



Patient Reported Outcomes

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Beginnings of PRO

- Patient-reported outcomes measures (PROMs) are a critical component of assessing whether clinicians are improving the health of patients.
- Until now, state and federal governments as well as private payers attempting to assess outcomes have mostly relied on measures of avoidable readmissions, hospital-acquired infections, and mortality.
- Yet the ultimate measure of health system performance is whether it helps people recover from an acute illness, live well with a chronic condition, and face the end of life with dignity.

PRO

- Patient-reported measures are expected to play a more prominent role in assessing performance and determining the comparative effectiveness of different treatments, in part because of a growing emphasis on patient-centered care and value-based payment approaches.
- Health care providers participating in accountable care organizations will have to provide evidence that the care they've delivered produced value for the patient—as reported by the patient. The Department of Health and Human Services' Office of the National Coordinator for Health Information Technology also plans to incorporate PROMs into meaningful use standards, which is likely to prompt more widespread use.

Accountable Care Organization

- **What is an ACO?**
- An ACO is a group of health care providers that take responsibility for the total cost and quality of care for their patients, and in exchange they can receive a portion of the savings they achieve, according to CMS.
- The Mayo Clinic Community ACO includes Mayo Clinic in Rochester and all Mayo Clinic Health System regions. Last year was the first time Mayo Clinic has participated in a Medicare ACO program. Mayo Clinic Community ACO provided care for about 57,000 Medicare beneficiaries assigned by CMS.
- **Quality measures for an ACO**
- In addition to the savings achieved, the ACO is assessed by CMS on quality performance in the following categories: patient experience (10 measures), care coordination and safety (4 measures), preventive health (6 measures) and care for at-risk populations (3 measures).

Quality External Rankings

	USNews Honor Roll Rank	CMS Stars Overall Stars	HCAHPS Stars	LeapFrog Safety Grade	Vizient Top Decile
Target:	50 or Above	4 or 5	4 or 5	A	90 or 75
Latest Reporting Date:	2020	January 2020	10/1/2020	Fall 2020	2020
Arizona	16	★★★★★	★★★★★	A	91
Florida	28	★★★★★	★★★★	A	99
Rochester	1	★★★★★	★★★★★	A	98
Albert Lea & Austin		★★★★	★★★	B	71
Eau Claire		★★★★★	★★★★	B	73
Fairmont		★★★★	★★★		87
La Crosse		★★★★★	★★★★	A	96
Mankato		★★★★	★★★	B	81
Red Wing		★★★★	★★★★★	A	99
Barron		★★★★	★★★★		



Quality, Experience & Affordability



Region Performance with Selected Measures by Selected Month

January 2021

Mayo Clinic Confidential
Data Extracted 2/7/2021 10:05:18 AM

Measure	MCHS MN	MCHS WI	NWWI	Rochester	Rochester ECH	SEMN	SWMN	SWWI
MSSP ACO Web Interface Adult Depression Remission at Twelve Months	16.78%	12.49%	13.12%	22.43%	22.43%	14.34%	20.41%	11.48%
MSSP ACO Web Interface DM: Hemoglobin A1c Poor Control (Lower is Better)	13.13%	14.56%	15.83%	14.52%	14.55%	14.43%	11.43%	12.99%
MSSP ACO Web Interface Falls: Screening for Future Fall Risk	95.45%	95.98%	96.16%	93.83%	93.80%	94.73%	96.36%	95.76%
MSSP ACO Web Interface Hypertension: Controlling High Blood Pressure	74.23%	78.93%	76.21%	65.54%	65.52%	69.52%	81.01%	82.18%
MSSP ACO Web Interface PREV: Breast Cancer Screening	82.85%	84.18%	81.97%	89.13%	89.09%	80.19%	86.37%	86.92%
MSSP ACO Web Interface PREV: Colorectal Cancer Screening	79.71%	80.74%	80.05%	86.97%	86.92%	77.06%	83.11%	81.60%
MSSP ACO Web Interface PREV: Influenza Immunization	17.85%	17.68%	17.76%	14.30%	14.35%	16.19%	19.97%	17.58%
MSSP ACO Web Interface PREV: Screening for Clinical Depression & Follow-up Plan	69.76%	71.36%	70.02%	61.77%	62.20%	68.45%	71.36%	73.07%
MSSP ACO Web Interface PREV: Tobacco Use: Cessation Intervention	77.15%	78.63%	83.85%	70.64%	70.58%	73.39%	82.38%	72.85%
MSSP ACO Web Interface PREV: Tobacco Use: Screening	99.83%	99.86%	99.87%	99.42%	99.41%	99.73%	99.95%	99.85%
MSSP ACO Web Interface PREV: Tobacco Use: Screening & Cessation Intervention	97.64%	97.19%	97.98%	97.83%	97.82%	97.07%	98.36%	96.18%
MSSP ACO Web Interface Statin Therapy for the Prevention and Treatment of Cardiovascular Disease	85.11%	83.55%	83.70%	84.62%	84.67%	84.09%	86.41%	83.40%

Why PRO

- The 2015 **Medicare Access and Children's Health Insurance Program Reauthorization Act**, (**MACRA** also known as the Permanent Doc Fix) providers will be evaluated based on quality and cost efficiency and ultimately receive adjusted reimbursement as per their performance.
- **MACRA included several provisions, some of which include:**
 - Repeals the sustainable growth rate (SGR) methodology for determining updates to the Medicare fee schedule.
 - Establishes two new payment tracks: the Merit-based Incentive Payment System (MIPS) that retains FFS but consolidates existing Medicare quality programs.

Why PRO?

