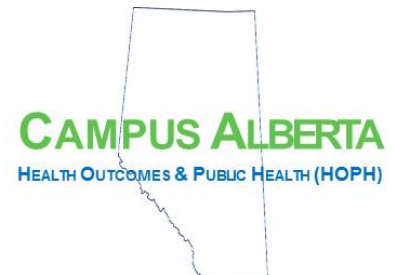
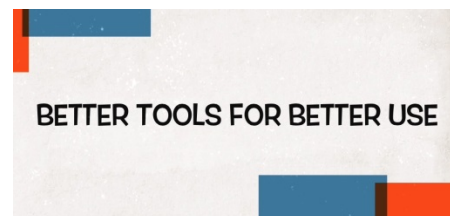


# Patient-centred Oriented Research: An Environmental Scan on the Use of Patient-reported Outcome Measures in Alberta

Methods for Research in Public  
Health Group (MORE-PH)



**UNIVERSITY OF CALGARY**  
O'Brien Institute for Public Health



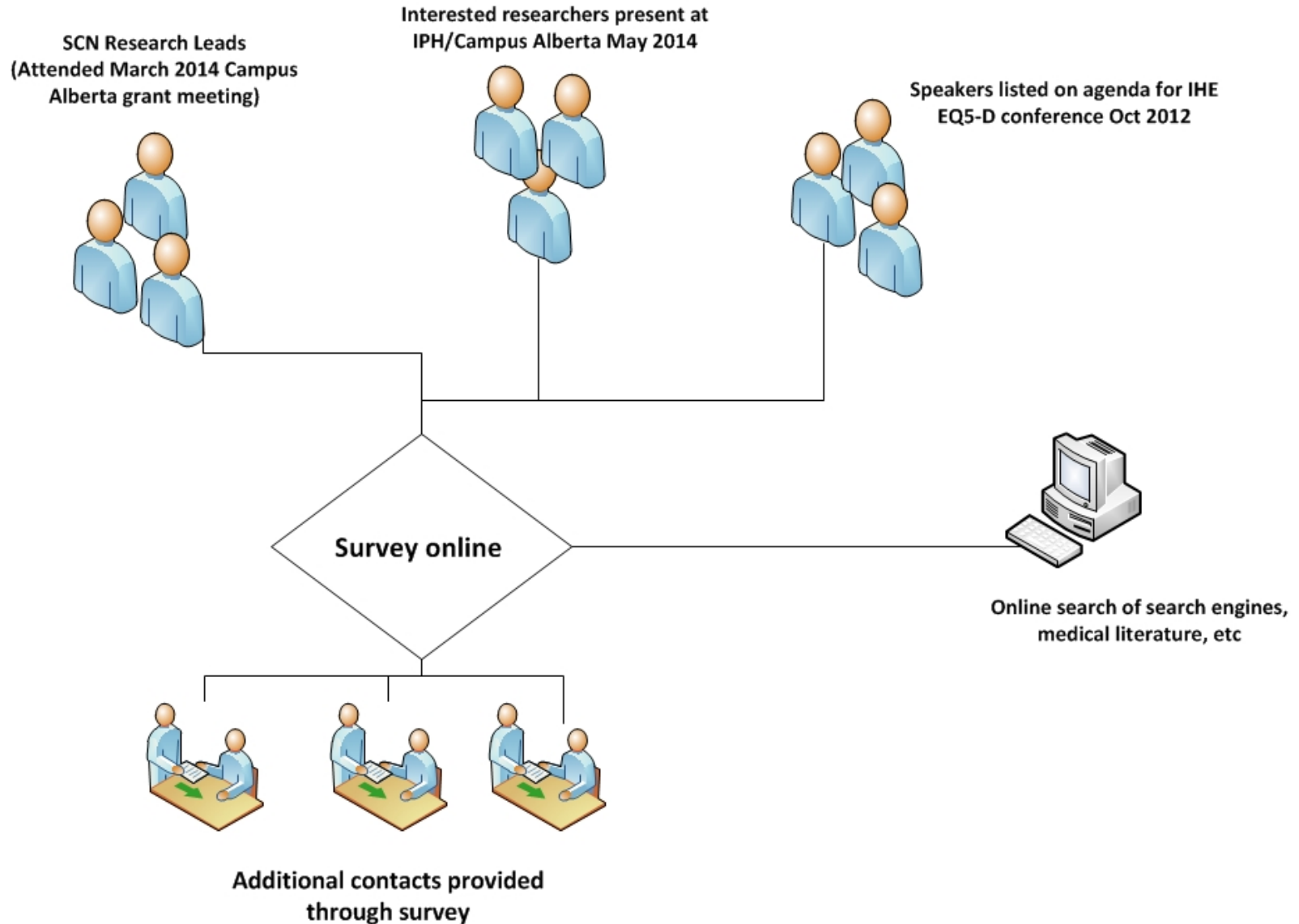
# Background

- MORE-PH hosted Campus Alberta grant meeting in March 2014 with SCN research leads to discuss PROMs.
- Need identified: Environmental scan on the use of PROMs in AB
  - Determine the purpose of using PROMs (research, quality improvement; clinical care)
  - Identify the different PROMs used
  - Explore standardization of the use of measures across the Province

# What we wanted to know

- Created fluidsurvey.com to collect questions about PROMs/PREMs.
- Survey items
  - What is collected?
  - Why is it collected?
  - How is it collected?
  - What is it used for?
- Included a few socio-demographic questions, such as job position (e.g., quality improvement manager), organization (e.g., HQCA)

# Who we asked



# Inclusion Criteria

1. Must be with an Alberta organization
2. Must collect/study PROMS or PREMS

# Survey Components

Component	Response categories
Collection or study of patient reported outcome measures (PROMs)	Y/N
Type of organization	<ul style="list-style-type: none"> <li>• Government</li> <li>• Regional health authority/local health integration network</li> <li>• Health quality council or patient safety institute</li> <li>• Health care/delivery organization</li> <li>• Professional association</li> <li>• University, academic health science center/research institute</li> <li>• Insurance company, program or fund</li> <li>• Health information technology organization or Vendor</li> <li>• Other</li> </ul>
Role in the organization	<ul style="list-style-type: none"> <li>• Senior Management (e.g., CEO, VP, Director)</li> <li>• Program Lead (e.g., Manager)</li> <li>• Analyst / Statistician</li> <li>• Project Coordinator/Manager</li> <li>• Health Care Provider / Clinician</li> <li>• Researcher</li> <li>• Student</li> <li>• Other</li> </ul>

