions and to increase the effectiveness of healthcare delivery in Alberta.

Introduction to the EQ-5D

Jeffrey A. Johnson, University of Alberta and Alberta Health Services
EQ-5D: Building Common Understanding

Abstract

The imperative for collecting patient-reported outcome measures (PROMs) has become stronger, and the rationale is relatively clear: the goal of a patient-centered healthcare system is to improve the health and functioning of patients. Patients' perspectives on the care they receive and outcomes they achieve are key elements of quality, as emphasized in the HQCA matrix. Moreover, self-care is an important part of healthcare, so obtaining some level of measurement of patient health and health behaviours will be important for the overall evaluation of health and healthcare in Alberta.

Broadly speaking, PROMs include measures of health-related quality of life (HRQL), patient experience/satisfaction, and self-reported behaviours (behavioural risk factors and self-care). HRQL measures can be classified in several ways, such as generic versus specific, profiles versus index.

The EQ-5D is one example of a generic index measure, which provides an assessment of health status on 5 different dimensions of health (mobility, self-care, usual activities, pain/discomfort and anxiety/depression). A respondent is asked to indicate their current health state across those dimensions, which can be described in a profile-like way and also summarized into an overall single index score, anchored at 1.0 being full health and 0.0 being dead. Various scoring functions to generate this overall index have been developed in different countries, the most prominent being the value sets from the United Kingdom and the United States. To date there has been no Canadian value set for the EQ-5D. The reason for having different, country-specific scoring systems is intended to reflect local values and preferences for health, to best inform local resource allocation decision-making (e.g., Americans value health differently than British, so may want to allocate resources differently).

One approach to incorporating HRQL information into resource allocation decision-making is in the form of quality-adjusted life years (QALYs) and cost-utility analysis. Apart from economic evaluations, HRQL measures, whether index or profiles, have been applied in other areas, including assessment of healthcare interventions, programs and services, as well as indicators of population health status. The EQ-5D has become a commonly used measure for all of these purposes, in various settings around the world. There is a strong research community supporting the use and future developments of the EQ-5D in its various forms. The EuroQol Group (see www.euroqol.org) is an international, multi-disciplinary group that has been in existence for 25 years. The raison d'etre for the EuroQol Group is the research and development of 'products' to measure health status. Recognizing important limitations in the original version of the EQ-5D, which had 3 levels of functioning across the 5 dimensions, the EQ Group recently introduced a 5 level (5L version), which provides better measurement in the general and patient populations. There are currently a number of studies going on around the world to generate preference-based value sets for scoring this new 5L version. This will include a Canadian scoring system, which will be available by September 2013. In addition to the EQ-5D-5L, a youth version (EQ-5D-Y) has been produced and is currently being used in Alberta by researchers at the School of Public Health, University of Alberta.

Discussion:

The main discussion points were centered around the characteristics of the EQ-5D and its application in Alberta.

- The 5 level EQ-5D maintained most of its language from the 3 level EQ-5D.
- The scaling of the EQ-5D is 0 to 1 and this was chosen for practical purpose (1 is for one calendar year).
- The version that will be implemented in Alberta will be the 5 level version since it better accounts for the limitations of the 3 level. It will be integrated into AHS SCN thinking and projects.
- There is currently work in progress for a Canadian validated index score for the EQ-5D-5L.
- Index scores incorporate a wide range of information into a single index and this makes it easier to incorporate into decision-making compared to a profile score.
- The difference between the UK and US index scores were due to the different score algorithms and these reflect a difference in methodological approach and different weightings of health states between countries. For example, the UK scoring algorithm weighted severe health states more heavily than did the US.

Theme 1: Patient-Reported Outcome Measure (PROM) Applications

Nancy Devlin, Office of Health Economics, London
National Health Service Experience with the EQ-5D as an Outcome Measure

Abstract

The EQ-5D is widely used in the United Kingdom's (UK) healthcare system, both in the clinical trials and observational studies that inform health technology appraisal decisions (e.g., by National Institute for Health and Clinical Excellence – NICE) and in population health surveys. It is also routinely collected from National Health Service (NHS) patients as part of the NHS PROMs program. The increasing acceptance and widespread use of the EQ-5D reflects both a growing recognition of the relevance of the patient's perspective in NHS decision-making; as well as an increased emphasis on the importance of measuring outcomes from healthcare. The selection of the EQ-5D as the generic instrument for use in the PROMs program reflects the body of evidence on its reliability, validity and sensitivity across most (with known exceptions) clinical areas. The NHS PROMs program is a very important step forward in outcomes measurement, and represents the first example of the collection and use of patient-reported outcomes at a whole health system level. In this talk, I explain the rationale for the PROMs program, what data are collected, and touch on some recent and planned developments. Examples are provided of a variety of ways that EQ-5D data can be used and analysed to obtain insights into healthcare quality, and to identify variations in performance and efficiency between healthcare providers. The potential exists to use the data to inform a very wide range of healthcare decisions by patients, clinicians, hospitals, and healthcare funders.