- **MACRA replaces** the current Medicare reimbursement schedule with a new pay-for-performance program that's focused on quality, value, and accountability.
- MACRA related regulations also address incentives for use of health information technology by physicians and other providers. It created the Medicare Quality Payment Program.
- Clinicians can choose to participate in the Quality Payment Program through the Merit-based Incentive Payment System (MIPS) or Advanced Alternative Payment Models (APMs)

PRO Impact	Patient	Clinical Provider	Academic Researcher	Institution/ Employer/ Organization	Payer	Research Funding Agency	Regulatory Agency
Evaluation of Novel Treatments	X	X	X		X	X	X
Shared Decision Making	X	X					
Evaluating Provider Performance	X	X		X	X		
Determining Treatment effectiveness	X	X	X		X	X	
System Level Quality Improvement		X		X	X		

Reported Outcomes

- Clinician Reported
 - Performance of the patient
- Caregiver Reported
 - Functional Status
- Patient Reported
 - Symptoms

General Advantages of PRO

- Can Measure Swallowing, Speech,
- Psychological Well Being
- Social Well Being
- Cognitive Functioning
- Give Indications for specific clinical trials

Advantages of PRO for Patients with Head and Neck Cancer

- Determining negative effects of Radiation/Chemotherapy
- Identifying Need for Supportive/Palliative Care
- Comparing 2 standard therapies for similar survival outcome
- To find out if a new therapy is superior to standard therapy
- To find out if a specific therapy is better than supportive care alone when survival time is short
- Targeting Problems and making communication easier in clinical practice

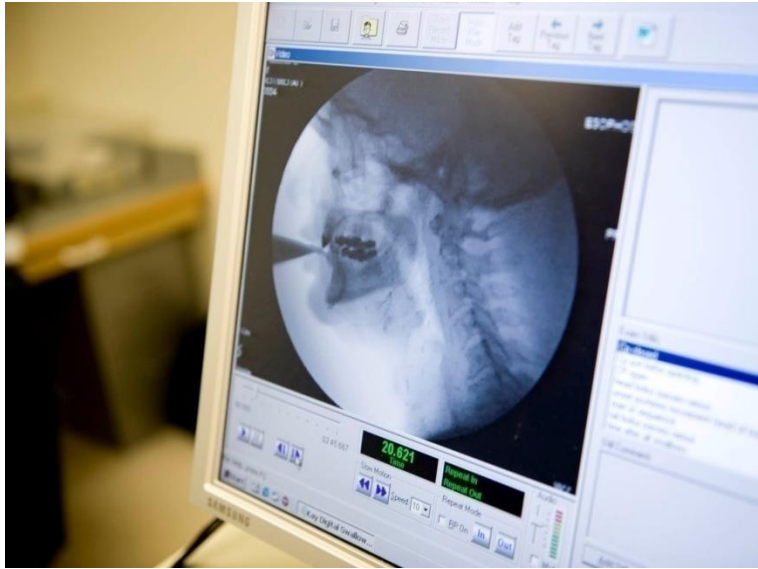
Head and Neck Research Network Edmonton 33

www.hnrn.org

Objectives

- To be a clinical research network that studies functional outcomes in individuals with defects of the head and neck
- To maintain an international database
- To study longitudinal outcomes in all head and neck patient groups

Data on functional outcomes

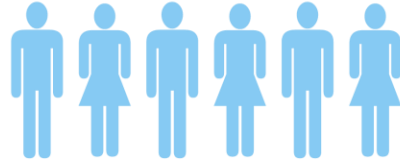


- Systematic
- Standardized
- PRO
 - Edmonton 33

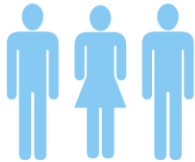


NETWORK DIRECTOR

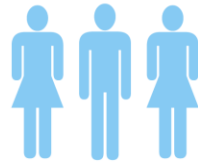
CORE TEAM



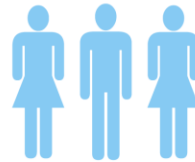
**Management
Committee**



**Research
Committee**



**Quality
Assurance
& Database
Committee**



NETWORK



Team Sites

Edmonton (AB, Canada)

Turku (Finland)

Gainesville (FL, USA)

Calgary (AB, Canada)

Infrastructure

- Collaboration Agreements
- Inter-Institutional Agreements
- Policies and Procedures Manual
- Terms of Reference and processes for all committees
- Program Coordinator manual
- A core set of variables

HNRN database

The screenshot displays the HNRN (Head & Neck Research Network) database interface. At the top, there's a title bar with 'CCM' and window controls. Below it, a navigation bar includes 'Patient Manager', 'Clinic Manager', and 'Reporter'. A large banner features the HNRN logo and the text 'Head & Neck Research Network'. The main interface is divided into two primary sections: 'Patient' and 'Appointments'. The 'Appointments' section is active, showing a list of appointments on the left and a detailed form on the right. The appointment list includes categories like 'head and neck', '1 month', '1 year', '6 month/postRT', 'pre-op/RT', 'intra-oral implant', 'Other', 'prosthetic', and 'trauma'. The detailed form on the right has tabs for 'General', 'Background', 'Mastication', 'Tongue Function', 'Swallowing', 'QoL', and 'Speech'. The 'General' tab is selected, showing fields for 'G-Tube' (Yes/No), 'Weight' (77.0 kg, 169.4 lbs), 'Height' (191.0 cm, 75.2 inches), 'Diet' (Liquid, Pureed, Soft/Solid, Mechanical soft/Mixed, Diced, Normal, Not Recorded), and 'Fluids' (Level 1 [nectar], Level 2 [honey], Thin, Not Recorded). The 'Appointment Name' is '1 month', 'Appointment Category' is 'head and neck', 'Appointment Date' is '10/20/2009', 'Next Appointment's Date' is '3/16/2010', and 'Appointment Missed' is 'Completed'.