# Survey Components

Component	Response categories
Patient reported outcomes collected	<ul style="list-style-type: none"><li>• Health-related quality of life (e.g., EQ-5D) - specify measure</li><li>• Patient Experience (e.g., CAHPS) - specify measure</li><li>• Other</li></ul>
Population for which the PROMs are collected	Free text
Collection methods used	Free text
How data is collected	<ul style="list-style-type: none"><li>• Phone</li><li>• Mail</li><li>• Online</li><li>• Other</li></ul>
How data is stored	<ul style="list-style-type: none"><li>• Single Spreadsheet (e.g. excel)</li><li>• On servers (note whether seperate tables)</li><li>• Paper records</li><li>• Other</li></ul>

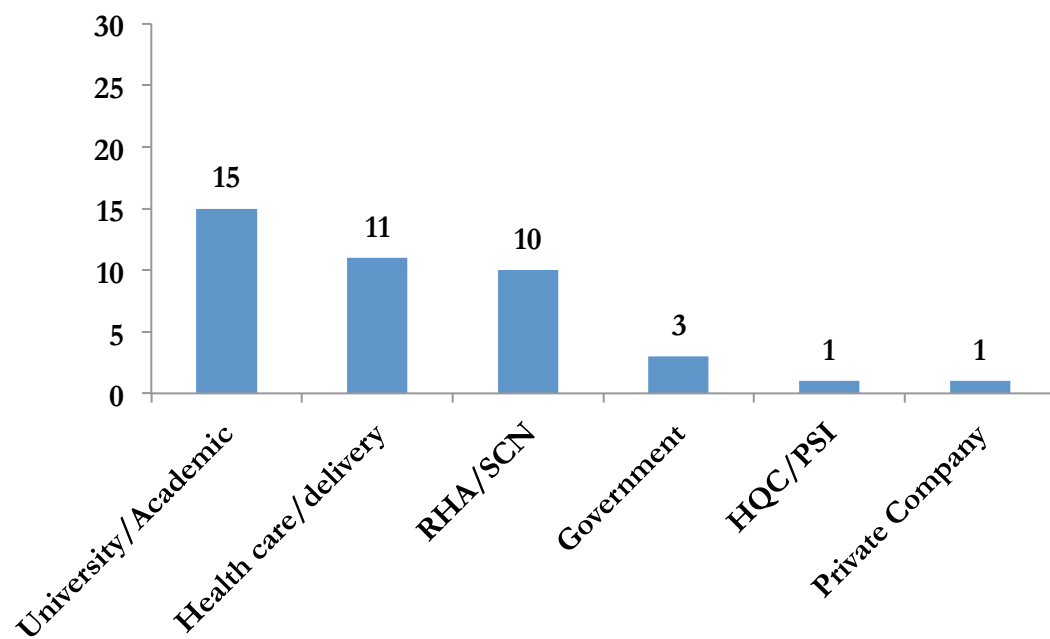
# Survey Components

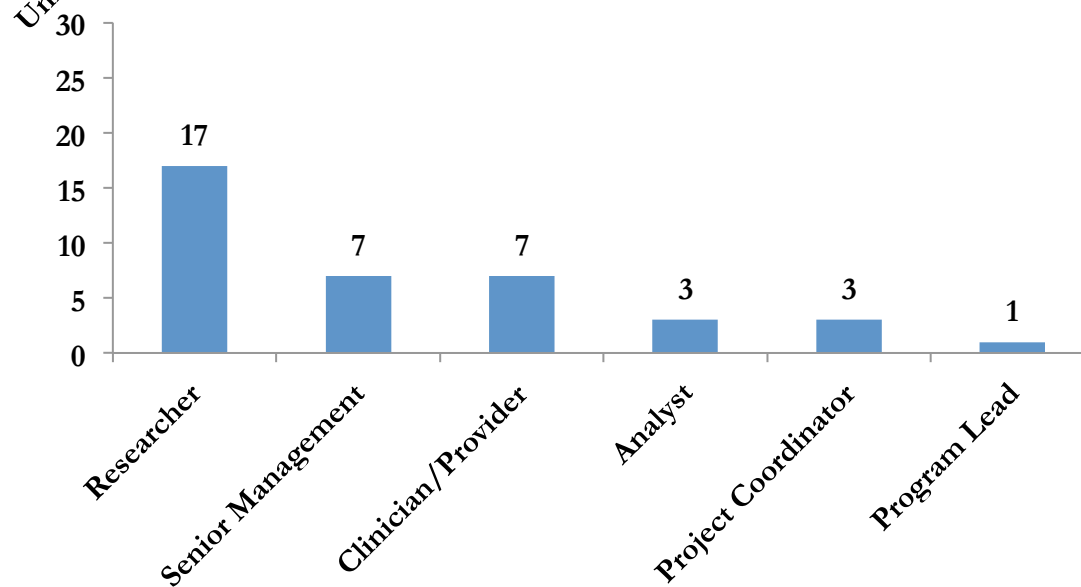
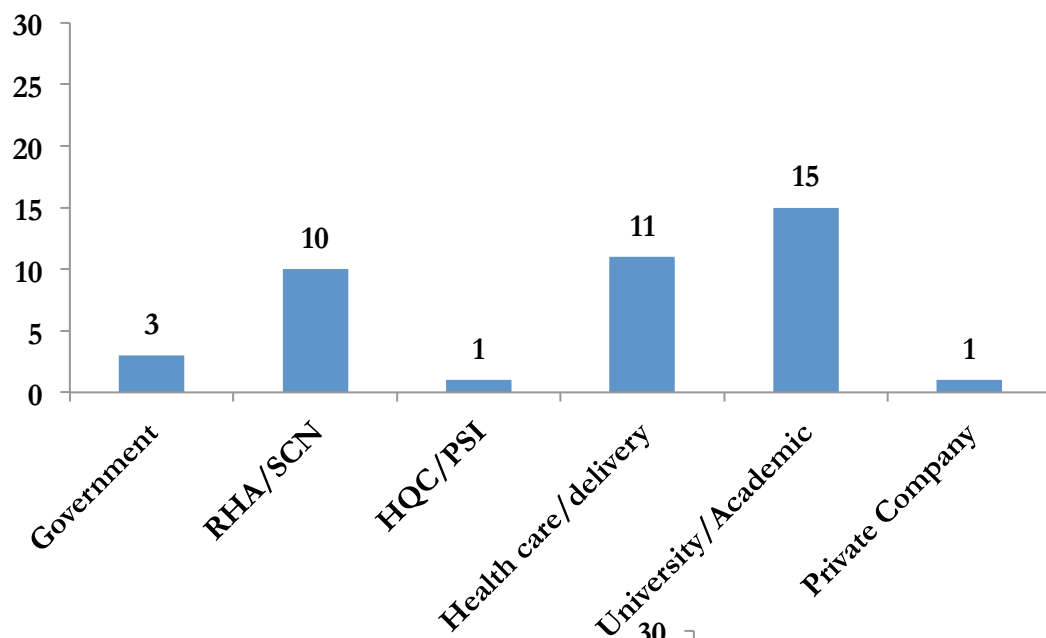
Component	Response categories
Data Dictionaries/Manuals available	Y/N
Reasons for data collection	<ul style="list-style-type: none"><li>• Research</li><li>• Quality Improvement</li><li>• Clinical Practice</li><li>• Administrative</li><li>• Other</li></ul>
How data is currently used	Free text
Outputs from the data	Free text
Additional documentation related to the data	Free text
Name of database	Free text
Contact/Principal Investigator of data	Free text