Jeffrey A. Johnson, University of Alberta and Alberta Health Services
Application of the EQ-5D in the Alberta's Caring for Diabetes (ABCD) Project

Abstract

The ABCD project is a partnership project between Alberta Health and the Alliance for Canadian Health Outcomes Research in Diabetes (ACHORD) Group, involving the development of collaborative management initiatives aimed at improving the quality and efficiency of care for diabetes in Alberta. This project is funded under the Alberta Diabetes Strategy, and is led by Dr. Jeff Johnson at the University of Alberta. The ABCD project is intended to link data from various sources, including the Alberta Diabetes Surveillance System and laboratory data from Alberta Health Services, but with a particular effort of primary data collection at the clinical and patient level. Several ongoing projects are run under the ABCD umbrella, including TeamCare and Healthy Eating and Active Living for Diabetes (HEALD), as well as an ongoing ABCD cohort study. In all cases, the main focus has been on working with patients cared for within the primary care network setting. The two interventions (TeamCare and HEALD) are being piloted in a controlled fashion, and will provide evidence of the effectiveness as well as the implementation of the interventions. In particular, the TeamCare study will evaluate the nurse-led collaborative care model, which aims to improve outcomes for patients with diabetes and depression. The main outcome measures are depressive symptoms, measures by the Patient Health Questionnaire 9-item survey (PHQ-9), and clinical outcomes (i.e., A1c, systolic blood pressure and LDL cholesterol). In addition to these, a wide range of secondary PROMs are included in the patient completed survey, including the EQ-5D-5L and SF-12 (version 2). Completion of follow-up for the approximately 160 patients enrolled in TeamCare will be completed in early 2013. Baseline data from the TeamCare study was presented, showing the distribution of the overall EQ-index score or degree of problems across the 5 dimensions on the EQ-5D, and by clinically relevant subgroups of patients (e.g., severity of depression, degree of obesity). Correlation of the EQ-index score with a range of other PROMs indicates that there are important relationships, but the EQ-5D captures different aspects of health than more condition-specific measures.

Panel Discussion – Theme 1: PROM Applications

In their presentations, Drs. Nancy Devlin and Jeffrey Johnson talked about their experiences with the EQ-5D and its application in their respective areas of research and countries. The questions during the panel discussion centred on the potential applications of the EQ-5D in Alberta and barriers to its implementation. Four main issues were discussed:

1. **Patient access to EQ-5D data**
   In the UK through the NHS PROMS program patients have access to EQ-5D data. In Alberta, patients want access to a wide variety of information, ranging from post-surgical mortality rates to parking information. However, patients generally want clinical information to be filtered through their family physician and generally will not actively search for specific types of information. Making EQ-5D data available to the public will be of limited use.
2. **Appropriate EQ-5D measurement time points (before intervention and 6 months after intervention)**
   There is a natural variation to when people complete the EQ-5D survey (some fill out the survey right away, while some fill it out a month later). In addition, there is an issue about the reliance on a simple before and after measurement because there is a lot of missing information between those two time points and clinicians evaluating the data do not know what is happening in between. This highlights the need for additional information when evaluating health outcomes.
3. **Mode of data collection (paper and pencil and/or electronic)**
   In the UK, data collection was subcontracted out with paper and pencil questionnaires. Since providers are now required to pay for their own data collection, they are given a choice of agencies to work with. The UK may see a shift from paper and pencil questionnaires to electronic as a more efficient means of data collection.
4. **Clinician buy-in**
   A concern was raised about how to engage physicians in EQ-5D data collection and how this will be added onto other PROMs (e.g., condition-specific tools). Also, clinicians will want to see a benefit of the EQ-5D to their clinical decision-making. One strategy to get buy-in is to involve physicians in the implementation process, from inception and planning to implementation. Some research has been done on the application of the EQ-5D in clinical decision-making but currently its main application has been in decision-making at the program planning level. Another benefit of measuring EQ-5D is that it provides information beneficial to clinicians on the case mix of the patient population as well as allowing for cross-comparisons between clinics and practices.

   There was a concern expressed that individuals may believe that the EQ-5D is being implemented as the 'sole' PROM that will be incorporated into decision-making. It is clear that the EQ-5D is a consistent measure that can be used across conditions and programs, but is insufficient on its own. There is still a need for condition-specific PROMs. The EQ-5D is only one of many tools that will help guide decision-making in Alberta's health system.

