



Providence Health Care  
Heart Centre

# **PROMs and PREMs: Opportunities for improving outcomes and health services**



Sandra Lauck PhD, RN

St. Paul's Hospital Professorship in Cardiovascular Nursing at UBC

Clinician Scientist, Heart Centre St. Paul's Hospital

Associate Professor, UBC School of Nursing

**UBC Division of Cardiology Research Rounds**

**Monday November 4, 2024**

# The value of PROMs and PREMs



# What matters most to patients?

Ende et al. BMC Health Services Research (2021) 21:474  
<https://doi.org/10.1186/s12913-021-06459-4>

BMC Health Services Research

RESEARCH ARTICLE Open Access

Understanding what matters most to patients in acute care in seven countries, using the flash mob study design

Eva S. van den Ende<sup>1†</sup>, Bo Schouten<sup>2†</sup>, Marjolien N. T. Kremers<sup>3,4</sup>, Tim Cocksley<sup>5</sup>, Chris P. Subbe<sup>6,7</sup>, Immo Weichert<sup>8</sup>, Louise S. van Galen<sup>1</sup>, Harm R. Haak<sup>4,9</sup>, John Kellett<sup>10</sup>, Jelmer Alma<sup>11</sup>, Victoria Siegrist<sup>12,13</sup>, Mark Holland<sup>14</sup>, Erika F. Christensen<sup>15,16</sup>, Colin A. Graham<sup>17</sup>, Ling Yan LEUNG<sup>17</sup>, Line E. Laugesen<sup>18</sup>, Hanneke Merten<sup>7</sup>, Fraz Mir<sup>19</sup>, Rachel M. Kidney<sup>19</sup>, Mikkel Brabrand<sup>10,20</sup>, Prabath W. B. Nanayakkara<sup>21</sup>, Christian H. Nickel<sup>11</sup> and on behalf of all local collaborators




**Getting better/being in good health**

Why?

- To be with family
- To pick-up like again

**Getting home**

Why?

- To take care of someone
- To be in own space

**Having a diagnosis and a plan**

Why?

- To feel less anxious and uncertain

**Table 2** Patient perspective: does your doctor know what matters most to you?

Does your doctor know what matters most?	No (%)
Yes	886 (48.1)
No <sup>a</sup>	861 (46.7)
No, but someone else from the health care professional team knows <sup>a, b</sup>	96 (5.2)

## Patient-Reported Outcome Measurements (PROMs)

## Patient-Reported Experience Measurements (PREMs)

### Definition

- Measure patients' perception of their ***disease and treatment as it relates to their health status and health-related quality of life***

- Measure patients' perception of their ***experience of the health care*** they receive

### Examples of Domains Measured

- Symptoms, pain/discomfort
- Physical, mental/emotional, social health status
- General quality of life

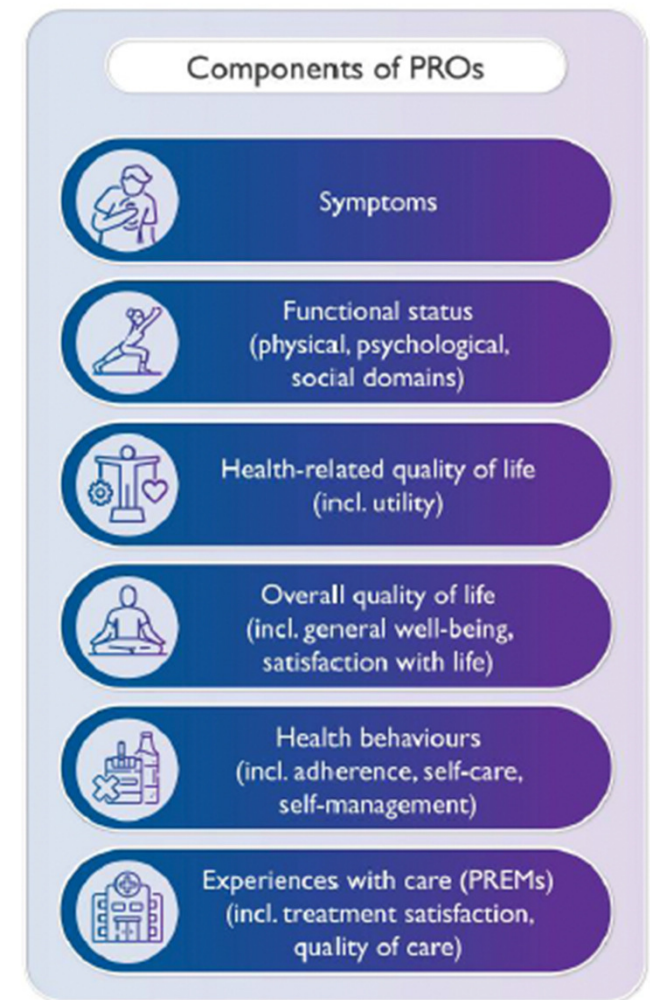
- Communication
- Involvement in decision-making
- Patient education

### Source of Data

- ***The patient is the only source of data:*** Based on self-assessment
- Outcomes and experiences only known to the patient
- Use of validated questionnaires/tools selected to meet the goals of measurement
- No interference or interpretation from health care provider

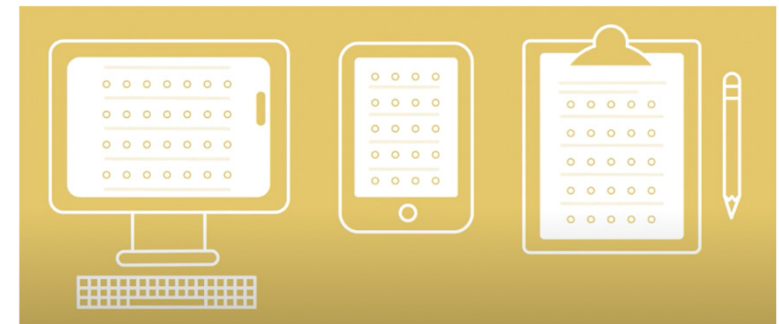
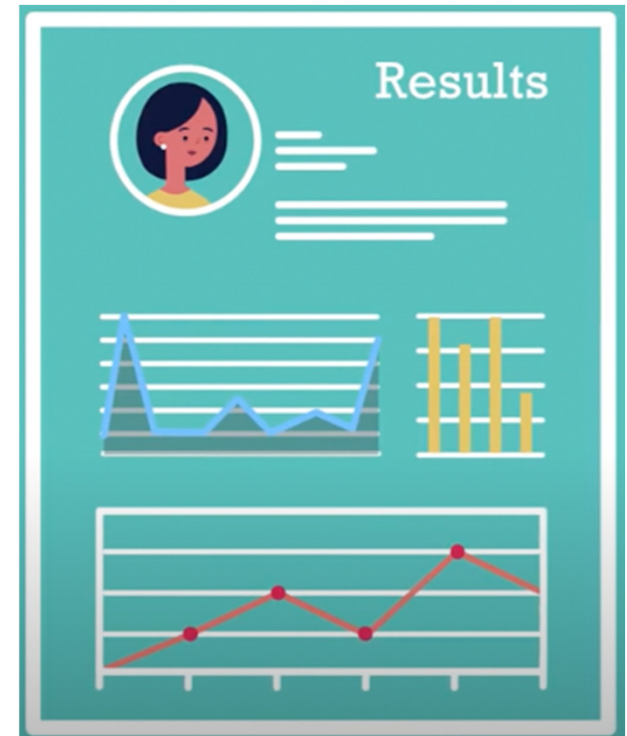
## Patient-reported outcomes: When the patient is the only source of data

Any report of the status of a patient's health condition, health behaviour, or experience with healthcare that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else



## Understanding PROMs: Validated measures

1. Provide a comprehensive picture of the impact of disease and treatment from the patient's perspective
2. Focus on symptoms and psycho-social concerns that are relevant to the patient
3. Capture key indicators of a patient's experience
  1. Physical symptoms
  2. Mental health
  3. Emotional wellness
  4. ...



# Understanding PROMs: Informing clinical care

1. Offer real time information
2. Helps prioritize health concerns that matter most to the patient
3. Track response over time
4. Help HCPs deliver care that is responsive to patient needs



