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Alberta PROMS and EQ-5D Research and Support Unit

November 15-16 | 2017

MEETING PROCEEDINGS

Alberta PROMs & EQ-5D Research & Support Unit (APERSU): 3rd Annual End-user, Board of Directors, and Scientific Advisory Committee Meeting

November 15-16, 2017
Coast Canmore Hotel
511 Bow Valley Trail
Canmore, AB

Alberta PROMs & EQ-5D Research & Support Unit (APERSU), School of Public Health, University of Alberta
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INTRODUCTION

The ***Alberta PROMs and EQ-5D Research and Support Unit*** (APERSU) is an intermediary office that connects the EuroQol foundation with non-commercial users of EQ-5D instruments and other patient reported outcome measures (PROMs) in the province of Alberta, Canada. It was officially launched in October 2015 and has been in operation for two years now. This unit secures licensing for the use of EQ-5D instruments, and supports research and use of these instruments and other PROMs in Alberta. APERSU was developed in partnership with the EuroQol Research Foundation, Alberta Health Services (AHS) and Health Quality Council of Alberta (HQCA), and is hosted at the School of Public Health, University of Alberta.

APERSU's **vision** is to improve decisions by end-users and stakeholders about health and health care in Alberta by promoting, coordinating, and supporting the use of PROMs including the EQ-5D for the measurement and valuation of health.

During the last year, we have worked with an additional 44 EQ-5D end-users in the province of Alberta, totally 110 end-users being supported by APERSU in registering and use the EQ-5D instruments. In this year's meeting, we had Dr. Chris Gibbons from the University of Cambridge who provided a very inspiring and thought-provoking talk on recent developments in PROMs research and application. We also invited several Canadian and international speakers to present on their research and experience in implementing EQ-5D/PROMs in health systems. Additionally, this meeting was an opportunity to present to end-users and stakeholders some of the research projects that is being undertaken by APERSU researchers.

The event started with the end-user conference lasting for one and half days. At the end of day 1 of the conference, there was a Board of Directors meeting, and at the end of day 2, a Scientific Advisory Committee meeting was held. We hosted 46 people, including APERSU staff and leadership, HQCA and AHS partners, Alberta Health (ministry) representatives, primary health care and strategic clinical networks representatives, key PROMs researchers from several academic institutions in Canada, and representatives from the EuroQol group.

We would like to thank all of our partners for their input and feedback on the planning of this meeting, and all end-users whose participation made this meeting a success.

The APERSU Team

December 18, 2017

MEETING DETAILS

Day 1: Wednesday, November 15, 2017

Opening Remarks – Jeff Johnson

Jeff Johnson, Professor, University of Alberta (APERSU Co-director)

Presentation title: "Overview and Update on APERSU"

Summary: Jeff Johnson provided an overview of APERSU establishment, agreements and partnerships, vision, objectives, collaborations, data sharing, organizational structure, and services provided by the unit, as well as an update on APERSU's operations and research activities in the last two years, and the second annual evaluation.

Keynote Speaker

Chris Gibbons, Director of Health Assessment and Innovation, University of Cambridge

Presentation title: "More than a tick-box exercise: Leveraging modern technology to realise the potential of PROs in clinical practice"

Summary: This talk demonstrated how the application of cutting-edge psychometric methods can transform patient-reported assessments from lengthy paper-based questionnaires to efficient computer-administered assessments capable of intelligently targeted questions providing meaningful feedback for both patients and clinicians. Examples of progress and innovation in patient-reported outcomes assessment are provided alongside cutting-edge developments in the fields of computational behavioural science and Big Data analytics.

Routine PROMs Measurement in Health Systems

David Parkin, Professor of Health Economics and Senior Visiting Fellow, City University of London and Office of Health Economics, London

Presentation title: "Progress and regress in the English NHS PROMs programme: what can be learned?"

