

Patient Perspective and Feedback on a Dysphagia Specific Question Prompt List (QPL) **Communication Tool**

Gyawali⁹, Ronnie Fass¹⁰, John O. Clarke¹, Arjan Bredenoord¹¹, George Triadafilopoulos¹, Afrin N. Kamal¹

¹Stanford University, Stanford, CA; ²Mayo Clinic Arizona, Scottsdale, AZ; ³University of Milan, Italy; ⁶Medical College of Wisconsin, Milwaukee, WI; ⁷Mayo Clinic Rochester, Rochester, MN; ⁸Northwestern University, Chicago, IL; ⁹Washington University in St. Louis, MO; ¹⁰Metrohealth Medical Center, Cleveland, OH; ¹¹University of Amsterdam, Amsterdam, The Netherlands

INTRODUCTION

- Question prompt lists (QPLs) are structured sets of disease-specific questions intended for patient use
- QPLs encourage patients to ask questions about their disease
- QPLs can decrease anxiety, improve informed decision-making, and reduce decisional conflict
- Dysphagia is associated with a wide range of conditions, both benign and malignant, and may cause significant patient distress

AIM To make an expert-derived dysphagia QPL more patient centered by incorporating patient feedback

METHODS

- Consecutive patients with esophageal dysphagia followed at Stanford University Esophagus Clinic between 11/2021-6/2022 were recruited to modify a preliminary expertderived dysphagia QPL
 - > After receiving the QPL in Qualtrics patients independently rated questions on a 5-point Likert scale where 1= "should not be included," 2= "unimportant," 3= "don't know/depends," 4= "important," and 5= "essential."
 - > Questions were accepted for inclusion had an a priori inter-agreement of \geq 80% ranking (range 4 to 5). Patients were encouraged to propose additional questions by an openended question added to the survey.

