

## Welcome

Introduction and Time Commitment Thank you for your interest in this research study on online health forums and personalized support groups. This study aims to explore your preferences, perceived benefits, and concerns related to online health support. Before beginning the survey, you will be asked to read through detailed consent information and background definitions to ensure that you are fully informed about the study. Reading this information may take approximately 5–7 minutes. If you choose to proceed, the study consists of two survey parts:

**Part 1** : This survey will ask about your experiences with online health forums and your preferences for support group features. This section will take approximately 15–20 minutes to complete.

**Part 2 (One Week Later)**: You will be asked to review a hypothetical match with a personalized support group based on your previous responses and provide feedback. This follow-up survey will take approximately 30 minutes.

Thus, your total time commitment across both parts of the

study is approximately 50–60 minutes, with participation spread over two separate sessions.

## **Definitions of Online Health Forum and Online Support Group**

**Online Health Forum:** An online health forum is a broad, digital platform designed for open discussions about a variety of health topics. These forums are typically accessible to a wide range of users, allowing them to post questions, share information, and exchange insights. Not all members in an online health forum actively participate – some just view posts and threads. Conversations within these spaces often feature a mix of professional perspectives, such as those from healthcare providers, and personal experiences shared by other users. The primary goal is information-sharing, covering diverse health issues, and providing an open space for health-related dialogue. Health forums may have minimal moderation, which allows for a broad spectrum of opinions and less restricted discussions. Example: A user posts on a general health forum such as PatientsLikeMe seeking advice on managing seasonal allergies, and they receive responses from both medical professionals and fellow forum participants who share their experiences and strategies.

**Online Support Group:** An online support group, by contrast, is a small-scale, closed digital community specifically tailored for individuals dealing with similar

health challenges. Interactions in support groups are often not public and there may be an expectation that all members actively participate in group discussions and activities. These groups are designed to facilitate peer-to-peer interaction, where members can connect, share experiences, and provide emotional support. Support groups often focus on a particular health condition or life experience, such as chronic illness, mental health struggles, or caregiving. Due to the sensitive nature of the topics discussed, online support groups often feature structured discussions, scheduled meetings, and are moderated by a trained facilitator to ensure a safe and supportive environment for participants. Example: Members of a chronic pain support group meet regularly in an online space to discuss coping strategies, share personal stories, and offer encouragement to one another, under the guidance of a facilitator who helps maintain the group's focus and emotional safety.

**Eligibility Criteria:** To participate in this study, you must meet the following criteria:

- You are 18 years or older.
- You have participated in an online health forum or online support group in the past 12 months.
- You have actively engaged (at least once a month) in online health-related discussions.

**Benefits and Risks:** There are no significant risks involved in participating in this study. However, your participation will contribute valuable insights to research aimed at improving the design of personalized support groups for individuals in online health spaces. Confidentiality: Your survey responses will be stored securely in a HIPAA-compliant environment (Qualtrics). Any personal identifiers, such as email addresses, will be deleted before data analysis. All data will be de-identified and securely stored on encrypted devices for five years after the study's completion.

**Compensation:** Only participants who complete both Survey 1 and Survey 2 are eligible for compensation. Each eligible participant will have an equal chance to win one (1) of up to 34 \$20 cash prizes. Participants who complete only one of the two surveys are not eligible for the cash prizes. For U.S. participants, cash will be distributed via PayPal, Venmo, or Zelle. For international participants, cash will be distributed via PayPal.

**Consent to Participate:** By agreeing to participate in this research, you are providing valuable information that will help us design more effective personalized support group systems for online health forum users.

If you have any questions or concerns about the study or your participation, please contact the Principal Investigator, Pronob Kumar Barman, at [pbarman1@umbc.edu](mailto:pbarman1@umbc.edu).

Please confirm that you meet the eligibility criteria listed above and that you agree to participate in this two-part study.

- ☐ Yes
- ☐ No

Thank you for your interest in participating in this survey. Based on your responses, it appears that you are not eligible for the survey. We truly appreciate your time and effort, and we hope you have the opportunity to participate in future studies. Thank you again!

Please enter your email address below to receive the second part of the survey in about a week. Your email will be securely stored and deleted upon completion of the study.

## Online Health Forums and Online Support Groups Experience

Have you ever participated in any of the following online platforms? (As a reminder, online health forums are broadly accessible digital spaces for health-related discussions, while online support groups are smaller, closed communities focused on shared health experiences.)

- ☐ I have only participated in online health forums
- ☐ I have only participated in online support groups
- ☐ I have participated in both online health forums and online support groups
- ☐ No, I have not participated in either

Thank you for your interest in participating in this survey. Based on your responses, it appears that you are not eligible for the survey. We truly appreciate your time and effort, and we hope you have the opportunity to participate in future studies. Thank you again!

