

## Appendix 1. Survey results

\* Total samples (n=184)

### **Demographics (8 features)**

- [PatientOrCare] Are you a patient or a caregiver of the health problem you identified above?

Patient	103 (56.0%)
Caregiver	24 (13.0%)
Other	7 (3.8%)

- [YearDiag] How long were you or the patient diagnosed with the health problem identified above?

Less than one year	8 (4.3%)
1~3 years	26 (14.2%)
3~5 years	11 (6.0%)
5~10 years	9 (4.9%)
10~15 years	21 (11.4%)
15~30 years	13 (7.1%)
30 years ~	12 (6.5%)

- [Experienced] How much do you feel you are experienced in managing or caring for the health problems identified above?

Very experienced	44 (23.9%)
Somewhat experienced	54 (29.3%)
Little experienced	23 (12.5%)
Not experienced at all	26 (14.1%)

- [Education] What is the highest level of education you have completed?

Some high school	37 (20.1%)
Some college	76 (41.3%)
Post graduate	60 (32.6%)

- [Age] What is your age?

Under 18 years old	9 (4.9%)
18~29 years old	13 (7.1%)
30~49 years old	62 (33.7%)
50~64 years old	69 (37.5%)
64 years old or older	25 (13.6%)

- [Gender] What is your gender?

Male	56 (30.4%)
Female	119 (64.7%)

- [Employment] Employment status: are you currently

Employed	93 (50.5%)
Not employed	69 (37.5%)

- [Satisfaction] In general, how satisfied are you with the online health support group?

Very satisfied	2 (1.1%)
Satisfied	46 (25%)
Unsure	56 (30.4%)
Dissatisfied	5 (2.7%)
Very dissatisfied	48 (27.1%)

- **[FindSearch/FindRecommend]** Pick one online health support group that you most visit. How did you find out about the support group? (*Open ended*)

Found through search

Yes:	67 (36.4%)
No:	32 (17.4%)

Found through recommendation

Yes:	33 (17.9%)
No:	66 (35.9%)

### **Reading Behavior (9 features)**

Please check how much you agree with the following statements. (\*Scale 1 to 5, Strongly Disagree (1), Disagree (2), Neither agree nor disagree (3), Agree (4), Strongly Agree (5))

- **[ReadAll]** I read all messages in online health support groups as much as possible.

Strongly agree	16 (8.7%)
Agree	34 (18.5%)
Neither agree nor disagree	48 (26.1%)
Disagree	30 (16.3%)
Strongly disagree	23 (12.3%)

- **[TrustOthers]** I trust what people post in the online health support groups I go to.

Strongly agree	4 (2.2%)
Agree	31 (16.8%)
Neither agree nor disagree	67 (36.4%)
Disagree	32 (17.4%)
Strongly disagree	14 (7.6%)

- **[NeedEvidence]** I need scientific evidence for me to believe what people post in online health support groups. ( $3.01 \pm 1.17$ )

Strongly agree	16 (8.7%)
Agree	37 (20.1%)
Neither agree nor disagree	53 (28.8%)
Disagree	25 (13.4%)
Strongly disagree	21 (11.4%)

- **[UnusualInfo]** I look for unconventional information otherwise difficult to find elsewhere. ( $2.99 \pm 1.13$ )

Strongly agree	12 (6.5%)
Agree	39 (19.6%)
Neither agree nor disagree	53 (28.8%)
Disagree	26 (14.1%)
Strongly disagree	19 (10.3%)

- **[LookForNewInfo]** I regularly visit the online health support groups to look for new messages posted that I haven't read yet. ( $3.01 \pm 1.25$ )

Strongly agree	20 (10.9%)
Agree	36 (19.6%)
Neither agree nor disagree	42 (22.8%)
Disagree	28 (15.2%)
Strongly disagree	23 (12.5%)

- [SelectByTitle/SelectByTopic/SelectByAuthor/ScanAll] How do you select which message to read? (*Open-ended*)

Select by title

Yes:	11 (6.0%)
No:	38 (20.7%)

Select by topic

Yes:	24 (13.0%)
No:	25 (13.6%)

Select by author

Yes:	7 (3.8%)
No:	42 (22.8%)

Scan all

Yes:	10 (5.4%)
No:	39 (21.2%)

### **Posting Behavior (10 features)**

- [PostFreq] How often do you post messages in online health support groups? (2.08 ± 1.36)

Everyday	11 (6.0%)
A few times a week	22 (12.0%)
A few times a month	24 (13.0%)
A few times a year	16 (8.7%)
Never	87 (47.3%)