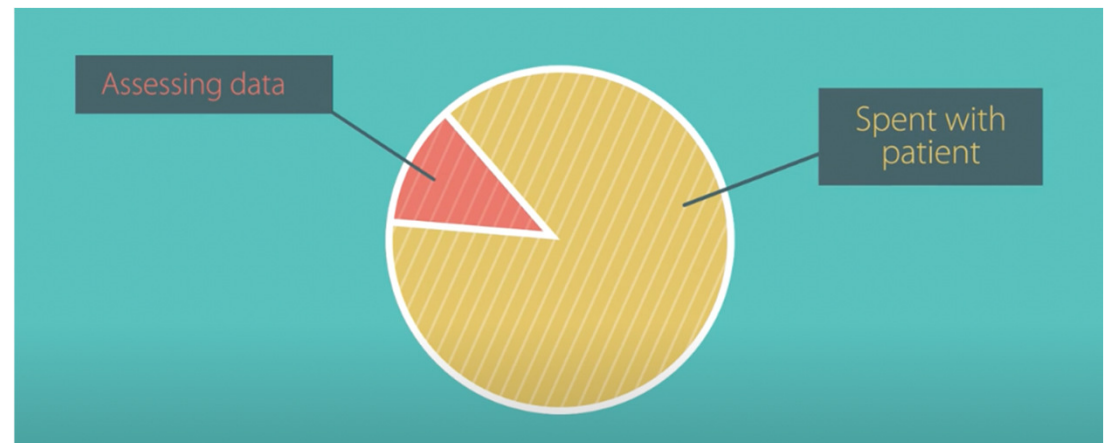
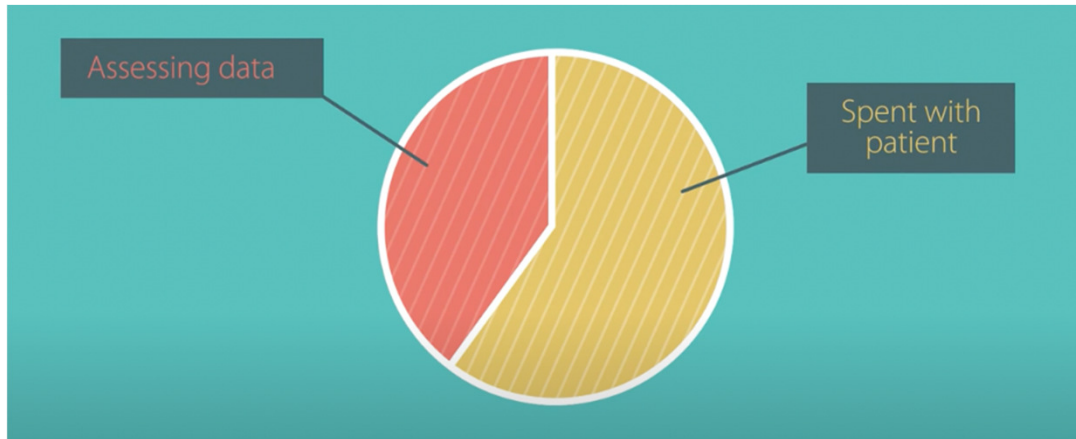
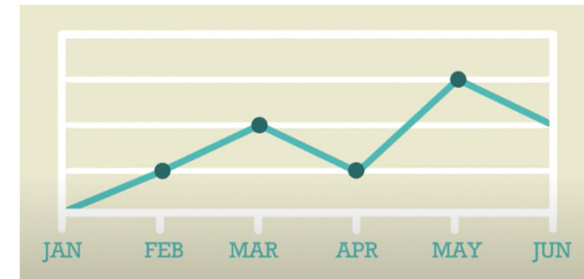
- 1 Physical symptoms
- 2 Emotional wellness
- 3 Mental health



- 1 Mental health
- 2 Physical symptoms
- 3 Emotional wellness



# Understanding PROMs: Making the best of the consultation





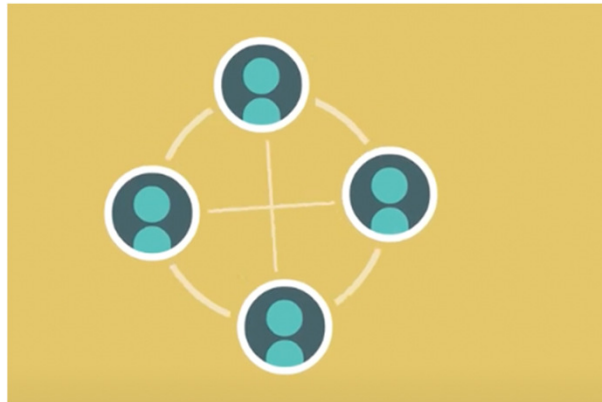
## Why use PROMs?

Early identification and treatment of patient needs



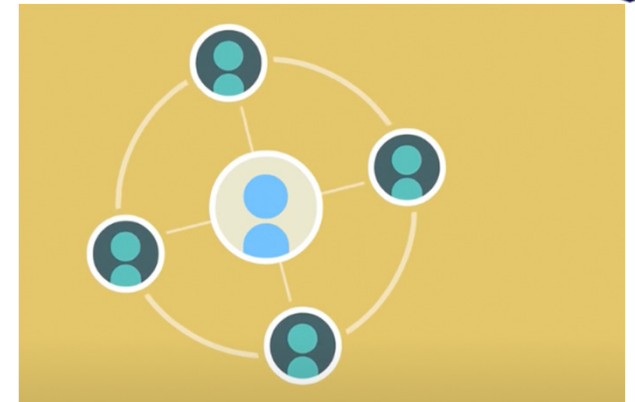
- ✓ Improve ability to detect worsening symptoms
- ✓ Provide information that may have otherwise been missed

Better coordination and multidisciplinary teamwork



- ✓ Reduce drop-out

Empowerment of patients to be active partners in their care



- ✓ Enhance shared decision-making
- ✓ Ensure voice of user is integrated in health planning, research and innovation

Lambert, 2010; Miller, 2016; Coulter 2010; Greenhalgh 2019; Moons et al., 2024



## Why use PROMs?

1. More detailed understanding of a patient's symptoms and emotional state: Using validated measures with demonstrated sensitivity to change to guide the development of a personalized care plan
2. Standardize the symptom assessment process to enable clinicians to focus their time on symptom intervention – or at health system level to facilitate evaluation and planning, and drive system-wide improvement
3. Support health policy planning and research



# Selection of validated instrument(s): Key principles

1. PROMs and PREMs must be **reliable, valid, precise and responsive tools** that accurately capture the domains of interest in the patient population



## Reliability

*Does the instrument provide a repeatable and consistent measurement?*

- ✓ Test-retest reliability?

## Validity

*Does the instrument measure what it is meant to?*

- ✓ Content validity?
- ✓ Face validity?
- ✓ Criterion validity?
- ✓ Construct validity?

## Precision

*Does the instrument discriminate between:*

- ✓ Patient groups?
- ✓ Health states?
- ✓ Treatments?

## Responsiveness

*Is the instrument responsive to change when change is present?*

## Selection of validated instrument(s): Key principles

2. PROMs and PREMs must be **acceptable** to patients



# Selection of validated instrument(s): Key principles

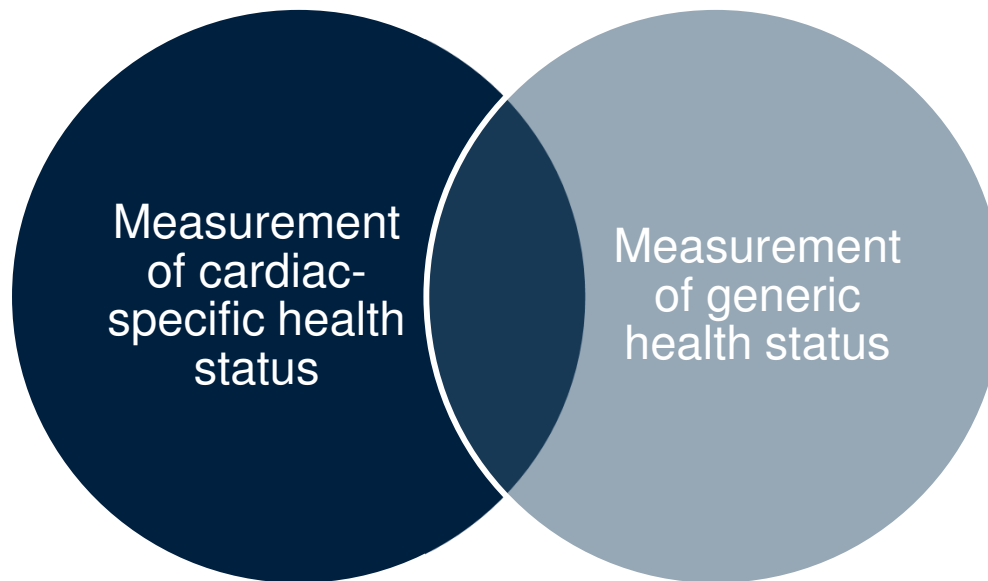
## 3. PROMs and PREMs must be integrated in health systems



# Capturing the domains of self-reported health in cardiac care



- ✓ *Specific to disease group*
- ✓ *Sensitive to detect clinically significant changes*
- ✓ *Content relevant to target group*
- ✓ *Cannot compare with general population*



- ✓ *Suitable for the general population*
- ✓ *Not sensitive to detect disease-specific issues*
- ✓ *Can compare across groups*

# Measurement tools: Generic health – EQ5D



**MOBILITY**

I have no problems in walking about

I have slight problems in walking about

I have moderate problems in walking about

I have severe problems in walking about

I am unable to walk about

**SELF-CARE**

I have no problems washing or dressing myself

I have slight problems washing or dressing myself

I have moderate problems washing or dressing myself

I have severe problems washing or dressing myself

I am unable to wash or dress myself

**USUAL ACTIVITIES** (e.g. work, study, housework, family or leisure activities)

I have no problems doing my usual activities

I have slight problems doing my usual activities

I have moderate problems doing my usual activities

I have severe problems doing my usual activities

I am unable to do my usual activities

**PAIN / DISCOMFORT**

I have no pain or discomfort

I have slight pain or discomfort

I have moderate pain or discomfort

I have severe pain or discomfort

I have extreme pain or discomfort

**ANXIETY / DEPRESSION**

I am not anxious or depressed

I am slightly anxious or depressed

I am moderately anxious or depressed

I am severely anxious or depressed

I am extremely anxious or depressed

The best health you can imagine

100

95

90

85

80

75

70

65

60

55

50

45

40

35

30

25

20

15

10

5

0

The worst health you can imagine

## Development:

- Index-based score
- 30+ years use and development
- Used extensively in health technology development and cost effectiveness studies

## Versions:

- 5 items
- Available in >200 languages

## Scales, sub-scales and scoring:

- Responses are converted into a single index score (utilities – preference-weighted health status assessments): 1= Best possible health to 0= worst health/death<sup>10</sup>
- Domains: Mobility, self-care, usual activities, pain/discomfort, anxiety/depression
- Visual analog scale (VAS): 0= worst imaginable health state to 100 (best imaginable health state)
- Available with 3 or 5 levels of responses

# Measurement tools: Generic health – SF-36

## Development:

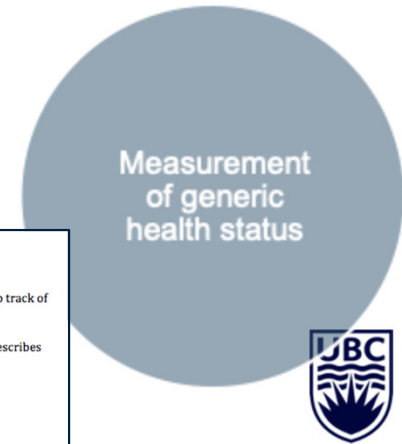
- Rand Corporation: Medical Outcomes Study Short Form

## Versions:

- 36, 20 and 12-item versions
- Validated in patients with cardiovascular disease

## Scales, sub-scales and scoring:

- Domains: Physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional, mental health
- Physical and mental component summary sub-scales with comparison to societal norms



**YOUR HEALTH AND WELL-BEING**

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

For each of the following questions, please mark an  in the one box that best describes your answer.