CCM

Patient Manager Clinic Manager Reporter

HNRN
Head & Neck Research Network

Patient Appointments

New Patient Open Patient Save Patient Delete Patient Edit List Values Help

Appointments:

- head and neck
- 1 month
- 1 year
- 6 month/postRT
- pre-op/RT
- intra-oral implant
- Other
- prosthetic
- trauma

Add Delete

Appointment Name:
1 month

Appointment Category:
head and neck

Appointment Date:
10/20/2009

Next Appointment's Date:
3/16/2010

Appointment Missed:
Completed

General Background Mastication Tongue Function Swallowing QoL Speech

General Liquid Pudding Cookie MBSImP

G-Tube ☐ Yes ☒ No

Weight kg
 lbs

Height cm
 inches

Diet ☐ Liquid
☐ Pureed
☐ Soft/Solid
☐ Mechanical soft/Mixed
☐ Diced
☒ Normal
☐ Not Recorded


Fluids ☐ Level 1 [nectar]
☐ Level 2 [honey]
☒ Thin
☐ Not Recorded

HNRRN database

General		Background		Mastication		Tongue Function		Swallowing		QoL		Speech		Prosthetic		Research Studies	
QoL Scores		QoL EORTC 35		QoL EORTC 30		QoL MDADI		QoL OFS		QoL VHI		QoL Economic Outcomes PreTM		QoL Economic Outcomes PostTM		Speech Handicap Index	
																OHIP	
																EAT-10	
																Performance Status Scale	
MDADI		EORTC35				VHI											
Global Score	5	Pain	8			Total Score											
Emotional Score	100	Swallowing	0			Oral Health Impact Profile											
Functional Score	100	Senses problems	0			Functional limitation											
Physical Score	100	Speech problems	0			Physical pain											
		Trouble with social eating	0			Psychological discomfort											
		Trouble with social contact	0			Physical disability											
		Less sexuality	0			Psychological disability											
		Teeth	0			Social disability											
		Opening mouth	0			Handicap											
		Dry mouth	0			Total Score											
		Sticky saliva	0			Eating Assessment Tool											
		Coughing	0			Total score											
		Felt ill	0			Karnofsky Performance Scale Index											
		Pain killers	0			Total score											
		Nutritional supplements	0			Performance Status Scale for Head and Neck Cancer											
		Feeding tube	0			Normalcy of Diet											
		Weight loss	0			Eating in Public											
		Weight gain	0			Understandability of Speech											

HNRN database

[Patient Manager](#)
[Clinic Manager](#)
[Reporter](#)



[New Patient](#)
[Open Patient](#)
[Save Patient](#)
[Delete Patient](#)
[Edit List Values](#)
[Help](#)

[Patient](#)
[Appointments](#)

[General](#)
[Diagnosis/Treatment](#)
[Surgery](#)
[Radiation](#)
[Chemo](#)
[Prosthetic](#)

[General](#)
[Face](#)
[Mandible](#)
[FGH](#)
[Mouth](#)
[Tongue Depth](#)
[Laryngopharynx](#)

Chart Number:

First Name:

Last Name:

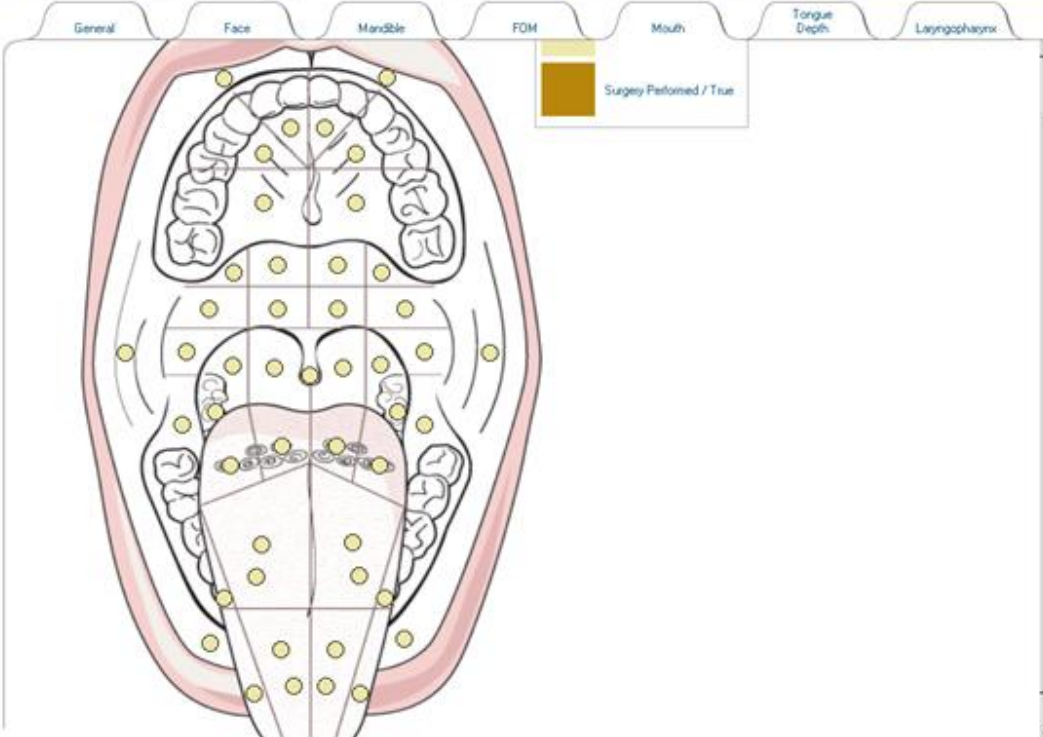
Date of Birth:

Gender:

Inactive:

Treatment Completed:

Photo:



