Psychometric Properties of Patient-reported Outcome Measures for Dysphagia in Head and Neck Cancer: A Scoping Review

Beatrice Manduchi [1,2,3], Zhiyao Che[1,2,3], Margaret Fitch[4], Jolie Ringash[5,6], Doris Howell[7,8] Rosemary Martino[1,2,3,6,9]

[1]Rehabilitation Sciences Institute, University of Toronto; [2]Department of Speech-Language Pathology, University of Toronto; [3]The Swallowing Lab, University of Toronto; [4]Bloomberg Faculty of Nursing, University of Toronto; [5]Department of Radiation Oncology, Princess Margaret Cancer Centre, University of Toronto; [6]Department of Otolaryngology-Head and Neck Surgery, University of Toronto; [7]Princess Margaret Cancer Centre; [8]University of Toronto; [9]Krembil Research Institute, University Health Network.

Background

- Dysphagia is one of the main complaints for patients with Head and Neck Cancer (HNC).

- Dysphagia-related patient-reported outcome measures (PROMs) are critical to provide patient information, tailor interventions, and improve communication between patients and clinicians. Dysphagia-related PROs can be classified into different domains as described in our conceptual framework below (Figure 1).

- Presently, there is no inventory detailing psychometric properties of PROMs specific to dysphagia in HNC [1].

Objectives

- This study aims to identify and report psychometric properties of PROMs specific to dysphagia symptoms, swallowing functional status, swallowing-related health status, and swallowing-related quality of life (QoL).
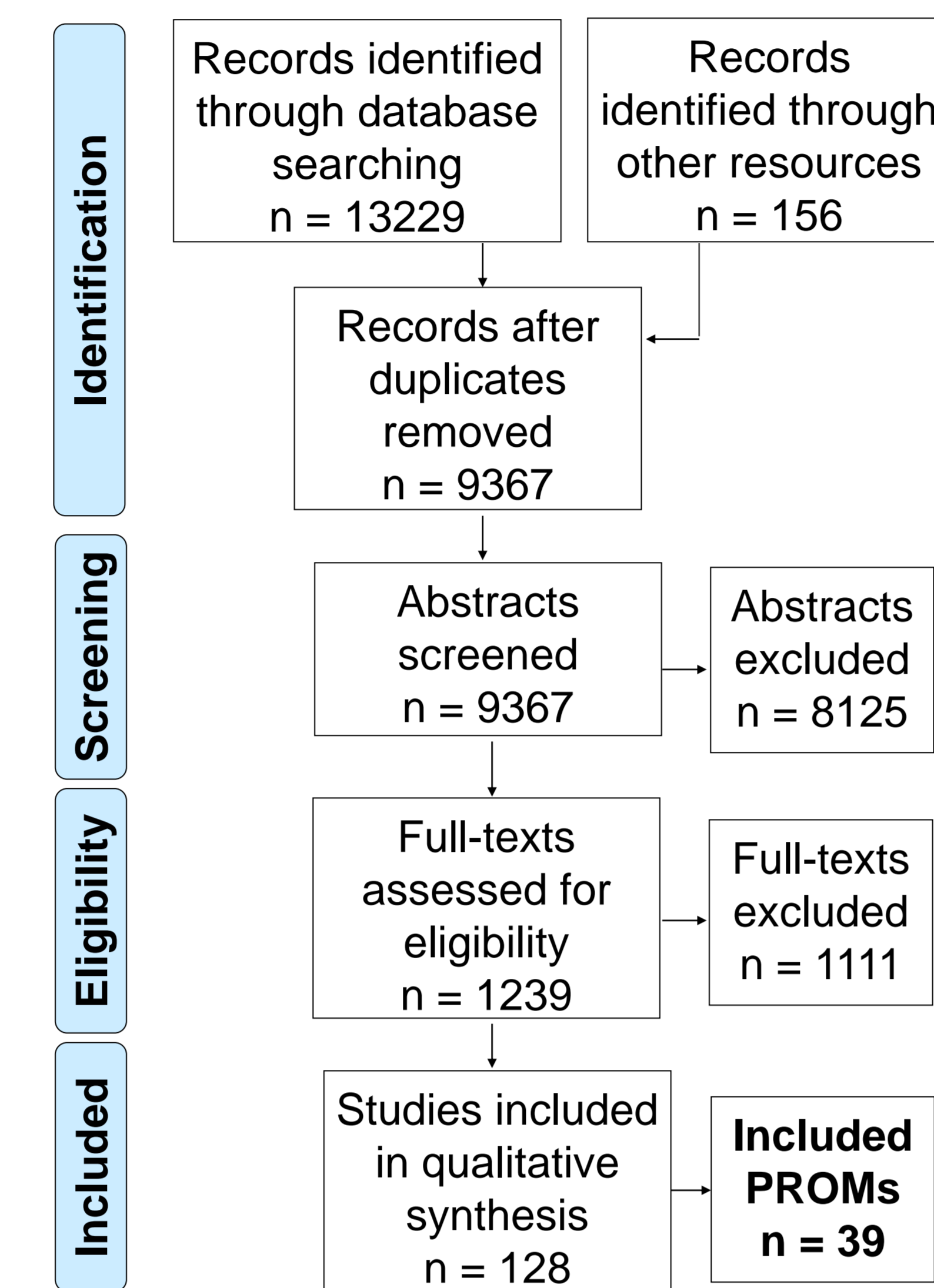
Methods