**1. In general, would you say your health is:**

Excellent	Very good	Good	Fair	Poor
▼	▼	▼	▼	▼
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**2. The following questions are about activities you do every day. Does your health now limit you in these activities?**

	Yes, limited a lot	Yes, limited a little	No, not limited at all
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.....	▼	▼	▼
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Climbing several flights of stairs.....	▼	▼	▼
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**3. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?**

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Accomplished less than you would like.....	▼	▼	▼	▼	▼
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Were limited in the kind of work or other activities.....	▼	▼	▼	▼	▼
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your emotional problems (such as feeling depressed or anxious)?**

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Accomplished less than you would like.....	▼	▼	▼	▼	▼
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Were limited in the kind of work or other activities.....	▼	▼	▼	▼	▼
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**5. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?**

	Not at all	A little bit	Moderately	Quite a bit	Extremely
▼	▼	▼	▼	▼	▼
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Ware et al., *Med Care* 1992  
 Kiebzak et al., *Heart Lung* 2002  
 Falide et al., *J Clin Epid* 2000



# Measurement tools: Kansas City Cardiomyopathy Questionnaire (KCCQ)

## Development:

- Developed for patients with heart failure

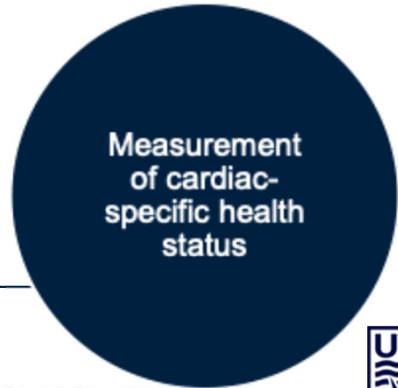
## Versions:

- Original: 23 items; Short version: 12 items
- Available in multiple validated translations

## Scales, sub-scales and scoring:

- Overall score (KCCQ-OS): 0-100, higher scores indicate less symptom burden and better QOL
- Sub-scales:
  - 23-item: Physical function, social function, symptoms, self-efficacy and knowledge, QOL
  - 12-item: Physical limitation, symptom frequency, QOL, social limitations

Spertus et al., *Circ Cardiovasc Qual Outcomes*. 2015  
 Arnold et al., *Circ Heart Failure* i2013



**KCCQ-12V**

The following questions refer to your **heart failure/valve disease** and how it may affect your life. Please read and complete the following questions. There are no right or wrong answers. Please mark the answer that best applies to you.

1. **Heart failure/valve disease** affects different people in different ways. Some feel shortness of breath while others feel fatigue. Please indicate how much you are limited by **heart failure/valve disease** (shortness of breath or fatigue) in your ability to do the following activities over the past 2 weeks.

Activity	Extremely limited	Quite a bit limited	Moderately limited	Slightly limited	Not at all limited	Limited for other reasons or did not do the activity
a. Showering/bathing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Walking 1 block on level ground	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Hurrying or jogging (as if to catch a bus)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

2. Over the **past 2 weeks**, how many times did you have **swelling** in your feet, ankles or legs when you woke up in the morning?

Every morning	3 or more times per week but not every day	1-2 times per week	Less than once a week	Never over the past 2 weeks
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

3. Over the past 2 weeks, on average, how many times has **fatigue** limited your ability to do what you wanted?

All of the time	Several times per day	At least once a day	3 or more times per week but not every day	1-2 times per week	Less than once a week	Never over the past 2 weeks
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

4. Over the past 2 weeks, on average, how many times has **shortness of breath** limited your ability to do what you wanted?

All of the time	Several times per day	At least once a day	3 or more times per week but not every day	1-2 times per week	Less than once a week	Never over the past 2 weeks
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

---

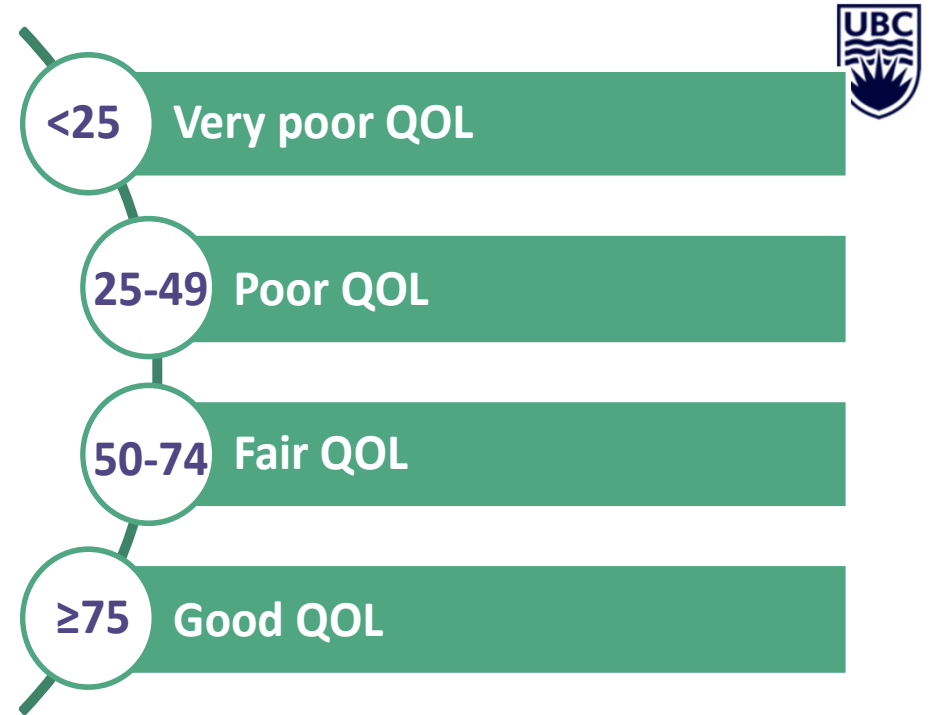
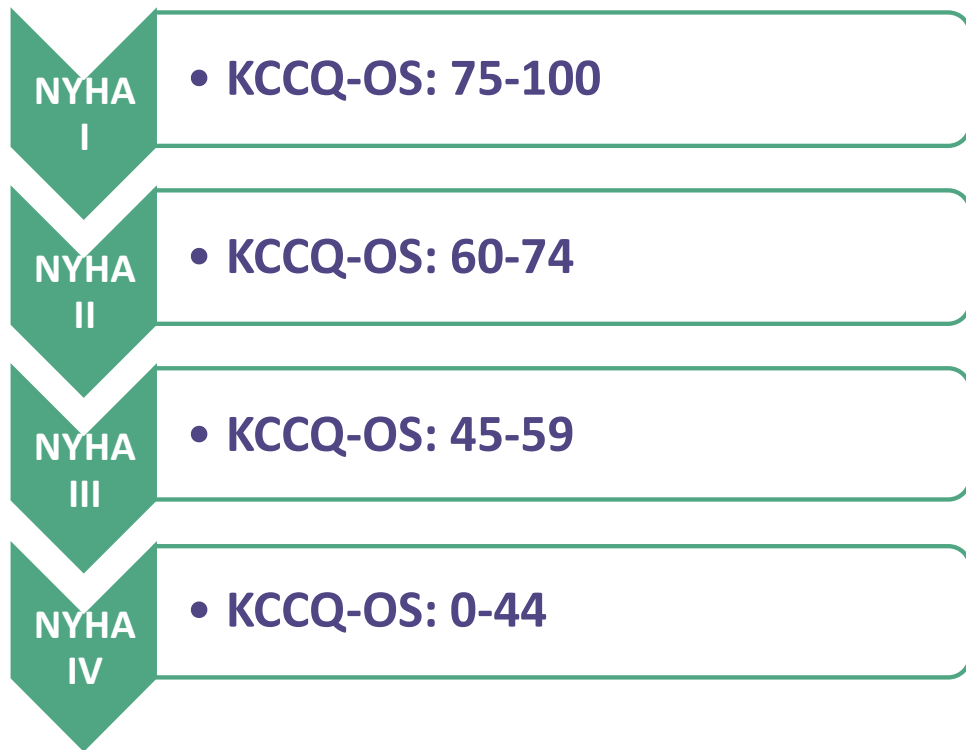
5. Over the past 2 weeks, on average, how many times have you been forced to sleep sitting up in a chair or with at least 3 pillows to prop you up because of **shortness of breath**?

