PE012

Partnering with Patients to Guide the Development of Impactful Educational Resources for Warm Autoimmune Hemolytic Anemia (wAIHA)

Azreen Iqbal[1], Zia Choudhry[2], Lisa Shea[2], Emily Clifford[3], Surbhi Shah[4], Nora Sandorfi[5]

[1]Patient Author; [2]Johnson & Johnson, Horsham, PA, USA; [3]Center for Information & Study on Clinical Research Participation (CISCRP), Boston, MA, USA; [4]Mayo Clinic Hospital Phoenix, Phoenix, AZ, USA; [5]University of Pennsylvania, Philadelphia, PA, USA

Key Takeaways

- ✓ Including perspectives of individuals living with wAIHA in the development of patient-facing educational resources is key to helping create impactful tools for the intended user
- ✓ Insights collected from this exploratory research directly contributed to the improvement of the concept for a wAIHA disease state education website, to make it more impactful and engaging
- ✓ This research demonstrates the value of focus groups in gaining insight into patient preferences for educational resources and guiding their development to be customized for the end user

Background

Warm autoimmune hemolytic anemia (wAIHA) is a rare autoantibody disease associated with a significant physical, emotional, and quality of life burden on patients and caregivers[1–3]

In rare diseases like wAIHA, patients often rely on publicly available online disease information to improve their health literacy; however, available data and educational resources on the internet are often limited[4,5]

Rapidly evolving technology has led to a rise in patients and care partners utilizing online digital health resources to gather information and seek support[6,7]

Developing patient-facing educational materials in collaboration with the end user may help increase utilization and engagement, which would facilitate improving patient health and potential outcomes[8,9]

Objective

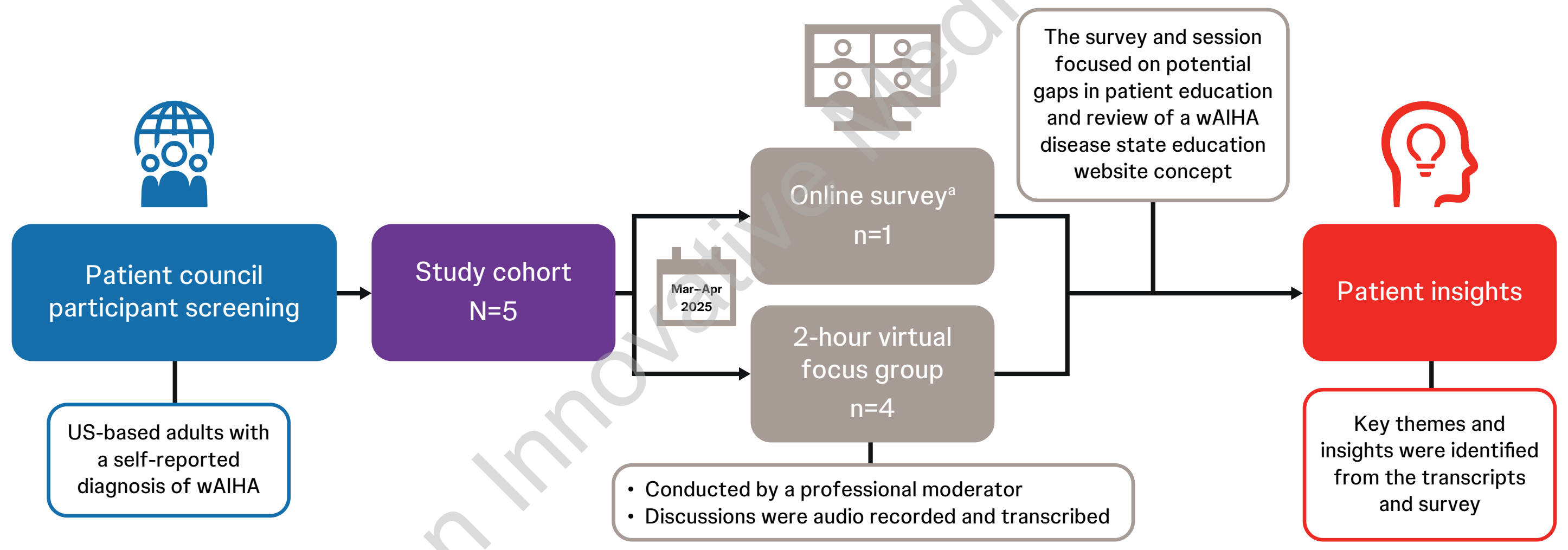
This qualitative patient research aimed to identify potential gaps in patient education and to gather feedback from individuals living with wAIHA on initial concepts for a disease state education website

Methods

A wAIHA patient council was convened to better understand the perspective of individuals living with wAIHA (Figure 1)

- US-based adults with a self-reported diagnosis of wAIHA who were members of the patient council participated in a 2-hour virtual focus group or online survey about educational resources
- The survey and session focused on discussing potential gaps in patient education and review of a wAIHA disease state education website design concept and proposed content areas
- Focus group discussions were audio recorded and transcribed
- Transcripts were qualitatively analyzed to identify key themes and insights