Theme 2: Economic Analysis Applications

Stirling Bryan, University of British Columbia and Vancouver Coastal Health Research Institute

National Institute for Health and Clinical Excellence (NICE): Experience with using the EQ-5D in Economic Analysis

Abstract

This presentation provided an overview of the UK's National Institute for Health and Clinical Excellence (NICE) and its decision-making approach to the coverage of new healthcare technologies. One of the main messages was the primary focus on economic evaluation evidence as a driver of decisions at NICE, with a strong preference for data on quality-adjusted life years (QALYs). The currently stated incremental cost-effectiveness ratio (ICER) thresholds for NICE are £20,000 and £30,000 per quality-adjusted life year (QALY) gained. Technologies with an ICER less than £20,000 are likely to be

recommended for coverage whereas those with an ICER beyond £30,000 will not be supported. Empirical evidence supports these policy statements from NICE. The current NICE methods guidance explicitly steers researchers and those preparing submissions to make use of EQ-5D data, where available, in their QALY calculations. The presentation also considered the challenges posed in situations where EQ-5D data are unavailable and where such data may not be appropriate (e.g., key descriptive items are missing from the generic measure). The option of mapping from one instrument (e.g., a condition-specific measure) over to the EQ-5D was explored but the evidence does not support widespread validity of this practice. The sensitivity concerns with EQ-5D are being addressed through the new 5-level version of the instrument and some details of the Canadian valuation work were shared. The new value set should be available in fall 2013. The presentation closed with a review of some health technology assessment developments in Canada that are relevant and might support the wider use of EQ-5D across the country. Of particular note is the establishment of a non-drug technology review process at the national level by the Canadian Agency for Drugs and Technologies in Health (CADTH). Historically the work of CADTH has been more focused on pharmaceuticals and so this development, in creating the Heath Technology Expert Review Panel, is a broadening of their work program.

Braden Manns, University of Calgary
Using the EQ-5D to Inform Choice of Dialysis Modality in Patients with Kidney Failure

Abstract

The EQ-5D has been used to measure overall quality of life in Albertan patients with end-stage kidney disease who were being treated with different treatment modalities including hemodialysis, peritoneal dialysis, and kidney transplantation. These studies showed that patients on peritoneal dialysis have similar or better quality of life compared with those on hemodialysis, but that kidney transplantation offers the best quality of life. Combined with careful costing analyses of the different modalities showing that peritoneal dialysis is the least expensive modality, the Southern Alberta Renal Program actively promotes the use of peritoneal dialysis. The EQ-5D has also been used within a clinical trial that was completed within Alberta comparing thrice weekly hemodialysis and nocturnal hemodialysis. The results of this study, which also included a detailed costing analysis, have impacted funding for nocturnal hemodialysis locally, across Canada, and internationally.

Panel Discussion – Theme 1: PROM Applications

Dr. Stirling Bryan and Dr. Braden Manns presented on some applications and the strengths and weaknesses of the EQ-5D in economic analysis. Dr. Bryan talked about how NICE incorporates and uses EQ-5D in their economic analysis and their potential applications (decision thresholds) and the challenges to decision-making (unavailable data for population of interest, missing data, etc.). Dr. Manns spoke about using EQ-5D as a tool to compare different treatment modalities (hemodialysis, peritoneal dialysis and kidney transplantation) and how the addition of cost data can inform decision-making. The panel discussion centered around two main issues:

1. Different perspectives on how economic analysis information is used in decision-making (balance sheet approach vs. cost/quality of life ratio).
2. Need for critical analysis skills to understand the uncertainty and 'values' present in the economic analysis studies and the political environment.

Regarding the first discussion point, there was a concern about how different stakeholder groups utilize and understand information for decision-making purposes. For example, medical and administrative leads may find a balance sheet approach more meaningful than cost/quality of life ratio. This is due to their differing perspectives, which involves looking at the information in two parts; first by looking at the outcomes of an intervention/modality and then at the cost of each intervention/modality. Presenting economic information in various ways can help decision-makers understand the link between outcomes and costs. Cost/quality of life ratios are useful to ensure consistent and fair decision-making across a variety of medical conditions and treatments.

The second major point of discussion was related to the knowledge and critical analysis skills necessary to understand and critically evaluate how the presented information can aid in decision-making. For example, decisions made based on economic analysis have a lot of uncertainty and require critical analysis skills as well as a sense of how the political climate may affect/change the policy decision-making process. Some training will be required to enable clinicians, administrators and executives to use this kind of data in decision-making, to recognize the strengths and limitations of the different data, and to treat each piece of information as a small piece of a larger puzzle needing to be solved.