Summary: In 2010, the English Department of Health (DH) introduced an world-beating innovation: the NHS PROMs programme, in which patient reported outcomes data were to be routinely collected from all patients in the NHS. Initial efforts focussed on the collection of PRO data before and after four elective surgical procedures: hip replacement, knee replacement, hernia repair and varicose veins. The ambition was to roll this out over both acute and chronic conditions. However, these extensions did not happen, although pilot projects and localised efforts continue in the NHS. In 2017, following a 2016 consultation exercise, two of the PROMs programme procedures have been dropped and the EQ-5D is being dropped from a nationwide GP patient survey. Why did the PROMs programme fail to develop as initially intended? A key factor was that responsibility moved from the DH, which regarded it as a scientific initiative integral to an outcomes-led NHS, to the central commissioning board of the NHS, NHS England, which thought of it as a patient feedback tool like the 'Family & Friends Test', competing

with 'Patient centred outcome measures' (PCOMs). This loss of vision meant the programme struggled to realise its potential and was vulnerable to cutbacks at a time of deteriorating NHS finances. More fundamentally, the initial focus was on collecting data rather than ensuring that it would be used to drive improvements in care quality and benefit patients. The initial driver was informing patients' choice of providers, but other objectives included understanding the effectiveness and cost effectiveness of treatments and identifying provider performance variations. This top-down approach resulted in data that were neither directly available to nor used by those to whom they are most relevant: patients and doctors. There were also delays with some of the academic projects intended to support this by researching user-friendly data reporting.

Ellis Chow, Program Lead, PROMs, Canadian Institute for Health Information

Presentation title: "Routine PROMs Measurement in Health System – CIHI Update"

Summary: This presentation provided an overview of CIHI and PROMs activities since the last APERSU meeting and describe CIHI's activities to support the development of standardized PROMS data collection and reporting nationally and internationally. Topics will include: international activities for patient-reported measures with the OECD, considerations for selecting PROMs instruments and their administration; progress in priority clinical areas of hip and knee arthroplasty; and considerations for developing comparable measures and reports that will support both clinical and health system decision making. An overview of future activities and plans to support pan-Canadian PROMs collection and reporting will be also provided.

Routine PROMs Measurement in various clinical areas

Andrea Deiure, Provincial Coordinator, Patient Reported Outcomes, CancerControl Alberta, Alberta Health Services, **and Olga Maciejewski**, Senior Project Manager, CancerControl Alberta, Alberta Health Services

Presentation title: "Implementing PROMS & PREMS in CancerControl Alberta"

Summary: This presentation summarized the work currently underway in CancerControl Alberta related to the use of PROMS and PREMS. Currently, the PROMS being used in CCA are the Putting Patients First form (formally known as Screening for Distress), composed of the ESAS-r and the Canadian Problem Checklist (CPC), and the use of the EQ5D. This presentation will discuss how CCA is working to utilize these PROMS to develop meaningful electronic outputs (dashboards) that are currently being piloted in one of the community cancer centres in the province. The hope is that this pilot will shed light on important lessons learned for moving forward with a large-scale provincial implementation. The most predominate PREMS being used in CCA is the Ambulatory Oncology Patient Satisfaction Survey (AOPSS). The results from this annual national survey are being analyzed to highlight areas for targeted Quality Improvement efforts in the provincial cancer care system to improve patient satisfaction.

Colin Bruce Josephson, Assistant Professor of Neurology, Department of Clinical Neurosciences and a full member of the O'Brien Institute for Public Health and the Hotchkiss Brain Institute, University of Calgary

Presentation title: "EQ-5D variations in a large, hospital-based registry of epilepsy patients"

Summary: Epilepsy is a chronic neurological condition characterized by (i) two unprovoked or reflex seizures greater than 24 hours apart or (ii) one unprovoked or reflex seizure and a 60% 10-year risk of recurrence or (iii) an electro-clinical syndrome. Epilepsy often co-occurs with other comorbidities, such as cardiovascular, respiratory, and other inflammatory diseases, which can also complicate epilepsy management and treatment. Epilepsy is also associated with a higher prevalence of psychiatric comorbidities, such as depression and anxiety. Ultimately, people with epilepsy have 2-3 times the risk of premature death compared to people without epilepsy. Despite this, there remains a paucity of information in the current literature with regards to risk factors, outcomes, and costs of health service utilization in epilepsy within a Canadian context. Clinic-based studies are required to explore and describe the epidemiology of a disease, define relevant outcomes, and to determine factors that influence health states in a local population. Thus, to this end, in 2007 we created the Calgary Comprehensive Epilepsy Program (CEP) Registry that now currently contains almost 6000 patients with baseline and longitudinal data. Although the objectives are broad, a critical aspect of this study is that of describing patient-reported outcome measures (PROMs) and their association with other health states, demographic variables and socioeconomic status. Included in this are measures of quality of life that include the EQ-5D. The purpose of this talk was to outline the methods through which we collect EQ-5D indices in patients with epilepsy, and to provide preliminary analyses on these data stratified by demographics, seizure freedom, response to anti-epileptic drugs, response to epilepsy surgery, and with respect to comorbidity status. The results will be compared to general populations and within disease-specific strata to describe and explain variations in general health status.

