The use of routinely collected PROMs data in economic analyses

IHE INSTITUTE OF
HEALTH ECONOMICS
ALBERTA CANADA

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APERSU Webinar

IHE INSTITUTE OF HEALTH ECONOMICS ALBERTA CANADA — **Outline**

- What PROMs are
- What PROMs are not
- Routine collection of PROMs
- Using routinely collected PROMs for measuring outcomes
- Using routinely collected PROMs for economic evaluation
- Examples

Outline

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- **What PROMs are**
- **What PROMs are not**
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- Using routinely collected PROMs for economic evaluation
- Examples

What PROMs are

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- PROMs
  - **P**atient **R**eported **O**utcome **M**easures
  - Subjective assessment of a person's health or wellbeing
  - Used to measure
    - Quality of life
    - Capabilities
    - Functioning
    - Symptoms
    - Symptom burden
    - Physical health
    - Mental health
    - …
    - …

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What PROMs are

- PROMs are a set of tools that help us understand how health care impacts on the health and wellbeing of patients

- Generic v Condition specific

- They have many uses:
  - Economic evaluation
  - Clinical outcomes
  - Policy evaluation

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What PROMs are

- A set of tools that help us understand how health care impacts on the health and wellbeing of patients

- Generic v condition specific
- Preference v non-preference based

- They have many uses:
  - **Economic evaluation**
  - Clinical outcomes
  - Policy setting

	With Preferences	Without preferences
Generic	EQ-5D	KIDSCREEN
Specific	MSIS-8D-P	HAD

What PROMs are

- PROMs in health economics
  - A measure of benefit
    - Different approaches to doing so (eg functioning, capability)

  - Preference based
    - We have knowledge about which states of being are preferred in relation to one another
    - Some can be used to estimate utility (those based on measures of health)
    - Others have rankings but are not measures of utility (those based on capability

  - Focus is on those that can be used to estimate utility

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What PROMs are

- Ranking
  - Describes preferences for different states
    - Combined set of responses define a set of unique health states
    - It is these unique health states that are ranked to determine preferences
    - Individuals may rank states differently (important later!)
    - Population preferences are a set of aggregated individual preferences (also important later!)
    - Must be transitive: A > B > C
    - Must be complete: Cannot leave some states unranked

  - Preferences typically determined by the 'general' population
    - Different methods exist, but aim is to understand rankings between states

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What PROMs are

- Utility
  - A measure of welfare, or benefit
  - Formally: The level of satisfaction a consumer gets from consuming a good
  - If :
    a) We know the complete set of possible health states
    b) Have a ranking for each of those health states
    c) Have a value for each of those health states (eg in terms of time)

    Then we can estimate utility.

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What PROMs are

- PROMs used in health economics
  - EQ-5D-X / SF-X / HUI X
    - Focus on health via functioning
    - Suitable for estimating utility values
    - Multiple versions of each
    - Value sets (ie rankings) across different populations

  - ICECAP-X
    - Focus on health via capabilities
    - Not suitable for estimating utilities (maybe)
    - Rankings exist for some, in smaller number of populations
    - Increasing use reflects perceived limitations of functioning based measures

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What PROMs are

- EQ-5D-X
  - Different versions of the EQ-5D
    - 3-level, 5-level, Youth
    - Measure five domains of health
      - Mobility
      - Self-care
      - Usual activities
      - Pain
      - Anxiety/Depression
    - 3L = 243 unique states plus dead
    - 5L = 3,125 unique states plus dead

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What PROMs are not

- They are not universal
  - No PROM can cover everything

- They are not substitutes for one another
  - one PROM is not the same as another

- They are not 'sufficient'
  - They are part of the evidence base

- They are not substitutes for objective or clinical outcomes
  - A treatment that patients like is not the same as a good treatment
  - Must be used alongside other evidence

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- Background
- What PROMs are
- What PROMs are not
- **Routine collection of PROMs**
- Using routinely collected PROMs for evaluation
- More research needed

IHE INSTITUTE OF HEALTH ECONOMICS ALBERTA CANADA | **Routine collection of PROMs**

