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Patient-Reported Outcomes: Opportunities and Limitations

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INTRODUCTION



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Introduction

Policymakers are increasingly interested in using patient reported outcome measures (PROMs) to better:

- measure “value” of health care interventions
- understand the effectiveness of care
- allocate resources
- inform investment / disinvestment decisions

PROMs has the potential to compliment current methods for case mix adjusting hospital episodes



Patient-Reported Outcome Measures

PROMs are generally defined as:

- standardized, validated questionnaires
- completed by patients
- measuring their self-perceived functional well-being and health status

Different types of measurement:

- generic health status
- condition-specific health status
- co-morbidities



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Patient-Reported Outcome Measures

Value and Limitations in Hospital Utilization and Expenditures (VALHUE):

- one of the largest systematic collection of PROMs in Canada
- aims to evaluate the changes in patients' health status pre- and post- elective surgery.

Before VALHUE could be initiated, needed to select appropriate PROMs instruments



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Purpose

The purpose of this study is to report on the selection and review of instruments for collecting PROMs for elective surgery.



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CONTEXT: VALHUE STUDY



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VALHUE

3-year operating grant funded by Canadian Institutes for Health Research (CIHR)

Principal investigator: Jason Sutherland, PhD

Longitudinal study design, collecting primary data from patients before (two collection points) and after (one collection point) surgery

Setting:

Vancouver, BC



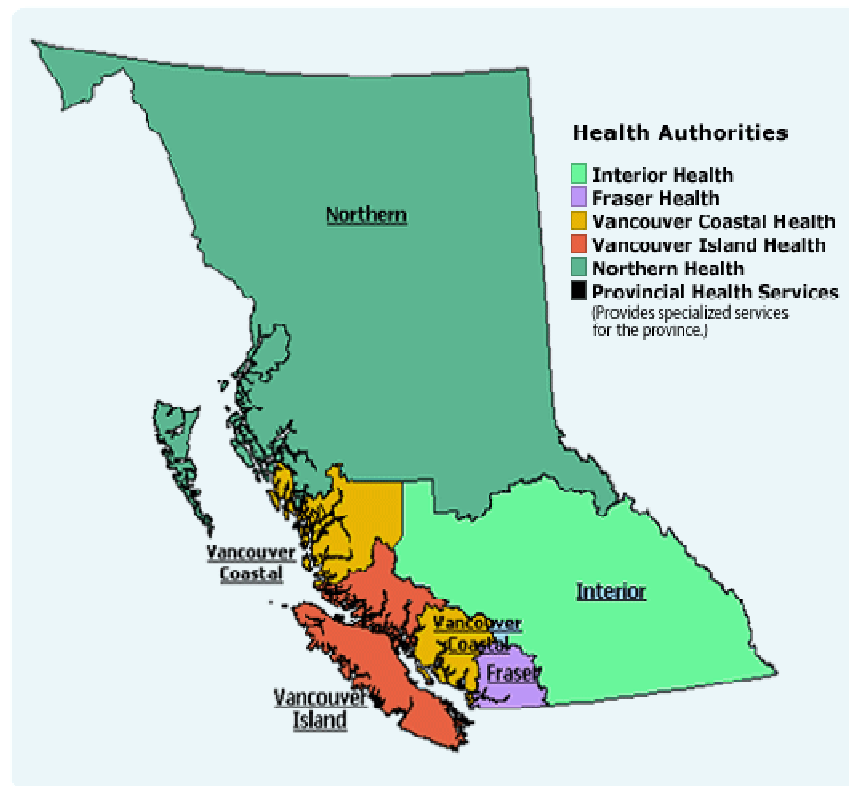
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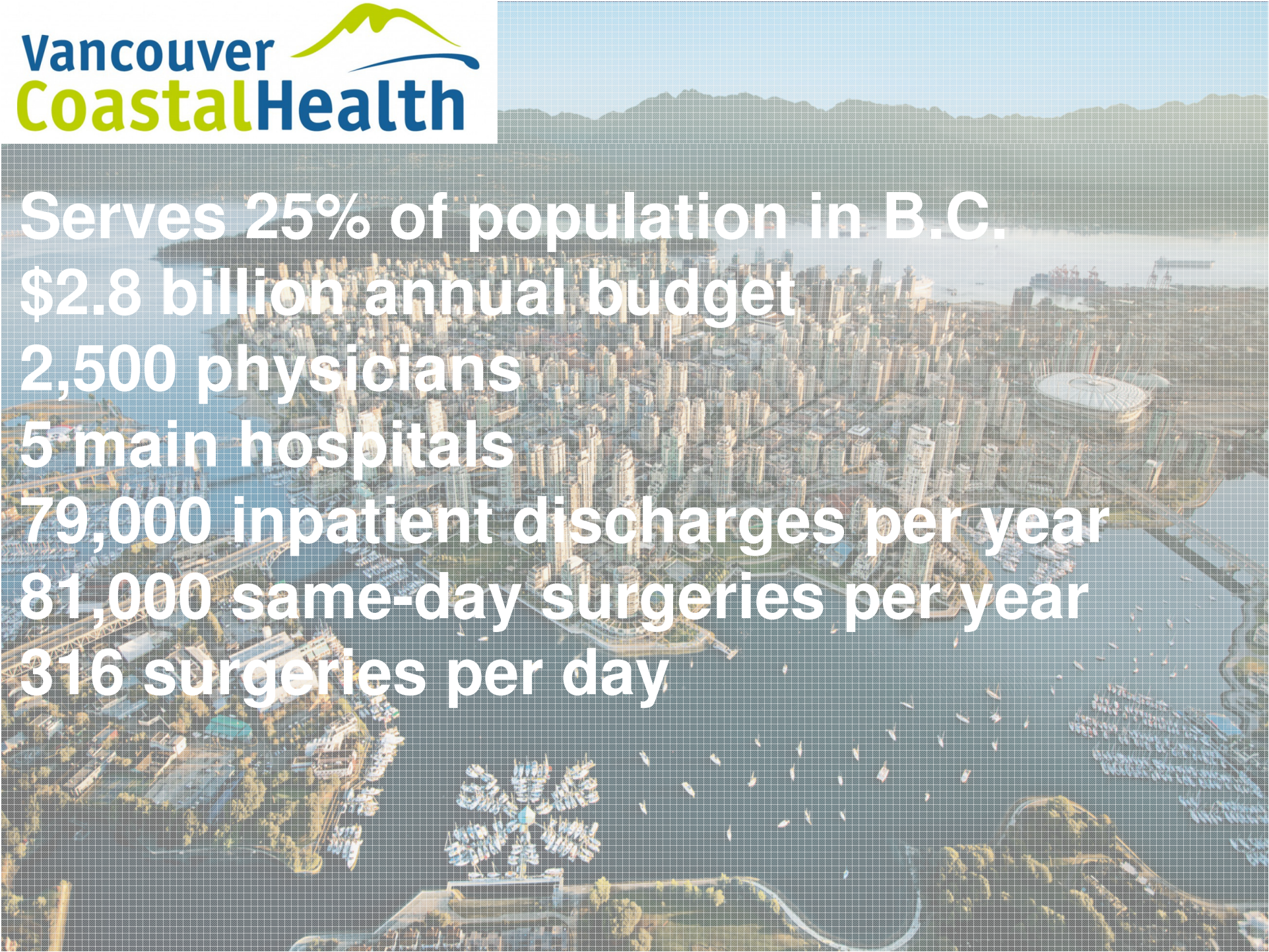
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Vancouver Coastal Health



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The background of the slide is an aerial photograph of Vancouver, British Columbia. It shows the city's dense urban core, including the downtown skyline with numerous skyscrapers, the waterfront area with the Vancouver Convention Centre and the Olympic Stadium, and the surrounding water and mountains. The image is overlaid with a semi-transparent grid pattern.