Tova Leveille, Lead, Primary Data Support, Analytics, Alberta Health Services

Presentation title: "Self-Reported Quality of Life Among Patients living with COPD: Feasibility & Preliminary Results"

Summary: Alberta Health Services has embarked on a quality improvement project to improve the health outcomes of inpatients with Chronic Obstructive Pulmonary Disease (COPD) who were admitted to hospital due to an exacerbation. Health related quality of life (HRQoL) was identified as a key outcome for measurement. Unlike administrative data, HRQoL data is not routinely collected for this patient population nor reported on. This presentation describes the procedures used to collect EQ-5D data within the hospital unit environment and 3-months post- discharge via telephone survey. Preliminary results will be shared including the data visualization dashboards created using Tableau.

Research Trainees Presentations

Tahmid Kashem, MPH student, University of Alberta, School of Public Health

Presentation title: "Relationship of Deprivation with Health-related Quality of life (HRQOL) in General Population"

Summary: the objective of this project was to examine the association of deprivation with HRQOL in general population. Data from the Alberta Community Health Survey were used. Deprivation was assessed using the Canadian Deprivation Index (CDI) and the Ontario Deprivation Index (ODI), and HRQOL using the EQ-5D-5L. Differences in health problems reported in EQ-5D-5L dimensions, index and visual analogue scale (VAS) scores across levels of deprivation were examined. Multivariate logistic and linear regression models adjusted for known characteristics were used to examine the independent association between deprivation and HRQOL. Approximately 60% of participants (N=6314) were female; 39% were aged between 18 and 44 years, and 38% between 45 and 64 years. Mean EQ-5D-5L index and VAS scores were 0.85 (standard deviation [SD] 0.14) and 79.6 (SD 17.7), respectively. Almost one-third (30.6%) of respondents reported no problems on all dimensions. Most participants reported no problems with mobility (76.2%), self-care (93.8%) and usual activities (74.8%), while 59.3% and 35.5% reported some levels of pain/discomfort and anxiety/depression, respectively. Differences between the most and least deprived in reporting problems in EQ-5D-5L dimensions, index and VAS scores were statistically significant and clinically important. In adjusted regression models, the least well-off had a higher likelihood of reporting problems in all EQ-5D-5L dimensions compared to the most well-off on both deprivation indices. Compared to the most well-off, the least well-off had an index score decrement of 0.18 ($p<0.01$) and 0.17 ($p<0.01$) for the CDI and ODI, respectively. Similarly, an inverse association was found between the VAS score and the CDI ($\beta=-17.3$, $p<0.01$) and ODI ($\beta=-13.3$, $p<0.01$). Individual-level deprivation is associated with worse HRQOL. Poverty reduction strategies should consider the effects of both neighbourhood-level and individual-level deprivation to improve overall health.

Andrews Tawiah, PhD Student, University of Alberta-Faculty of Rehabilitation Medicine

Presentation title: "Discriminative Validity of the EQ-5D-5L and SF-12 in Older Adults with Arthritis"

Summary: Aim: To examine the discriminative validity of the EQ-5D-5L and SF-12 in capturing the health-related quality of life (HRQoL) of older adults with arthritis. Method: Cross-sectional data from the Alberta Retired Teachers Association online survey were used. Known groups approach and a priori hypotheses were established to examine the discriminative validity. Groups were defined by presence of arthritis; chronic pain was used to define severity of arthritis, while number of comorbidities and general health status were used to define their overall health. Magnitude of differences was assessed with tests of correlation, statistical significance and effect size estimates. Results: Mean age of participants (N=2844) was 68.6 (standard deviation [SD] 5.9) years; 54.8% were female, with a body mass index (BMI) of 27.2 kg/m2 (SD 4.8). The overall mean EQ-5D-5L and SF-6D index scores were 0.86 (SD 0.11) and 0.79 (SD 0.13)