- PROMs have long been used in research contexts
  - Typically as a secondary measure or outcome
  - Increasingly recognised as a suitable primary outcome measure
    - Often in studies where survival not a key endpoint
    - eg in mental health studies
    - MIR trial used Becks Depression Inventory
  - EQ-5D has also been used as a primary outcome measure
    - Less common
    - What is clinically meaningful difference?
    - "Laser in Glaucoma and Ocular Hypertension (LiGHT) trial. A multicentre, randomised controlled trial: design and methodology"

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- Routine collection of PROMs data less common

- Some PROMs collected more than others
  - Condition specific rather than generic
  - Non-preference rather than preference based

- But! Routine collection of generic, preference based PROMs is starting to happen
  - UK NHS
    - EQ-5D-3L
    - CLINICAL AREAS
  - Alberta
    - EQ-5D-5L
    - Cancer Control Alberta, Community rehab, PCNs
    - AHS - aims to have more comprehensive coverage as part of EHR

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IHE INSTITUTE OF HEALTH ECONOMICS ALBERTA CANADA — **Evaluations**

- Collect all the PROMs data you want
  - Easy
  - Quick
- What matters is what you do with it

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- Collecting EQ-5D or other preference based PROM does not mean you can use these as measures of individual outcome
- Remember this:
  - Individuals may rank states differently (important later!)
  - Population preferences are a set of aggregated individual preferences (also important later!)
  - Imagine a patient being followed over time with two PROMs
    - EQ-5D-3L
    - PHQ-9 (for depression)

Routine collection of PROMs

- Imagine a patient being followed over time with two PROMs
  - EQ-5D-3L
  - PHQ-9 (for depression)

- PHQ-9 is scored by adding responses together
  - Higher scores mean worse health
  - Over time possible to track changes in health and infer better/worse

- EQ-5D-3L gives 243 possible states
  - Scoring 1 on all dimensions is written as 11111
  - Scoring 2 on all dimensions is written as 22222
  - **But!** These are not scores, they are descriptions

Routine collection of PROMs

- EQ-5D-3L

Domain	Time 1	Time 2
Mobility	1	1
Self-care	2	1
Usual Activities	2	2
Pain	2	2
Anxiety/Depression	2	3
Utility Score	0.585	0.157

- Does the patient feel better off in T1 or T2?
- Utility score is a societal preference for states – ie the utility society would get from consuming resources to achieve that state

IHE INSTITUTE OF HEALTH ECONOMICS ALBERTA CANADA | **Evaluations**

- UK NHS (PROMs) programme
  - Captured PROMs for groin-hernia surgery, varicose vein surgery, and knee and hip replacement
  - Generic (EQ-5D-3L) and condition specific (eg Oxford Hip Score, Aberdeen Varicose Vein Questionnaire)
  - Data collected between 2009 and present
  - Data collection on G-H and VV surgery stopped in 2017
  - Data still collected on hip and knee replacement

IHE INSTITUTE OF HEALTH ECONOMICS ALBERTA CANADA | **Evaluations: Example**

- Using PROMs data in research
  - Eibich P, Dakin HA, Price AJ, et al. ***Associations between preoperative Oxford hip and knee scores and costs and quality of life of patients undergoing primary total joint replacement in the NHS England: an observational study***. BMJ Open 2018
  - Routinely collected PROMs data
    - Baseline measurement at day of surgery
    - Follow-up at least 6-months post surgery
    - EQ-5D-3L and Oxford Hip/Knee Score
  - Routinely collected resource use data (Hospital Episode Statistics) for inpatient care
  - Did **not** try to infer causality

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Evaluations: Example

- Using PROMs data in research (Eibich P, Dakin HA, Price AJ, et al.)
  - Post-op EQ-5D index scores higher than pre-op for index surgery
  - Average hip cost = £5,522
  - Average knee cost = £6,053
  - preoperative and postoperative quality of life were higher for patients with high OHS/OKS scores (higher scores are better)

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Evaluations: Example

- Using PROMs data in research (Eibich P, Dakin HA, Price AJ, et al.)
  - Could not evaluate cost-effectiveness of joint replacement
    - No data on the costs and quality of life for patients without joint replacement
  - This is a key shortcoming of using routinely collected data – identification of control groups
    - We only have data for those who receive treatment
    - Patients in the UK NHS only routinely complete PROMs if they are having surgery