During the discussion concerns were raised again about the need to get full stakeholder buy-in for the EQ-5D to be successful and useful in Alberta.

Theme 3: Population Health Applications

Erica Lubetkin, City University of New York

Understanding the Impact of Smoking and Obesity on Population Health in the United States

Abstract

Healthy People has shifted its emphasis from healthcare to determinants of health. Healthy People 2020 Secretary's Advisory Committee recommends assembling the "best possible information" on selected criteria to assist users in prioritizing health objectives, including the overall burden associated with a particular risk factor, determinant, disease, or injury. Burden of disease represents loss of years of healthy life through disease or specific conditions in a specified population and can be measured by quality-adjusted life years (QALYs).

In the United States (US), heart disease and cancer comprise the leading causes of death while tobacco use, poor diet and lack of physical activity are viewed as the actual causes of death. We initially examined EQ-5D scores using data from the 2000 Medical Expenditure Panel Survey (MEPS). Mean health-related quality of life scores (HRQOL) differed according to age, income, educational attainment, and chronic conditions. With regard to behavioural risk factors, scores differed according to smoking status and physical activity as well as according to category of weight.

Because MEPS only was administered from 2000-2003, we developed an indirect estimation method to obtain EQ-5D scores from the Behavioral Risk Factor Surveillance System's Healthy Days measures (which have been administered since 1993). We used data from the National Health Measurement Survey to validate the EQ-5D equation. We initially estimated annual QALYs lost and examined life expectancy and quality-adjusted life expectancy (QALE) according to gender as well as the percent of QALE lost contributed by specified risk factors at the national and state levels. We then compared trends in HRQOL for the general population and New York City. Additionally, we viewed the percentage of QALYs lost for the general US population attributable to smoking and overweight/obesity and compared this with trends for New York City.

Our next series of investigations compared the trends in QALYs lost per adult contributed by obesity and smoking during 1993 to 2008. For these analyses, we accounted for the total QALYs lost, defined by the sum of the QALYs lost due to a decrease in HRQOL score and the future QALYs lost in the expected life-years due to premature deaths. In 2008 obesity resulted in a slightly greater burden of disease than did smoking. With regard to morbidity and mortality, smoking had a bigger impact on mortality while obesity had a bigger impact on morbidity. In terms of gender and race/ethnicity, Black women had the highest obesity rates and lost the greatest number of QALYs due to obesity.

Viewing potential solutions, a direct correlation between obesity-related QALYs lost and the percentage of the population reporting no leisure-time physical activity at the state level was found. For smoking, the state tobacco tax rate was strongly and negatively associated with the state smoking prevalence and smoking-related QALYs lost. Regarding other behavioural risk factors, population life expectancy loss and QALE loss due to inactivity were highly related to the prevalence of inactivity in the population and variations were seen at the state level.

Markus Lahtinen and Emmanuel Ngwakongnwi, Health Quality Council of Alberta

Incorporating the EQ-5D into Population Level Surveys in Alberta

Abstract

The Health Quality Council of Alberta (HQCA) has a legislated mandate to measure, monitor and assess patient safety and health service quality. In doing so, the HQCA assesses healthcare experiences of Albertans, their perceptions of the healthcare system and quality of care received. High performing healthcare systems are characterized by a healthy population. The capacity of the EQ-5D questionnaire to measure change in health status and patient-reported outcomes led to its inclusion in three cross-sectional HQCA surveys:

1. Satisfaction and Experiences with Health Care Services: A Survey of Albertans (An annual cross-sectional survey of Albertans from 2009 to 2012).
2. Emergency Department patient experience surveys (A bi-weekly sample of users of 15 emergency departments in Alberta).
3. 2011 Commonwealth Fund International Health Policy Survey of Sicker Adults in 11 countries (A sample of respondents from Alberta, Ontario, Quebec, who self-report diagnosis for any of 8 chronic conditions).

The data collected thus far can be treated as descriptive population 'norms' for Alberta, as it provides baseline values for monitoring variations in health for specific population groups or by geography; and the potential for linking this information to local health records data, for surveillance purposes and to better understand health services utilization.

Here, we present preliminary results from the various surveys for which the EQ-5D was incorporated in order to demonstrate the usefulness of the tool for patient-reported outcome measures in Alberta. The objectives of our presentation are threefold:

1. To highlight the utility of the EQ-5D, its indices, and the visual analogue scale (VAS) for exploring the relationships between patients' health status and their experiences with healthcare and health services utilization (regular doctor and emergency department visits).
2. To examine prevalence of chronic conditions, arbitrary disability, multi-morbidity and how it impacts health of Albertans.
3. To examine care for sicker patients and identify areas that may need improvement.