respectively. Participants with arthritis reported lower EQ-5D-5L and SF-6D index scores (0.83, SD 0.13 and 0.75, SD 0.13), compared to those without arthritis (0.88, SD 0.09 and 0.81, SD 0.12 respectively). EQ-5D-5L pain/discomfort and mobility were the most frequently reported (86.8% and 49.2% respectively). SF-12 bodily pain (BP) had the highest discriminative validity with a moderate effect size of 0.6. Related dimensions and domains between EQ-5D-5L and SF-12 (e.g., mobility & PCS, pain/discomfort & BP) were strongly correlated. Both instruments failed to adequately discriminate between participants with moderate and severe chronic pain of 6-month duration. Conclusion: EQ-5D-5L pain/discomfort and mobility dimensions, and SF-12 BP had the highest discriminative ability. In the assessment of chronic pain using either instrument, other factors including pain duration, severity, location and time of assessment should be considered due to their effect on the discriminative validity of these instruments.

Fatima Al Sayah (on behalf of Xuejing (Jennifer) Jin), Research Manager of APERSU, University of Alberta (Jennifer Jin is a post-doctoral fellow with APERSU, University of Alberta)

Presentation title: "A comparison of cross-sectional psychometric properties of EQ-5D-3L and EQ-5D-5L among patients who received hip and knee replacements"

Summary: Aim: This presentation aims to provide preliminary results of a cross-sectional comparison of measurement properties of the EQ-5D-3L and EQ-5D-5L among the hip and knee arthroplasty patients in Alberta, Canada. Method: This study used data from the Alberta Hip and Knee Replacement project, which is facilitated by the Alberta Bone and Joint Health Institute. Patients (n=) who received total hip or knee replacement in Alberta between 2010 and 2017 and responded to EQ-5D (either 3L or 5L) before the surgery were included in this study. We used a non-replacement 1:1 propensity score matching method to match patients who used EQ-5D-3L to patients who used EQ-5D-5L by controlling the covariables including age, gender, and pre-surgery WOMAC domain scores. Measurement properties in terms of responses to EQ-5D-3L and EQ-5D-5L by dimension and level, construct validity (against WOMAC), known-group validity (comorbidities and age group), and informativity (Shannon index and Shannon Evenness index) were examined and compared. Results: There were no missing values on responses to EQ-5D questions. After matching, 3644 pairs of hip replacement patients and 5428 pairs of knee replacement patients were included in the analysis. No significant ceiling effects and floor effects were observed of the two versions of EQ-5D in our study. At domain level, for patients who used EQ-5D-3L, 93.91% hip replacement patients and 92.78% knee patients reported "have some problems in walking about", 72% hip replacement patients and 79% knee patients reported "have some problems with performing usual activities." The response distributions among the five-level version were more evenly. Compared to the EQ-5D-3L, EQ-5D-5L index score and domain responses consistently had higher Spearman correlation coefficient with the WOMAC total score and domain scores for both hip and knee patients. Informativity improved considerably with the 5L version. Known-groups validity was confirmed for both 5L and 3L versions.

Day 2: Thursday, November 16, 2017

Roland Simon, Senior Analyst, Health Quality Council of Alberta

Presentation title: "EQ-5D Measurement at the HQCA"

Summary: The presentation provided a summary of the current areas where the HQCA is using the EQ-5D within its measurement and survey work. Topics discussed will include the HQCA's emergency department survey, future work with continuing care surveys, and the newly developed primary care patient experience survey.

Deborah Marshall, Professor, University of Calgary

Presentation title: "Validating the EQ5DY in Juvenile Idiopathic Arthritis (JIA) in UCAN CANDU"

Summary: UCAN CANDU is a Canadian-Dutch Collaboration building in the UCAN Network (Understanding Childhood Arthritis Network - an international federation of research networks) funded through the CIHR Personalized Medicine in Inflammation Network. The commitment of all pediatric rheumatology care providers across the Netherlands and Canada to UCAN CANDU to integrate innovative precision medicine strategies into care provision will transform the care of children with arthritis. The three main deliverables are: 1) A disease taxonomy/classification of children with JIA; 2) A clinical tool to predict response to therapy; and, 3) risk of disease relapse after discontinuation of therapy. Three corresponding patient cohorts have been assembled to achieve these goals. As part of the health economics integrated data platform, UCAN CANDU offers a unique opportunity to collect patient-reported outcomes measures (PROMs) in children with JIA, including the EQ5DY at baseline and in repeated measures over time as part of the prospective clinical cohort. The aim of this presentation was to explore and prioritize the possible research that could be conducted in the context of the UCAN CANDU study that would provide scientific and practical contributions to the literature. For example, we could explore the comparison of the 3 level and 5 level versions of the EQ5DY instrument and examine the discriminatory performance of each and the test-retest reliability; define and execute the valuation work to support the EQ5DY and explore the relationship between EQ5DY and JIA specific PROMs.