Every night	3 or more times per week but not every day	1-2 times per week	Less than once a week	Never over the past 2 weeks
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Rev. 2012-04-19

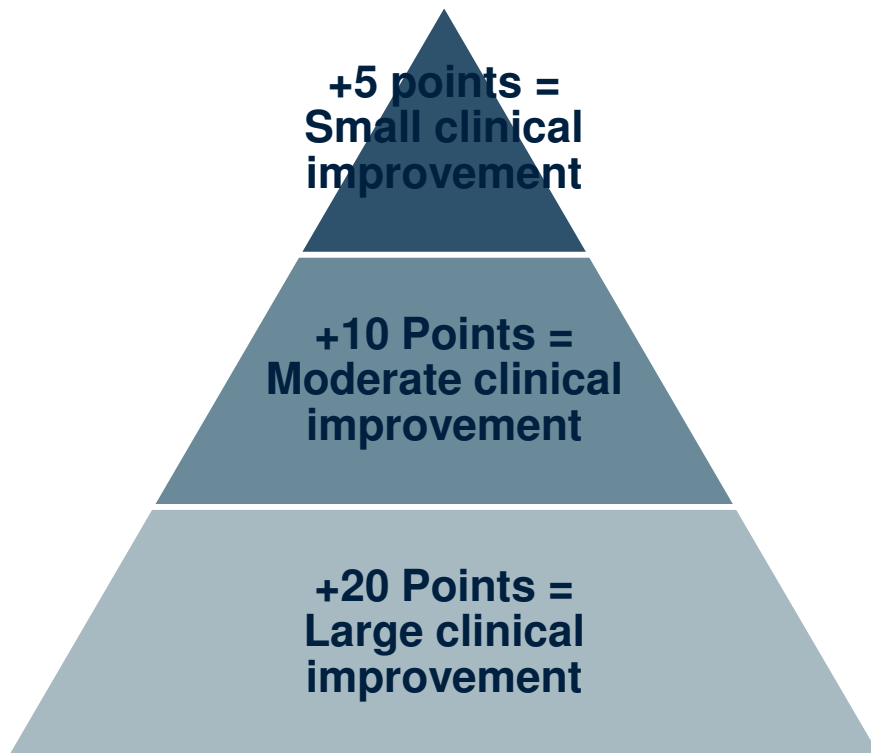
# KCCQ: Psychometric properties

## Correlates with clinical assessment



# KCCQ: Psychometric properties

## Clinically important differences



**JACC STATE-OF-THE-ART REVIEW**

### Interpreting the Kansas City Cardiomyopathy Questionnaire in Clinical Trials and Clinical Care

JACC State-of-the-Art Review

John A. Spertus, MD, MPH,<sup>a</sup> Philip G. Jones, MS,<sup>a</sup> Alexander T. Sandhu, MD, MS,<sup>b</sup> Suzanne V. Arnold, MD, MHA<sup>a</sup>

The complex block contains the title and authors of a JACC State-of-the-Art Review. It also features three logos: the UBC logo in the top right corner, the BBAC logo (a heart with a pulse line) on the right side, and the ABIM CME MOC Accredited logo (a book icon) on the right side.

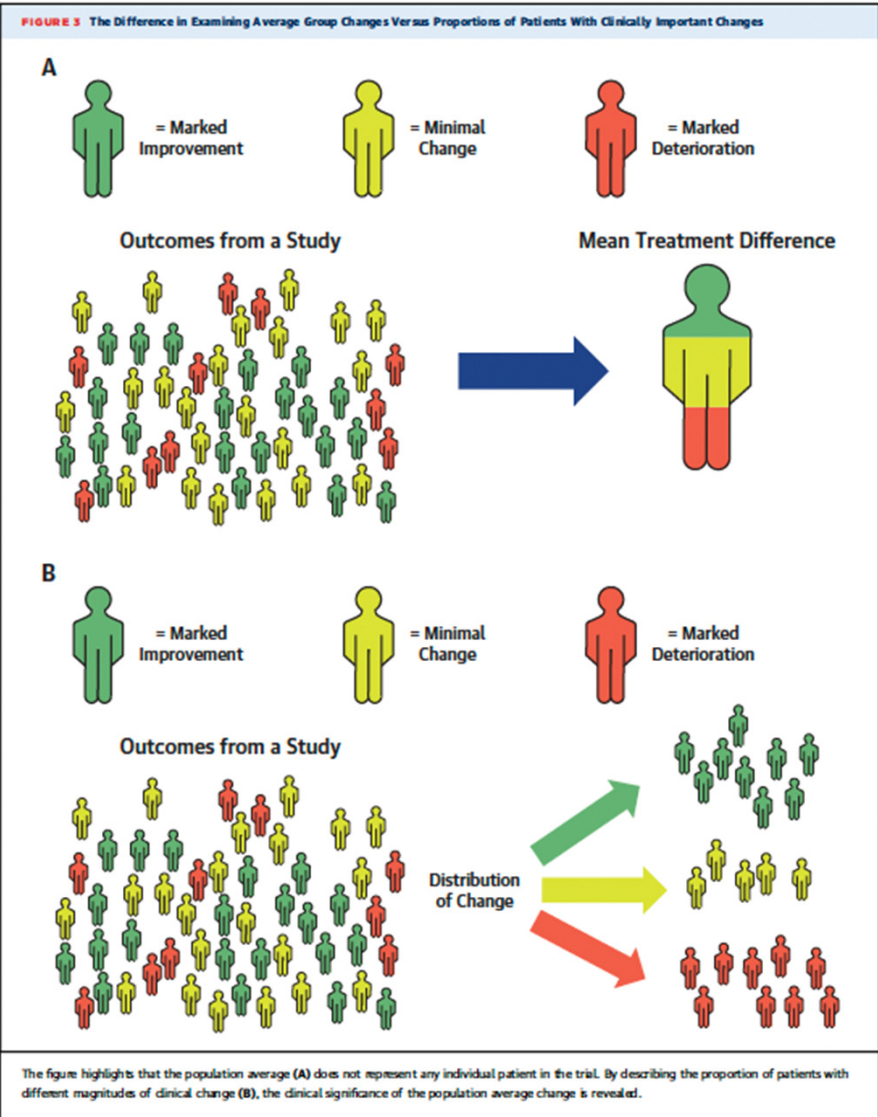
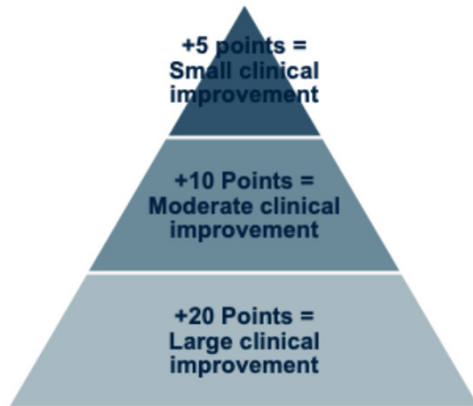
# KCCQ: Psychometric properties

JACC STATE-OF-THE-ART REVIEW

## Interpreting the Kansas City Cardiomyopathy Questionnaire in Clinical Trials and Clinical Care

JACC State-of-the-Art Review

John A. Spertus, MD, MPH,<sup>a</sup> Philip G. Jones, MS,<sup>b</sup> Alexander T. Sandhu, MD, MS,<sup>b</sup> Suzanne V. Arnold, MD, MHA<sup>a</sup>



# Integrating PROMs in research and registry-based evaluation



# Reducing the risk of “disconnect” in health care



## Clinician-Reported Outcomes

*Will they live longer?*

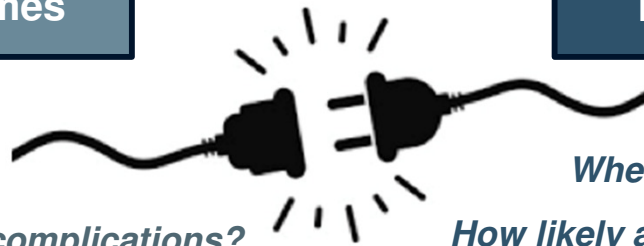
*How long will the valve last?*

*What is their risk for in-hospital complications?*

*How likely are they to experience delirium?*

*What is their risk for a new pacemaker?*

*Are they at risk for readmission?*



## Patient-Reported Outcomes

*Will I feel better?*

*When will I be able to return to work?*

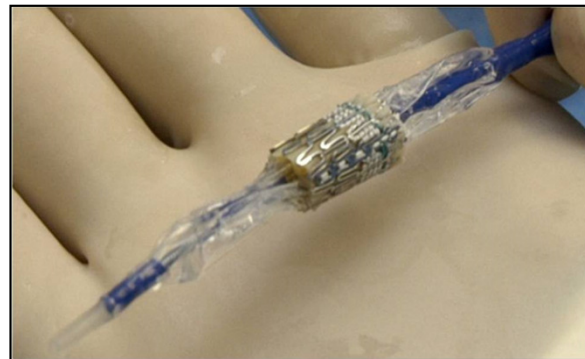
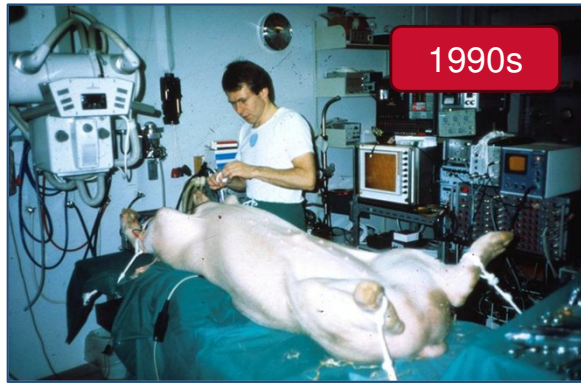
*How likely am I to experience depression after my valve procedure?*

*How soon will I be able to look after my spouse?*

*How long will it take for me to feel well?*

*Will I have pain?*

# Paradigm shift in the treatment of heart valve disease





# Circulation

JOURNAL OF THE AMERICAN HEART ASSOCIATION

American Heart Association   
Learn and Live™

2006

**Percutaneous Aortic Valve Implantation Retrograde From the Femoral Artery**  
John G. Webb, Mann Chandavimol, Christopher R. Thompson, Donald R. Ricci,  
Ronald G. Carere, Brad I. Mumt, Christopher E. Buller, Sanjeevan Pasupati and  
Samuel Lichtenstein

*Circulation* 2006, 113:842-850: originally published online February 6, 2006  
doi: 10.1161/CIRCULATIONAHA.105.582882  
Circulation is published by the American Heart Association, 7272 Greenville Avenue, Dallas, TX 75231  
Copyright © 2006 American Heart Association. All rights reserved. Print ISSN: 0009-7322. Online ISSN: 1524-4539

# Circulation

JOURNAL OF THE AMERICAN HEART ASSOCIATION

American Heart Association   
Learn and Live™

**Transapical Transcatheter Aortic Valve Implantation in Humans : Initial Clinical Experience**  
Samuel V. Lichtenstein, Anson Cheung, Jian Ye, Christopher R. Thompson, Ronald G. Carere, Sanjeevan Pasupati and John G. Webb

