

Sharing Health Information on Facebook: Practices, Preferences, and Risk Perceptions of North American Users

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a place of mind
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health information (HI) on the Internet

- Shared online since the 1990s [Pew Research Center]

More recently,

- 80% of internet users looked online for different health topics
- Increasing number of users who share/seek HI on social networking sites (SNSs):
 - 26% followed friends' health experiences
 - 16% looked for others with similar health concern
 - 11% posted comments, queries, or information about health

to share HI on SNSs or not?

- Expectation of **benefits**
 - Social support, learning from shared experience, and self-management education
 - The benefits are **two-way**
- Perceptions of **risks**
 - HI is **personal** information
 - Privacy invasion, unintended information disclosure, shared information misuse
- Other **factors** (e.g., health status, privacy attitudes)

why, how, and with whom people share their HI on FB?

investigate

- the main factors that influence users' motivation to share
- features that enable effective and safe sharing

methodology

1. Exploratory study (1 hour interviews)

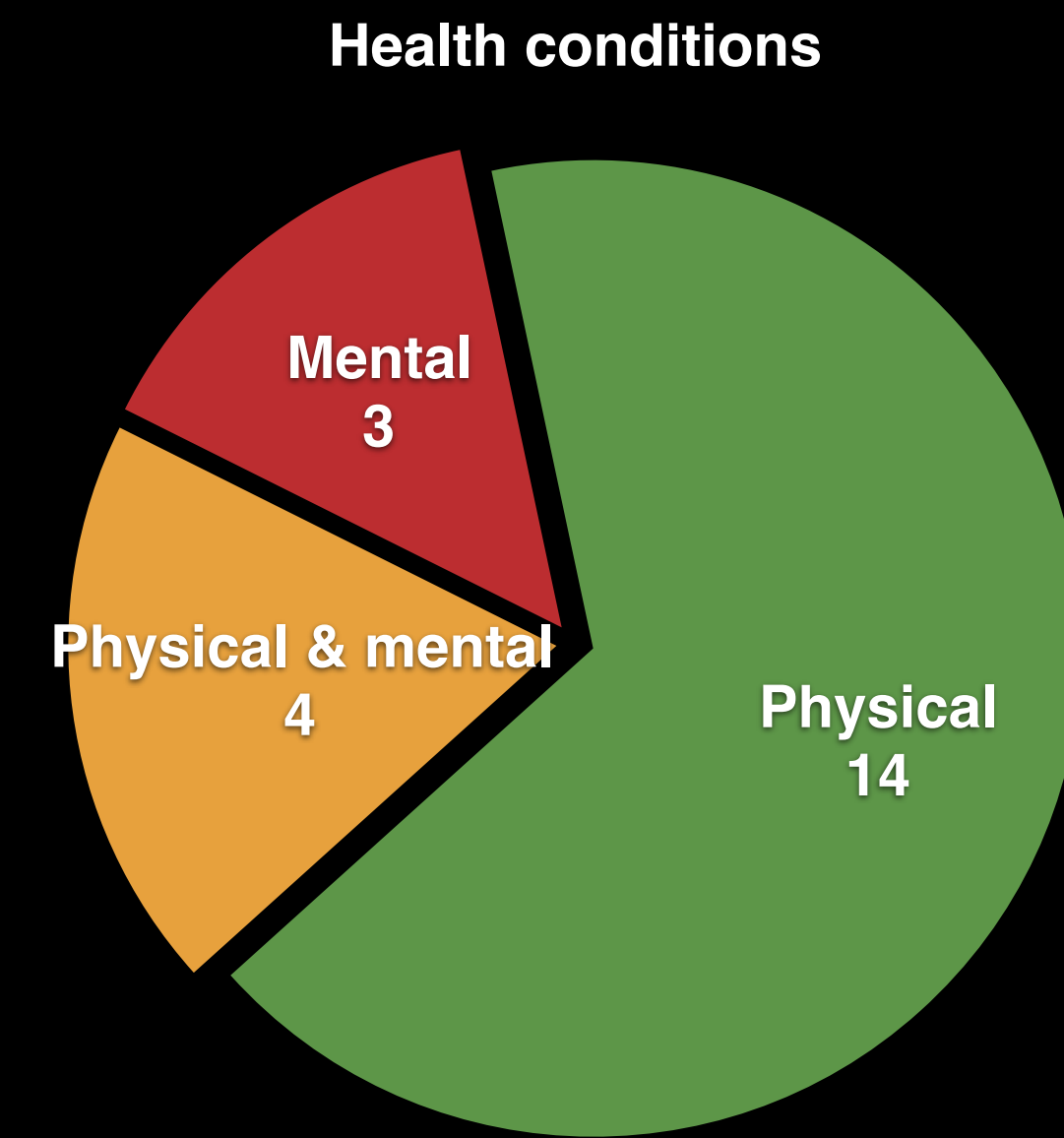
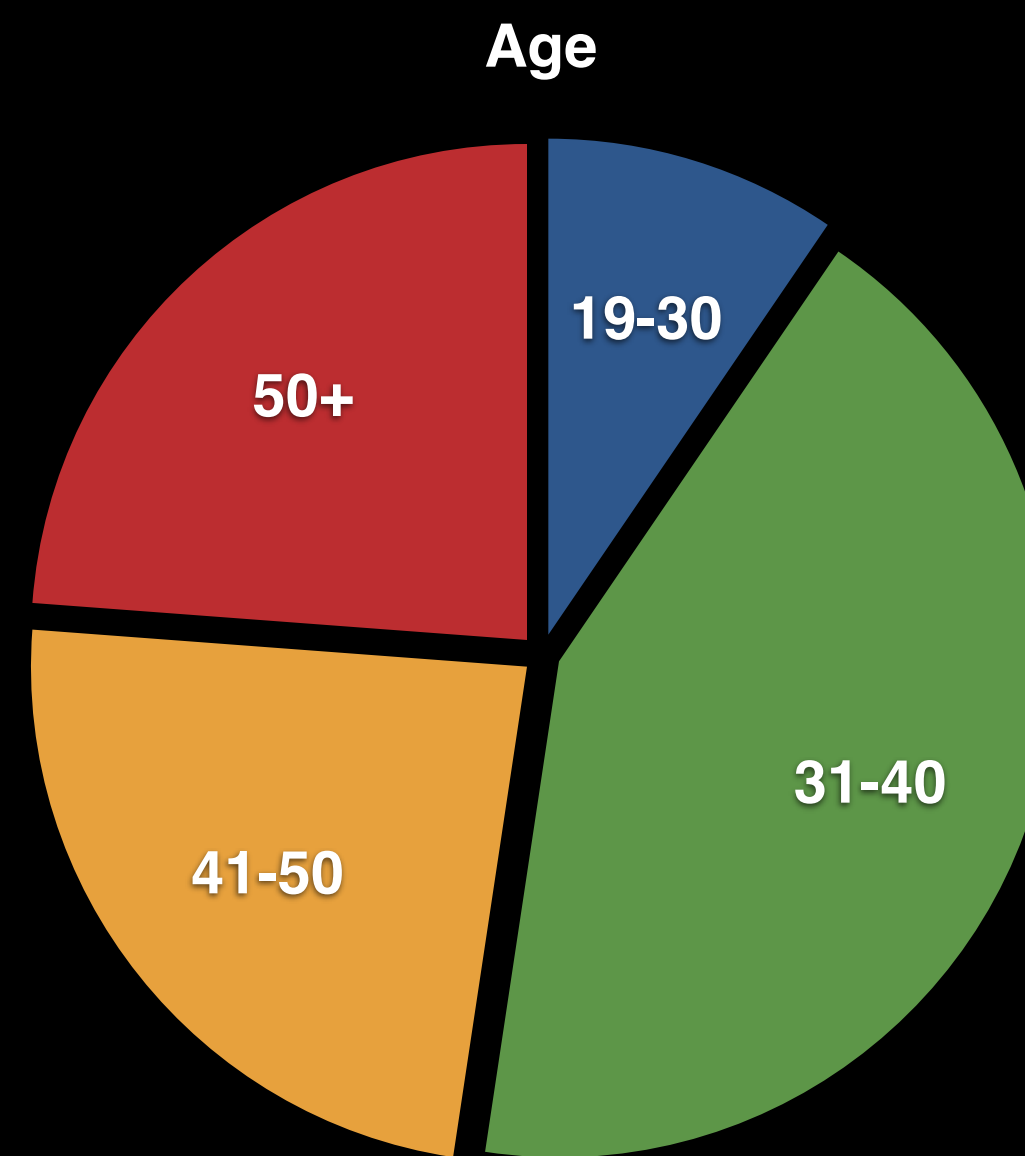
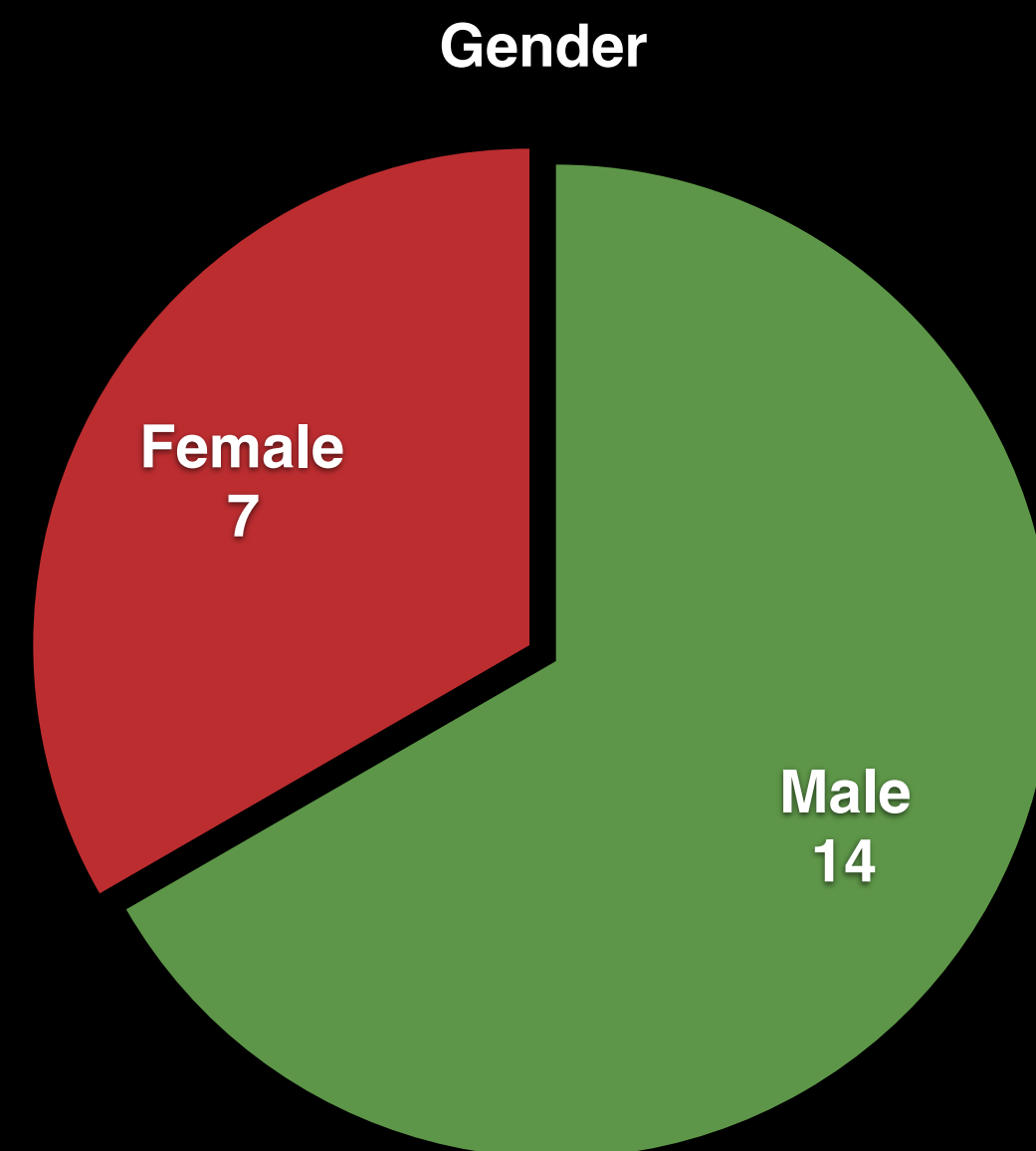
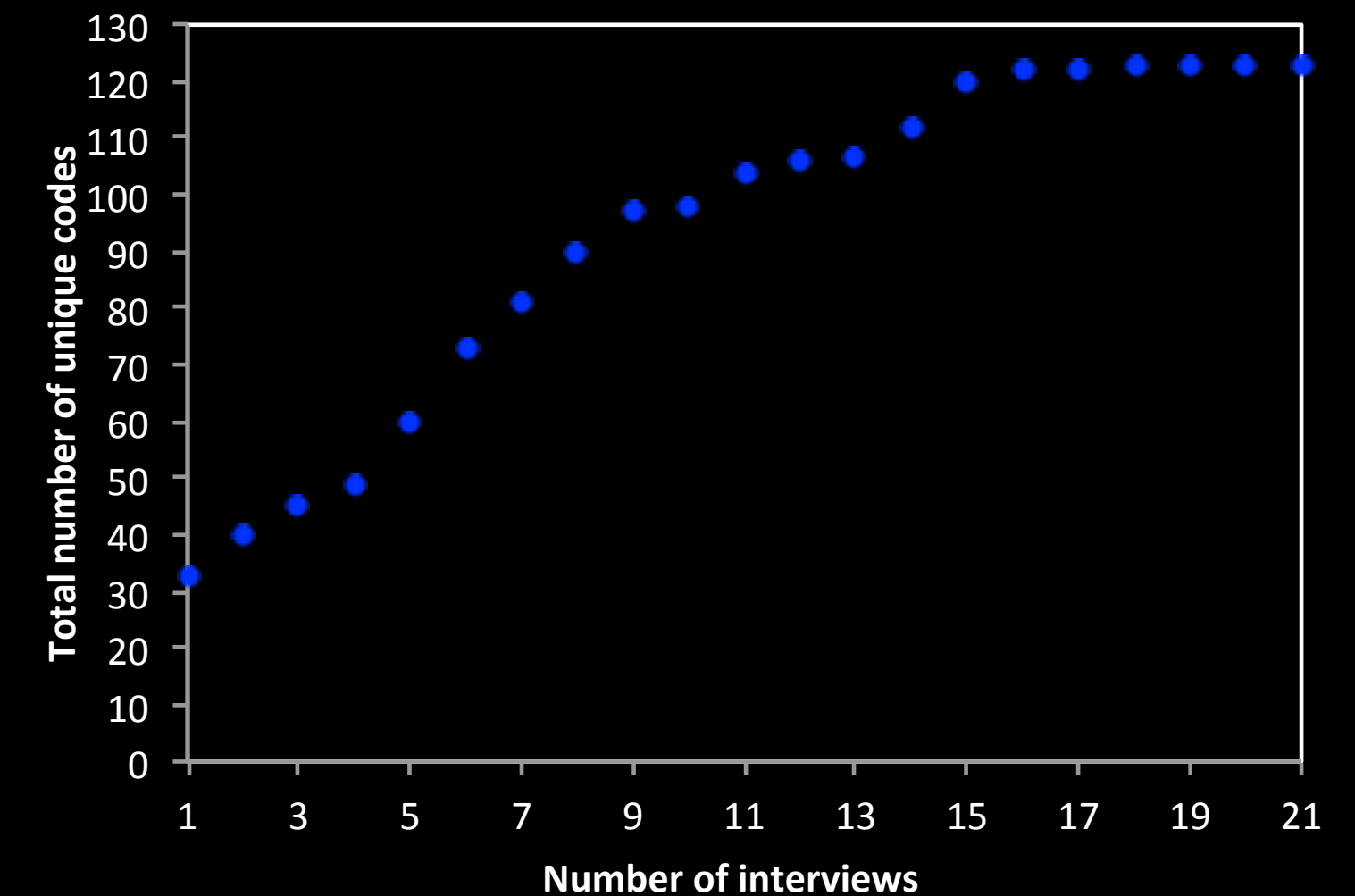
- Guided by **grounded theory** (sampling, data collection, and analysis)
- Interviewed **SNS users** with chronic **health condition(s)**
- Explored HI sharing **practices**, risk **perceptions**, and **motivation** to share HI on FB