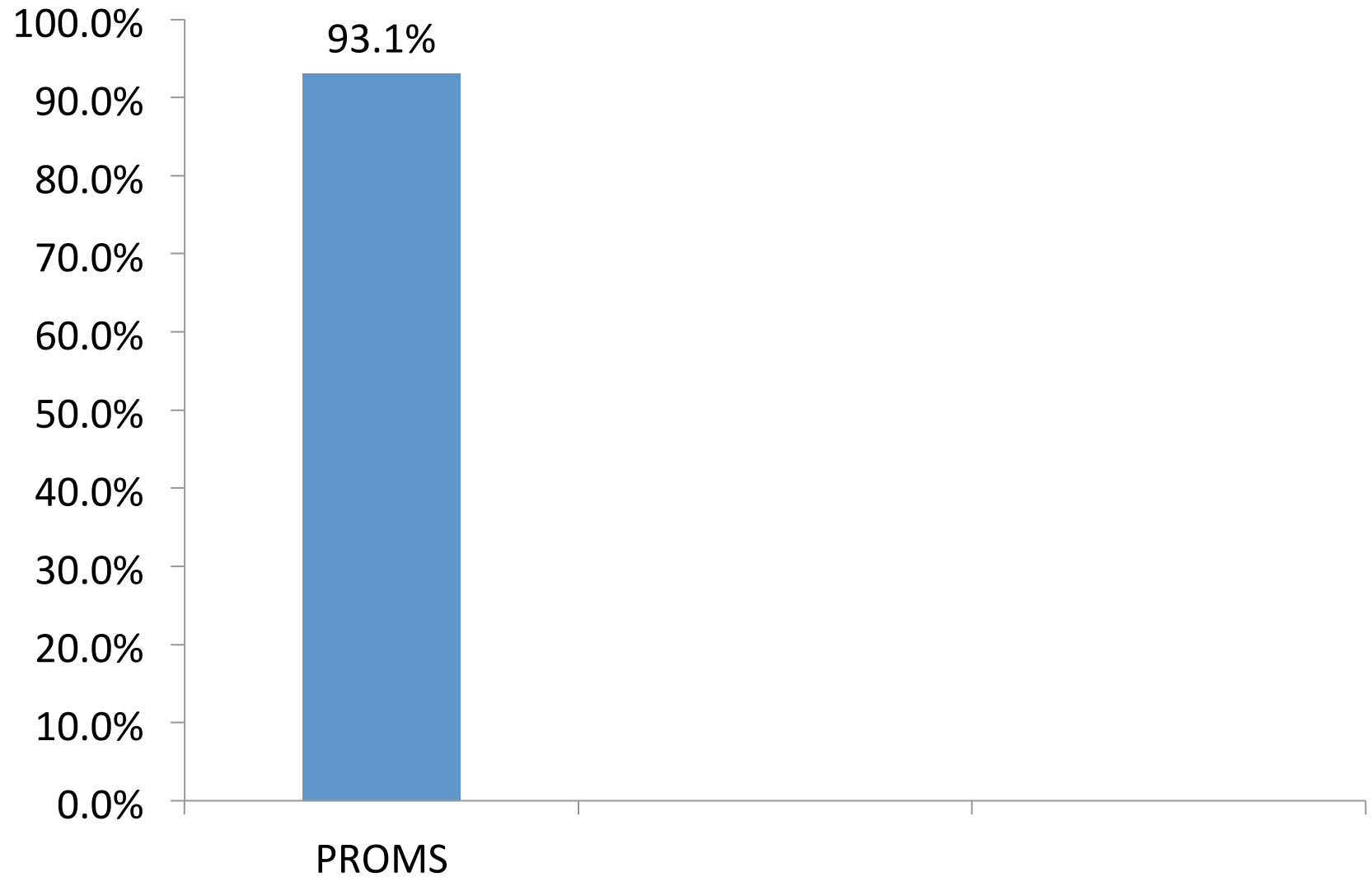
# Results

- We identified a list of 70 stakeholders to contact & reminder emails were sent to those who did not complete the survey.
- To date 32 participated in the survey, with 29 having identified as studying or collecting PROMs/PREMs.