We used the US population-based preference weights to derive mean weighted health status (EQ-index) for our sample. We found the EQ-5D and the US EQ-index are useful for exploring variations in experiences with care, health services utilization. Respondents categorized as least healthy (mean EQ-index < 0.79) used more regular doctor and emergency services, were less likely to report quality of care as good or excellent, less likely to report easy access to care, more likely to report serious complaints than other categories (mean EQ-index > 0.79). This shows the utility of the EuroQol products for investigating the different healthcare experiences Albertans face due to discrepancies in health status across the province. Increased utilization is to be expected given that the least healthy experience a higher burden of disease, implying greater healthcare needs. In addition, increased exposure to different facets of the health system may increase the likelihood of experiencing shortcomings of care should they exist.

There were gender differences in prevalence of chronic conditions; obesity was prevalent in women; whereas diabetes, sleep apnea and stroke were prevalent in men. Chronic pain was part of the top 5 disease pairs that impacted health the most. Arbitrary disability increased with burden of disease and varied by sub-regional levels of geography. Finally, Albertans who reported unmet healthcare needs had significantly poorer health status compared to those who did not. A similar pattern was observed in Ontario and Quebec. Going forward, the HQCA will seek to promote the use of EQ-5D for patient-reported outcomes, particularly pre / post measurement of planned medical interventions or for assessing recovery from episodes of care.

Panel Discussion – Theme 3: Population Health Applications

Drs. Erica Lubetkin, Markus Lahtinen and Emmanuel Ngwakongnwi outlined potential applications of the EQ-5D in their areas of research. For example, Dr. Lubetkin used the EQ-5D to document differences in health-related quality of life by age, income, education, chronic disease, smoking status, physical activity and weight, and utilized the EQ-5D to examine life expectancy and quality-adjusted life years lost by behavioral risk factors. Drs. Markus Lahtinen and Emmanuel Ngwakongnwi used the EQ-5D to explore 1) relationships between patients' health status and healthcare utilization, 2) patients' health status across different chronic conditions, and 3) variations in population health (identify high risk groups). The discussion revolved around two main issues:

1. Is the EQ-5D the right tool to aid in decision-making?
2. How will the EQ-5D be utilized in Alberta?

In response to the first question, the presenters tried to address a common misconception during the symposium that the EQ-5D will be the 'sole' measure to aid in decision-making. They emphasized that the EQ-5D is one tool of many that will be utilized to answer questions regarding value for money in Alberta's health system. In addition, the EQ-5D provides a starting point to measure health and creates common ground to initiate dialogue between all key stakeholders with an interest in increasing the quality of care. In response to the second question, the presenters acknowledged that different stakeholder groups will have different questions to be answered and there is a need for a clear understanding of the benefits and limitations of the EQ-5D in answering certain questions.

Day 1 Wrap-up: What We Heard

The last session of the day was led by Stafford Dean, Vice President, Data Integration, Measurement and Reporting with AHS. He stated that AHS fully supports the implementation of the EQ-5D and feels strongly that using the EQ-5D as a common PROM is the correct path for Alberta to pursue. Healthcare costs are rising in the province and there is an urgent need to create a common base of understanding and a common dialogue to improve the quality of care. The EQ-5D is one of many strategies that will help start the dialogue and address much needed system changes. There is a need to monitor the health of Albertans using a population-level survey and to disseminate information on meaningful measures of the health of the population and risk factors such as smoking, diet, and physical inactivity. A basic measurement system gives a meaningful indication of how the population is aging, its health and disease burden. One of the strengths of Alberta is that there is one healthcare system. We need a means to address resource trade-offs and bring transparency to the decision-making process where resource allocation between programs is difficult.

Day Two: Friday, October 19, 2012

Theme 4: Working Towards Implementation of the EQ-5D in Alberta

The second day of the symposium used break-out groups and large group discussion to identify challenges and brainstorm solutions to implementation of the EQ-5D in Alberta. The report for each question discussed incorporates ideas from both the small group discussions as well as the large group debrief that followed.

Question 1: What do you see as potential applications of the EQ-5D in your area?