*Circulation* 2006, 114:591-596: originally published online July 31, 2006  
doi: 10.1161/CIRCULATIONAHA.106.632927  
Circulation is published by the American Heart Association, 7272 Greenville Avenue, Dallas, TX 75231  
Copyright © 2006 American Heart Association. All rights reserved. Print ISSN: 0009-7322. Online ISSN: 1524-4539



Edwards SAPIEN THV

Open

Closed



# M&M Program Rounds: “the valve went well”

- Mr. David R. admitted for elective TF TAVI; General anaesthesia and TEE
- **Successful TAVI**
- Significant dysphagia after extubation
- Delayed oral hydration and nutrition; Swallowing assessment positive for dysphagia
- Slow to mobilize and delayed transfer out of critical care; Weight loss and deconditioning due to poor oral intake
- Discharge on POD6
- On-going dysphagia at home; Required insertion of temporary feeding tube
- At 30-day, reported *“My heart is just fine. My worse problem is that now, I can’t swallow real food. It’s like I’ve lost so much”*

2010

# M&M Program Rounds: “the valve went well”

2010

- *Mrs. Parminder S. admitted for elective TF TAVI*
- *General anaesthesia with extubation in procedure room*
- *Bedrest x 8 hours (overnight)*
- *Restless due to back pain; treated with low dose hydromorphone*
- **Successful TAVI**
- *Incontinent while on bedrest; Limited oral intake*
- *Delirium POD1*
- *Delayed discharge from critical care*
- *Slow to mobilize; Deconditioned*
- *Ready for discharge on POD8; Unable to return home due to care needs; Transfer to intermediate care home*



# Goals of the Vancouver TAVI Clinical Pathway

## TAVI Patient Journey

Same-day admission

Minimalist Procedure

Accelerated Reconditioning

Safe Transition Home

Discharge plan  
Clear expectations

Local anaesthesia  
Avoidance of invasive lines

4-hour bedrest  
Hydration and nutrition

Discharge criteria  
Discharge plan

*“Get it right for every patient at every touch point every time”*

### Innovations in Care

#### Vancouver Transcatheter Aortic Valve Replacement Clinical Pathway

#### Minimalist Approach, Standardized Care, and Discharge Criteria to Reduce Length of Stay

Sandra B. Lauck, PhD; David A. Wood, MD; Jennifer Baumbusch, PhD; Jae-Yung Kwon, MSN; Dion Stub, MBBS, PhD; Leslie Achtem, BSN; Philipp Blanke, MD; Robert H. Boone, MD; Anson Cheung, MD; Danny Dvir, MD; Jennifer A. Gibson, MSN; Bobby Lee, MD; Jonathan Leipsic, MD; Robert Moss, MD; Gidon Perlman, MD; Jopie Polderman, BSN; Krishnan Ramanathan, MD; Jian Ye, MD; John G. Webb, MD

2016



Multimodality  
Multidisciplinary  
but  
Minimalist



Centre for  
Heart Valve Innovation  
St. Paul's Hospital, Vancouver

Using *existing technology, up to date knowledge* (objective anatomical and functional screening, procedural expertise) and a *standardized clinical pathway* to facilitate **NEXT DAY DISCHARGE HOME** and *optimal outcomes*

To provide a rigorous assessment of the efficacy, feasibility and safety of the Vancouver Clinical Pathway in patients undergoing elective TF TAVR with a balloon expandable transcatheter heart valve



Centre for  
Heart Valve Innovation  
St. Paul's Hospital, Vancouver

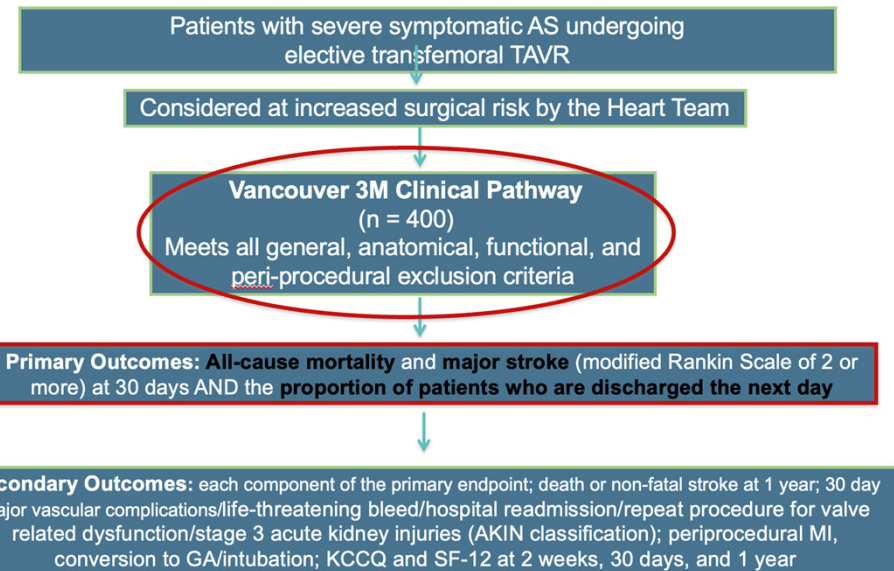
### The Vancouver 3M (Multidisciplinary, Multimodality, But Minimalist) Clinical Pathway Facilitates Safe Next-Day Discharge Home at Low-, Medium-, and High-Volume Transfemoral Transcatheter Aortic Valve Replacement Centers



The 3M TAVR Study

#### 3M TAVR Study Design

To evaluate the efficacy, feasibility and safety of next day discharge home in patients undergoing balloon expandable transfemoral TAVR utilizing the Vancouver 3M Clinical Pathway



# The Vancouver Multidisciplinary, Multimodality, but Minimalist Clinical Pathway Facilitates Safe Next Day Discharge Home at Low, Medium, and High Volume Transfemoral Transcatheter Aortic Valve Replacement Centres: The 3M TAVR Study

David A Wood MD, Sandra Lauck PhD, John Cairns MD, Karin Humphries DSc, and John G Webb MD on behalf of the 3M TAVR Study Investigators  
 Centre for Heart Valve Innovation, St. Paul's and Vancouver General Hospital  
 University of British Columbia

tct2017

Cardiovascular Research Foundation



13 North American centres  
 N = 411 patients



Vancouver: Dr. D. Wood, Dr. J. Webb, Dr. R. Cook, S. Lauck PhD  
 Edmonton: Dr. R. Welsh, Dr. B. Tyrell



Calgary: Dr. F. Al-Qoofi

Hamilton: Dr. J. Velianou, Dr. M. Natarajan

Sunnybrook: Dr. H. Wijeyesundera, Dr. S. Radhakrishnan

St. Michael's: Dr. C. Buller, Dr. M. Peterson

Hôpital du Sacré-Coeur de Montréal: Dr. P. Goggin, Dr. D. Palsaitis

Centre Hospitalier de l'Université de Montréal: Dr. JB. Masson

Toronto General: Dr. Eric Horlick, Dr. M. Ooster

Institut de Cardiologie de Montréal: Dr. A. Asgar

Columbia University Medical Center: Dr. T. Nazif, Dr. S. Kodali, Dr. M. Leon

Emory University Medical Center: Dr. V. Thourani, Dr. V. Babaliaros



tct2017

(Submitted for expedited review, JACC, 2017)

Cardiovascular Research Foundation

## Vancouver TAVR Clinical Pathway

Minimalist Peri-Procedure Approach

Facilitated Post-Procedure Recovery

Criteria-Driven Discharge

PATIENT JOURNEY

**Procedure Room**  
Cath Lab or Hybrid OR

**Access and Closure**  
Percutaneous

**Equipment**  
Peripheral IV  
Radial artery monitoring  
No urinary catheter  
No PA catheter  
Temporary Pacemaker removed in procedure room

**Anesthesia**  
Local anesthesia with no or minimal procedural sedation

**Echocardiogram**  
TTE peri or post procedure

**Monitoring**  
Vital Signs: Q15 x4, Q30 x2  
ECG, eGFR, CBC on admission and POD1  
Removal of all remaining lines < 2 hours

**Facilitated Recovery**  
Bedrest x 4 hours  
Nurse-led mobilization  
Hydration, nutrition, elimination

**Communication**  
Multidisciplinary communication to maintain pathway  
Patient and family education  
Implementation of pre-procedure discharge plan

**Monitoring**  
Review of TTE  
Absence of:  
persistent conduction delay  
vascular access complications  
laboratory contraindications

**Facilitated Recovery**  
Return to baseline mobilization  
Absence of elimination issues  
Return to baseline hydration

**Communication**  
Multidisciplinary agreement of safety for discharge  
Review discharge plan with family  
Review follow-up appointments

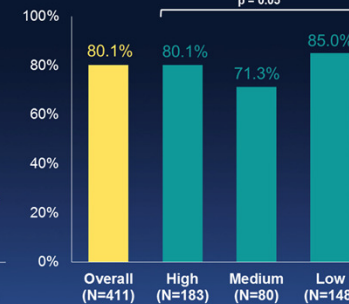
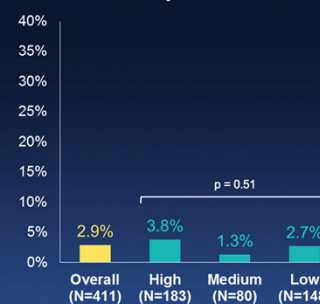
tct2017