- We searched 6 electronic databases from inception to December 2020 for all primary studies in any language and design detailing PROM development, psychometric testing, interpretability, and cross-cultural adaptation.

- Eligibility criteria targeted PROMs for patients with HNC (≥90% of study sample) with ≥20% of their items pertaining to dysphagia.

- Two independent raters screened all citations and a third rater resolved discrepancies. Accepted full-text articles were screened for eligibility by one rater.

- Data were extracted on PROM's domain, % of dysphagia-related questions, language of the PROM and psychometric property tested.

- PROMs were classified according to our conceptual framework and their psychometric properties were summarized descriptively according to the COSMIN taxonomy [2].

Figure 1: Dysphagia-related PROs framework
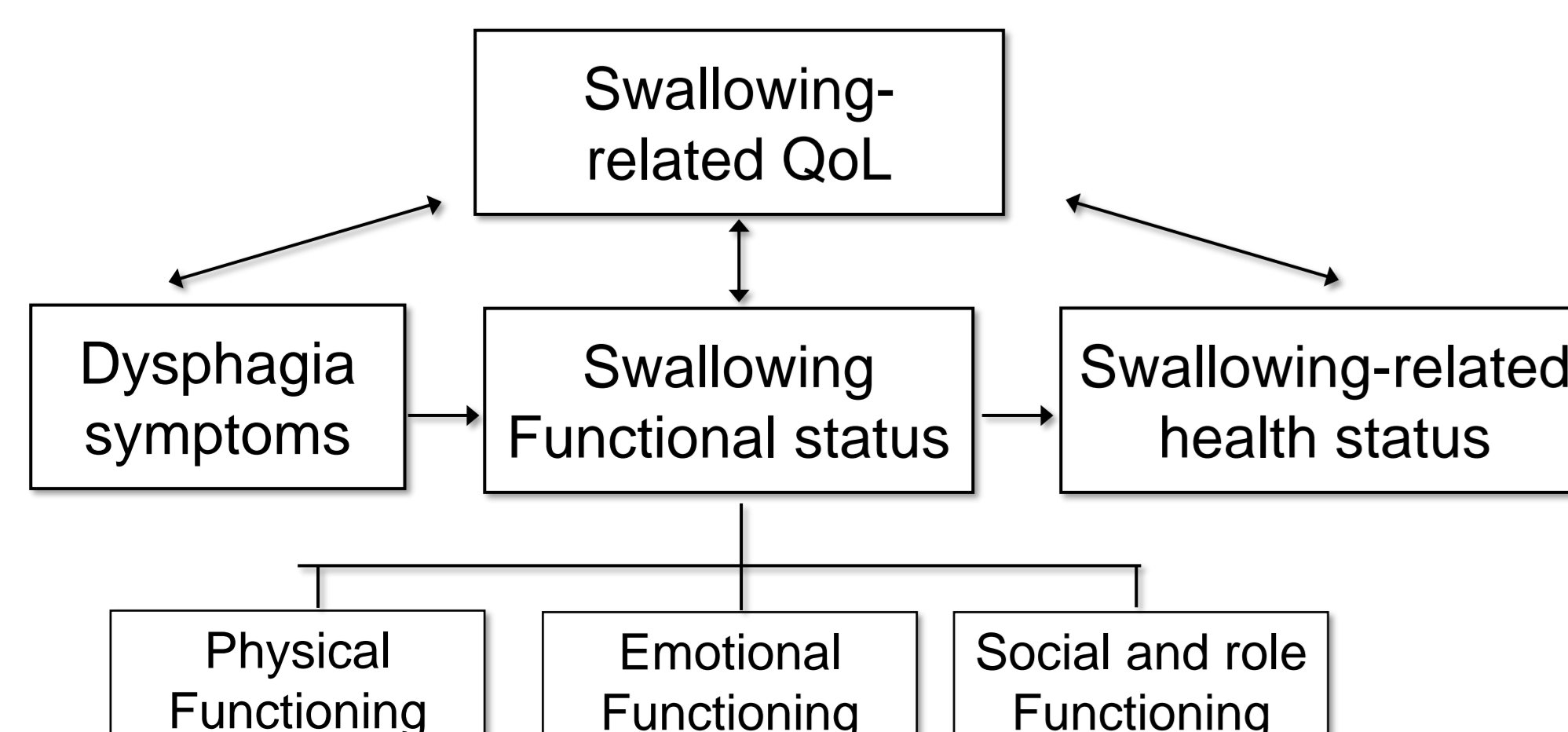
Results

