

Supplementary Material

File S1. Survey

Dear respondent,

Past studies have reported the increasing use of Patient Social Network Systems (PSNS) to seek health information and peer to peer support among patients and families. A PSNS is a virtual platform for informal health communities where members can find others with similar health issues; exchange detailed data about symptoms, treatments, and experiences related to specific diseases. Some examples of PSNS are PatientsLikeMe (www.patientslikeme.com), Ben's Friends (bensfriends.org), Society for Participatory Medicine (participatorymedicine.org), and BrainTalk Communities for neurological disease (braintalkcommunities.org).

If you are 18 years old or older and a user of one or more PSNS for at least one month, please take a few minutes about your perception of participating in a PSNS. Your responses may help us learn more about how patients use PSNS to share health information and support other patients. Your participation in this online survey is completely voluntary. You may withdraw at any time prior to the completion of this survey by simply abandoning this survey. Your responses will be confidential and will be used for research purposes only.

Thank you very much for your participation.

PSNS Profile Usage

What patient social network system(s) do you use for health-related activities? (Please select all answers that apply)

- ☐ PatientsLikeMe
- ☐ Ben's Friends
- ☐ Other (please specify):

Period of use (please check one answer for PSNS that you use the most):

- ☐ 1 month - 1 year
- ☐ > 1 year

Frequency of use (please check one answer for PSNS that you use the most):

- ☐ Daily
- ☐ Weekly
- ☐ Monthly
- ☐ As the need arises

Your role in using PSNS (please check one answer that best describes your role):

- ☐ Patient
- ☐ Family of a patient
- ☐ Caregiver of a patient

Demographic Profile

Gender	: <input type="checkbox"/> Male <input type="checkbox"/> Female
Age	: <input type="checkbox"/> 18 – 30 <input type="checkbox"/> 31 - 40 <input type="checkbox"/> 41 - 50 <input type="checkbox"/> 51 - 60 <input type="checkbox"/> > 60
Occupation	: <input type="checkbox"/> Student: undergraduate, graduate <input type="checkbox"/> Professional (e.g., academic professor, health professionals, manufacturing engineer, etc.) Please specify: <input type="checkbox"/> Entrepreneur <input type="checkbox"/> Retired <input type="checkbox"/> Other:

Perception on Participation in a PSNS

Please check (✓) one answer of each statement which corresponds most closely to your agreement / disagreement based on the following scale:

1: strongly disagree; 2: disagree; 3: somewhat disagree; 4: somewhat agree; 5: agree; 6: strongly agree

Question	1	2	3	4	5	6
Interest to engage in a patient community						
I joined PSNS because I would like to help other patients with similar health conditions.						
I am interested to share my experience and knowledge about specific health topics to others.						
I am willing to go extra miles to participate in PSNS.						
Empathy						
I can feel the distress of other patients who have just been diagnosed with the disease.						
I am willing to share my detail experiences to cope with the disease to support other patients.						
I open myself more to others in PSNS.						
I enjoy participating and having good discussions via PSNS.						
Use of Patient Social Network System						
I frequently engage in PSNS.						
I intend to continue using PSNS.						
My interest to use PSNS is high.						