Potential applications of the EQ-5D identified by all discussion groups were focused on assessing health needs at the clinical, population, and program level to assist in resource allocation to increase quality of care as well as to assess 'value for money'. Evaluation of interventions and technologies was also mentioned. For example, at the clinical level in continuing care, assessing health needs on the 5 dimensions of the EQ-5D (mobility, self-care, usual activities, pain/discomfort and anxiety/depression) could help match staff mix to the resident population for improved efficiency and quality of care. If the population (e.g., elderly in care homes) is highly depressed and immobile, this information can then be utilized to adjust the staff mix to provide the care that the population needs, such as more psychiatric care, occupational and physical therapists. At the population level, assessing health needs will allow for a standardized picture of the quality of life of Alberta, and assist with service planning by matching the needs of the population in geographical areas of the province with the healthcare services provided. At the program level, programs can be assessed using a common language (EQ-5D and costs) and comparisons can be made to aid in resource allocation decisions.

One of the most prominent themes to surface from the discussions was the use of EQ-5D for evaluation of interventions including prevention programs, technologies, chronic disease management, and surgery. Experience with HRQOL measures already in use in Alberta were used as examples to emphasize the benefits of a standardized measure with broad applicability across conditions. For example, the Alberta Bone and Joint Institute is currently using numerous HRQOL measures including the EQ-5D before and after surgery to monitor and compare the cost-effectiveness of different surgical interventions (e.g., hip resurfacing vs. total hip replacement). In Alberta, the EQ-5D will provide a standardized health profile as well as an index score to: 1) aid in evaluation of interventions; 2) allow for comparison across interventions; and 3) determine which intervention offers the best value for money (cost-effectiveness). This will hopefully increase 'value for money', and quality of care while containing healthcare costs in Alberta.

The overall mood of the discussion was optimistic, however there were concerns raised regarding obstacles that could hamper the implementation and uptake of the EQ-5D in Alberta. These concerns centered around the way different stakeholder groups use data in decision-making to achieve different goals. For example, the EQ-5D measure has primarily been used to address wider policy goals of resource allocation and evaluation of interventions and their associated health outcomes. However, in order for the EQ-5D to be effectively implemented, demonstration of its effectiveness and its usefulness to all key stakeholders is crucial. For example, physicians will want to see a benefit of the EQ-5D to their decision-making at the clinical level where their primary responsibility is to their patients. Administrators and policy-makers will use the EQ-5D at the program and population level as a tool to aid in resource allocation. The final issue raised was the need for timely and consistent access to the data collected from the implementation of the EQ-5D for decision-making. It was emphasized again that the EQ-5D will not be the sole measure of health outcomes in Alberta, but is a small piece of a larger measurement picture that will be used in conjunction with other already established surveillance and evaluation systems.

Overall, participants were positive about the potential application of the EQ-5D in Alberta. The objectives for the EQ-5D were to help prioritize healthcare issues and aid in resource allocation decisions, resulting in increased value for money of interventions, improved quality of care and containment of healthcare costs for Albertans.

Question 2: What resources would be required to implement or integrate the EQ-5D in your area?

One theme of this discussion was the need described above to demonstrate some value of the EQ-5D measure for different stakeholders which will be important to create buy-in and support implementation. The other major theme related to concerns about how the data will be collected, quality and frequency of data collection and the relevance and usefulness of the data collected. Some questions raised included:

1. Who will administer the surveys (paper and/or electronic)?:
   - **In-house** administration and follow-up of surveys or **outsourced** to companies for the administration and follow-up of surveys?
   - If paper, who will **administer, collect** and **input** data to a central location?
   - Shifting to electronic data capture poses new challenges
     - Who will administer/maintain/troubleshoot the equipment if it breaks down?
   - Who will remind (follow-up with) individuals to respond to the survey at the appropriate time points?
   - How do we prevent overlap of data collection (double counting)?
   - Will there be dedicated IT support?
     - Not all sites have the infrastructure for electronic data capture (e.g., no internet access)
2. How can we make the data collected relevant to front-line staff and clinicians? As noted repeatedly, this is critical for buy-in from key stakeholders particularly if the data is to be collected during a physician visit.
3. There needs to be a consistency in data collection.

There was a general consensus that there **must** be buy-in from key stakeholders, especially front-line staff, clinicians and patients before full implementation. The overall tone of the discussion sent a message that it would be dangerous to flood the province with increased responsibilities for collecting EQ-5D data without a clear objective, developed infrastructure in place and full stakeholder support.

Several solutions were suggested during the discussion to increase stakeholder buy-in and to improve the chances of a successful uptake of the EQ-5D. There needs to be:

1. Protocols for data collection, reporting tools, data repository.
2. Training infrastructure for front-end users.
3. Education for patients to increase awareness of the instrument and its benefits.
4. Data sharing and data analysis resource capacity and infrastructure.
   - Infrastructure that enables the free flow of information from point of collection to policy makers.
5. Clear modes of communication and consistent feedback to policy makers, clinicians, other healthcare workers and front line staff.
   - Bone and joint program posts data for units/sites for patients and staff to see.
6. Change champions at both the system and program level with a vision to create a cohesive culture of open communication and dialogue that values constructive feedback from policy makers to clinicians, as well as clinicians to policy makers.