Cardiovascular Research Foundation

## Primary Endpoint

30-Day Mortality or Stroke

Next Day Discharge

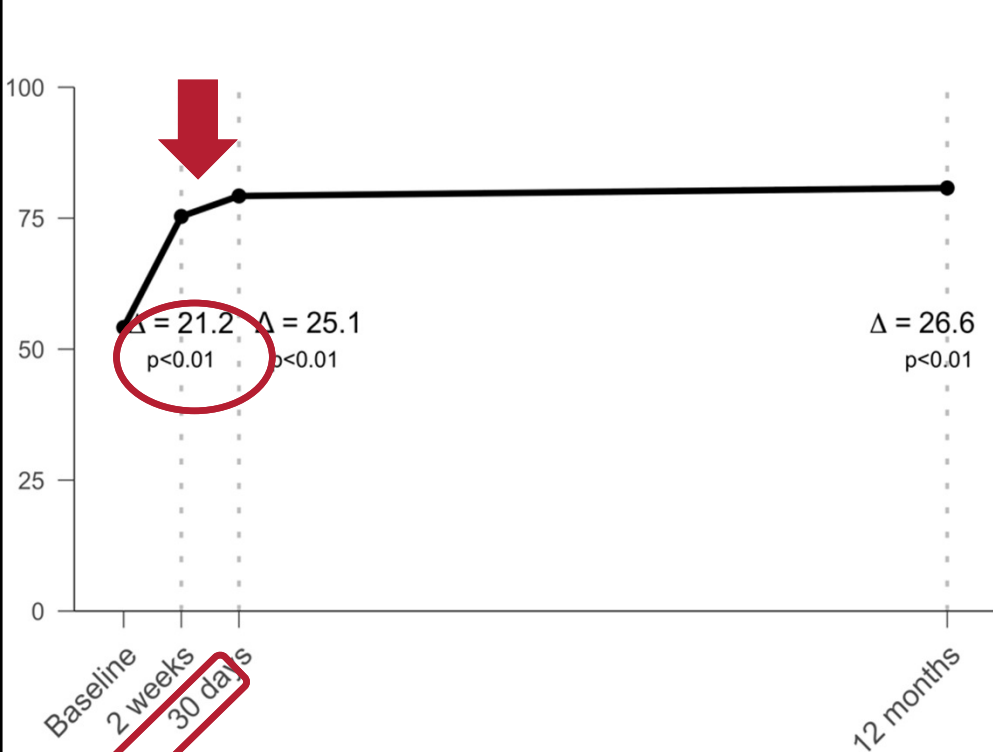


tct2017

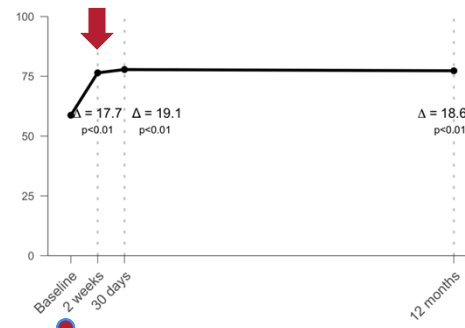
Cardiovascular Research Foundation

# Temporal changes in QOL: KCCQ

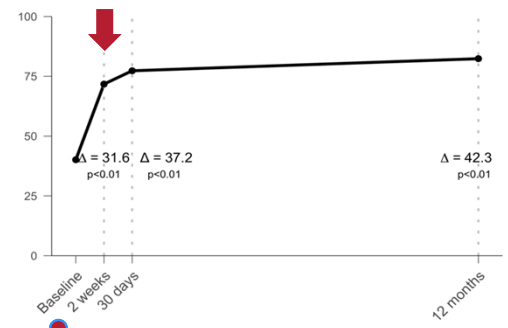
### Overall Summary Score



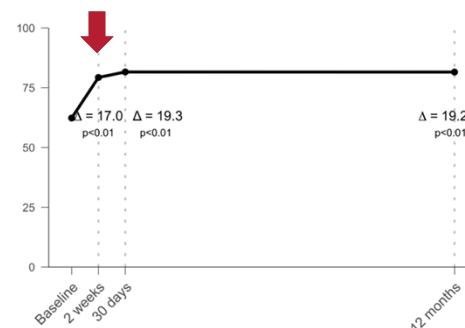
### Physical Limitations



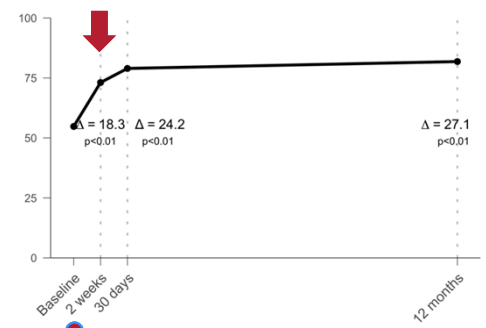
### Quality of Life



### Total Symptoms



### Social Limitations

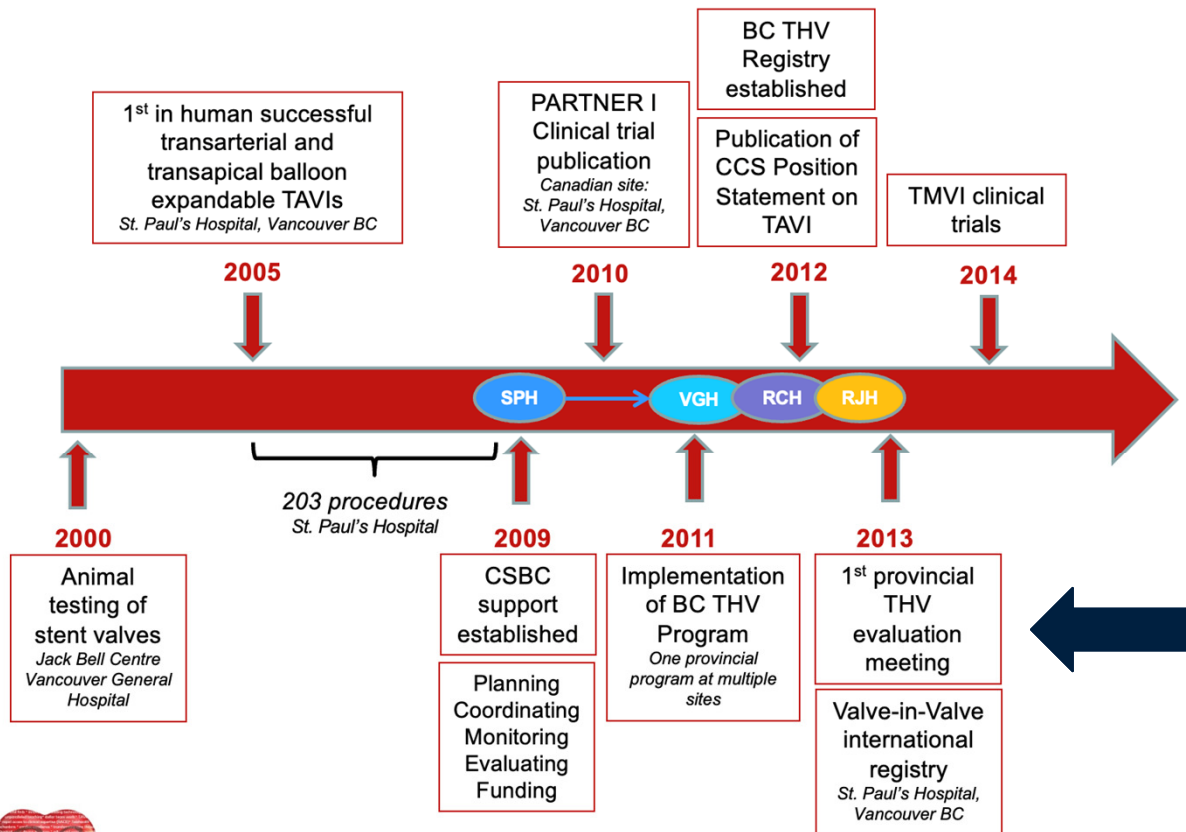


# Good outcome analysis

Cohort	Time Point	N	Patients with good outcome*	Crude proportion	95% CI
Alive Patients #	2 weeks	289	213	73.7%	68.2, 78.7
	30 days	279	218	78.1%	72.8, 82.8
	12 months	253	208	82.2%	76.9, 86.7
All Patients <sup>§</sup>	2 weeks	317	226	71.3%	66.0, 76.2
	30 days	307	230	74.9%	69.7, 79.7
	12 months	277	208	75.1%	69.6, 80.1

**Baseline KCCQ: Single significant predictor of poor outcome at all time points**

# The BC THV Program: Early days of health policy



Canadian Journal of Cardiology 20(12) xxx  
**Society Position Statement**  
**Transcatheter Aortic Valve Implantation: A Canadian Cardiovascular Society Position Statement**  
 John Webb, MD, FRCPC,<sup>a</sup> Josep Rodés-Cabau, MD, FRCPC,<sup>b</sup> Stephen Fremes, MD, FRCSC,<sup>c</sup> Philippe Pibarot, DVM, PhD,<sup>d</sup> Marc Ruel, MD, FRCSC,<sup>d</sup> Reda Ibrahim, MD, FRCPC,<sup>e</sup> Robert Welsh, MD, FRCPC,<sup>f</sup> Christopher Feindel, MD, FRCSC,<sup>g</sup> and Samuel Lichtenstein, MD, FRCSC<sup>h</sup>

<sup>a</sup> St. Paul's Hospital, University of British Columbia, Vancouver, British Columbia, Canada  
<sup>b</sup> Quebec Heart and Lung Institute, Quebec City, Quebec, Canada  
<sup>c</sup> Sunnybrook Hospital, Toronto, Ontario, Canada  
<sup>d</sup> University of Ottawa Heart Institute, Ottawa, Ontario, Canada  
<sup>e</sup> Montreal Heart Institute, Montreal, Quebec, Canada  
<sup>f</sup> University of Alberta, Edmonton, Alberta, Canada  
<sup>g</sup> Toronto General Hospital, Toronto, Ontario, Canada





# The BC THV Program: Early days of health policy

JACC: CARDIOVASCULAR INTERVENTIONS  
 © 2015 BY THE AMERICAN COLLEGE OF CARDIOLOGY FOUNDATION  
 PUBLISHED BY ELSEVIER INC.