**Serves 25% of population in B.C.
\$2.8 billion annual budget
2,500 physicians
5 main hospitals
79,000 inpatient discharges per year
81,000 same-day surgeries per year
316 surgeries per day**



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VALHUE Study

All patients undergoing one of 641 elective surgical procedures

General surgery
Gynaecology / obstetrics
Neurosurgery
Orthopedics

Otolaryngology (ENT)
Plastics
Thoracic
Urology



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METHODS



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Methods

We established a set of criteria to evaluate instruments.

We scanned the peer-reviewed and grey literature to identify the most commonly used health status instruments and reviewed their applications.

We reviewed the websites for each of the instruments to extract the most current information



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Methods

Framework	
Type of instrument	Preference of an instrument that leads to health index vs. health profile
Respondent burden	Minimize the total number of questions included in the survey package
Affordability	Minimize costs associated with using the instruments
Canadian applicability	Normalized distribution of the Canadian population-based health statuses
Use in similar settings	Appropriate for use in a self-administered mail survey



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RESULTS



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Results: Generic Health Status

	Type of Instrument	Respondent burden	Affordability	Canadian applicability	Example of similar applications
EuroQoL EQ-5D	Health index	6 questions	No license fee	Canadian norms available	US National Health Measurement Study (NHMS) National Health Service (NHS)
Health Utilities Index (HUI3)	Health index	15 questions (but can vary)	\$4,000 - \$6,000	Canadian norms available	Canadian Community Health Survey (CCHS) Canadian National Population Health Survey (NPHS)
Quality of Well-Being Scale (QWB)	Health index	50 questions	No license fee	No Canadian norms	US National Health Measurement Study (NMHS)
SF-12	Health profile	12 questions	Fees vary	Canadian norms available	US Medical Expenditure Panel Survey (MEPS)



Results: Condition-Specific Health Status (Example in Obstetrics)

	Type of Instrument	Respondent burden	Affordability	Canadian applicability	Example of similar applications
Uterine Fibroid Symptom (UFS-QOL)	Health profile	37 questions	No license fee	No Canadian norms	Clinical
International Consultation on Incontinence Modular Questionnaire (ICIQ-UI)	Health profile	4 questions	No license fee	No Canadian norms	Clinical
Pelvic Floor Impact Questionnaire (PFIQ)	Health index	7 questions	No license fee	No Canadian norms	Community surveys
Pelvic Floor Distress Inventory (PFDI)	Health index	20 questions	No license fee	No Canadian norms	Community surveys
Pelvic Organ Prolapse Urinary Incontinence Sexual Function Questionnaire (PISQ)	Health index	12 questions	No license fee	No Canadian norms	Clinical
Urogenital Distress Inventory (UDI)	Health index	6 questions	\$250 w/ IIQ	No Canadian norms	Community surveys
Incontinence Impact questionnaires (IIQ)	Health index	7 questions	\$250 w/ UDI	No Canadian norms	Community surveys



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DISCUSSION



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Generic Health Status Instruments

All were:

- Easily identified in the literature
- Widely supported by empirical research

Ultimately, the EuroQoL EQ-5D was incorporated into VALHUE

- Supplemented by a depression (PHQ-9) and pain (PEG) co-morbidity questionnaires



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Condition-Specific Health Status Instruments

More challenging to identify and evaluate

Most are designed for clinical assessment rather than classification purposes. Consequently:

- many do not have the ability to rank order health states
- population norms are rare (except for the high volume procedures)
- many have large number of questions

Many are still maintained by original researchers who are easily accessible and do not charge any licensing costs.



Why is this important?

PROMs represent promising tools for outcomes measurement

Data collected from PROMs could be used for characterizing the effectiveness:

1. Across different elective surgeries (generic health status)
2. Across hospitals for the same elective surgery (condition-specific health status)

This information could be used to inform policy decisions:

- Quality measurement / improvement
- Funding and financial incentives
- Allocation of resources



However...

Requires rigorous measurement and classification systems...

...generic health status instruments have much of this in place

...condition-specific health status instruments are not

Considerable work remains to be done in order to use PROMs as a method of classification



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CONCLUSION



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Conclusion

Using an evaluation framework, we were able to successfully identify and select PROMs instruments for evaluating elective surgeries.

These instruments varied in quality and in their abilities to meet our selection criteria.



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