HNRN Web Portal



Local data

Submit Data

- ✓ Seen after 2009
- ✓ Consented to be participate in HNRN study

Submitted data

- ✓ De-personalize
- ✓ Assign ID

sent

De-personalized data

receive

De-personalized data

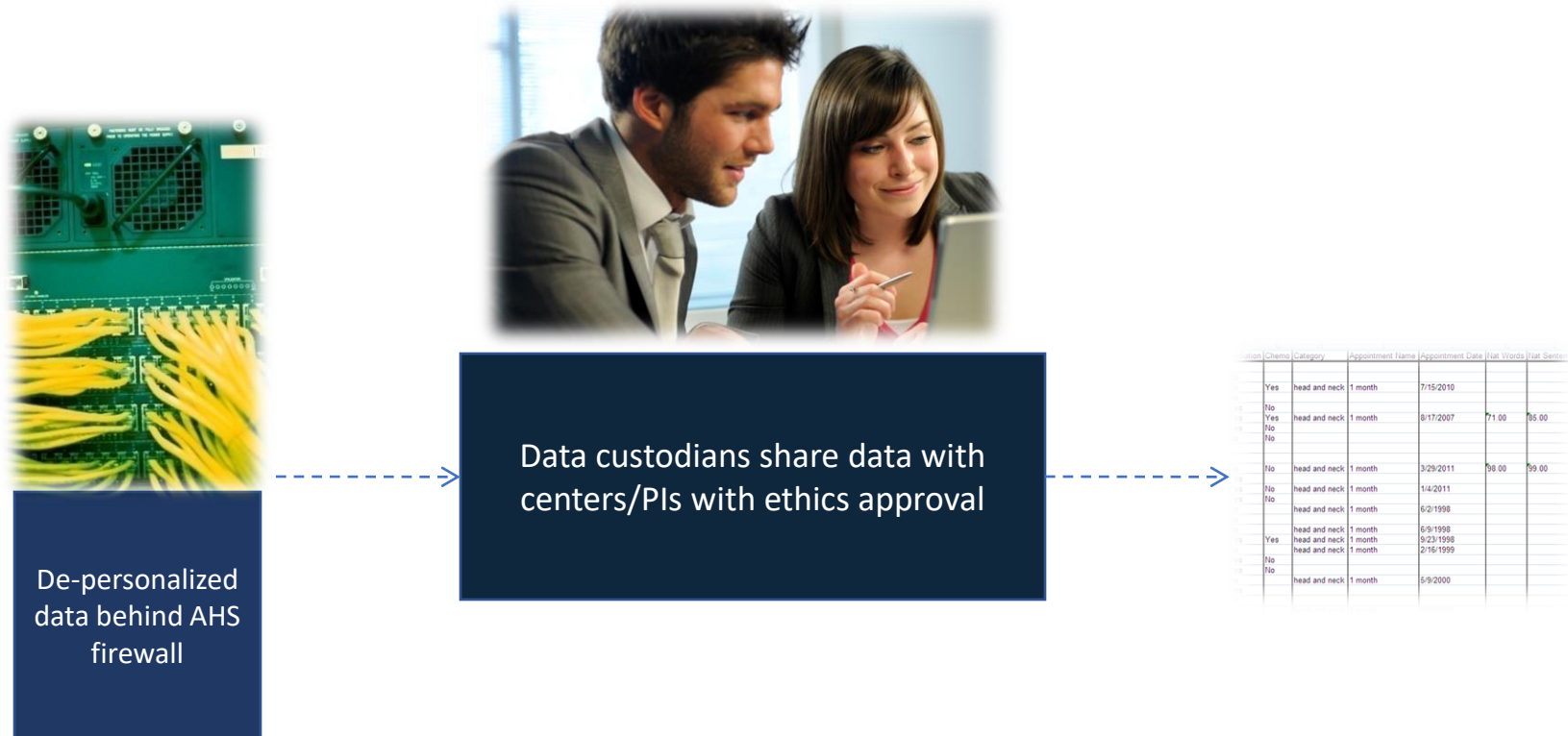
De-personalized data

De-personalized data

De-personalized data



HNRRN data retrieval



Edmonton 33

Adrian Mendez

Patient Centered Functional Outcomes in Head and Neck Oncology Patients

A.I. Mendez, D. Côté, J. Wolfaardt, D. O'Connell, H. El-Hakim,
M. Urken, C. Lazarus, J. Rieger, D. Eurich, H. Seikaly