2. Confirmatory study (online survey)

- Recruited a more **representative** sample of FB users
- **Validated** and **extended** our findings

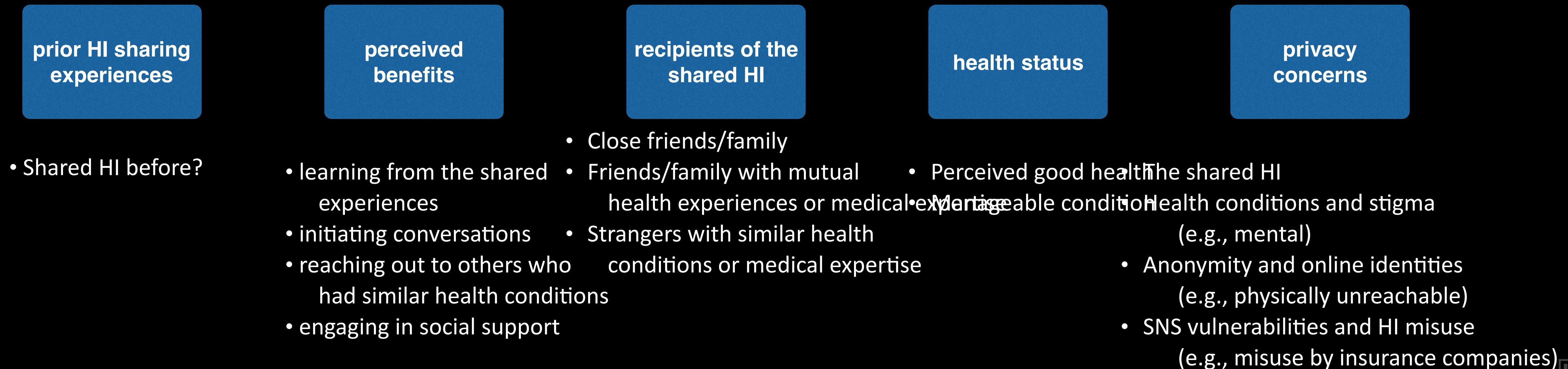
results: interview study

- recruited through Spinal Cord Injury BC, Craigslist, kijiji
- 21 FB users with different chronic health conditions