Figure 2: PRISMA Flow Diagram

- Included studies were published between 1994 and 2020. Sixty-three had a cross-sectional design, 26 a mixed-methods, 25 a prospective observational, and 14 other designs.

- The HNC sample of included studies ranged from 10 to 1136 participants (excluding development/pilot testing studies), with mean age ranging from 46 to 75 years old. HNC sample of studies on PROM development or pilot testing ranged from 5 to 114.

- Of the 39 included PROMs, 8 were developed to assess swallowing in HNC, 8 to assess swallowing in other patient populations, and 23 were developed for HNC, but not to assess swallowing specifically.

- Number of items of included studies ranged from 1 to 50.

Table 1: PROMs on dysphagia symptoms

PROM	% dysphagia Qs	Lang (n)	Psychometric properties tested (n of studies)
EAT-10	100%	4	S(1), IC(2), CRC(2),CR(1), CC(2), K(1), L(2), I(1)
MDASI-HN-S	100%	1	CR(1), CC(1), I(1)
PRO-CTCAE-Dysphagia	100%	1	C(1), CR(1)
Dysphagia Severity scale	100%	1	R(1), CR(1), CC(1), I(1)
HNSAM	79%	1	D(1), S(1), IC(1), R(1), CR(1), K(1)
GTQ	48%	1	D(1), S(1), IC(1), CC(1), K(1), L(1), I(1)
ScreenIT V2	31%	1	CR(1)
FHNSI-7	29%	1	IC(1), R(1), CR(1), K(1), L(1)
VHNSS V2	26%	3	D(1), C(1), S(2), IC(3), CRC(2), R(1), CR(1), CC(2), K(1), L(8), I(2), F(1)
LORQ V3	25%	2	IC(1), CRC(1), CR(1), K(2)
HNDS	22%	1	D(1), IC(1), CC(1), K(1), F(1)
FHNSI-10	20%	3	C(1), S(1), IC(3), CRC(2), R(3), CR(2), CC(3), K(6), L(3), MIC(1), I(1)

