

Participant Experiences with the American Registry for Migraine Research: A Qualitative Study

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BACKGROUND

Migraines

According to the American Migraine Foundation, 37 million individuals in the United States suffer from migraines.

- Within the top 10 most disabling disorders in the world (WHO, n.d).
- Costs the United States roughly \$20 million annually from loss of productivity and medical treatment.
- 3rd most common disease in the world.

The **American Migraine Foundation (AMF)** established the **American Registry for Migraine Research (ARMR)** to be a useful tool and database to collect information about individuals with migraines and other headache disorders.

Current Efforts

This registry collects the following information:

- Patient demographics
- Diagnosis and treatment
- Patient reported symptoms, headache frequency and characteristics
- Personal medical history and family medical history
- Blood samples for biorepository

Participants are given access to multiple resources:

- ARMR Patient Portal
- ARMR Daily Headache Diary

OBJECTIVE

To understand the perceptions and self-reported experiences of respondents in order to improve the registry structure and patient experience.

METHODS

3 of 8 ARMR participating sites agreed to be involved in this study.

Participants were approached by the Clinical Research Coordinator assigned to each participating site and were encouraged to volunteer in a phone interview to discuss:

- Perceptions of the registry enrollment process
- Experience of support within the registry
- Experiences with survey tools and the Daily Headache Diary
- Additional suggestions for improvement
- Overall feedback

Ten (10) interviews were completed. Each interview was conducted over the phone, recorded, and transcribed.

NVivo software was used to facilitate qualitative analysis.

RESULTS: PARTICIPANTS' PERSPECTIVES

Participant perspectives were organized into 4 thematic categories. Shared below with operational definitions and exemplar participant quotations.

Experience

Patience experience with processes of:

- Enrollment
- Surveys
- Dashboard
- Daily Diary Application

Enrollment

"I didn't really get a explanation as to what resources are available, how the website is structured and what I can and can't do with it."

"...didn't inform me of too much about what I was signing up for other than keeping a journal and some access about my information..."

Daily Diary App/Surveys

"the signing in is really frustrating especially for somebody with head pain."

Resource Use

Ways in which participants are using resources provided by ARMR

Migraine Information Resources

"my doctor"
"Google/WebMD"
"Podcast"
"Mayo Clinic Search"

Social Media or AMF/ARMR Website

0 of 10 respondents reported using the Facebook community page or website

0 of 10 respondents reported being knowledgeable of the Facebook community page or website

Suggestions

Patients' thoughts on how the platform can improve

"I would love getting reminders."

"some of [questions] are very repetitive."

"fixing the glitches, not so many questions"

"If I didn't have to sign in"

"having options to fill in my own answers"

"shortening [surveys]"

"what do I look like [headache symptoms, diagnosis, etc.] compared to other patients?"

Utility

Patients' thoughts on what they consider "benefits" and "barriers" to their success

Perceived Benefits

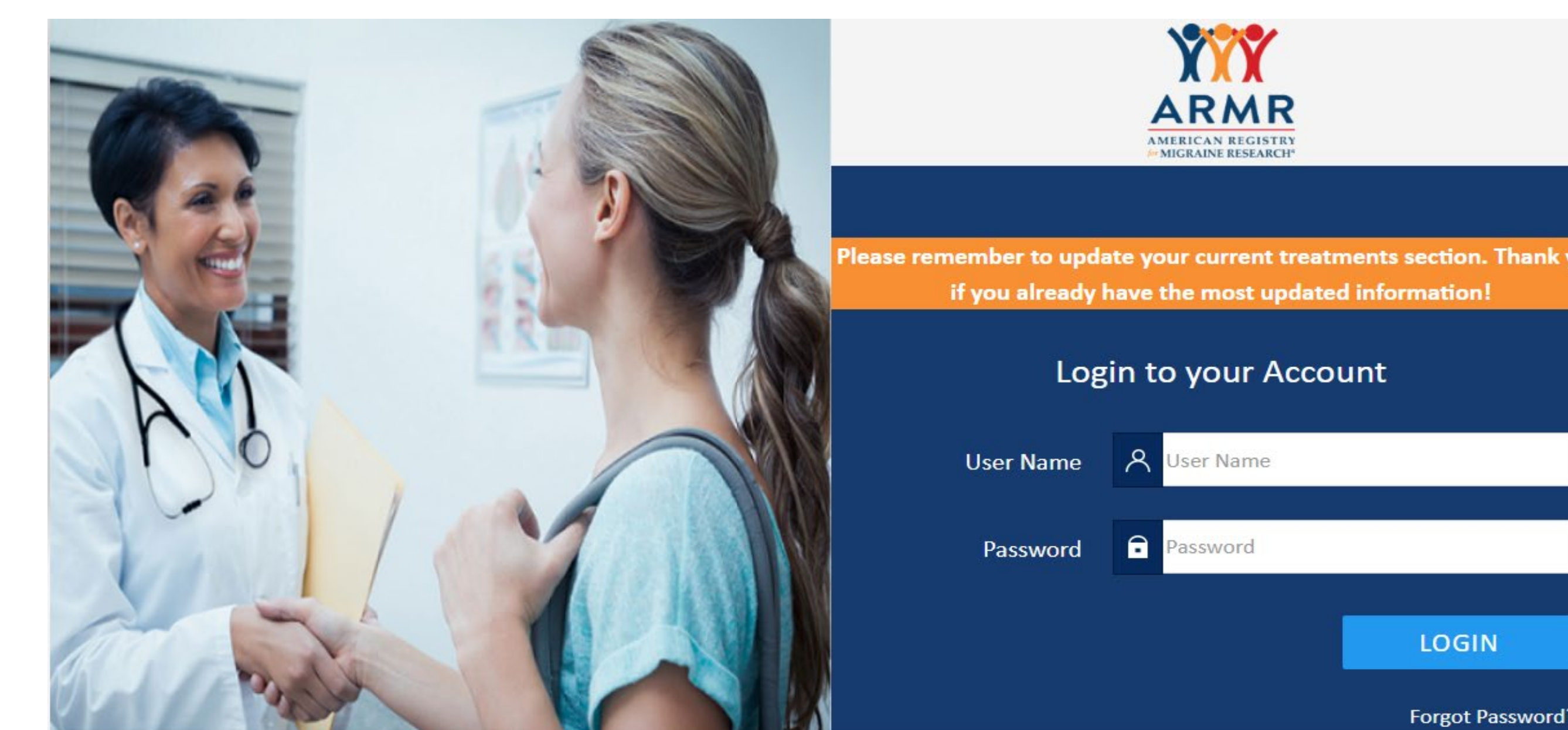
- having a space to record headache frequency, potential triggers, medications, etc.
- having a mobile app
- Research coordinator support

Perceived Barriers

- Logging in repeatedly
- App does not save their treatment, diagnosis information, etc.
- Long surveys
- No reminders
- Not fully understanding diagnosis

NEXT STEPS

Next steps will involve utilizing the information gathered in this study, including patient perceptions, their suggestions, and self-reported experiences to find ways to improve the platform and enhance the patient experience.



ACKNOWLEDGEMENTS

A special thank you to:

- Rosemary Frasso, PhD, MSc, CPH
- John McAna, PhD, MA
- Anna Quinn, MPH
- American Registry for Migraine Research (ARMR)