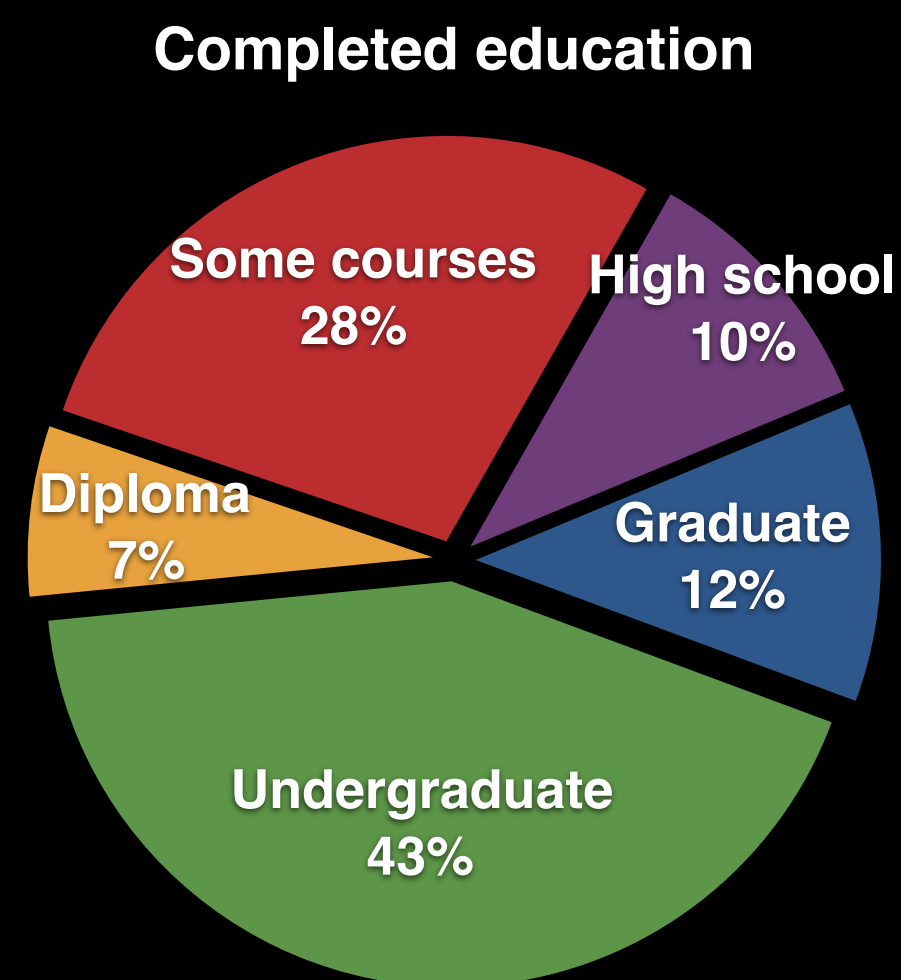
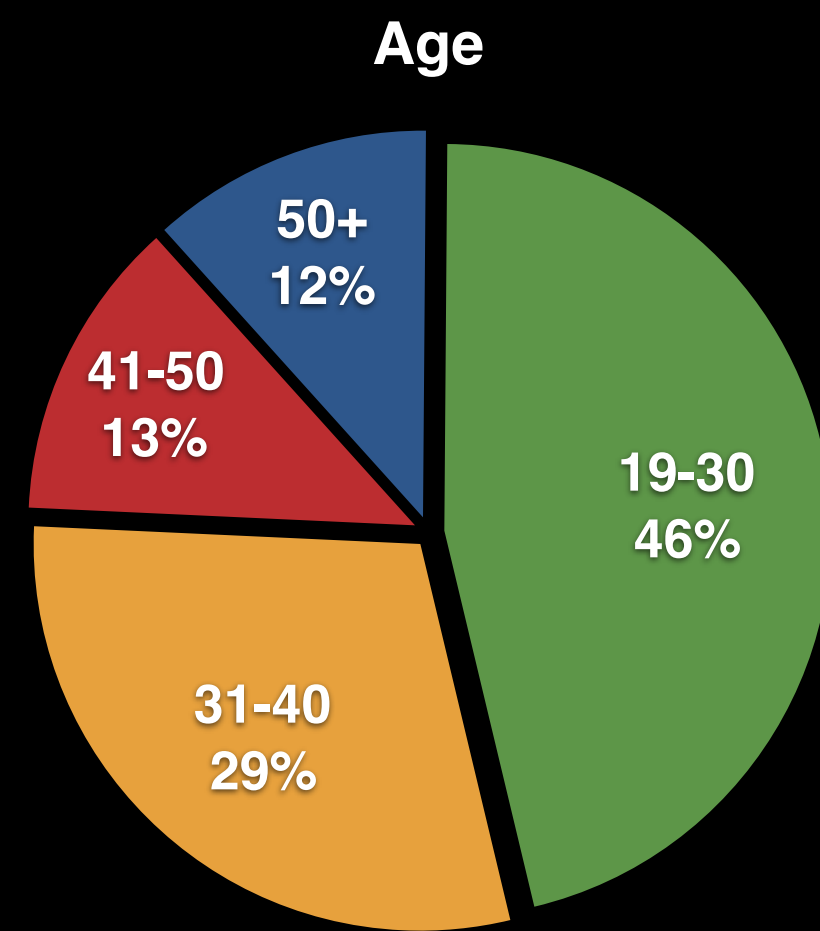
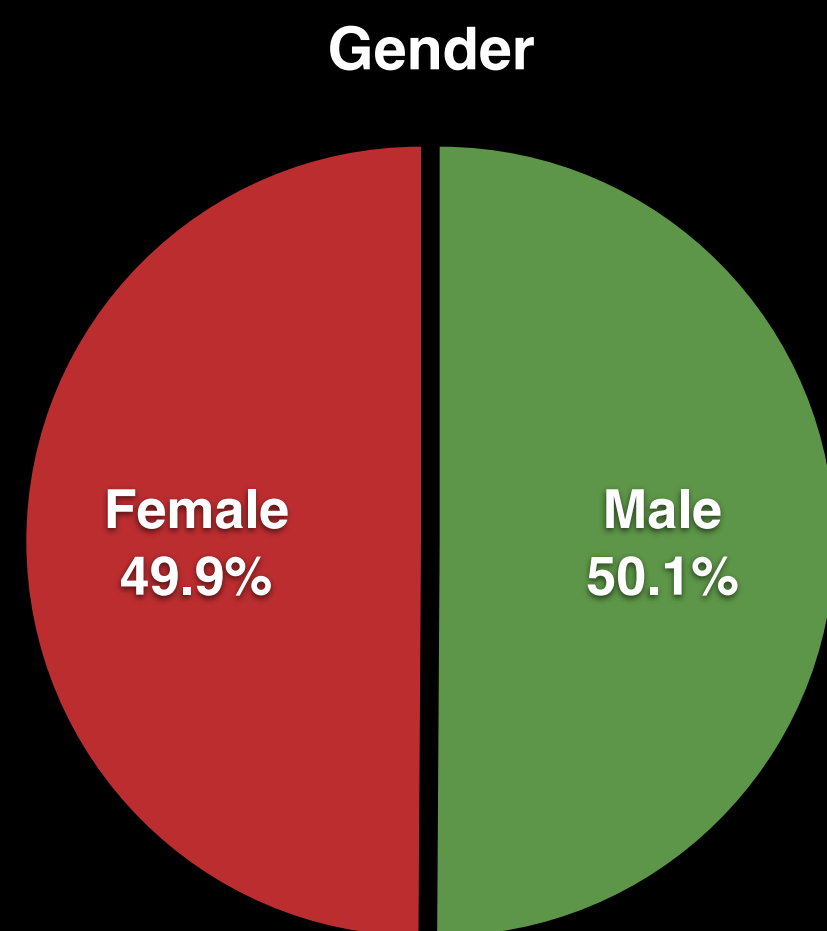
results: qualitative data analysis