Edmonton-33



Swallowing assessment

Speech assessment

E-33

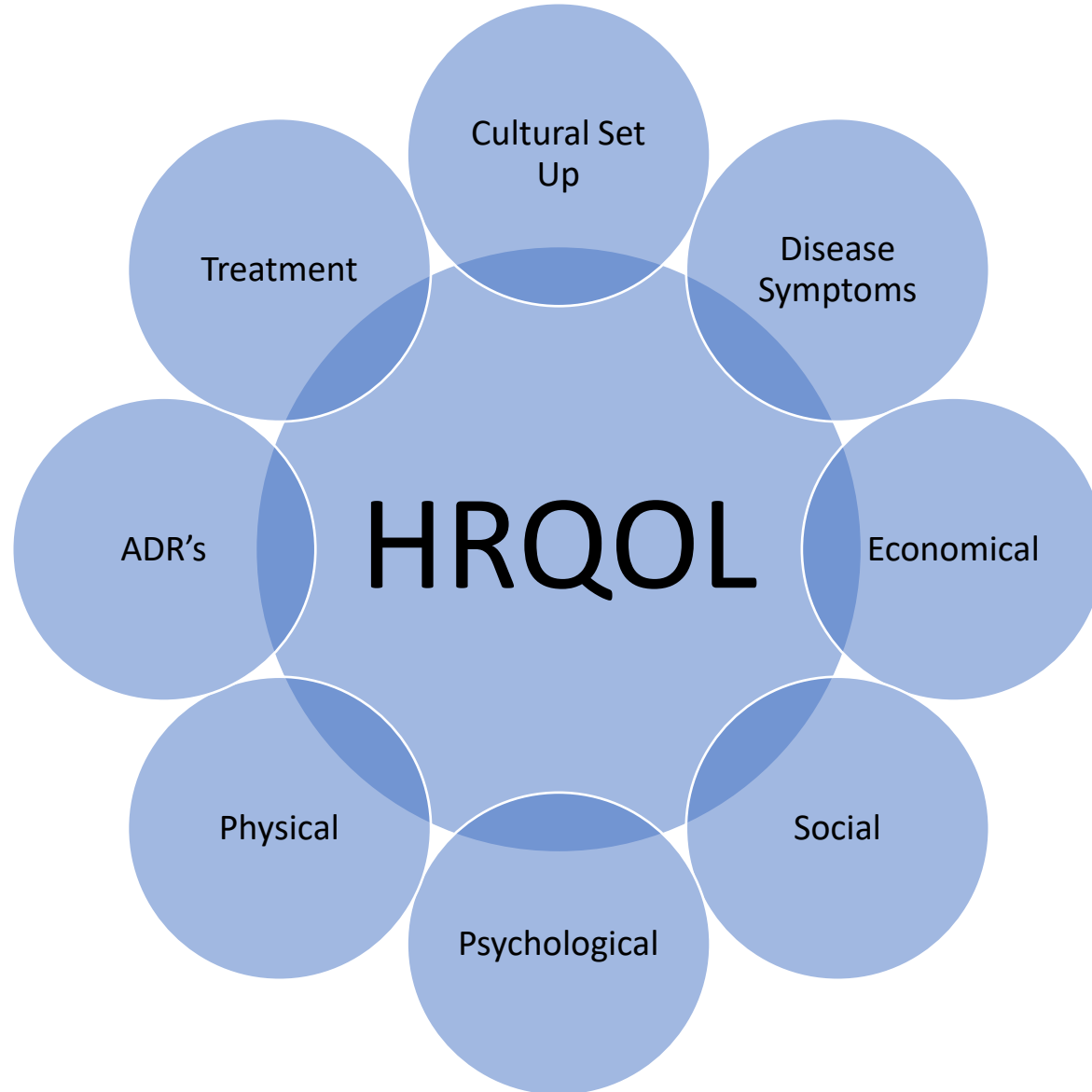
Chewing assessment

Salivary assessment

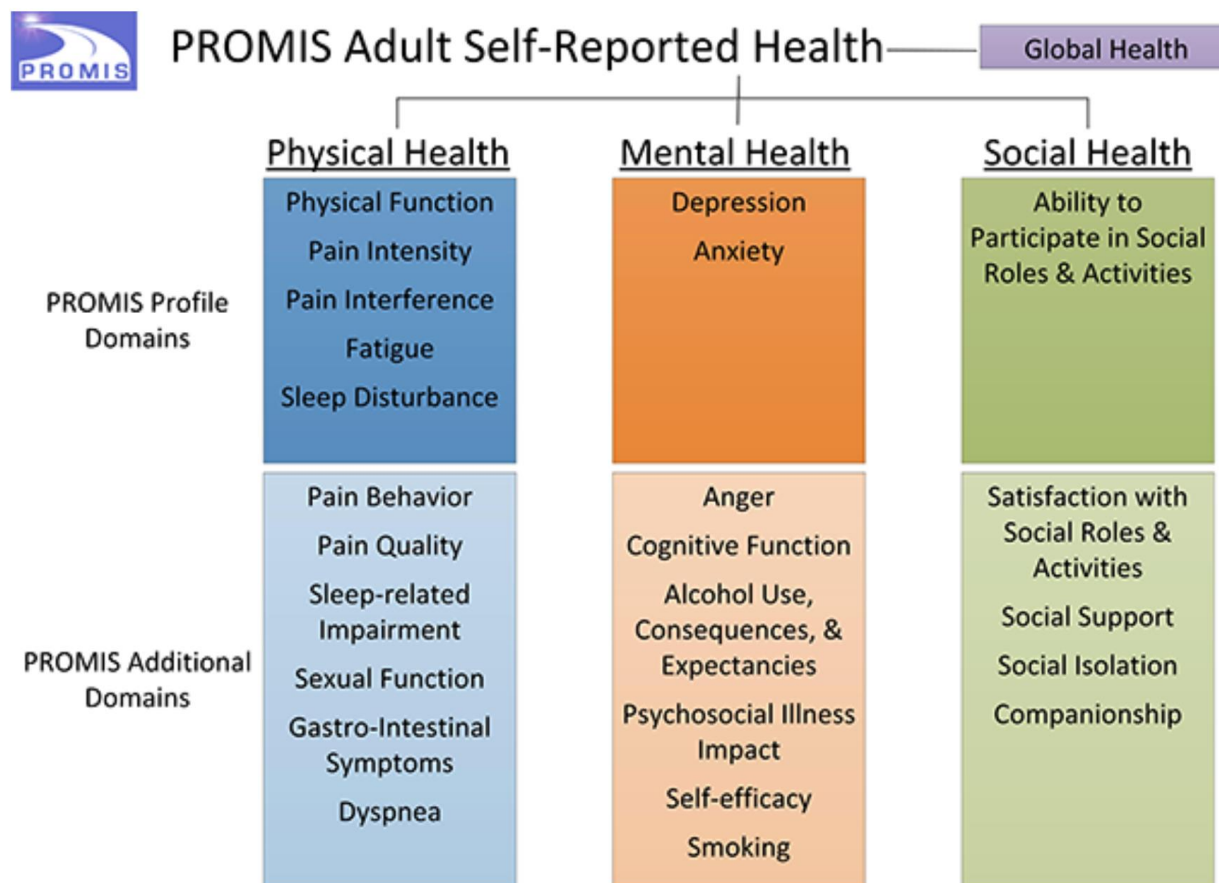
www.hnrrn.org

<https://irsmyeg.ca>

Health Related Quality of Life



Patient Reported Outcomes Measurement Information System



Common Measurement of PROMIS domains

- The measures, which are in the public domain for use by researchers and health care organizations, were developed across several different domains of well-being, such as
 - pain,
 - fatigue,
 - depression, and
 - social or physical functioning.
- Each domain includes several items from which users can select the most appropriate type and number, and then roll up to create an overall score—allowing for flexibility in use for different conditions and enabling computerized-adaptive testing, in which patients are given the most appropriate questions, based on their answers to previous questions.

Types of Instruments

- General (Psychologic Well Being Index)
- Disease Specific (University of Washington Head and Neck QOL (UW-QOL))
- Dimension Specific (Physical Activity Index) PAI
- Region Site specific (MD Anderson Symptom Inventory-head and Neck (MDASI-HN))
- Individualized

Instruments used to establish relative baseline functioning:

- MD Anderson Symptom Inventory-head and Neck (MDASI-HN)
- Patient Concern Inventory (PCI)
- Head and Neck Cancer Inventory
- University of Washington Head and Neck QOL (UW-QOL)
- Vanderbilt Head and Neck Symptom Survey



<http://www.omeract.org>

Mission Statement

OMERACT, through a data driven multi-stakeholder consensus process, strives to identify and improve relevant health outcome domains, endorsing valid, responsive, feasible health outcome measures in patients with musculoskeletal conditions.