Data Integration, Measuring and Reporting (DIMR) within AHS was cited to play a key role in the data management. However, the discussants felt that there still is a lack of infrastructure across the province, and stakeholder support to facilitate the implementation, maintenance, and analysis of the EQ-5D in Alberta. For example, there were concerns about the lack of infrastructure for the continual analysis of the data that will be of specific interest and relevance to different stakeholders (clinicians, policy makers, patients etc.). Other concerns voiced include a need for:

1. Stable sources of funding to support the project(s).
2. Continual evaluation of the quality and progress of implementation and integration of the EQ-5D.
3. Clear infrastructure for data sharing (data ownership concerns).

Overall the tone of the discussion was contemplative and optimistic about the usefulness of the EQ-5D, however there was some hesitation about the immediate implementation and integration of the EQ-5D because of the lack of infrastructure. The central messages regarding the resources needed to implement the EQ-5D are:

1. There needs to be buy-in by all stakeholders.
2. Infrastructure needs to be developed and put into place before implementation (data collection, data analysis and data dissemination).
3. There is a need for new dialogue among stakeholders and a need for new channels of communication to ensure goals are met in all interested groups.

Question 3: To move implementation of the EQ-5D forward in Alberta, what 3 specific actions (next steps) are required at the academic, research, program and clinical levels?

Discussion continued on common themes raised earlier and the key pillars that need to be in place to address major obstacles that exist for the successful implementation of the EQ-5D in Alberta. There was a sense that the same actions were required at all levels and most groups did not address the needs of each level separately. Before the implementation of the EQ-5D can move forward in Alberta, there needs to be:

1. Buy-in from all stakeholder groups (executives, policy makers, clinicians, healthcare workers, patients etc.).
2. Common understanding of the uses and limitations of the EQ-5D.
3. Infrastructure for implementation by building new capacity and/or leveraging existing infrastructure.
4. Establishment of a central data repository with capacity to evaluate, manage, analyze, and disseminate information and results to relevant stakeholders.

There was a strong emphasis on the importance of communicating the vision of the EQ-5D and how it fits into the future direction of Alberta healthcare. This will require open and continuous dialogue between all key stakeholders (research level, academic level, program and clinical levels) and emphasizing that the EQ-5D is only a small piece of a larger healthcare measurement strategy to prevent misunderstanding of the uses and limitations of the EQ-5D.

Some specific actions were identified for the academic, research, and program and clinical levels. One of the major themes arising was that there needs to be steps taken to incorporate the EQ-5D into current conversation as well as future conversations.

- At the academic level, faculties and schools (medicine, public health, nursing etc.) should incorporate the EQ-5D into the curriculum, starting the conversation at an earlier stage about the benefits, limitations and applications of PROMs including the EQ-5D.
- At the research level, researchers should incorporate PROMs (and/or the EQ-5D) into current and ongoing research proposals/grants.
- At the program and clinical level, success stories of established programs utilizing PROMs measures (and/or the EQ-5D) should be shared to promote buy-in by clinicians and administrators. For example, stories about the benefits of collecting and analyzing PROMs measures such as the EQ-5D and how it contributes to increased accountability, increased value for money and increased effectiveness. This will help create a culture of open dialogue, free sharing of information and a culture that values PROMs, and facilitate a culture that strives for continual measurable improvement.

Throughout the discussion, there was a general consensus that there needs to be a clear articulation of the resources and supports that are available and will be developed for collecting, analyzing and reporting the data. Transparency during implementation is key. This dialogue will help facilitate a common understanding for the implementation of the EQ-5D.

Overall, the tone of the final discussion was filled with excitement for productive health systems change facilitated by the use of PROMs and the EQ-5D. However, there was a general consensus that there remains a lot of work to be done before the implementation and integration of the EQ-5D in Alberta. The general feeling was the time for systems change is now, and that the EQ-5D is a powerful tool that enables health policy makers, clinicians and patients to evaluate and compare programs/interventions, outcomes of treatment and provide constructive feedback regarding a patient's health state over time, respectively.