Which online health forums have you used? (Select all that apply)

- ☐ Facebook groups
- ☐ Sub-Reddits
- ☐ PatientsLikeMe
- ☐ HealthUnlocked
- ☐ MedHelp
- ☐  Other, please specify

If you selected multiple, which forum have you used the most?

From now on, please answer all remaining questions based on the forum you selected as the one you use the most. Your responses should reflect your experiences specifically with that selected platform.

How long have you been involved in the online health forum?

- ☐ Less than 6 months

- ☐ 6-11 months
- ☐ 12-24 months
- ☐ More than 24 months

How often do you perform each of the following activities in the online health forum? If a feature is not available or not used by you, please select "Not Applicable (N/A)."

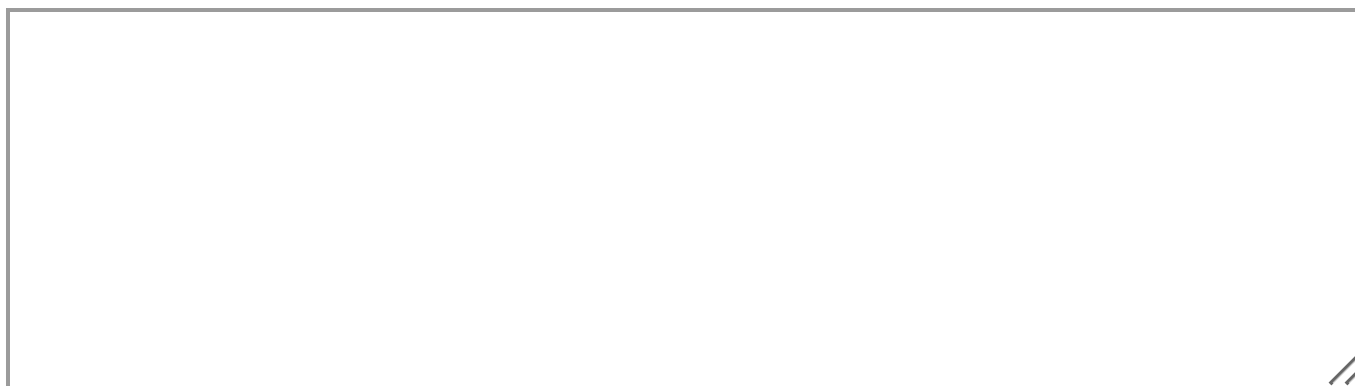
|                                              | Online Health Forums          |
|----------------------------------------------|-------------------------------|
| Read posts or information                    | <input type="text" value=""/> |
| Posted updates                               | <input type="text" value=""/> |
| Participated in conversations or discussions | <input type="text" value=""/> |
| Attended scheduled meetings or events        | <input type="text" value=""/> |
| Asked questions                              | <input type="text" value=""/> |

How often do you experience the following benefits in the online health forum? If a benefit is not applicable or not experienced by you, please select "Not Applicable (N/A)."

- ☐ Emotional support from others facing similar challenges
- ☐ Health-related insights, tips, and personal stories shared by others
- ☐ Social connections and friendships built through shared experiences
- ☐ Access to tailored information relevant to my health conditions or concerns
- ☐ Validation and reassurance from people with similar health experiences
- ☐ Guidance or advice provided by healthcare professionals or facilitators
- ☐ Support in making health-related decisions based on shared information
- ☐ Opportunities to participate in structured discussions or scheduled meetings
- ☐ Access to direct consultations or advice from peers
- ☐ Access to direct consultations or advice from experts
- ☐ Peer encouragement to engage in health-promoting activities (e.g., fitness, diet)
- ☐ Practical tips for coping with day-to-day health challenges
- ☐  Other, please specify
- ☐ None of the above

Looking back, what have you gained by participating in online health forums? How has your participation in online health forums shaped your views on managing your health

or connecting with others? For example, you may describe a specific moment, shift in mindset, or meaningful interaction.



What kind of online support groups have you participated in? (Select all that apply)

Please note this question focuses on the nature and format of the support groups rather than the specific platform or website.

- ☐ Condition-specific (e.g., diabetes, cancer, depression)
- ☐ General wellness or lifestyle (e.g., stress relief, mindfulness)
- ☐ Caregiver-focused support groups
- ☐ Peer-to-peer emotional support networks
- ☐ Facilitator-led support groups
- ☐ Self-directed support groups (no facilitator)
- ☐  Other, please specify

If you selected multiple, which type of support group do you use the most?

Please answer all remaining questions based on the support group you selected as the one that you use the most. Your responses should reflect your experiences specifically with that selected group.

How long have you been involved in the online support group?

- ☐ Less than 6 months
- ☐ 6-11 months
- ☐ 12-24 months
- ☐ More than 24 months

How were you matched with members of your online support group?