VOL. 8, NO. 15, 2015  
 ISSN 1936-8798/\$36.00  
<http://dx.doi.org/10.1016/j.jcin.2015.09.017>

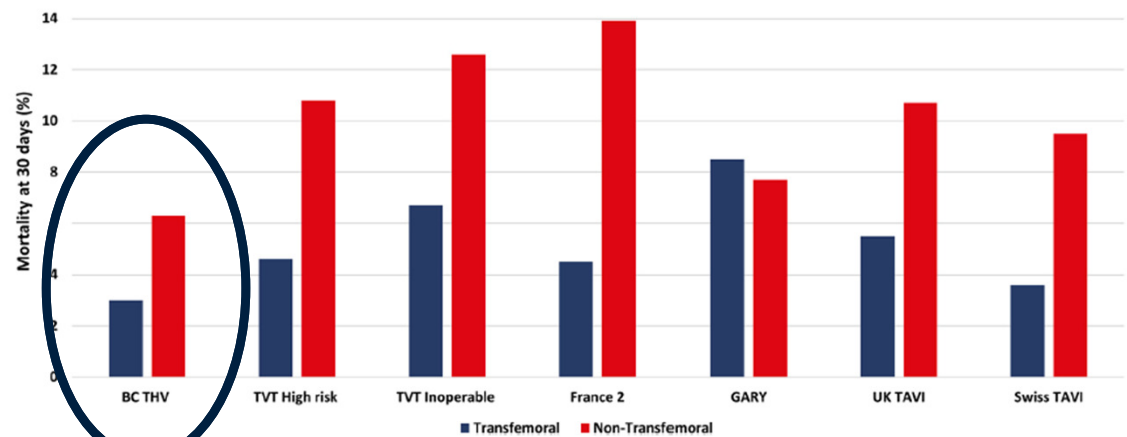
## Regional Systems of Care to Optimize Outcomes in Patients Undergoing Transcatheter Aortic Valve Replacement



Dion Stub, MBBS, PhD,<sup>†</sup> Sandra Lauck, PhD,<sup>†‡§</sup> May Lee, MSc,<sup>||</sup> Min Gao, MD, PhD,<sup>||</sup> Karin Humphries, DSc  
 Albert Chan, MD,<sup>†¶</sup> Anson Cheung, MD,<sup>†\*</sup> Richard Cook, MD,<sup>†‡#</sup> Anthony Della Siega, MD,<sup>\*\*</sup> Jonathon Leips  
 Jay Charania, MD,<sup>¶</sup> Danny Dvir, MD,<sup>†\*</sup> Tim Latham, MD,<sup>¶</sup> Jopie Polderman, BSN,<sup>§</sup> Simon Robinson, MBC<sup>¶</sup>  
 Daniel Wong, MD,<sup>¶</sup> Christopher R. Thompson, MD,<sup>†\*</sup> David Wood, MD,<sup>†‡#</sup> Jian Ye, MD,<sup>†\*</sup> John Webb, MD



**FIGURE 1 30-Day Mortality in International High-Risk Transcatheter Aortic Valve Replacement Registries**



BC = British Columbia; GARY = German Aortic Valve Registry; TAVI = transcatheter aortic valve implantation; THV = transcatheter heart valve.

# The BC THV Program: Early days of health policy

JACC: CARDIOVASCULAR INTERVENTIONS  
© 2015 BY THE AMERICAN COLLEGE OF CARDIOLOGY FOUNDATION  
PUBLISHED BY ELSEVIER INC.

VOL. 8, NO. 15, 2015  
ISSN 1936-8798/\$36.00  
<http://dx.doi.org/10.1016/j.jcin.2015.10.023>

EDITORIAL COMMENT

## Balancing Optimal Outcomes With Access to Care

It Can Be Done!\*

Michael Mack, MD



1. (2)  
comes  
aortic  
The  
eter-  
, and  
sis (3).  
grade  
er in  
going

ient outcomes achieved province-wide demonstrated the potential benefits of a regional system of care.

The authors and the health care authorities in British Columbia are to be congratulated for such a rational and thoughtful approach to health care, balancing first and foremost superior outcomes with expanded access to care, which is a not insignificant issue in this elderly population living across a large geographic area.

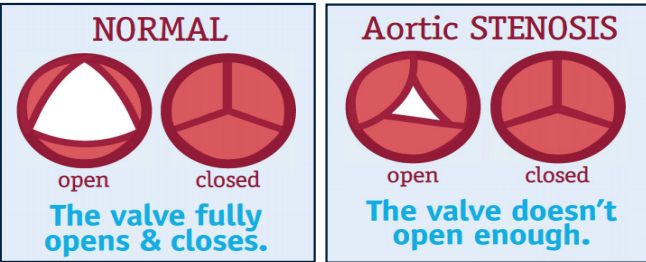
One is left however, wanting to know more details



# Building the BC THV Registry:

*Clinician vs. patient-reported outcomes the management of aortic stenosis*

## Living with Aortic Stenosis



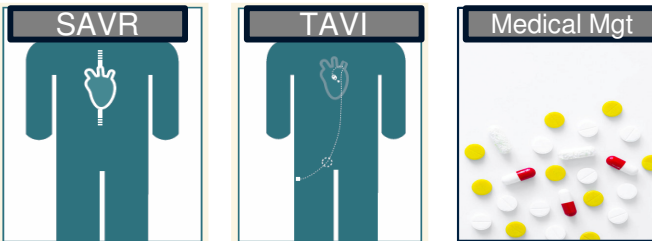
## Clinician-Reported Outcomes

- Mortality on wait list
- Timing of treatment
- Hospitalization rate

## Patient-Reported Outcomes

- Symptoms
- Activities of daily living
- Mobility
- Social and mental/emotional health

## Choosing the Right Treatment



- 30-day, 1-year and long term mortality
- 30-day and 1-year readmission
- Length of stay
- New pacemaker

- Change in symptoms, ADLs, mobility, social, and mental/emotional health
- Rate of recovery
- Pain

# PROMs and health policy: Canada

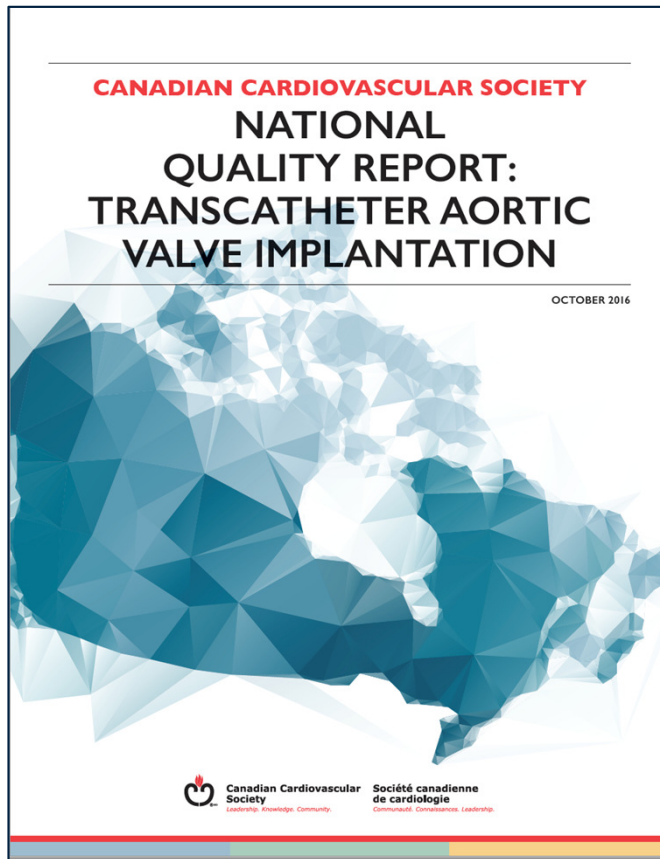


Figure 1. Structural, process and outcome quality indicators for TAVI in Canada.



EVALUATION OF QUALITY OF LIFE					
	Ontario (N=396)	Québec (N=294)	British Columbia (N=270)	Alberta, Manitoba, New Brunswick, Nova Scotia (N=162)	Canada (N=1,122)
KCCQ and EQ5D* (mean and range, %)					
Pre-TAVI	0.0	0.0	97.8 (80.6-100)	60.1 (0-100)	31.9 (0-100)
Post-TAVI	0.0	0.0	21.5 (6.5-25.9)	55.8 (0-100)	12.4 (0-100)

# PROMs and health policy: BC



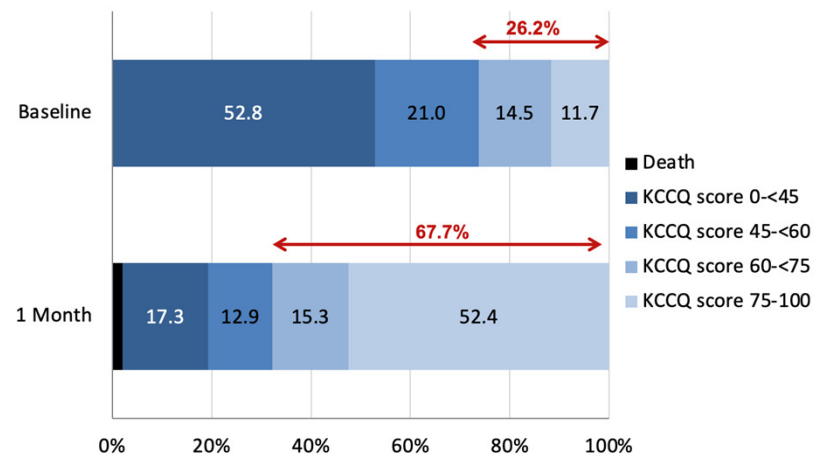
**Provincial Transcatheter Heart Valve (THV) Program  
2016 Evaluation Meeting**