OMERACT Filter Process in Creating Core Domain Sets

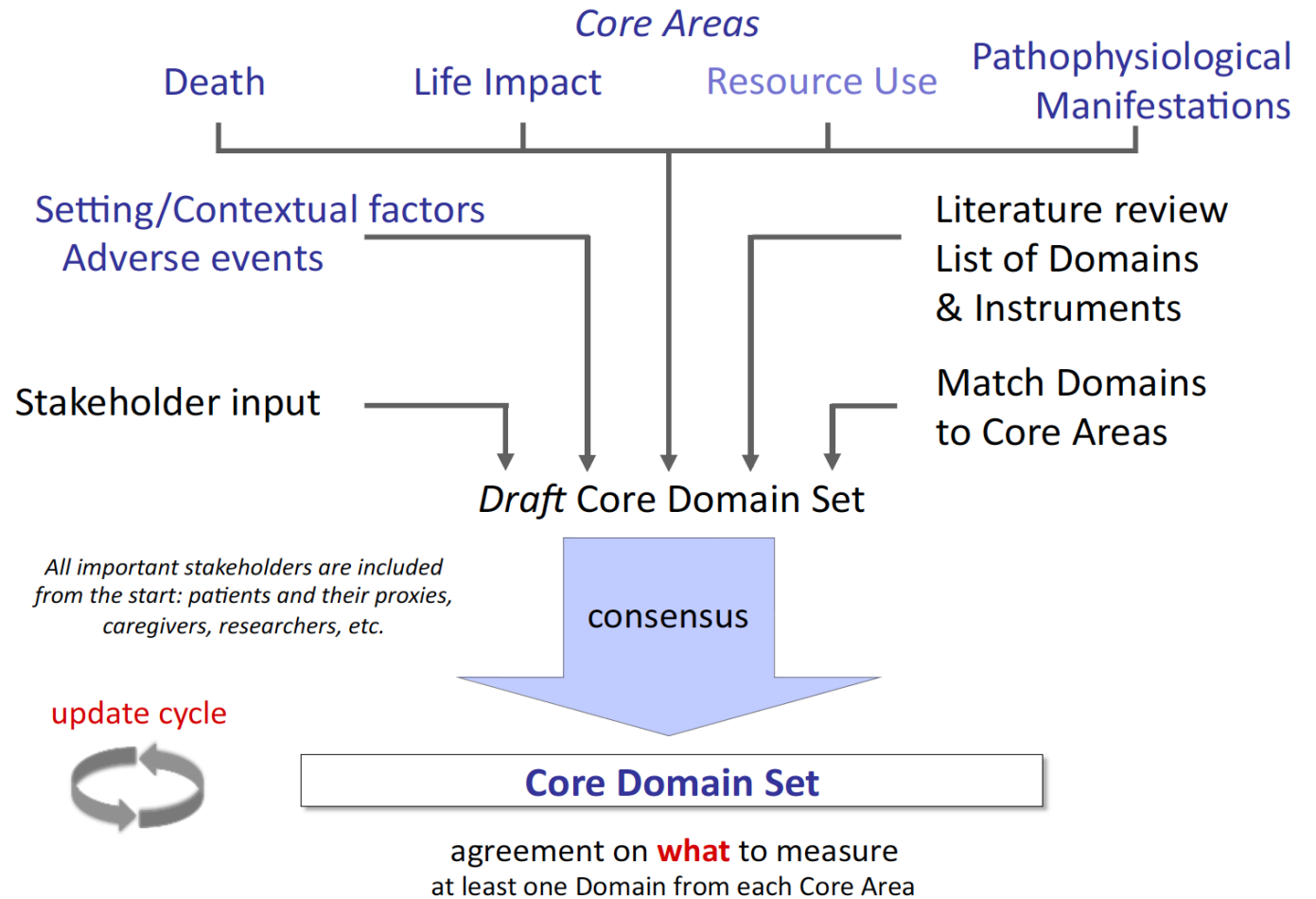


Fig 2.2: OMERACT Filter 2.0 Developing a Core Domain Set

Core Outcome Measures in Effectiveness Trials

- <https://www.comet-initiative.org/>

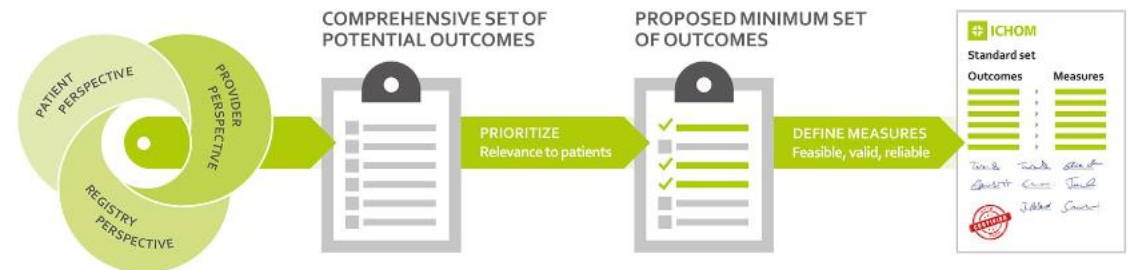
PROMIS
PCORI
OMERACT

- The issue is here is a struggle or disagreement between these instruments. Kirwan and Nowell, J. Rhem 38(8): 1699-1701), defined an approach:
- **Define the domains of interest, develop a questionnaire, validate the instrument with cognitive interviewing.**

International Consortium for Health Outcomes Measurement (ICHOM)

- ICHOM seeks to help standardize and align outcome measurement efforts globally.
- Standardization and alignment of this sort does not exist for head and neck cancer.
- Cleft Palate and Adult Oral Health are standard sets that are established.
- ICHOM hopes this standardization effort will increase quality and value in oral health care.