- Open coding (**line-by-line** coding): 90 unique codes after analyzing 8 interviews
- Axial coding (**interrelated** codes/categories): 10 categories
- Selective coding (**core** category): ***Motivation to share HI on FB***



confirmatory study: online survey

- Close- and open-ended questions about HI sharing practices, preferences, and motivation
- Recruited 492 Facebook users through Amazon MTurk (95% approval rate, \$1 compensation)

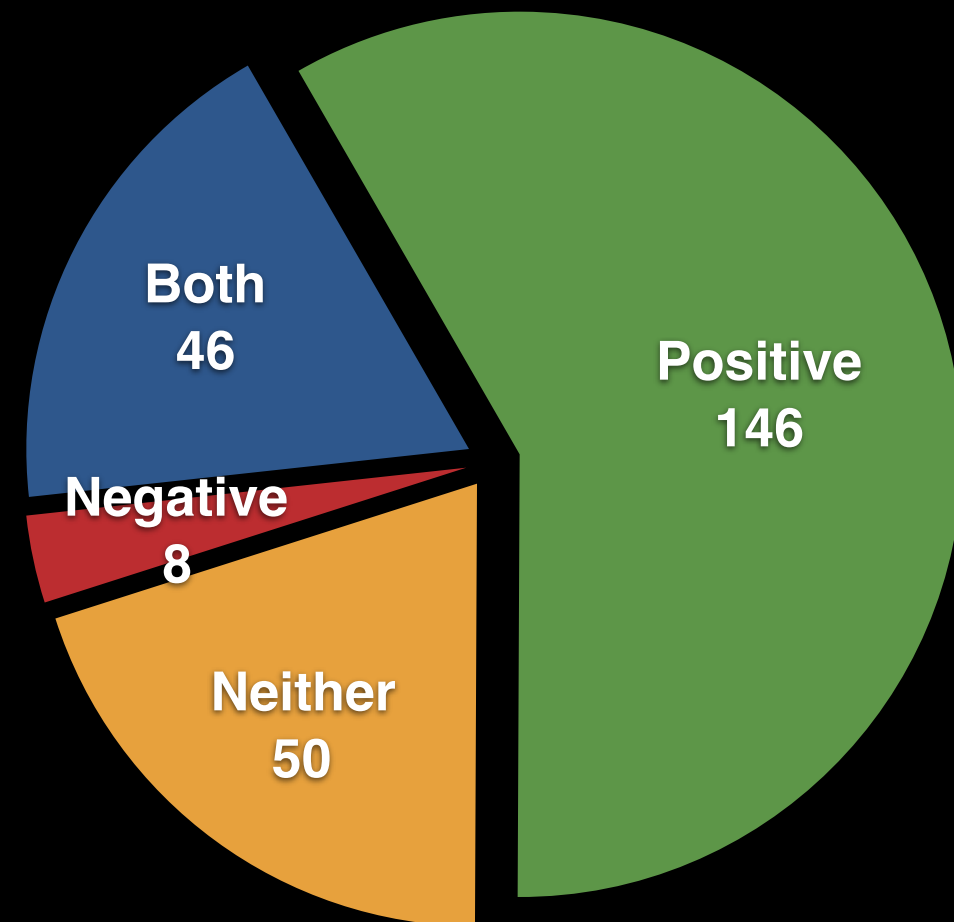


participant characteristics	%
Had degree or experience related to IT/Computer	20
Spent 2 hours or more on the internet every day	91
Checked Facebook on daily basis	85
Were on Facebook for at least 4 years	97

motivation to share HI on SNSs

prior HI sharing experiences

- 51% shared the HI on SNSs
- **Sig. difference between both groups**
- experience with HI sharing