- ☐ The group was formed organically (e.g., I joined based on shared interests, experiences, or topics)
- ☐ The group formation was facilitated by an organizer or moderator (e.g., I was matched with others through a system or administrator)
- ☐ A combination of both organic and facilitated methods
- ☐ I am not sure how the group was formed
- ☐  Other, please explain

How often do you perform each of the following activities in the online support group? If a feature is not available or not used by you, please select "Not Applicable (N/A)."

|                                    | Online Support Groups |
|------------------------------------|-----------------------|
| Read posts or information          | <input type="text"/>  |
| Posted updates                     | <input type="text"/>  |
| Participate in peer activities     | <input type="text"/>  |
| Engage with facilitators           | <input type="text"/>  |
| Attended scheduled meetings/events | <input type="text"/>  |
| Asked questions                    | <input type="text"/>  |

How often do you experience the following benefits in online support groups? If a benefit is not applicable or not experienced by you, please select "Not Applicable (N/A)."

- ☐ Emotional support from others facing similar challenges
- ☐ Health-related insights, tips, and personal stories shared by others
- ☐ Social connections and friendships built through shared experiences
- ☐ Access to tailored information relevant to my health conditions or concerns
- ☐ Validation and reassurance from people with similar health experiences
- ☐ Guidance or advice provided by healthcare professionals or facilitators
- ☐ Support in making health-related decisions based on shared information
- ☐ Opportunities to participate in structured discussions or scheduled meetings
- ☐ Access to direct consultations or advice from peers
- ☐ Access to direct consultations or advice from experts
- ☐ Encouragement to engage in health-promoting activities (e.g., fitness, diet)
- ☐ Practical tips for coping with day-to-day health challenges
- ☐  Other, please specify
- ☐ None of the above

Looking back, what have you gained by participating in online support groups? How has your participation in online support groups shaped your views on managing your health or connecting with others? For example, you may

describe a specific moment, shift in mindset, or meaningful interaction.

Which online health forums have you used? (Select all that apply)

- ☐ Facebook groups
- ☐ Sub-Reddits
- ☐ PatientsLikeMe
- ☐ HealthUnlocked
- ☐ MedHelp
- ☐  Other, please specify

If you selected multiple, which forum have you used the most?

What kind of online support groups have you participated in? (Select all that apply)

Please note this question focuses on the nature and format of the support groups rather than the specific platform or website.

- ☐ Condition-specific (e.g., diabetes, cancer, depression)
- ☐ General wellness or lifestyle (e.g., stress relief, mindfulness)
- ☐ Caregiver-focused support groups
- ☐ Peer-to-peer emotional support networks
- ☐ Facilitator-led support groups
- ☐ Self-directed support groups (no facilitator)
- ☐  Other, please specify

If you selected multiple, which type of support group do you use the most?

From now on, please answer all remaining questions based on the forum and support group that you selected as the one you have used the most. Your responses should reflect

your experiences specifically with that selected platform or group.

How long have you been involved in that forum or group?

|                      | Less than 6<br>months | 6-11 months           | 12-24 months          | More than 24<br>months |
|----------------------|-----------------------|-----------------------|-----------------------|------------------------|
| Online Health Forum  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  |
| Online Support Group | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>  |

How often do you perform each of the following activities in the online health forum or online support group? If a feature is not available or not used by you, please select "Not Applicable (N/A)".

|                                              | Online Health Forums          | Online Support Groups         |
|----------------------------------------------|-------------------------------|-------------------------------|
| Read posts or information                    | <input type="text" value=""/> | <input type="text" value=""/> |
| Posted questions or updates                  | <input type="text" value=""/> | <input type="text" value=""/> |
| Participated in conversations or discussions | <input type="text" value=""/> | <input type="text" value=""/> |

|                                    | Online Health Forums     | Online Support Groups    |
|------------------------------------|--------------------------|--------------------------|
| Attended scheduled meetings/events | <input type="checkbox"/> | <input type="checkbox"/> |

How often do you experience the following benefits in the online health forum or online support group you use most frequently? If a benefit is not applicable or not experienced by you, please select "Not Applicable (N/A)."

|                                   | Online Health Forum      | Online Support Group     |
|-----------------------------------|--------------------------|--------------------------|
| Emotional support                 | <input type="checkbox"/> | <input type="checkbox"/> |
| Health-related information        | <input type="checkbox"/> | <input type="checkbox"/> |
| Peer advice or validation         | <input type="checkbox"/> | <input type="checkbox"/> |
| Structured activities or meetings | <input type="checkbox"/> | <input type="checkbox"/> |
| Professional input                | <input type="checkbox"/> | <input type="checkbox"/> |
| Help in health decision-making    | <input type="checkbox"/> | <input type="checkbox"/> |
| Social connection or friendship   | <input type="checkbox"/> | <input type="checkbox"/> |
| Motivation for health behavior    | <input type="checkbox"/> | <input type="checkbox"/> |

Online Health Forum

Online Support Group

None of the above

☐☐

Looking back, what have you gained by participating in online health forums and online support groups? How has your participation in these communities shaped your views on managing your health or connecting with others? For example, you may describe a specific moment, shift in mindset, or meaningful interaction.