Table 2: PROMs on swallowing functional status

PROM	% dysphagia Qs	Lang (n)	Psychometric properties tested (n of studies)
4 scales from FACE-Q-HN*	100%	1	D(2), S(1), IC(1), R(1), CC(1), F(1)
SSQ	100%	1	C(1), IC(1), R(1), CR(1), CC(1), K(1)
SOAL	88%	1	D(1), C(1), S(1), IC(2), R(1), CR(1), K(2), I(1), F(1)
PPSFQ	75%	1	IC(1), K(1)
MFIQ	65%	2	IC(1), CR(1)
FIGS score	67%	1	CC(1)
PSS-HN self-reported	67%	1	IC(1), CC(1)
Liverpool PEG questionnaire	56%	1	KC(1)
Edmonton 33-instrument	46%	1	D(1), S(1), CC(1)
FLiGS score	40%	1	D(1), IC(1), R(1), CC(1), F(1)
BCSQ-H&N V2	39%	1	D(1), R(1), CC(1), I(1)
FSH&N-SR	27%	1	D(1), IC(1), CC(1), K(1)

Table 3: PROMs on swallowing-related health status

PROM	% dysphagia Qs	Lang (n)	Psychometric properties tested (n of studies)
H&NS	46%	1	D(1), IC(1), R(1), CC(1)
HNCI	23%	2	D(1), S(2), IC(2), CRC(1), R(2), CR(1), CC(1), K(2), L(1), I(3), MIC(1)

Table 4: PROMs on swallowing-related QoL

PROM	% dysphagia Qs	Lang (n)	Psychometric properties tested (n of studies)
MDADI	100%	12	D(1), S(3), IC(14), CRC(7), R(7), ME (1), CR(7), CC(9), K(8), L(1), I (6), MIC(1)
DHI	100%	1	S(1), IC(1), R(1), CR(1), CC(1), I(1)
SWAL-QOL	89%	2	IC(3), CRC(2), R(2), CR(2), CC(3), K(3), I(2), MIC(2)
QOL-EF	50%	1	D(1), IC(1), R(1), CC(1)
HN module (QOL-RTI/HN)	43%	5	D(1), S(1), IC(5), CRC(4), R(4), CR(1), CC(2), K(3), L(4), I(2), F(1)
EORTC QLQ-H&N35	35%	26	D(1), C(5), S(13), IC(28),R(7), CRC(10), CR(4),CC(10),KC (17), L(8), I(10), MIC(2), F(13)
Questionnaire VADS	35%	1	D(1), S(1), IC(1), CC(1), K(1), I(1), F(1)
HN subscale (FACT-H&N V4)	33%	8	C(1), S(1), IC(12), CRC(4), R(1), CC(3), K(5), L(1), I (3); MIC(1), F(1)
QOL-OC	28%	1	D(1), S(1), IC(1), R(1), CC(1), F(1)
EORTC QLQ-H&N43	26%	18	D(1), S(2), IC(3), CRC(2), R(1), CC(3), K(3), L(1), I(3)
8-items UW-QOL	25%	1	IC(1), I(1)
NPCS subscale (FACT-NP)	25%	1	D(1), S(1), IC(1), R(1), CC(1), K(1), L(1)
HNQOL	20%	1	D(1), S(1), IC(1), R(1), CC(1), K(1)

Legend: Lang = Languages; D = development; C = content validity; S = structural validity; IC = internal consistency; CRC = cross-cultural validity; R = test-retest reliability; ME = measurement error; CR = criterion validity; CC = concurrent construct validity; K = known group construct validity; L = longitudinal validity; I = interpretability; MIC = minimal important change; F = feasibility.

*Eating, Eating distress, Swallowing, Oral competence subscales

Discussion

- This study identified 39 PROMs assessing dysphagia in HNC. Of these, most included psychometric testing for reliability (internal consistency and test-retest), and construct validity. However, only few assessed for other properties related to content and change (i.e., responsiveness and minimal important change).

- Future testing is required to ascertain whether existing tools can accurately detect longitudinal changes and clinically significant differences, both of which are essential for clinical and research purposes.

References

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