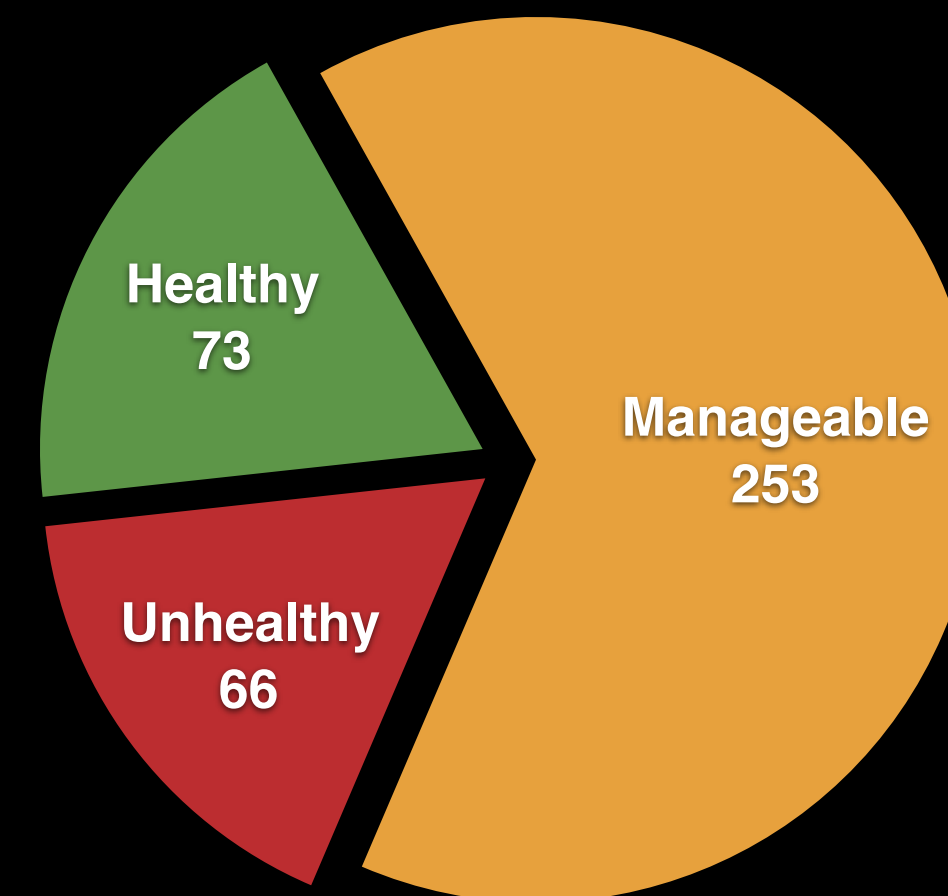
perceived benefits

- positive experiences correlated with benefits
- **Sig. difference between Positive & other groups**

health status (categories)