## Perceived Benefits and Added Value of Personalized Support Groups

The following questions relate to a new concept called “personalized support groups.” Everyone will answer these questions, regardless of your previous participation in online health forums or support groups.

Definition: A **personalized support group** is a smaller, more focused group created specifically to match

individuals with similar health conditions, emotional needs, or social preferences. These groups are tailored to meet the specific needs of participants using data such as health information and personal preferences to ensure a better fit. This is different from the online support groups you answered questions about earlier, which may be formed organically or through a facilitator but do not use automated or algorithmic matching to personalize group composition.

To what extent do you feel that a personalized support group system would enhance your experience or add value to your participation in an online health forum?

- ☐ 1 = Would not make a difference at all
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5 = Would make a significant difference

How might a personalized support group system compare to your current experience with online health forums and/or

## online support groups?

Please rank how important the following characteristics of an online support group experience are to you, where 1 = Most important to 6 = Least important.

People with shared health conditions

People with shared emotional or social needs

People with similar communication preferences (e.g., synchronous vs. asynchronous)

A mix of diverse perspectives or lived experiences

Small, focused group structure (e.g., group size and interaction format)

Other, please specify

What concerns, if any, do you have about algorithms used in online support groups for peer matching and content

## recommendations? (Select all that apply)

- ☐ Lack of control over the selection process
- ☐ Mismatch with personal preferences
- ☐ Concerns about privacy or data usage
- ☐ Fear of impersonal or less meaningful connections
- ☐ Trust in the system's ability to match accurately
- ☐ No concerns about automated matching
- ☐  Other, please specify

If you selected any concerns above, please describe them in more detail or share any other concerns you have about algorithm use in online support groups. (Open-ended)

Please rate how important the following aspects of personalization are in an online support group system.

|                                                                                 | 1 (Not at all important) | 2                     | 3                     | 4                     | 5 (Extremely important) |
|---------------------------------------------------------------------------------|--------------------------|-----------------------|-----------------------|-----------------------|-------------------------|
| Peer matching based on health data and social preferences                       | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>   |
| Tailored content and resources specific to my health condition                  | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>   |
| Personalized notifications based on your preferences, activity, or health data  | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>   |
| Personalized suggestions for group participation (e.g., prompts for discussion) | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>   |
| Customizable communication settings (e.g., anonymous or named interactions)     | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>   |

Who should have access to your shared information in the online support group? (Select all that apply)

- ☐ Only group members
- ☐ Group moderators
- ☐ Healthcare professionals

☐ Researchers (anonymized data)

☐ No one else but me

What are your primary concerns about privacy and data-sharing in an online support group? (Select all that apply)

☐ Misuse of personal health data

☐ Lack of control over who accesses my data

☐ Data breaches and cybersecurity risks

☐ Difficulty in opting out of data sharing

☐ None of the above

☐  Other, please specify

How often would you want to receive updates and notifications from your online support group?

☐ Never

☐ Rarely

☐ Monthly

☐ Weekly

☐ Daily

## Demographics and Health Information

Please specify your age.

- ☐  Please enter your age
- ☐ Prefer not to say

Please select your gender.

- ☐ Male
- ☐ Female
- ☐ Non-binary / third gender
- ☐ Prefer to self identify
- ☐ Prefer not to say

In which country do you currently reside?

Please select your race and ethnicity (Select all that apply).

- ☐ American Indian or Alaska Native

- ☐ Asian
- ☐ Black or African American
- ☐ Hispanic or Latino
- ☐ Middle Eastern or North African
- ☐ Native Hawaiian or Pacific Islander
- ☐ White
- ☐ Prefer not to say
- ☐  Prefer to self-describe

What type of health concern have you sought support for in online support groups? (Select all that apply)

- ☐ Chronic illness (e.g., diabetes, hypertension)
- ☐ Mental health (e.g., depression, anxiety)
- ☐ Acute medical conditions (e.g., surgery recovery)
- ☐ Caregiving support
- ☐  Other, please specify

Do you currently have a health-related need or concern?

- ☐ Yes
- ☐ No
- ☐ Prefer not to say

If yes, select the type(s) of your health-related need.  
(Select all that apply)

- ☐ Officially diagnosed condition (e.g., diabetes, heart disease, mental health condition)
- ☐ Symptoms without confirmed diagnosis
- ☐ Treatment or management advice
- ☐ Preventive or general wellness advice
- ☐  Other, please specify

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