Development of a Text-based Data Collection Tool for Patient Reported Health Data

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Introduction

Remote patient monitoring (RPM) allows for health data to be transmitted to a health care provider for review and to inform patient care management. Many platforms are in existence that collect objective data from devices such as blood pressure monitors and glucometers for collection and transmission to clinicians.[1] Patient reported outcomes is a newer application of RPM involving subjective data entered by patients such as pain, mood or asthma control symptoms.[2] Because this subjective data is provided by patient or caregiver report (rather than objective data from a device), collection requires a patient-facing interface to conveniently and efficiently gather the data. While good practices for collecting subjective have been recommended, less is known about creation of a collection tool that can gather this data and can be transferred to other institutions.

One condition that has been well-suited for RPM of a patient reported outcome is attention-deficit/hyperactivity disorder (ADHD). ADHD is a common neurobehavioral health condition that requires frequent assessment of symptoms to inform medication titration. The assessment of symptoms usually involves a validated tool such as the Vanderbilt Assessment to collect data from parents and teachers.[3] Increased collection of the data has been shown to allow for titration to optimal dosing faster.[4]

Overview of RAMP, an example of a Tool:

The Remote ADHD Monitoring Program (RAMP) is a text-based REDCap-based platform that sends requests for rating of a child’s ADHD symptoms data (symptoms of inattention and hyperactivity) to caregivers and teachers. The requests are sent out weekly in the first month after diagnosis followed by monthly for 5 months.

Requests for symptom report are sent out via text message to caregivers and teachers. The text message links to a survey that mirrors the Vanderbilt Assessment. Responses to the surveys are immediately available to clinicians and includes prior scores for comparison. A dashboard organizes all patients and their surveys for clinicians.

The RAMP platform was initially created as a research tool. This allows for study staff monitoring the program to easily aggregate and download data. The program is simple to modify and administer. Based on feedback from a group of clinicians who pilot tested the platform, a Spanish version was created and a chart with prior Vanderbilt Assessment scores was added. The platform was also packaged and recreated at another institution through their REDCap.

Platform Development Considerations from Patient-side

- It is best practice to use a validated scoring tool when gathering patient reported outcomes. RAMP surveys were based on the Vanderbilt Assessment.
- Beta testing of the RAMP platform with patients allowed for refinement of the program. This included development of a Spanish language version. With the introduction of a foreign language, consideration was taken in choosing to include or exclude free text responses which may need to be interpreted by a non-language speaking provide.

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- Because the requests are delivered by text-message, the content of messages included personalized details (ex. patient name, caregiver name, and doctor name) so that the content did not appear to be SPAM (other technical term?).
- Data is collected from school setting so additional privacy considerations also had to be made (ex. FERPA) in the research setting.

Platform Development Considerations from the provider side

- This tool was designed as a research tool for study staff to be able to monitor the intervention as well as to be used clinically. In future versions of the platform, a more clinically-focused platform may allow for additional features including integration in to the EHR.
- Assembling data into a dashboard allowed clinicians to see all enrolled patients in their clinic on one screen. As the program grows, it will allow for population level triage of patients who need more or less care management.
- Provider users also requested the data be presented in a table format to see change in symptoms over time.

Principals of Transfer of Platform

After development of a useful tool, an institution may want to package and transfer the program to other institutions. This process takes considerations and communication between bioinformatics at both transferring and receiving institutions. Platforms will often have different editions or versions with differing capabilities. Compatibility should be ensured. Any time patient data is being collected and transmitted, care should be taken to ensure that HIPAA is not being violated. Lastly, if the platform is used in the research setting, the programs should be identical in each instance to ensure fidelity of the intervention.

Lessons Learned & Key Findings

- Patient reported outcomes can be collected using commonly available and accessible tools for initial data collection and testing.
- Beta testing platform with potential end users will reveal considerations that are patient-specific for population and condition. These can include foreign language options, timing and frequency of data request to caregivers or others providing data.
- As large quantities of data are generated, it is often helpful to present this data into a dashboard or chart that can visually present changes over time. It also allows for stratification of a large number of patients to those needing more or less intervention, an important need in population health management.
- During transfer of a program, considerations include privacy of data. In the research setting, the program must be identical in each instance to ensure fidelity of the intervention.

For more information on this document or a consultation with our Center of Excellence, please contact telehealthcoe@musc.edu.

Resources

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3. Wolraich ML, Hagan JF, Jr., Allan C, et al. Clinical Practice Guideline for the Diagnosis, Evaluation, and Treatment of Attention-Deficit/Hyperactivity Disorder in Children and Adolescents. Pediatrics 2019;144(4), doi:10.1542/peds.2019-2528

4. Epstein JN, Kelleher KJ, Baum R, et al. Specific Components of Pediatricians' Medication-Related Care Predict Attention-Deficit/Hyperactivity Disorder Symptom Improvement. J Am Acad Child Adolesc Psychiatry 2017;56(6):483-490 e1, doi:10.1016/j.jaac.2017.03.014

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