

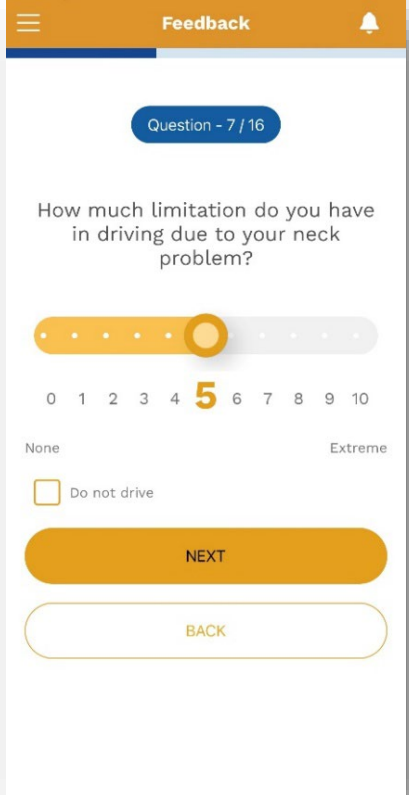
Title: Development of a Smartphone Application Able to Capture Patient-Centered Outcome (PCO) Measures for Dystonia

Authors: Paul Reyes, Arlann Erskine, Brian Berman, Sarah L. Schneider, Janet Hieshetter, Kimberly Kuman, Cynthia Comella, David Peterson, Gamze Kilic-Berkmen, Laura Wright, Fares Qeadan, Samantha Pentecost, Joel S. Perlmutter, Sarah Pirio Richardson, H. A. Jinnah

Introduction: Botulinum neurotoxin (BoNT) is a first line therapy for many types of dystonia and results in significant improvement, yet approximately one-third of patients discontinue use of BoNT suggesting that BoNT therapy may not fully address patient expectations. Symptom Snap was developed to capture Patient-Centered Outcome (PCO) measures across motor, disability, and psychosocial domains, enabling clinicians and researchers to characterize the therapeutic response to BoNT therapy over time on a frequent basis.

Methods: In collaboration with TekSynap, we developed a smartphone application able to capture PCO measures tailored for three major dystonia subtypes: cervical dystonia (CD), blepharospasm (BP), and laryngeal dystonia (LD). The app is accessible to users on both Android and iOS operating systems. We also developed a web-based admin panel able to track all data entered in the app. The admin panel is accessible to study personnel only. The admin panel is also used for generating login credentials.

Results: Symptom Snap features a user-friendly interface with easy-to-read text, making data entry a very straightforward process. Within the app, each major dystonia subtype has its own set of questions (16 questions for CD, 18 questions for BP, and 15 questions for LD). All questions are formatted in a numerical rating scale, and some have an additional answer box to choose when appropriate (the figure shows a screenshot taken from the CD category). Throughout each questionnaire and before submission, users have the option to revise their answers to previous questions. After submission, users are unable to enter questionnaire data until one week has passed. There are additional tools integrated into the app including a “Contact Us” menu option and a notification switch. The “Contact Us” menu option serves as a platform where users can submit troubleshooting inquiries. The notification switch, when turned on, allows the app to send push notifications when a weekly questionnaire is due for submission.



The screenshot displays a mobile application interface titled "Feedback". At the top, there is a blue header with a hamburger menu icon on the left, the word "Feedback" in the center, and a notification bell icon on the right. Below the header, a blue pill-shaped button indicates "Question - 7 / 16". The main content area contains the question: "How much limitation do you have in driving due to your neck problem?". Below the question is a horizontal slider with a yellow circle indicating the selected value. Underneath the slider is a numerical scale from 0 to 10, with the number 5 highlighted in yellow. Below the scale, the words "None" and "Extreme" are positioned at the left and right ends, respectively. There is a checkbox labeled "Do not drive" which is currently unchecked. At the bottom of the form, there are two buttons: a solid orange "NEXT" button and a white "BACK" button with an orange border.

Conclusion: Symptom Snap will be tested as a primary outcome measure and, in the future, may be used as a journal for users with dystonia to document the impact that their symptoms have over various lifestyle domains. Not only will their data help to improve the care they receive, but also allow researchers to assess which domain(s) BoNT therapy does not fully address, helping provide direction in the development of novel treatments for dystonia.