<https://www.ichom.org/portfolio/oral-health/>

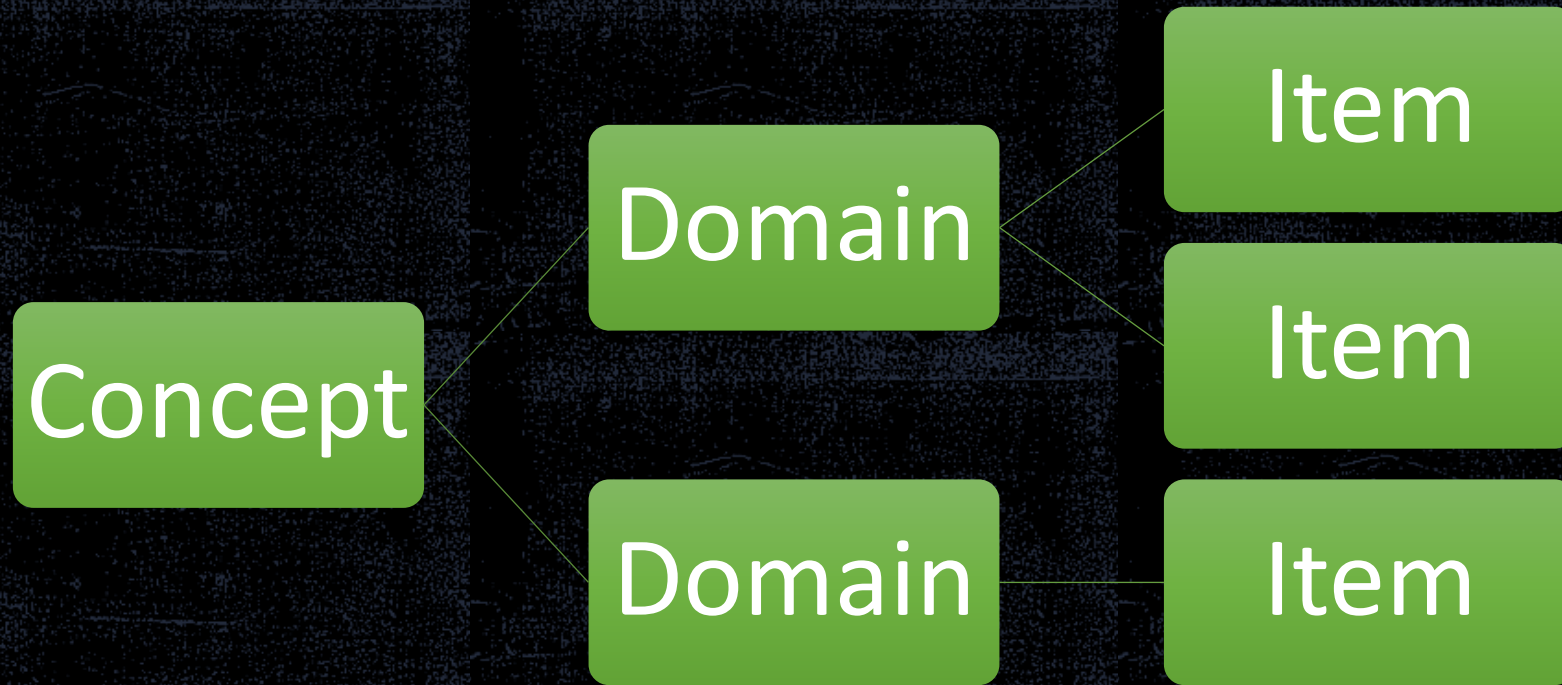


Face Q

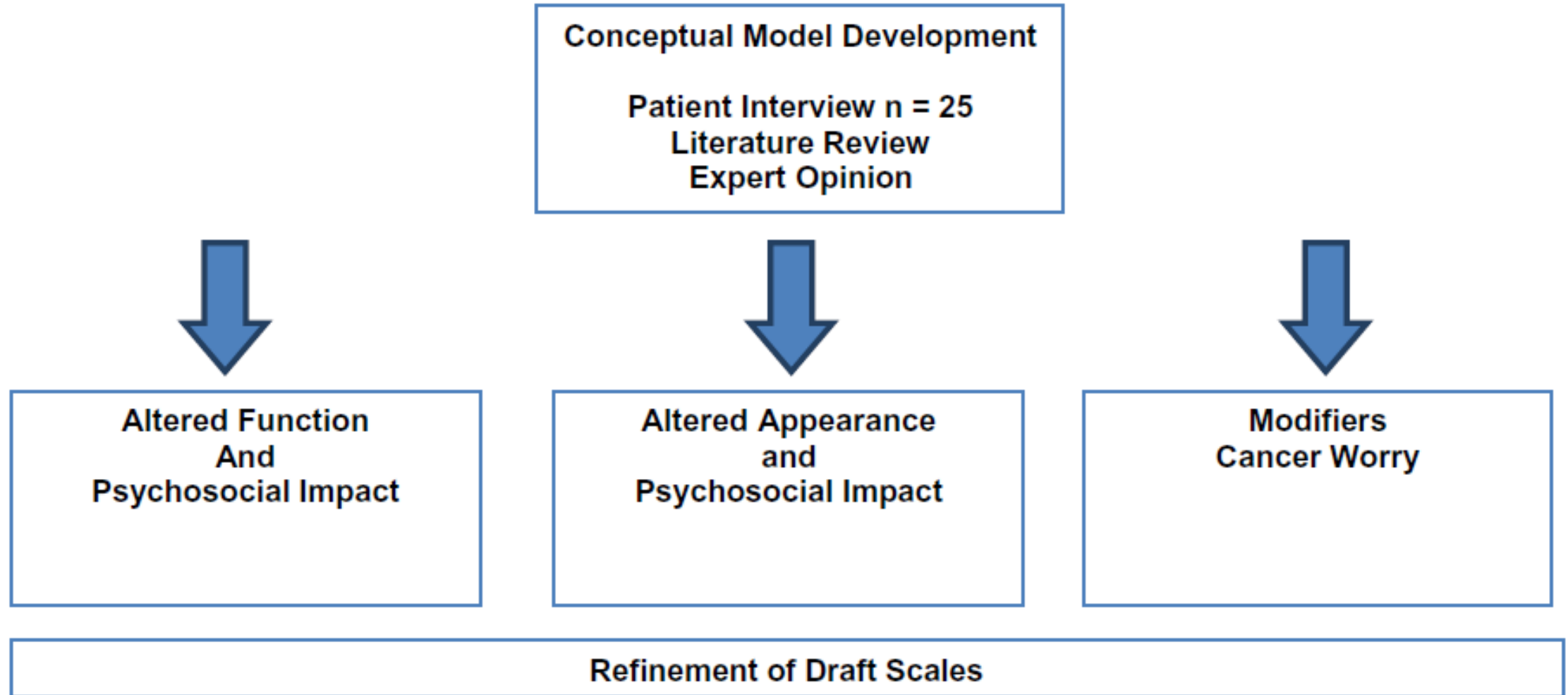
- Analyzes and normalizes answers for patients relating to:
 - Speaking
 - Lip Competence
 - Appearance
 - Swallowing
 - Eating

<http://qportfolio.org/face-q/head-neck-cancer/>

Conceptual framework in PRO instrument



Phase 1: Development of the Conceptual Model



Phase 2: Field Testing

Testing of 14 Draft Scales
Participants Completed Draft Scales $n = 302$



Item Reduction with Psychometric Analysis

Creation of the FACE-Q Head and Neck Module
Including 14 Independently Functioning Scales



Function

- 1) Eating
- 2) Oral Competence
- 3) Salivation
- 4) Speaking
- 5) Swallowing
- 6) Smile
- 7) Appearance



Psychosocial

- 1) Eating
- 2) Drooling Distress
- 3) Appearance
- 4) Smiling
- 5) Speaking
- 6) Cancer Worry



Experience

- 1) Satisfaction with Information

FACE-Q HEAD AND NECK CANCER™ – APPEARANCE

For each statement, circle only one answer. These statements are about your facial appearance.
In the past week, how much do you agree or disagree with each statement:

	Definitely Agree	Somewhat Agree	Somewhat Disagree	Definitely Disagree
1. Parts of my face look too big.	1	2	3	4
2. Parts of my face look sunken.	1	2	3	4
3. My face looks disfigured.	1	2	3	4
4. The shape of my face is not normal.	1	2	3	4
5. My face looks unattractive.	1	2	3	4
6. My face looks disproportionate.	1	2	3	4
7. My face looks damaged.	1	2	3	4
8. My face looks abnormal.	1	2	3	4
9. My face looks uneven.	1	2	3	4
10. The two sides of my face look different.	1	2	3	4

SUM SCORE	EQUIVALENT RASCH TRANSFORMED SCORE (0-100)
10	0
11	12
12	20
13	26
14	30
15	34
16	38
17	41
18	44
19	47
20	50
21	53
22	56
23	59
24	62
25	66
26	70
27	75
28	81
29	89
30	100

Conclusions

- Recognizing a new approach is needed
- Identifying Domains that are Patient Oriented and Identified
- The use of available H and N Instruments:
 - Edmonton 33: <http://www.hnrrn.org/>
 - Face Q: <http://qportfolio.org/face-q/>
 - ICHOMS- <https://www.ichom.org/standard-sets/>
 - PROMIS- <https://commonfund.nih.gov/promis/index>
 - PCORI- <https://www.pcori.org/>
 - COMET: <https://www.comet-initiative.org/>