Evaluations: Challenges

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- Administrative data is "…information collected primarily for administrative (not research) purposes."
  - No controls or randomization
  - Limited by what is being collected already
  - Legal and ethical barriers to access
  - Integrating disparate sources of data
  - Negotiating across jurisdictions
    - Departments, Provinces, International

Economic Evaluations: Challenges

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IHE INSTITUTE OF HEALTH ECONOMICS ALBERTA CANADA   **Economic Evaluations: Challenges**

- No controls or randomization
  - Evaluation of an intervention requires a counter-factual – that is, what would happen without intervention
    - UK NHS PROMs programme did not have this, so couldn't be evaluated fully
  - RCTs are ideal – one group get Rx, the other not
  - What do we do when we can't randomize?
    - Artificial counter-factual

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- Creating counterfactuals
  - Difference-in-Difference
  - Matching (including propensity score matching)
  - Instrumental variables
  - Before and after studies (Interrupted time series)
  - Regression discontinuity

IHE INSTITUTE OF HEALTH ECONOMICS ALBERTA CANADA | **Economic Evaluations: Challenges**

- Creating counterfactuals
  - Difference-in-Difference
  - Matching (including propensity score matching)
  - Instrumental variables
  - **Before and after studies (Interrupted time series)**
  - Regression discontinuity
  - **Modelling**

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- There are many established methods from economics and epidemiology for doing causal inference on admin data
  - But all have drawbacks and must be chosen with care!
- A key difference between econ and epi are measures of outcome
- Epi is interested in effect of exposure on some outcome like survival
- Economics is interested in effect of exposure on:
  - Resource use (easiest)
  - Costs (harder)
  - Health outcomes eg quality of life (hardest)

IHE INSTITUTE OF HEALTH ECONOMICS ALBERTA CANADA | **Economic Evaluations: Examples**

- Examples of ongoing research
  - Evaluation of endovascular therapy (modelling)

  - Evaluation of an online wellness program (interrupted time series)

  - Evaluation of a community support intervention (difference-in-difference)

Policy Question

What is the health system impact of alternative models of providing endovascular therapy in Alberta while taking into consideration the following:

- patient and clinical factors;
- distance, time, and other viability thresholds for endovascular therapy; and
- capacity within existing system resources to provide coordinated care and how they are impacted, including what new resources would be required?

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Technical Approach

Developed a two-stage model to assess the cost:

1. Decision tree model from stroke onset to 90 days

    - Outcome 1: medical costs

    - Outcome 2: probability of treatments

        – A patient can receive either EVT, or EVT plus tPA or tPA only

2. Markov model from 90 days to life year

    - Outcome: lifetime costs for the cohort of mRS 0 – 2 versus the cohort of mRS 3 – 5 at 90 days

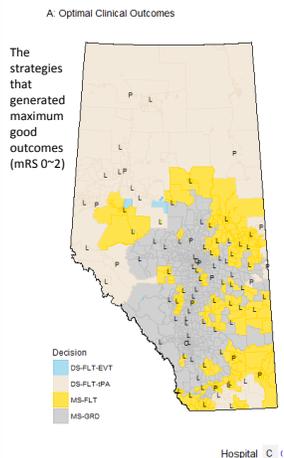   - Better outcome (i.e. mRS 0 – 2) is associated with fewer resources used

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Results: Distribution of optimal strategies

The Figure shows optimal transportation methods in each DAs.

A: Optimal Clinical Outcomes

The strategies that generated maximum good outcomes (mRS 0~2)

Decision
DS-FLT-EVT
DS-FLT-tPA
MS-FLT
MS-GRD

Hospital C

Note that optimal strategy is unique in each DA, but is a combination of transportation methods at higher level (e.g. health zone).

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Economic Evaluations: Examples

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Economic Evaluations: Alberta

- Economic evaluations require data on costs and benefits
- Administrative data primarily contains information on **activity** through contacts with the public part of the health system
  - Sometimes we have cost data (eg billing data, fee schedules)
  - Much of the time
- Routine collection of PROMs in Alberta is new
  - Few clinical areas (eg cancer, community rehab)
  - Within these, not 100% coverage yet
  - Needs historical data to help with controls

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