Day 2 Wrap-up: What we heard, where do we go from here

Stafford Dean adjourned the symposium by thanking individuals for their participation in the symposium and describing how the symposium demonstrated the different applications of the EQ-5D as well as the challenges that lay ahead. For example, to get stakeholder buy-in, there is a need to demonstrate value of the EQ-5D at all levels (patient, provider, program, executive and at the overall healthcare system level) as well as to demonstrate that the EQ-5D can be successfully integrated into current processes. In order to achieve the goal of a successful implementation, dissemination and uptake, there needs to be a clear communication and engagement strategy.

In outlining next steps, Stafford proposed that a general discussion paper be prepared to answer common questions about the EQ-5D and the vision for its application in Alberta:

1. What is the EQ-5D ?
2. What is the role of the EURO-QoL group?
3. How does the EQ-5D fit into an overall measurement strategy for the province and the various organizations that work together within the health system?
4. How does the EQ-5D relate to health services utilization?
5. What are the potential applications for the EQ-5D in Alberta?
6. How does the EQ-5D fit within a larger PROMs framework?

The discussion paper will synthesize and distill information on the benefits, limitations and challenges of the EQ-5D to provide a common ground for dialogue. In addition, by showcasing existing programs that are using the EQ-5D successfully, such as the Bone and Joint Program, it may accelerate buy-in by demonstrating the feasibility of its use in a clinical setting. Overall, Stafford's tone was optimistic and enthusiastic about the EQ-5D and its potential to improve Alberta's healthcare system and ultimately the quality of life for all Albertans.

LOOKING AHEAD

Alberta Health Services

The next steps will help AHS gain experience using EQ-5D and understand the value of implementing the patient-reported outcome measure EQ-5D.

1. Demonstrating the utility and value of the patient-reported outcome measure EQ-5D by documenting and learning from areas that have already implemented this measure.
2. Developing a central point of contact (Data Integration, Measurement & Reporting) within AHS as a resource for individuals, programs and services. In addition this will enable AHS to track where implementation and use of the EQ-5D has occurred.
   a. Part of this role would be to organize and develop educational materials and guidelines for the appropriate use of the EQ-5D and how to interpret information generated from the EQ-5D.
3. Leverage AHS resources, for example, Data Integration, Measurement and Reporting and Health Technology Assessment & Innovation to support the appropriate implementation, analysis and reporting of information generated from the EQ-5D to inform the healthcare system. A capacity building approach will be used to enable broader use of the instrument.
4. Gaining practical experience by implementing the EQ-5D in new areas and initiatives.
5. Developing a provincial research agenda. This would be a collaborative effort between Alberta Health Services, Alberta Health, University of Alberta, the Health Quality Council of Alberta and EuroQol. This work would facilitate a greater understanding of the value of the information generated by the EQ-5D and support AHS in developing an important measure as part of the AHS quality measurement framework.
6. A long-term strategy for implementing the use of this instrument across all appropriate health services in the province would be to integrate the instrument electronically to make it easier for clinicians to access as part of their daily work routine. This would further enable the ability to report patient-reported outcomes as part of a broader measurement framework on a routine basis and provide more immediate information (patient outcomes) to clinicians.

Health Quality Council of Alberta

In light of its mandate to measure, monitor and assess patient safety and health service quality, the Health Quality Council of Alberta (HQCA) uses PROMs to examine how patients with different levels of functional health experience healthcare, as well as the relationships between functional health status, utilization patterns and multimorbidity. To achieve this, from 2009 onwards, the HQCA incorporated the EQ-5D into its population surveys, and subsequently developed a partnership with the Institute of Health Economics (IHE) to address these questions. In a study to examine the associations between multimorbidity and health-related quality of life (HRQL), we reported that multimorbidity is associated with a reduction in the HRQL as well as frequent hospitalization and emergency department visits (Agborsangaya et al. 2012). This has been corroborated by our analysis of the 2011 Commonwealth sicker patient survey (unpublished). In this analysis, HRQL decreased with increasing burden of disease. Similarly, patients with lower EQ-5D scores were less likely to rate quality of care personally received as excellent or good; and more likely to perceive the healthcare system as needing fundamental changes as compared with those who reported no problems for the EQ-5D. Currently HQCA has collected EQ-5D-3L data for over 5000 patients and EQ-5D-5L for 4800 patients.

Going forward, the HQCA will seek to promote the use of EQ-5D for PROMs, particularly pre / post measurement of planned medical interventions or for assessing recovery from episodes of care. Additionally, the HQCA will continue collecting EQ-5D data to help with establishing Alberta population norms. The HQCA has embraced the EQ-5D descriptive system, EQ-5D-5L for use in the next round of population surveys. The data collected will be used as descriptive population 'norms' for Alberta, as it provides baseline values for monitoring variations in health for specific populations or by geography. It will also be useful for studies to test preference-based value sets for the general Alberta population.