- number of health conditions
- health status

Health categories

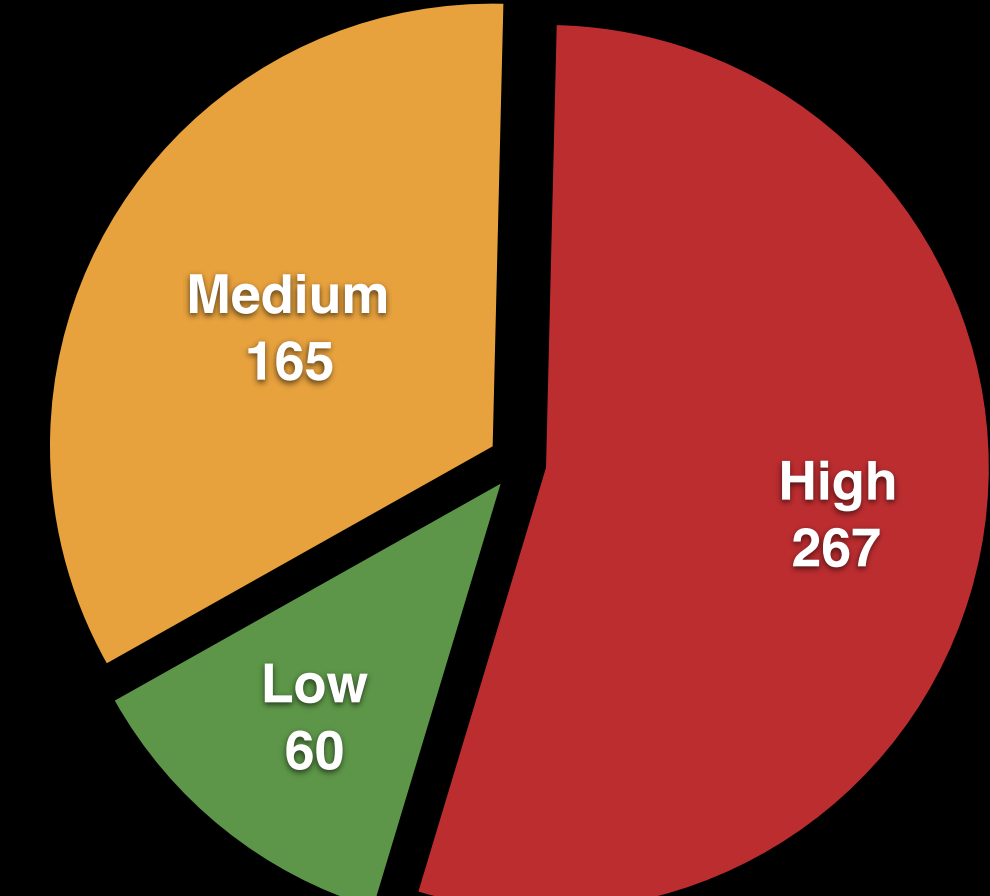


Sig. difference between Healthy & Unhealthy groups

perceived privacy

- inspired by the Westin Privacy Index

privacy concerns



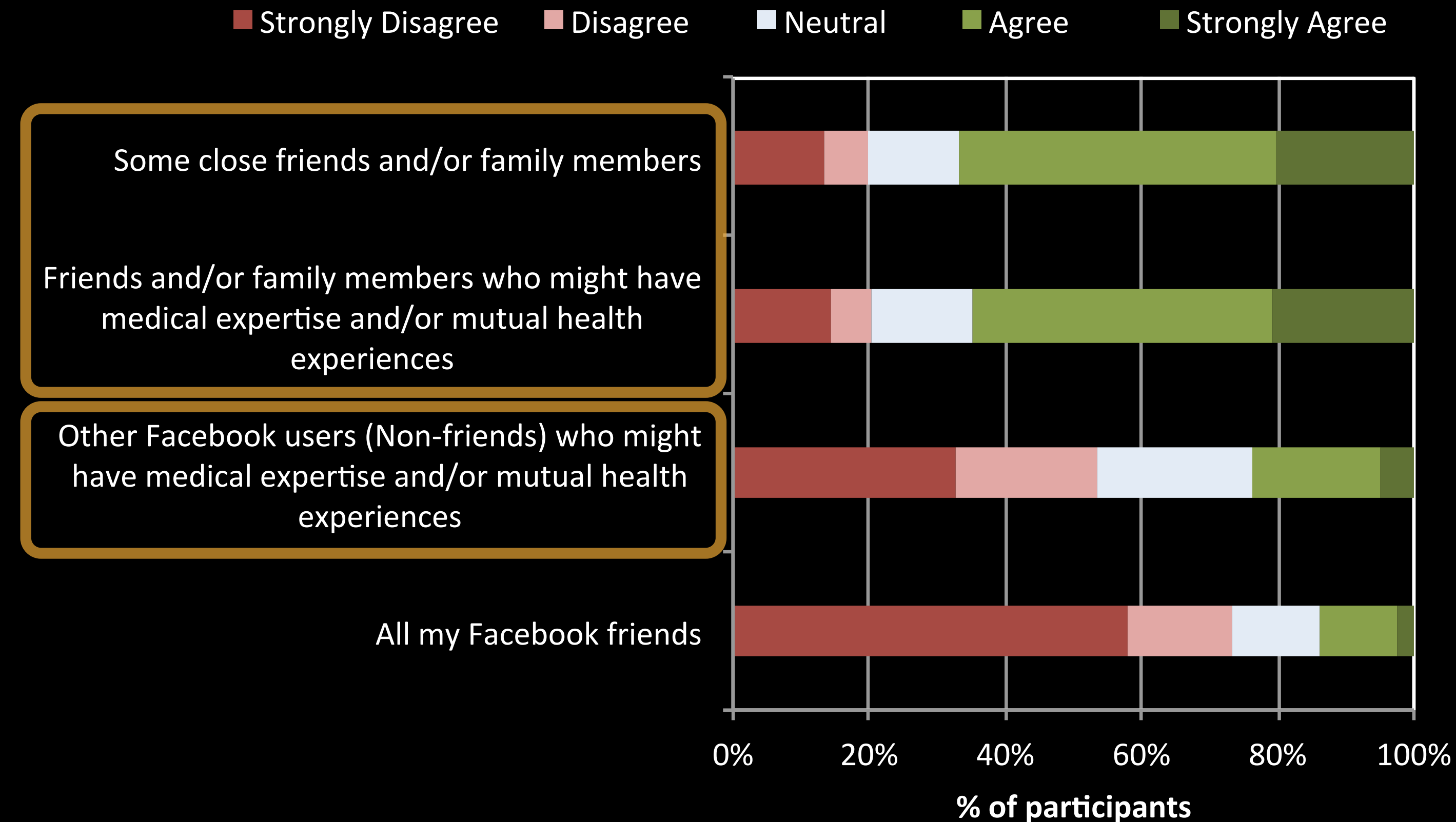
Sig. difference among all groups

between-subjects comparison using Kruskal-Wallis and Mann-Whitney U test

preferred recipients of the shared HI

“I would consider sharing my HI with the following FB users.”

- Friends/family members were preferred over other users
- Sharing HI with strangers
 - Unhealthy vs. Healthy



- Willingness to search for different users
 - with mutual health experiences vs. medical expertise