Judith Krajnak, Director of Evaluation and Analytics, Alberta Health Services, Primary Health Care Program

Presentation title: "Using EQ-5D as One Measure to Study Program Outcomes for a Self-Management Program: Using Results to Engage Staff"

Summary: When the Applied Research and Evaluation Services (ARES) department at Alberta Health Services (AHS) was asked to lead the evaluation of a provincial self-management program in the fall of 2014, it proved the perfect opportunity to incorporate the EQ-5D instrument into the overall survey. The program in question, a standardized six-week series that has been well studied in the United States, had not been evaluated for medium term outcomes (6 months post) within a provincial health

services setting here in Canada. In Alberta, the program is also offered in person or online and this evaluation would be recruiting from both modalities. The evaluation would incorporate a mixed methods study design with participant residence (urban/rural), as a Social Determinant of Health, being explored in relationship to expected program outcomes. The Edmonton based evaluation team was dependent on front line support to recruit program participants into the study. Keeping staff aware and engaged in supporting the evaluation was a key activity over the last few years. Judith will share initial EQ-5D results (pre-post) as well as how her team used findings from the EQ-5D to engage staff in conversations about health quality of life (as a measured construct) within the chronic disease management field and how such knowledge might inform their service to patients.

Nick Bansback, Associate Professor, School of Population and Public Health, University of British Columbia

Presentation title: "Bringing Patients Back to the PROM"

Summary: Most patients do not directly see the impact of completing their PROM. Rather they can benefit indirectly through system level utilization of PROMs data, which is used for a variety of purposes including quality improvement. There are, however, ways that PROMs data can be used to help patients understand: 1) how their outcomes compare to others, 2) what outcomes they might expect in the future, and 3) how their outcomes have changed overtime. This presentation described some examples of these approaches and motivates how they have the potential to improve decision-making and response rates. Software that easily enables these approaches to be implemented will be demonstrated.

Lara Russell, Post-Doctoral Fellow, Centre for Health Evaluation and Outcome Sciences

Presentation title: "The stories they tell: Findings from a side-by-side comparison of two generic PROMS, the EQ-5D-5L and the VR-12"

Summary: These analyses compared two widely-used generic PROMs: the EuroQOL EQ-5D-5L and Veterans Rand-12. While other studies have examined the psychometric properties and validity evidence pertaining to the use of these measures in various settings and populations, this study was motivated by the questions "What kinds of information do these PROMs provide? What 'stories' do they tell?". The overall goal was to help inform the selection a generic PROM to use in Canada to measure the self-reported health-related quality of life and health status of individuals who use healthcare services. Using data from a 2016/17 province-wide survey implemented in the Acute Inpatient Hospital sector in British Columbia, we compared the scores produced by each PROM across different patient groups and hospital settings to determine whether the two measures would lead to different conclusions. We also compared the associations of PROM scores with other measures of health status to see if these differed, and considered whether characteristics of the score distributions (e.g., skewness, ceiling effects) might lead to different conclusions about the sample. The results of our analyses suggest that the EQ-5D-5L and VR-12 would lead to similar

conclusions about the magnitudes of differences in scores between groups of patients and the associations of PROMs with other measures of health status and experience. The real differences lie in the content of the PROM items and the often distinct ways in which they characterize and measure self-reported health status (e.g., domains covered, timeframe referenced, focus on intensity vs. interference in activities). This is where different 'stories' emerge, and so content – in the context of the goals of measurement - is an important consideration in choosing between these PROMs.