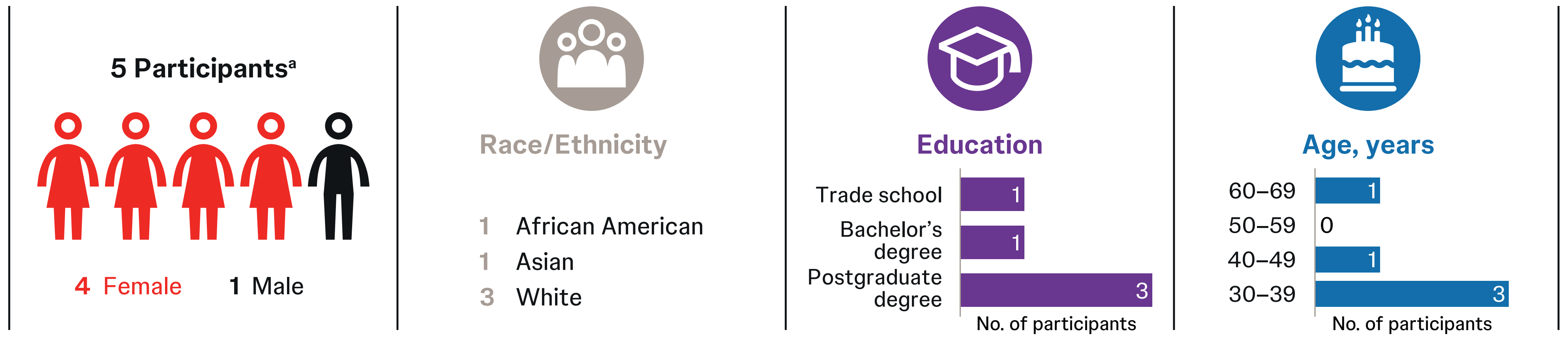
Figure 1. *Study design*



[a]Participants were permitted to provide feedback in an online questionnaire as an alternative to joining the session. **Apr**=April, **Mar**=March, **wAIHA**=warm autoimmune hemolytic anemia.

Results

Figure 2. *Five participants total; Four participants attended the virtual focus group and one gave feedback via the online survey; most were female (80%) and White (60%)*



[a]One participant gave feedback via the online survey as an alternative to joining the virtual focus group (female, white, age 30–39).

Table 1. *Participants expressed an unmet need for a reliable and easy-to-understand educational website that could be utilized by patients, care partners, and their loved ones throughout the wAIHA journey*

Unmet Needs and Overall Educational Website Perceptions

Unmet Educational Needs in wAIHA	Value of Educational Website	Utilization of Website During Patient Journey	Most Valuable Types of Information for a wAIHA Educational Website
• Resources on how to explain the disease to loved ones • List of all possible treatment options • All-encompassing guide of the wAIHA journey and patient expectations	• All participants agreed an educational website would be very valuable to both the patient community and care partners, loved ones, and friends	• Some participants felt the website would be most valuable early in the patient journey to provide helpful information • Other participants believed it would be most valuable during a relapse, helping them explore alternative treatment options	• Disease state information, ranging from basic disease explanations/definitions to comprehensive data on the disease • Resources for patient support groups and ways to connect with the community • All-inclusive list of potential treatment options • Common triggers of relapse • Patient testimonials

wAIHA=warm autoimmune hemolytic anemia.

Figure 3. *Proposed content areas for the wAIHA disease state education website were all deemed valuable by participants, and they recommended enhancements that would further fill unmet needs*

Suspected wAIHA (for undiagnosed patients)

Pathway to diagnosis, misdiagnosis, what to do if you suspect wAIHA, tests required for diagnosis

Suggested enhancements:
- wAIHA symptom checklist
- Potential treatment side effects
- Information on common exploratory tests

Understanding wAIHA (diagnosis and journey ahead)

What is wAIHA, who gets wAIHA, what the journey with wAIHA entails

Suggested enhancements:
- Information on the typical care pathway (e.g., PCP → Hematologist)
- Explain disease-related terms (i.e., warm vs cold autoimmune hemolytic anemia)

Living with wAIHA (management and coping)

Managing symptoms, communicating with others, working with wAIHA

Suggested enhancements:
- Family and care partner support section
- ADA rights & legal protections
- Guidance on parenting with wAIHA

Resources and Support

Advocacy, peer communities and support groups, wAIHA events, resources for access barriers

Suggested enhancements:
- Add purpose of each resource and what patients can expect to gain from them
- Downloadable patient journey guide

ADA=Americans with Disabilities Act, **PCP**=primary care physician, **wAIHA**=warm autoimmune hemolytic anemia.

Figure 4. *Insights gathered on the initial website concept provided actionable changes to content such as alternative visuals to emphasize the wAIHA community and refinement of text to reinforce the website as a guiding tool for patients and care partners*

Feedback on Initial Draft	Action
Some participants suggested revising the copy to place more emphasis on the support the website and wAIHA community will provide to patients	✓ Copy was revised throughout the website to incorporate participant suggestions
Some photos of single individuals were viewed as isolating	✓ Images that participants perceived as isolating were changed to reflect a community rather than single individuals
Most participants noted that they did not like the color scheme, finding some shades too sterile and others too dark	✓ The color palette was changed to different shades perceived as more empathetic and compassionate
Participants expressed that they felt the digital layout could be cleaner, more cohesive, and less busy	✓ The digital layout was simplified and more streamlined

Adapted from an illustration by Vecteezy (www.vecteezy.com). **wAIHA**=warm autoimmune hemolytic anemia.

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