Please answer how often you post in the online health support group with the following intentions. (\*Never (1), Rarely (2), Sometimes (3), Often (4), Very Often (5))

- [AskQ] I ask questions. (2.19 ± 1.16)

Very often	4 (2.2%)
Often	18 (9.8%)
Sometimes	42 (22.8%)
Rarely	29 (15.8%)
Never	60 (32.6%)

- [InitDiscussion] I initiate discussions. (2.10 ± 1.22)

Very often	6 (3.3%)
Often	15 (8.2%)
Sometimes	38 (20.7%)
Rarely	19 (10.3%)
Never	71 (38.6%)

- [AnswerQ] I answer others' questions. (2.31 ± 1.32)

Very often	8 (4.3%)
Often	28 (15.2%)
Sometimes	32 (17.4%)
Rarely	19 (10.3%)
Never	65 (35.3%)

- [SharePersonal] I share my personal experiences. (2.33 ± 1.34)

Very often	10 (5.4%)
Often	25 (13.6%)
Sometimes	35 (19.0%)

Rarely	18 (9.8%)
Never	65 (35.3%)
• [ShareOpinion] I share my opinions. ( $2.36 \pm 1.32$ )	
Very often	10 (5.4%)
Often	26 (14.1%)
Sometimes	33 (17.9%)
Rarely	25 (13.6%)
Never	60 (35.3%)
• [ShareUseful] I share useful information. ( $2.38 \pm 1.31$ )	
Very often	7 (3.8%)
Often	31 (16.8%)
Sometimes	33 (17.9%)
Rarely	19 (10.3%)
Never	59 (32.1%)
• [ShareEmotion] I share emotional support with other members. ( $2.39 \pm 1.39$ )	
Very often	14 (7.6%)
Often	25 (13.6%)
Sometimes	32 (17.9%)
Rarely	19 (10.3%)
Never	63 (34.2%)
• [WarnSpam] I warn about spams and advertisements. ( $1.93 \pm 1.20$ )	
Very often	8 (4.3%)
Often	11 (6.0%)
Sometimes	22 (12.0%)
Rarely	30 (16.3%)
Never	79 (42.9%)
• [Mediate] I mediate members to help conversations stay on track. ( $1.75 \pm 1.04$ )	
Very often	2 (1.1%)
Often	10 (5.4%)
Sometimes	25 (13.6%)
Rarely	25 (13.6%)
Never	87 (47.3%)

### **Role (5 features)**

- [RoleFamily/RoleObserver/RoleSupporter/RoleLearner/RoleTeacher] How would you describe your role in the online health support group? (Open ended)

Role as family member

Yes:	29 (15.8%)
No:	30 (16.3%)

Role as observer

Yes:	20 (10.9%)
No:	39 (21.2%)

Role as supporter

Yes:	19 (10.3%)
No:	40 (21.7%)

Role as learner

Yes:	9 (4.9%)
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	No:	50 (27.2%)
Role as teacher	Yes:	14 (7.6%)
	No:	47 (25.5%)

#### **Values Sought (4 features)**

The reason for visiting the online health support group is:

(\*Not true at all (1), Not true (2), I don't know (3), True (4), Very true (5))

- **[ExchangeEmo]** To exchange emotional support ( $3.17 \pm 1.32$ )

Very true	27 (14.7%)
True	42 (22.8%)
I don't know	38 (20.7%)
Not true	18 (9.8%)
Not true at all	25 (13.6%)

Binary

- Positive	69 (46.0%)
- Negative	81 (54.0%)

- **[HearExp]** To hear about personal experiences from other patients ( $3.56 \pm 1.14$ )

Very true	29 (15.8%)
True	60 (32.6%)
I don't know	34 (18.5%)
Not true	12 (6.5%)
Not true at all	12 (6.5%)

Binary

- Positive	89 (60.5%)
- Negative	58 (39.5%)

- **[GetUnusualInfo]** To gain nonmainstream information ( $3.32 \pm 1.19$ )

Very true	24 (13.0%)
True	48 (26.1%)
I don't know	44 (23.9%)
Not true	16 (8.7%)
Not true at all	16 (8.7%)

Binary

- Positive	72 (48.6%)
- Negative	76 (51.4%)

- **[SpecificSearch]** To gain information that I am looking for ( $2.91 \pm 1.14$ )

Very true	12 (6.5%)
True	35 (19.0%)
I don't know	54 (29.3%)
Not true	29 (15.8%)
Not true at all	20 (10.9%)

**Binary**

- Positive 57 (33.5%)
- Negative 113 (66.5%)

\* (mean  $\pm$  standard deviation)