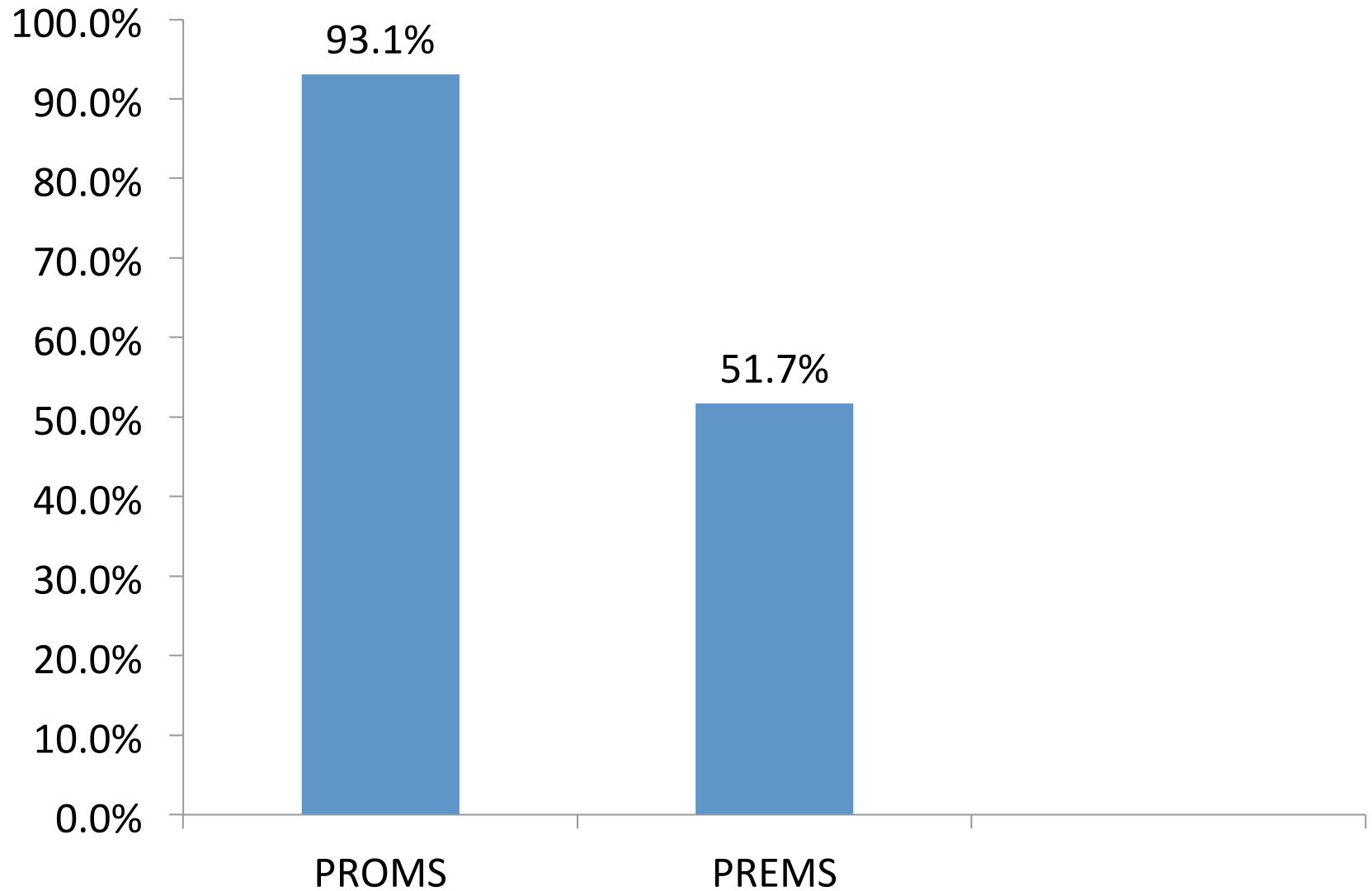




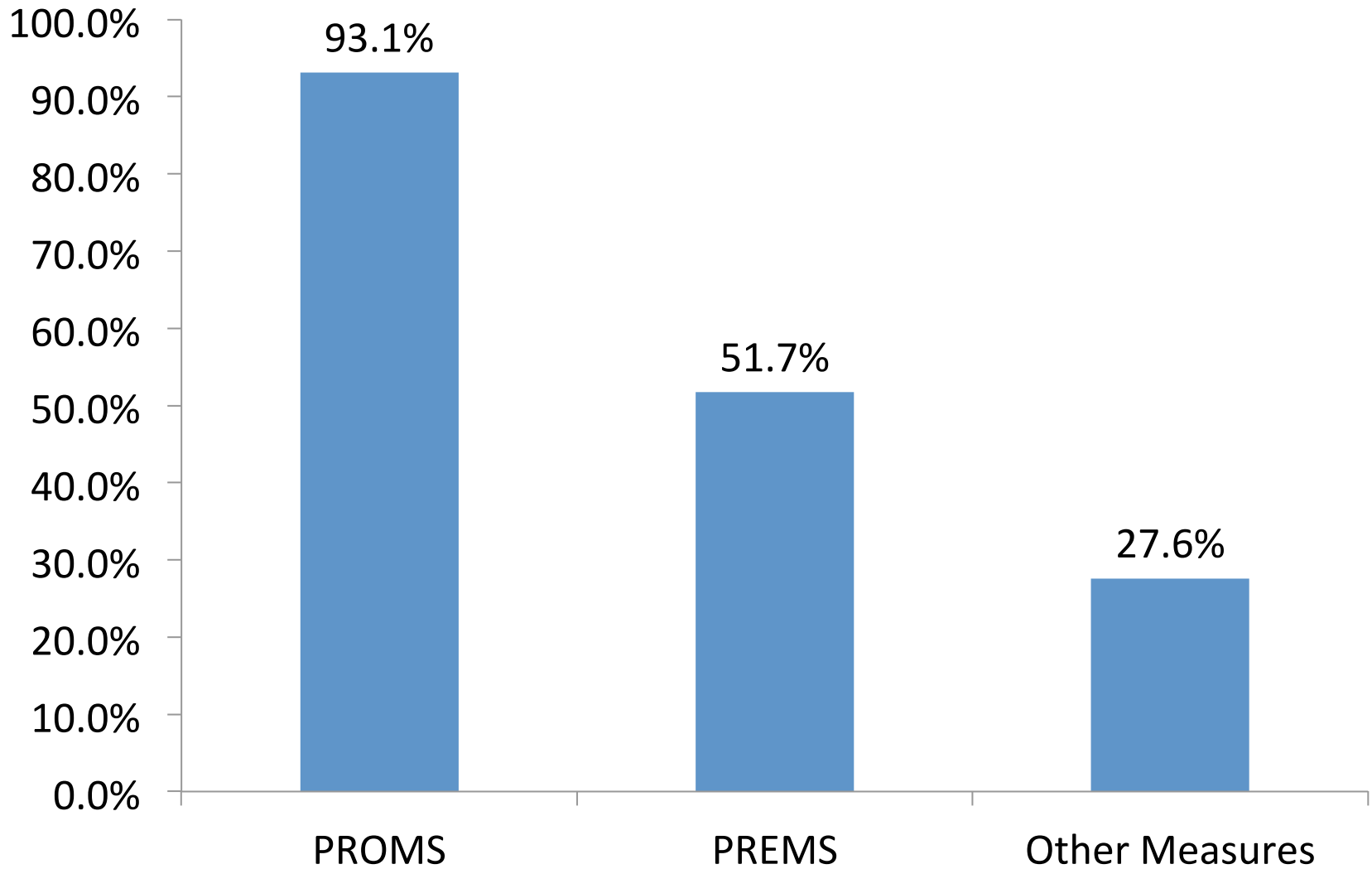
## PROMS/PREMs Collected



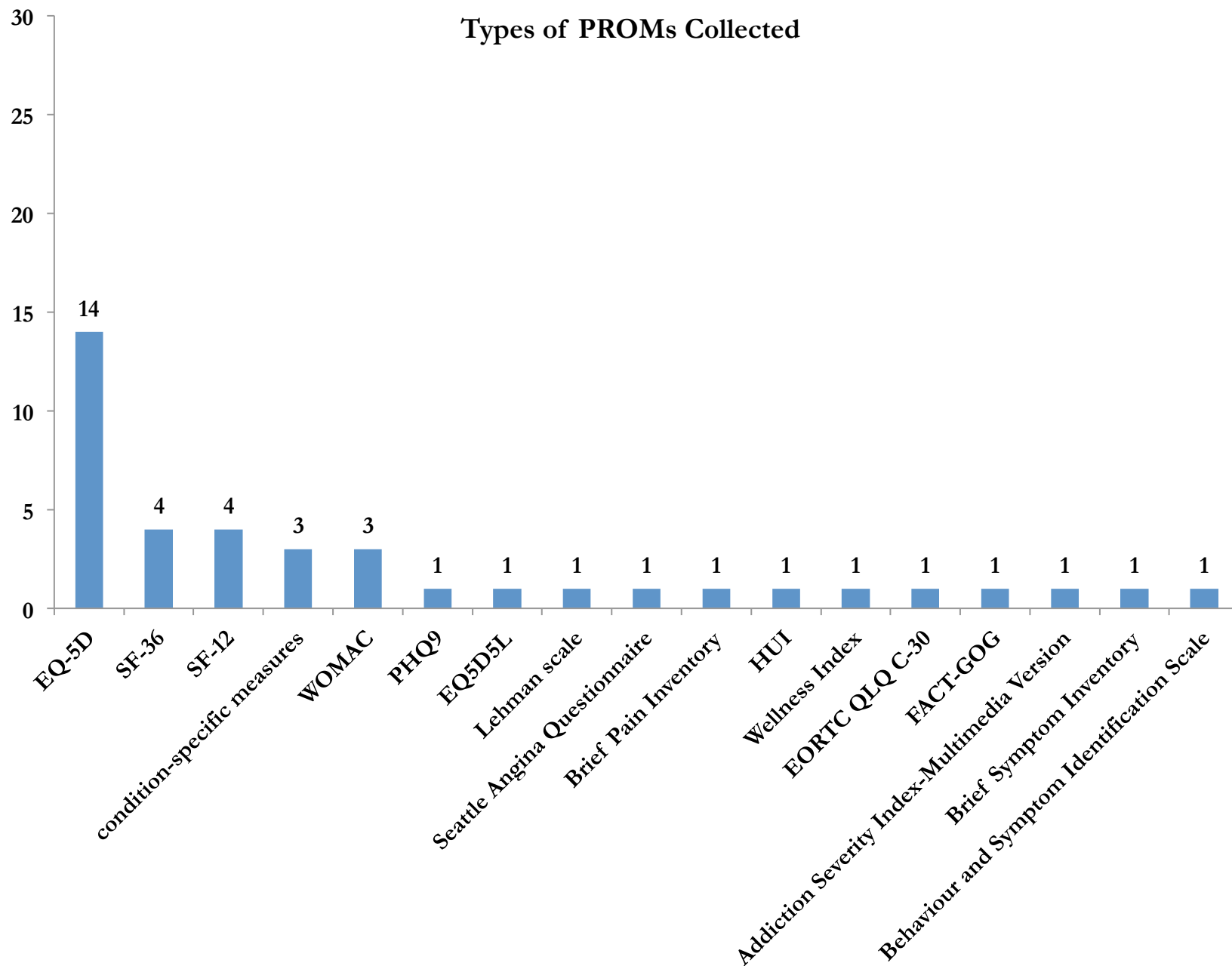
## PROMS/PREMs Collected



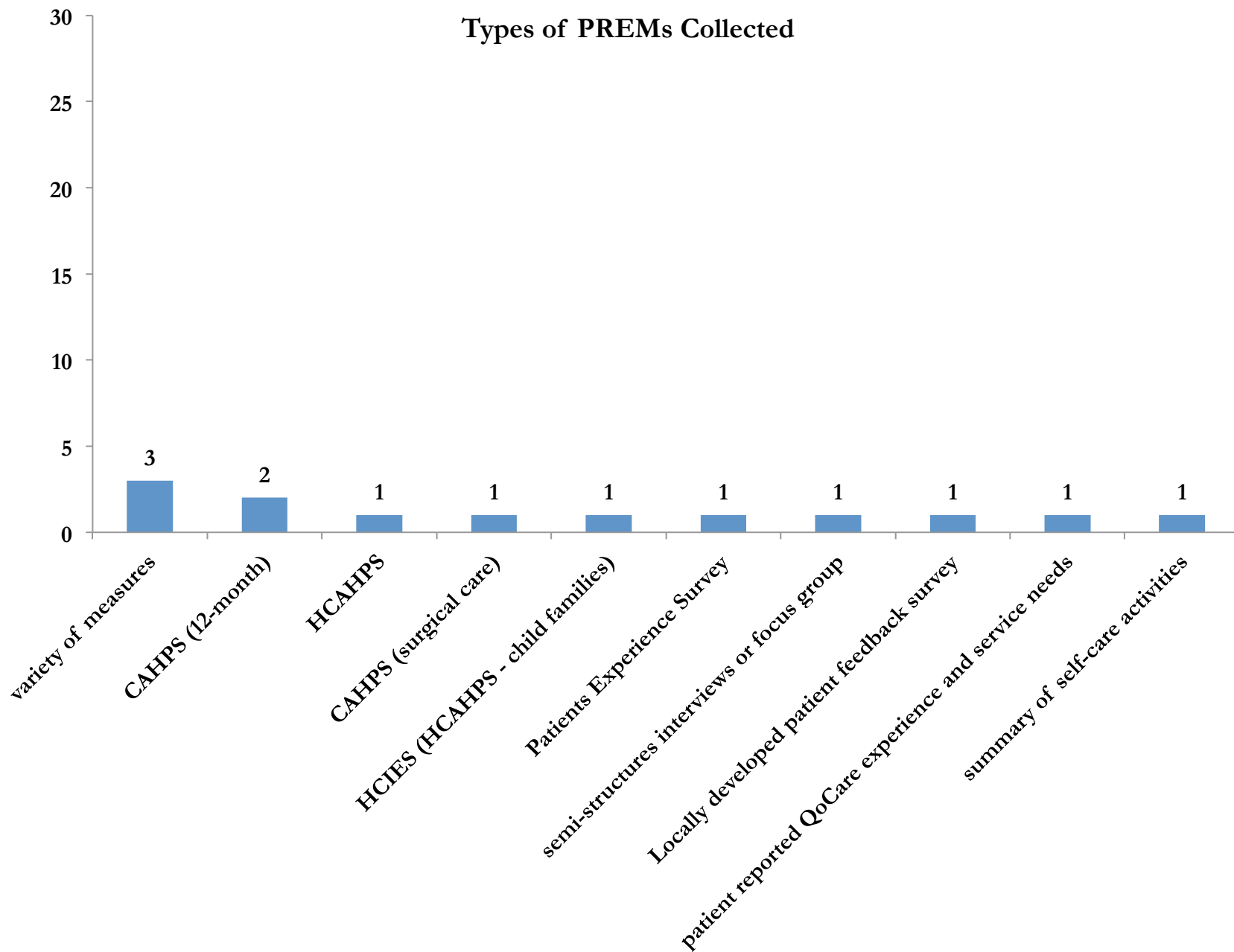
## PROMS/PREMs Collected



Types of PROMs Collected



## Types of PREMs Collected





# Collection Population

Diabetes

Elderly

Surgical patients

Emergency Department

COPD

Osteoarthritis

ICU

Chronic Pain

Hip & Knee patients (various subpopulations)

Cardiovascular

Patients who come in contact with SCN projects

Families w young children

Mentally disordered offenders

Patients receiving concurrent disorders treatment for addiction & mental  
health issues