Lara Russell, Post-Doctoral Fellow, Centre for Health Evaluation and Outcome Sciences **(on behalf of Rick Sawatzky,** Professor, Trinity Western University**),**

Presentation title: "Adaptation of the VR-12 Health Survey for use in Residential Care: Results from the Office of the Seniors Advocate's Provincial Residential Care Sector Survey"

Summary: The use of generic patient-reported outcome measures (PROMs) to assess mental and physical health status of seniors in long-term residential care (LTRC) has been limited due to a lack of validity evidence. Although the Veterans RAND 12 Item Health Survey (VR-12) has been widely used in general populations, its validity and use in LTRC populations is unknown. The aim of this study was to develop and validate an adapted version of the VR-12 for use with seniors living in LTRC. Methods: Adaptation of the VR-12 was informed by expert consensus and cognitive interviews with 18 seniors in residential care settings. Psychometric validation (factor analysis, internal consistency reliability, convergent validity) was based on a subsample of residents (n = 1,512) who participated in the BC Seniors in Residential Care Survey. The questionnaires were administered via in-person interviews by trained volunteers in 18 residential care settings. Results: Based on the cognitive interview results, two items of the physical functioning domain were replaced with two physical functioning items from the VR-36, which were deemed more applicable to the target population. In addition, the term "work" was omitted and replaced with "activities" for three of the items. Factor analysis provided support for a theoretically-defensible measurement structure consisting of two factors representing physical and mental health (reliability = 0.78 for both factors). Greater physical health was associated with fewer limitations in activities of daily living (r=-.44). Greater mental health was associated with fewer depressive symptoms (r=-.17) and improved social engagement (r=.18). Conclusion: The results provide initial validity evidence supporting the use of the adapted VR-12 in LTRC. Additional analyses are ongoing to develop adjusted scoring algorithms and examine the validity of responses at different levels of cognitive status.

LOOKING AHEAD

Going forward, Alberta PROMs and EQ-5D Research and Support Unit (APERSU) will build on the feedback and input of end-users and key stakeholders in Alberta and EQ-5D/PROMs researchers to enhance APERSU services and activities, as well as to further develop APERSU's research and collaborations.

The Board of Directors met on the afternoon of day 1 of the APERSU meeting after the general end-user meeting took place. We discussed APERSU's 2nd Annual Report at length, and focused on APERSU's activities to achieve and document intermediate and long-term goals as outlines in the evaluation form.

APERSU's Scientific Advisory Committee (SAC) met after the general end-user meeting on day 2, we discussed APERSU's 2nd Annual Report in this meeting. The focus was on the current research activities being undertaken by APERSU team, and how they meet APERSU's research agenda. Also, the SAC discussed potential areas of research, and possible finding opportunities.

MEETING EVALUATION

We asked the participants at the APERSU end-user meeting to evaluate different aspects of the meeting using the following survey. We received 23 complete forms; the following scores are the mean of scores of the 23 participants. Overall, the meeting was considered a success.

Using the scale from 1 to 5 (where 1 is "Unsatisfactory" and 5 is "Excellent") how would you rate the following:	
Meeting Organization and Proceedings	Average
General organization of the meeting	4.8
Meeting agenda	4.7
Time allocated to discussion	4.8
The venue and its facilities	4.7
Meeting Sessions & Presenters	
Overview and update on APERSU (Jeff Johnson; Arto Ohinmaa)	4.6
More than a tick-box exercise: Leveraging modern technology to realize the potential of PROs in clinical practice (Chris Gibbons)	4.7
PROMs in the NHS – England (David Parkin)	4.5
CIHI update on PROMs (Ellis Chow)	4.0
Implementing PROMS & PREMS in CancerControl Alberta (Andrea Deiure & Olga Maciejewski)	4.5
EQ-5D variations in a large, hospital-based registry of epilepsy patients (Colin Bruce Josephson)	4.4
Self-Reported Quality of Life Among Patients living with COPD: Feasibility & Preliminary Results (Tova Leveille)	4.4
Relationship of Deprivation with Health-related Quality of life in General Population (Tahmid Kashem)	4.0
Discriminative Validity of the EQ-5D-5L and SF-12 in Older Adults with Arthritis (Andrews Tawiah)	4.1
A comparison of cross-sectional psychometric properties of EQ-5D-3L and EQ-5D-5L among patients who received hip and knee replacements (Fatima Al Sayah)	4.4
EQ-5D Measurement at the HQCA (Roland Simon)	4.2
EQ-5D-Y: An example from pediatric rheumatology (Deborah Marshall)	4.5
Using EQ-5D as One Measure to Study Program Outcomes for a Self-Management Program: Using Results to Engage Staff (Judith Krajnak)	4.4
Bringing Patients Back to the PROM (Nick Bansback)	4.9
The stories they tell: Findings from a side-by-side comparison of two generic PROMS, the EQ-5D-5L and the VR-12 (Lara Russell)	4.0
VR-12 adaption for long-term residential care (Lara Russell)	4.1
Relevance to Your Work	
Relevance of this meeting to your current work or functions	4.5
Relevance of the meeting to your institution's need	4.5
Overall usefulness of the meeting and information you acquired	4.5
Overall Assessment of the Meeting	**4.7**