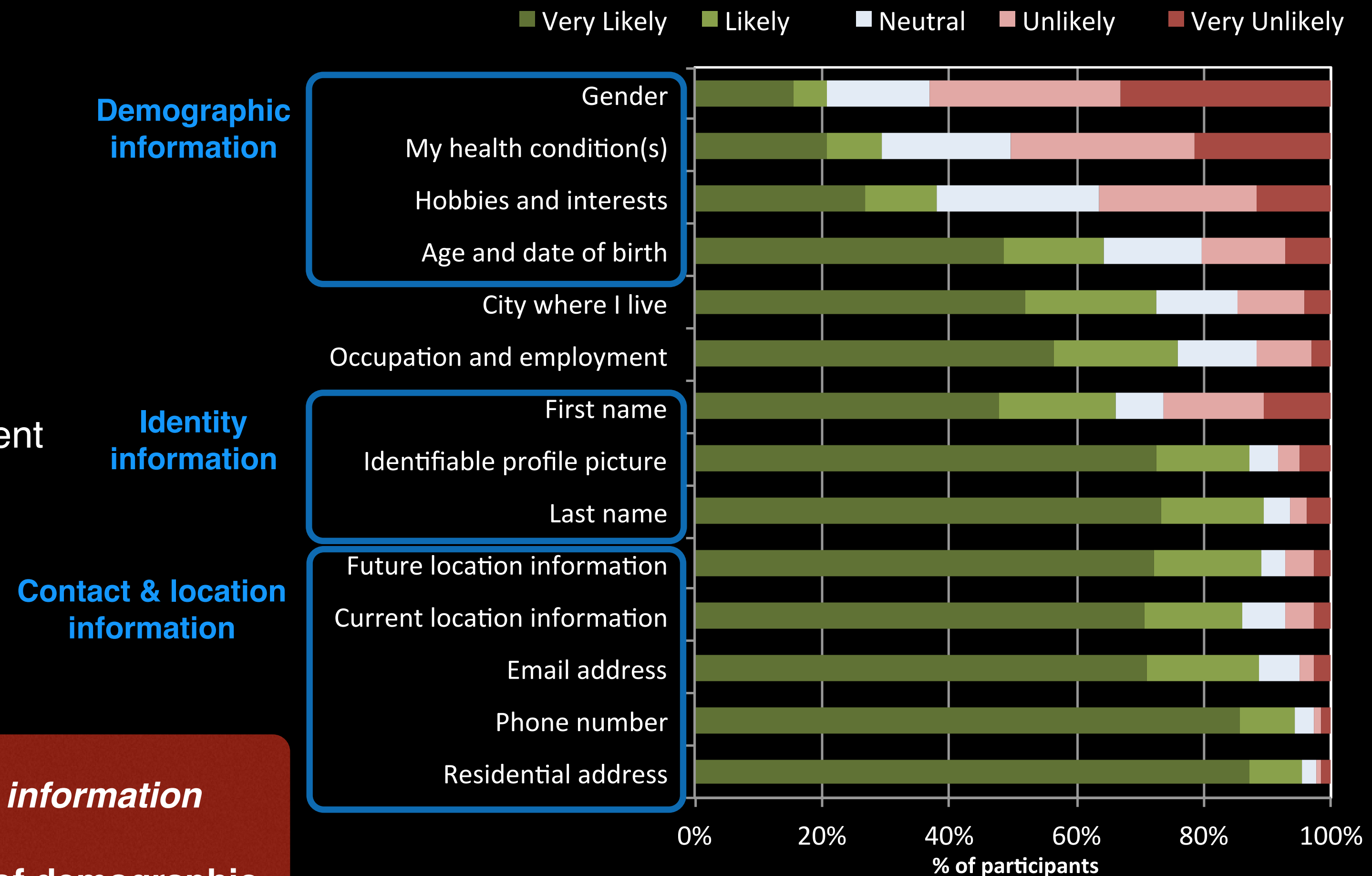
other preferences

- **Anonymous** online identity (e.g., hide last name, location info)
- Trusted SNS **provider** (e.g., governmental health authority)

anonymous online identity

“Suppose you want to create an anonymous identity in order to share your health information with strangers on Facebook. How likely would you ‘hide’ each of the following personal information?”

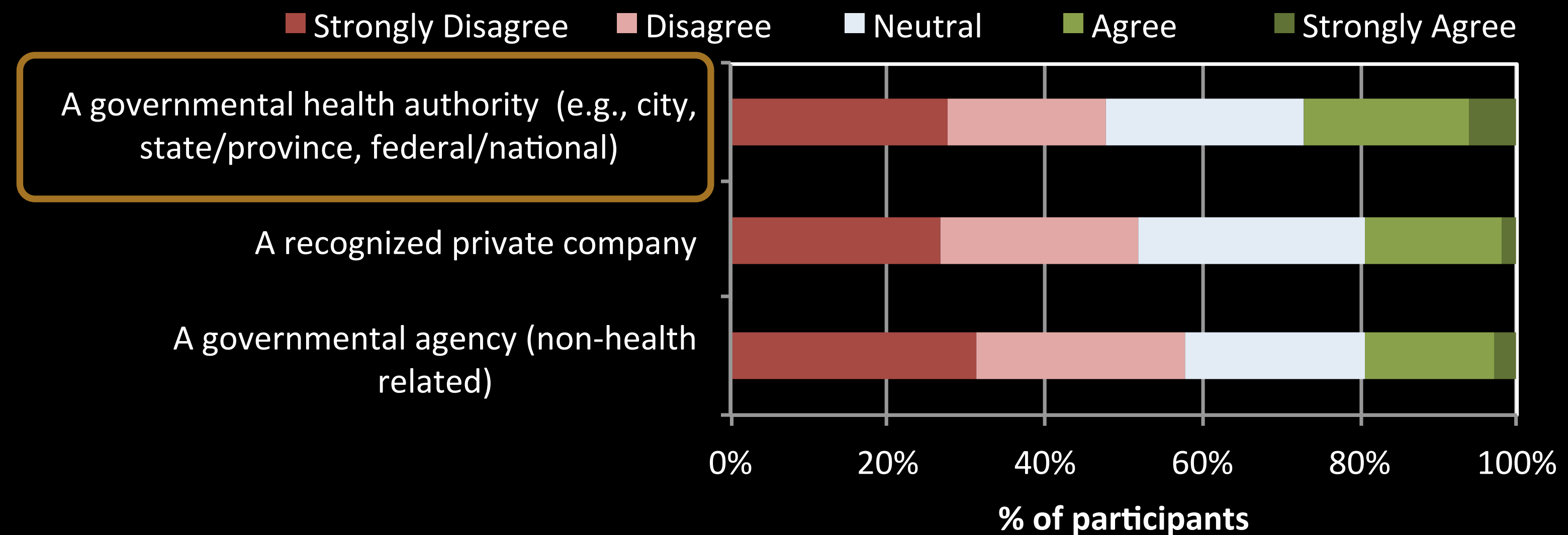
- 36% were **likely** to use anonymous identity for sharing HI with strangers
- Explored willingness to **hide** different information items
 - Identified **correlated** items using principle component analysis (PCA)



- Users were significantly less likely to hide **Demographic information**
- hiding of health condition(s) was correlated with hiding of demographic information

trusting the SNS provider

“In general, I’d trust an SNS with my HI if it is operated/owned by”



Trusting SNSs based on **recommendation** made by others?

- recommended by their doctor(s) vs. friends and/or family members

design implications

FB can motivate HI sharing by:

1. Facilitating finding others with mutual health experiences (e.g., automatic recommendations?)
2. Providing an option for creating anonymous online identities in order to share HI with strangers (e.g., hide contact, location, and identity information)
3. Motivating users' through their doctors (e.g., incentivize doctors to recommend FB)

contributions

- Explore HI sharing practices on FB
- Provide a better understanding of users' motivation to share
- Identify the main factors that influence users' motivation
- Shed light on features that could facilitate sharing

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