# PROMs and BC health policy (2016)

## KCCQ, Health Thermometer, and EQ-5D for TF-TAVI Patients

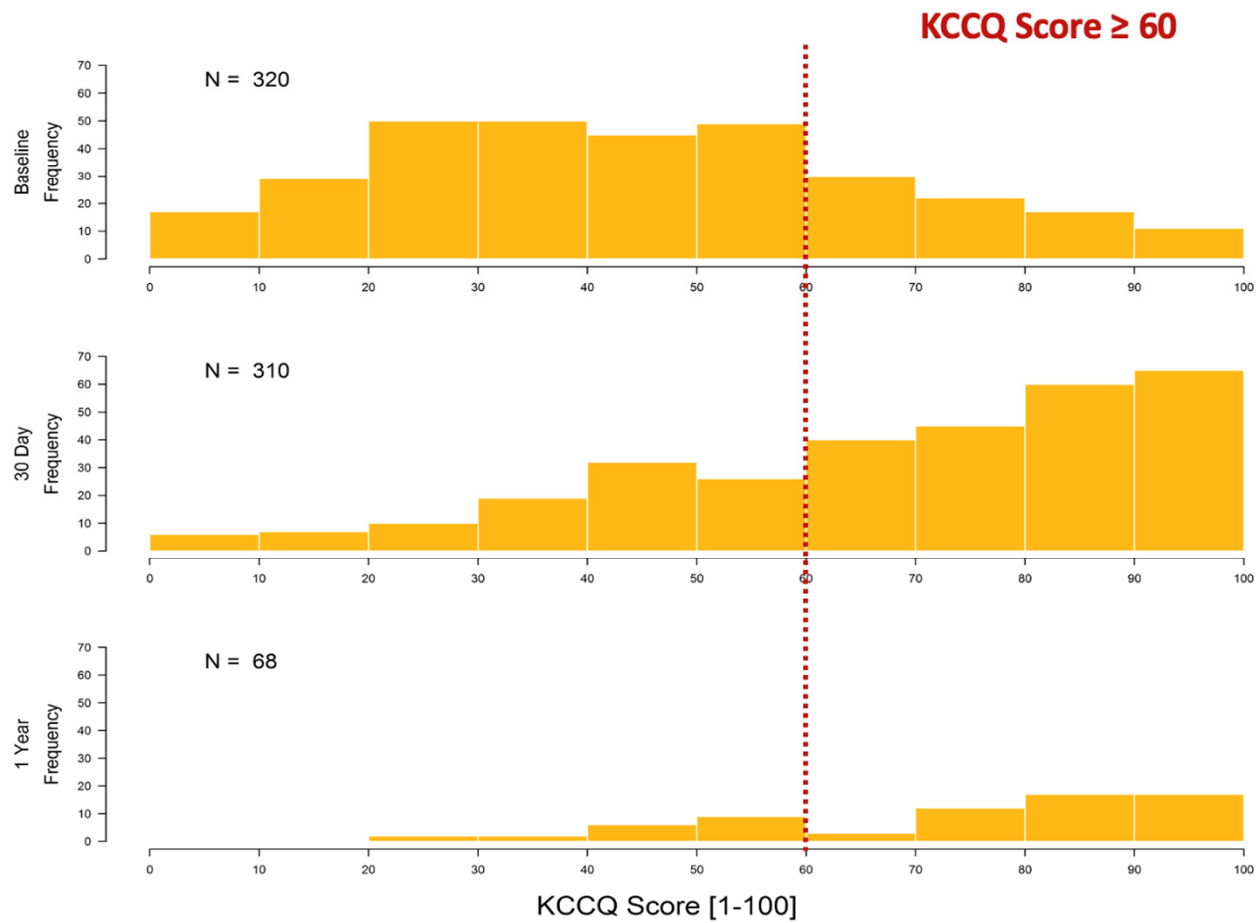
	Baseline		30 Day		1 Year	
	N	Median (IQR)	N	Median (IQR)	N	Median (IQR)
KCCQ [1-100]	320	42.3 (28, 60)	310	75.3 (53, 88)	68	80 (57, 90)
Health Thermometer [1-100]	251	60 (45, 75)	302	70 (50, 80)	67	80 (60, 85)
EQ-5D [0-1]	279	0.7 (0.6, 0.8)	304	0.8 (0.7, 0.9)	65	0.8 (0.7, 0.9)

## KCCQ Score at Baseline and 1 Month for TF TAVI (N=248)



Note: Only include patients with complete data. There were 243 TF TAVI patients who had KCCQ score at baseline and 1 month, and 5 patients were dead at 1 month.

# Distribution of KCCQ Score at Baseline and Follow-up for TF TAVI



# Clinical PROM Report



**Goal:** Integrate PROMs and PREMs in provincial THV programs to:

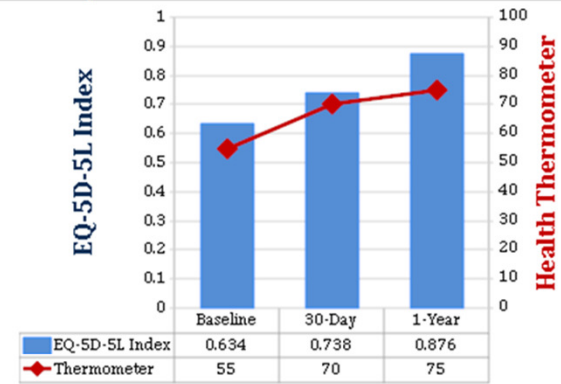
1. Inform treatment decision
2. Augment follow-up program
3. Strengthen evaluation



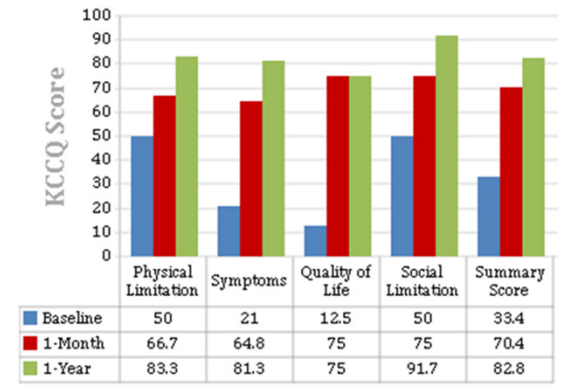
**BC Transcatheter Heart Valve Program**  
**Patient Questionnaire: Summary Report**

Name: **Mouse, Micky**  
 DOB: **01-Jan-1932** M  
 PHN: **9876 543 210**  
 Address: **123 abc street**  
**VANCOUVER, BC V2C 3J4**  
 Phone #: **(604) 123-4567**

**EQ-5D-5L Index Score and Health Thermometer**



**KCCQ-12V**



**Patient Satisfaction (30-Day)**

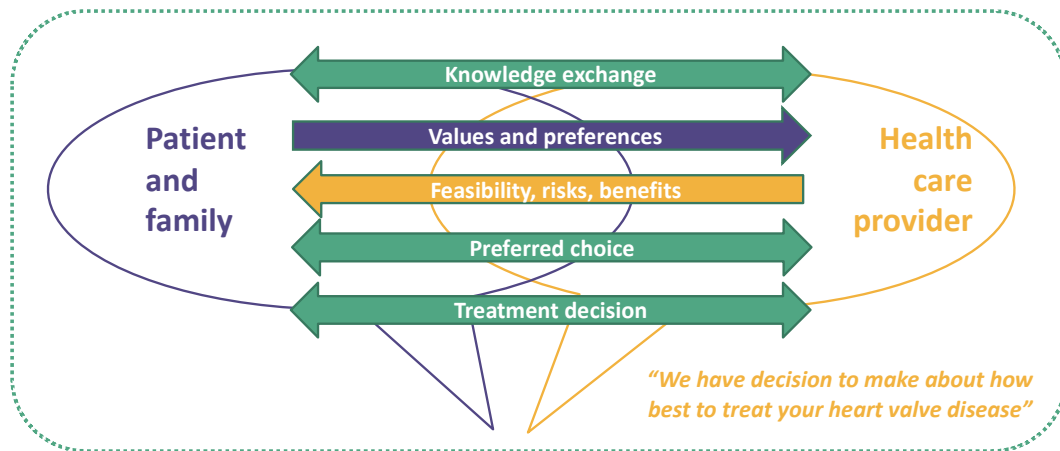
**SAPS Score: 21/28 (75.00 %)**



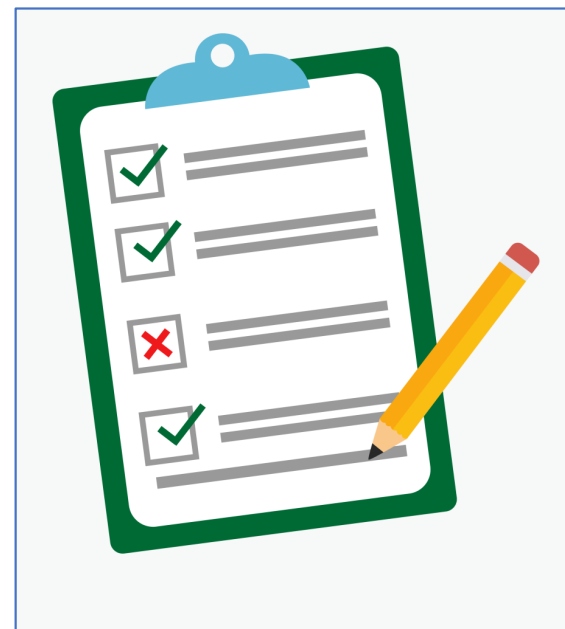
**Accelerating knowledge  
translation:  
Implementation of PROMs and  
PREMs in cardiac care**



# Shared decision-making and PROMs/PREMs



Shared decision-making and decision aids:  
Ask what matters to patients



PROMs and PREMs:  
Measure what matters to patients

# Moving the strategic plan forward

Improving cardiac care in BC:  
Paying attention to patient reported outcomes and experiences



## Phase 1:

1. Determine optimal implementation blueprint to overcome barriers for collection and use of PROMs and PREMs.
2. Evaluate PROM/PREM blueprint implementation and ability to extract data for use including linkage with administrative data.

### Faculty of Medicine Strategic Investment Fund (SIF)

The purpose of the Strategic Investment Fund (SIF) is to encourage members of the Faculty of Medicine (FoM) to advance the Faculty's strategic goals outlined in its strategic plan, Building the Future: 2021-2026. The SIF will invest up to \$1M per year to support new and innovative projects that result in impactful and sustainable outcomes.



THE UNIVERSITY OF BRITISH COLUMBIA