RESULTS

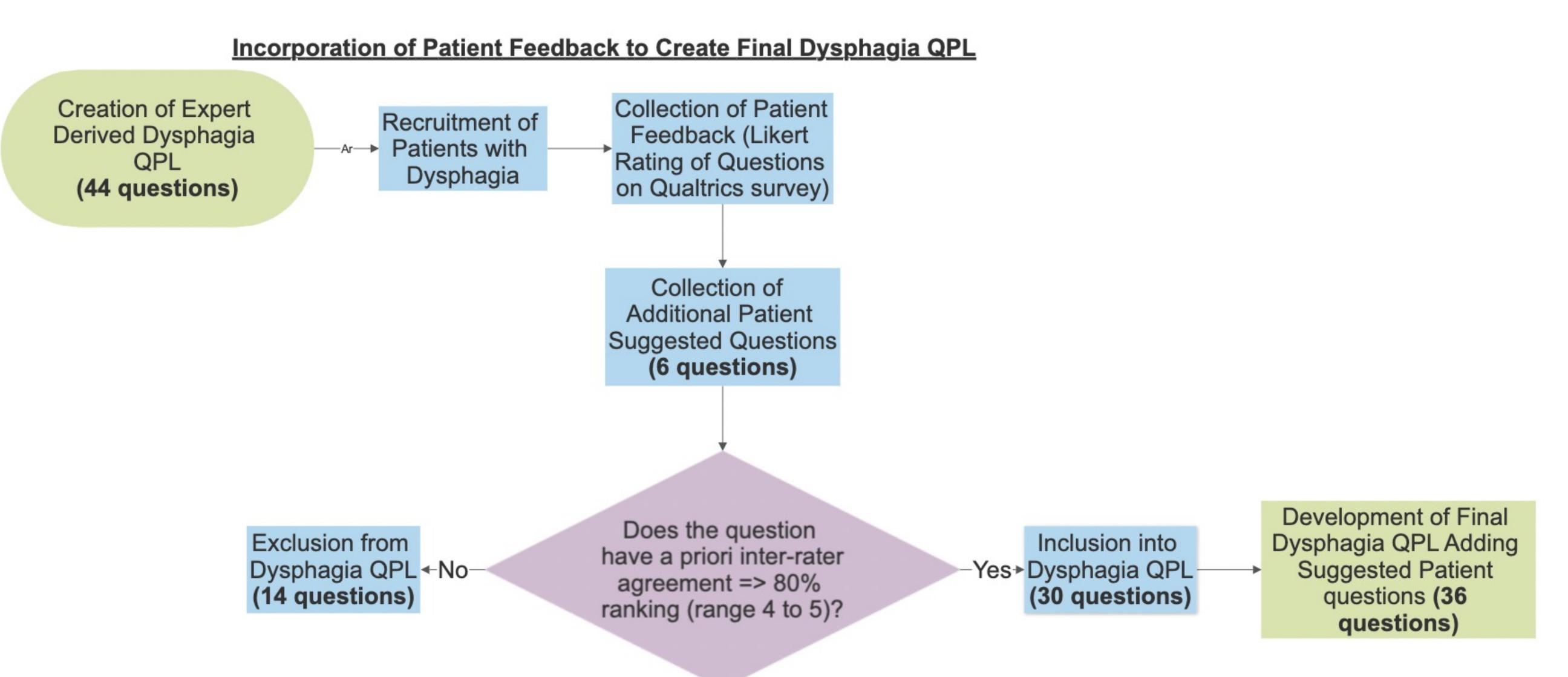


Figure: Flow chart illustrating the process used to create patient-centered Dysphagia QPL

Table 1 (top right): Expert derived questions excluded from Dysphagia QPL Table 2 (bottom right): Patient derived questions included in Final Dysphagia QPL

CONCLUSIONS

- QPL aimed to enhance patient-physician communication
- 2. This study highlights the disparity in what patients and physicians regard as essential or important with respect to esophageal dysphagia.

REFERENCES

Kamal, A., et al. Development of a preliminary question prompt list as a communication tool for adults with gastroesophageal reflux disease: A modified Delphi study. Journal of clinical gastroenterology, 2020. 54(10): p. 857-863. Yeh JC et al. Using a question prompt list as a communication aid in advanced cancer care. Journal of oncology practice. 2014 May;10(3):e137-41.

Sudharshan Achalu¹, Rani Berry¹, Marcelo F. Vela², Edoardo Savarino³, Sabine Roman⁴, Roberto Penagini⁵, Benson T. Massey⁶, David A. Katzka⁷, Peter J. Kahrilas⁸, C. Prakash

1. With expert input followed by patient feedback, we have developed the first ever patient-centered dysphagia

Physician-Patient Discordance of Question Inclusion	
Questions Recommended by Experts	Patient % Agreement
Do you think I have cancer? What is the likelihood I have cancer?	52.9
What can I do to avoid losing weight?	64.7
Why am I losing weight?	64.7
Why do I cough or choke when I try to eat or drink?	64.7
Are any of these conditions pre-cancerous?	70.6
I have food/seasonal allergies. Are those associated with dysphagia (difficulty swallowing)?	70.6
How urgently do I need to start my dysphagia (difficulty swallowing) workup?	70.6
Where in the chest do the food get stuck?	70.6
Do I need to worry?	76.5
Are my medications/habits responsible for dysphagia?	76.5
What is manometry? Will it hurt?	76.5
What diet should I follow?	76.5
How often do you evaluate and treat patients with symptoms?	76.5
Is heartburn associated with dysphagia (difficulty swallowing)?	76.5

Overview of Patient Suggested Questions

Does swallowing cold liquids make my swallowing worse?

Does tilting your head back while swallowing make me choke?

When food gets stuck in chest, how long does it take for food to move?

When food is stuck in my chest, how long does it take for the pain to go away?

Can I have problematic foods occasionally without concern for long term effects?

Am I able to eat after a choking episode or after food gets stuck?