Rheumatoid Arthritis

Children

Gynecologic cancer patients

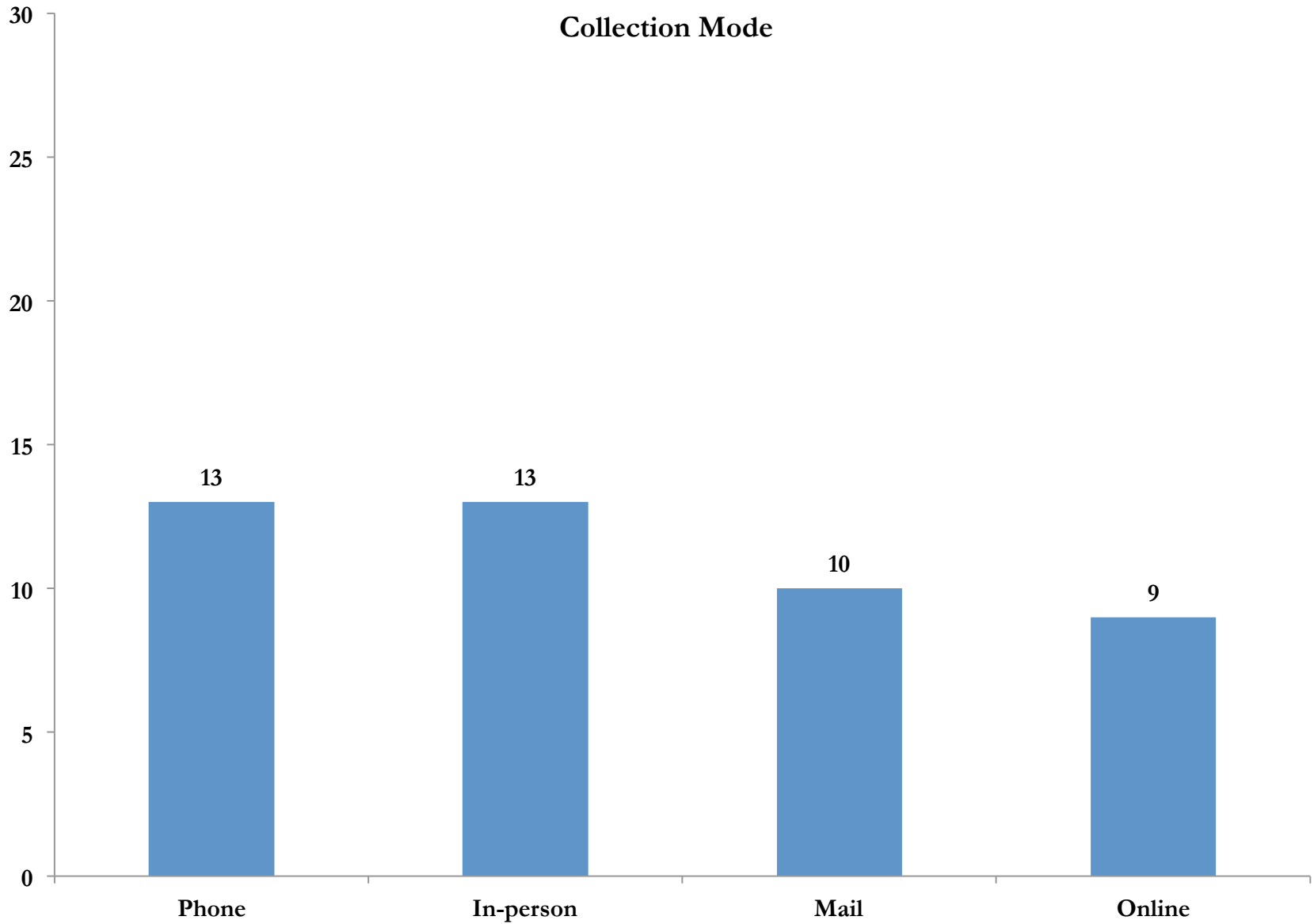
Chronic Disease

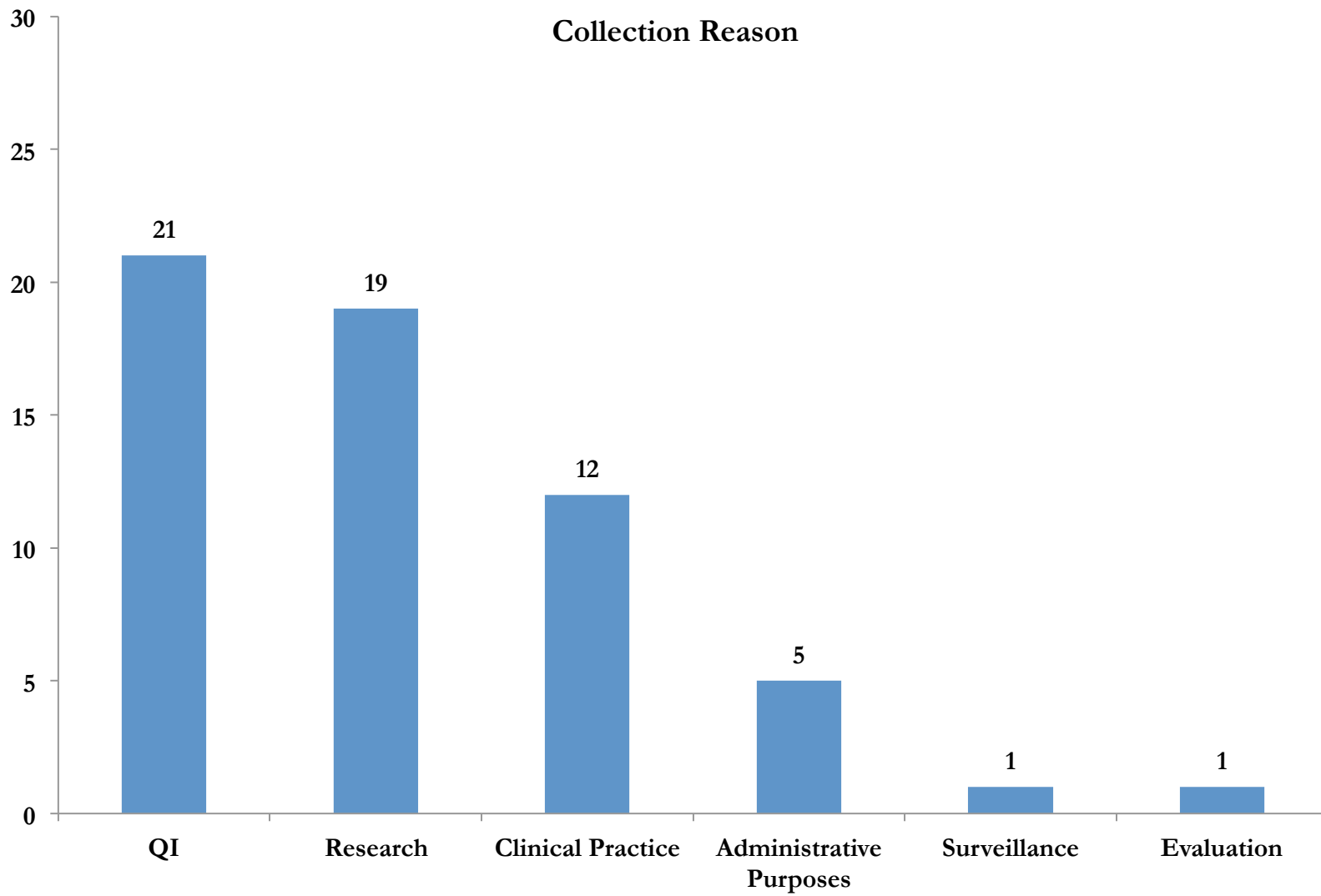
High Risk Patients (Framingham risk score, comorbidities)

Inpatients

Hospice patients Intensive Palliative Care Unit patients

**Collection Mode**





# Summary

- Much of the PROMS/PREMS work in Alberta is being done at universities & health care delivery organizations by researchers, managers & clinicians
- Most of the work is being done in PROMS with a smaller proportion being done in PREMS
- Measures collected are EQ5D & CAHPS
- Collection for QI or Research reasons

Database Example:

# APPROACH

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Alberta Provincial Project for  
Outcome Assessment in Coronary Heart Disease

# APPROACH Cohort

- Started as a Catheterization cohort (1995) & included all patients undergoing CATH in Alberta (PCI, CABG followed)
- Recently (2004) added ACS cohort in Southern Alberta – patients who arrive at a cardiac ward

# Data Collected

- Clinical information collected at time of CATH, PCI & CABG
- Admissions to cardiac wards in Southern AB
- Mortality on all patients in APPROACH
- Later procedures (PCI, CABG, CATH)
- Baseline, 1 year post-CATH, 3-year post-CATH & 5-year post CATH surveys mailed to patients with CAD

# Data Collected

- 1-year post-CATH date collection started in 1995
- 3-year post-CATH date collection started in 1998
- 5-year post CATH date collection started in 2000
- Baseline (within 1 week of CATH date) collection started in 2004



# Measures Collected

- *Seattle Angina Questionnaire*
- *EUROQOL EQ-5D Questionnaire*
- *QoL Scale (1-10)*
- *Hospital Anxiety & Depression (HAD) Scale*
- *Medical Outcomes Study (MOS) Social Support Survey*

# Additional Items

- Medications
- Smoking history
- Employment status
- Education status
- Ethnicity
- Languages spoken
- Consent for future studies

## Medical Outcomes Study (MOS) Social Support Survey

People sometimes look to other for compassionhip assistance, or other types of support.