LIST OF ATTENDEES

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Alberta PROMS and EQ-5D Research and Support Unit

3rd APERSU ANNUAL END-USER MEETING

NOVEMBER 15 - 16, 2017
Coast Canmore Hotel & Conference Centre, Canmore AB

PROGRAM

DAY 1 Wednesday, November 15, 2017

7:00 – 8:30 am	Breakfast	
8:00 – 8:30 am	Registration	
8:30 – 8:45 am	**Opening Remarks**	Jeff Johnson
8:45 – 9:30 am	**Overview and Update on APERSU**	Jeff Johnson Arto Ohinmaa
9:30 – 10:30 am	**More than a tick-box exercise: Leveraging modern technology to realise the potential of PROs in clinical practice**	**Keynote Speaker** Chris Gibbons
10:30 – 11:00 am	Break: Coffee and Snacks	
11:00 – 12:00 pm	**Session: Routine PROMs Measurement in Health Systems**	
	PROMs in the NHS – England	David Parkin
	Routine PROMs Measurement in Health System – CIHI Update	Ellis Chow
12:00 – 1:00 pm	Lunch and Networking	
1:00 – 2:30 pm	**Session: Routine PROMs Measurement in various clinical areas**	
	Implementing PROMS & PREMS in CancerControl Alberta	Andrea Deiure & Olga Maciejewski
	EQ-5D variations in a large, hospital-based registry of epilepsy patients	Colin Bruce Josephson
	Self-Reported Quality of Life Among Patients living with COPD: Feasibility & Preliminary Results	Tova Leveille
2:30 – 3:00 pm	Break: Coffee and Snacks	
3:00 – 4:00 pm	**Session: Research Trainees Presentations**	
	Relationship of Deprivation with Health-related Quality of life (HRQOL) in General Population	Tahmid Kashem
	Discriminative Validity of the EQ-5D-5L and SF-12 in Older Adults with Arthritis	Andrews Tawiah
	A comparison of cross-sectional psychometric properties of EQ-5D-3L and EQ-5D-5L among patients who received hip and knee replacements	Fatima Al Sayah (on behalf of Xuejing (Jennifer) Jin)
4:00 pm	**Closing Remarks for Day 1**	Jeff Johnson
4:00 – 5:00 pm	**APERSU Board of Directors meeting**	MEMBERS ONLY

DAY 2	**Thursday, November 16, 2017**	
7:00 – 8:30 am	Breakfast	
8:30 – 9:00 am	EQ-5D Measurement at the HQCA	Markus Lahtinen & Roland Simon
9:00 – 9:30 am	Validating the EQ5DY in Juvenile Idiopathic Arthritis (JIA) in UCAN CANDU	Deborah Marshall
9:30 – 10:00 am	Using EQ-5D as One Measure to Study Program Outcomes for a Self-Management Program: Using Results to Engage Staff	Judith Krajnak
10:00 – 10:30 am	Break: Coffee and Snacks	
10:30 – 11:00 am	Bringing Patients Back to the PROM	Nick Bansback
11:00 – 11:30 am	The stories they tell: Findings from a side-by-side comparison of two generic PROMS, the EQ-5D-5L and the VR-12	Lara Russell
11:30 – 12:00 pm	VR-12 adaption for long-term residential care	Lara Russell (on behalf of Rick Sawatzky)
12:00 pm	**Adjournment and Closing Remarks**	Jeff Johnson
12:00 – 1:00 pm	Lunch and Networking	
1:00 – 2:00 pm	**APERSU Scientific Advisory Committee meeting**	MEMBERS ONLY