How often is each of the following kinds of support available to you if you need it?

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
<b>Emotional</b>					
1. Someone you can count on to listen to you when you need to talk					
2. Someone to give you information to help you understand a situation					
3. Someone to give you good advice about a crisis					
4. Someone to confide in or talk to about yourself or your problems					
5. someone whose advice you really want					
6. someone to share your most private worries or fears					
7. Someone to turn to for suggestions about how to deal with a personal problem					
8. Someone who understands your problem					
<b>Tangible Support</b>					
9. Someone to help you if you were confine to bed					
10. Someone to take you to the doctor if you needed it					
11. Someone to prepare your meals if you were unable to do it yourself					
12. Someone to help with daily chores if you were sick					

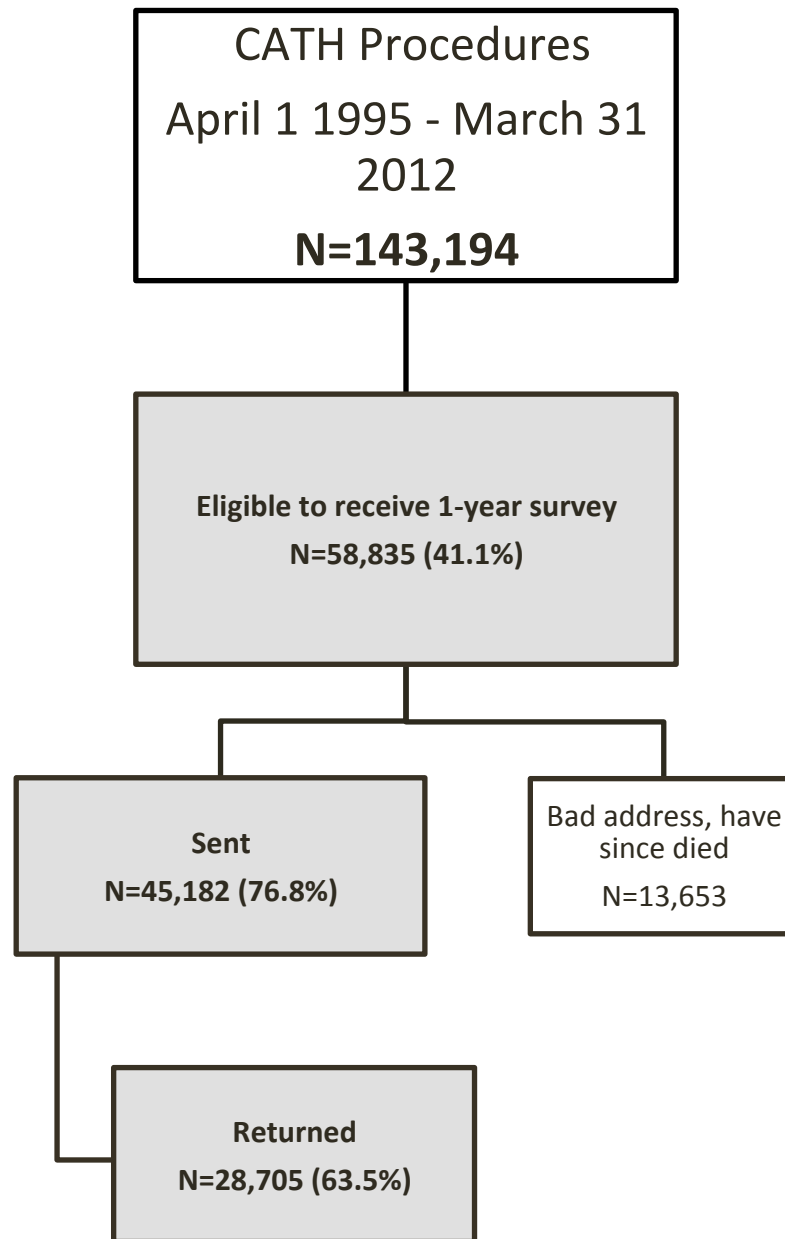
### Seattle Angina Questionnaire

*The following is a list of activities that people often do during the week. Although for some people with several medical problems it is difficult to determine what it is that limits them, please go over the activities listed below and indicate how much limitation you have had due to chest pain, chest tightness, shortness of breath or angina over the past 4 weeks*

<b>Activity</b>	<b>Extremely limited</b>	<b>Quite a bit limited</b>	<b>Moderately limited</b>	<b>Slightly limited</b>	<b>Not at all limited</b>	<b>Limited for other reason or did not do the activity</b>
<i>Dressing yourself</i>						
<i>Walking indoors on level ground</i>						
<i>Showering</i>						

# Survey Eligibility

- Patient must have a CATH procedure
- The patient has not died
- Patient has consented in APPROACH
- Extent of Native Coronary Artery Disease is ***NOT*** < 50%, Not Determined, and Angiographically Normal.
- Patient must be an Alberta patient



**1-year surveys**

**N=27,005**

**1-year surveys**

**N=27,005**

**3-year surveys**

**N=8,606**



**1-year surveys**

**N=27,005**

**3-year surveys**

**N=8,606**

**5-year surveys**

**N=4,579**

Baseline surveys

N=8,767

**1-year surveys**

**N=27,005**

3-year surveys

N=8,606

**5-year surveys**

**N=4,579**

# <http://www.approach.org/>

## The APPROACH Team

The following people administer the APPROACH project as directors, IT personnel, project managers, and researchers.



Merril Knudtson, MD  
Principal Investigator



Steve Wilton, MD, MSC  
Research Director



William Ghali, MD, MPH



Matt James, MD, PhD  
Research Director



Colleen Norris, MN, PhD  
Scientific Director SCN

Questions?