Privacy Aspects of Health Related Information Sharing in Online Social Networks

Presented by: Lujo Bauer

Authors:

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Presentation outline

- Introduction + Problem
- Methodology
- Results and discussion
- Summary + Future work

Health Related Information (HRI) sharing is beneficial for:

Individuals and people in their social network.

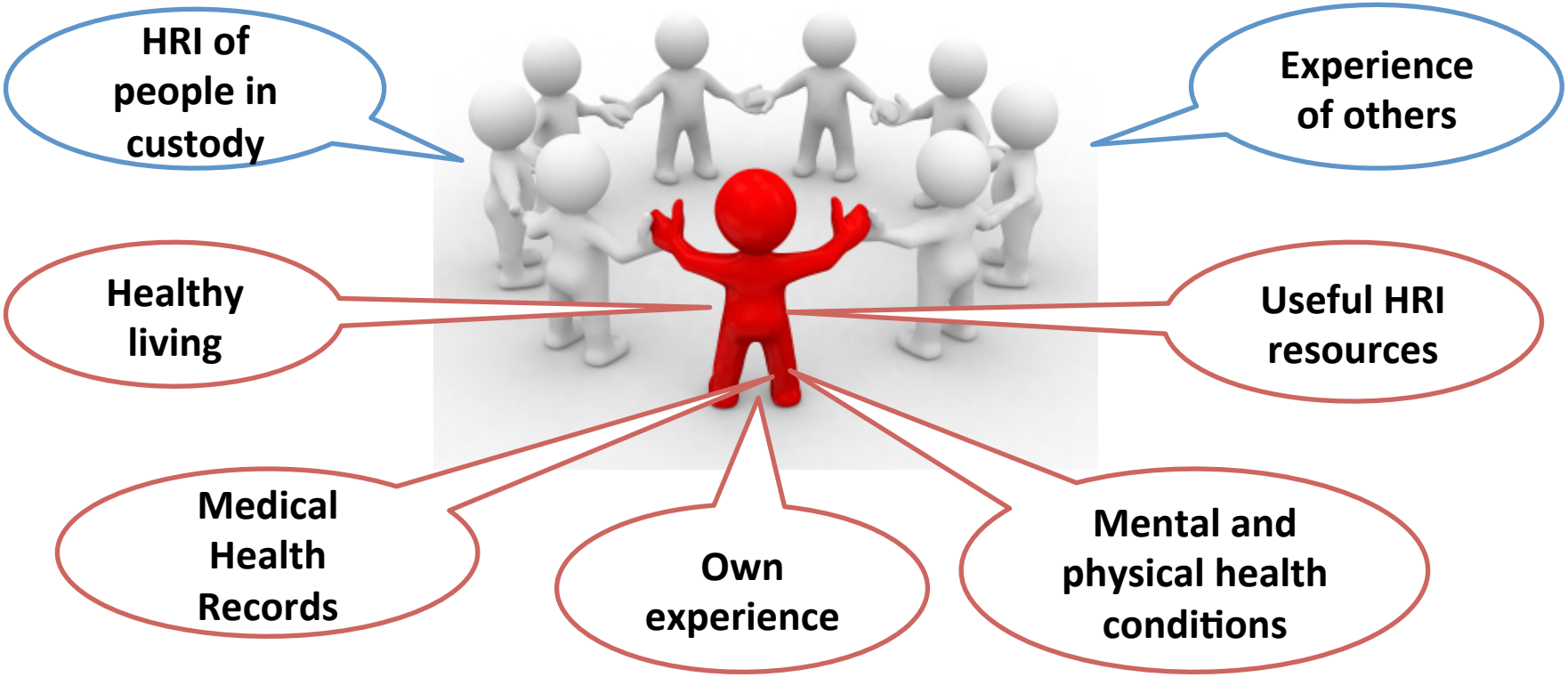
Examples:

- Social pressure and losing weight [1].
- Learning from others with similar conditions [2].
- Social support during treatments [3].

[1] F. Lupianez-villanueva, W. Lusoli, M. Bacigalupo, I. Maghiros, N. Andrade, and C. Codagnone, "Health-related information as personal data in Europe: Results from a representative survey in EU27," Medicine 2.0 Ethical and legal issues, confidentiality and privacy, 2012.
[2] D. M. Zulman, K. M. Nazi, C. L. Turvey, T. H. Wagner, S. S. Woods, and L. C. An, "Patient interest in sharing personal health record information a web-based survey," Annals of Internal Medicine, vol. 155, no. 12, pp. 805–810, 2011.
[3] M. M. Skeels, "Sharing by design: Understanding and supporting personal health information sharing and collaboration within social networks," Ph.D. dissertation, University of Washington, 2010.

What is HRI?

Any information related to the health of an individual and the health of people in her social network.



HRI sharing in OSNs

- Highly inter-connected virtual networks, with lots of active users.
- People share information including HRI.

Survey results (Pew Internet 2013):

- 26% of online users have followed their friends' personal health experiences during last year.
- 16% went online to find others with similar health concern.

Other studies:

- Sharing HRI is becoming a leading habit [1,2,4,5].

[1] F. Lupianez-villanueva, W. Lusoli, M. Bacigalupo, I. Maghiros, N. Andrade, and C. Codagnone, "Health-related information as personal data in Europe: Results from a representative survey in EU27," Medicine 2.0 Ethical and legal issues, confidentiality and privacy, 2012.
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[4] S. Fox and M. Duggan, "Health online 2013," Pew Research Center's Internet and American Life Project, January 2013.
[5] S. Fox, "The social life of health information," Pew Research Center Report, May 2011.

Privacy

It is a dynamic boundary regulation process [6].

Goal:

Minimize the difference between achieved and desired privacy.

How to achieve goal:

By adjusting behaviours with respect to surrounding conditions.

[6] I. Altman, "Privacy regulation: culturally universal or culturally specific?" Journal of Social Issues, vol. 33, no. 3, pp. 66–84, 1977.

Privacy perceptions and Behavioural responses

Depending on their knowledge and previous experience:

- People perceive risks differently,
- People behave differently in response to perceived risks.

Examples:

Younger patients and Facebook [7].

[7] M.Velden and K. ElEmam,"not all my friends need to know: a qualitative study of teenage patients, privacy, and social media," Journal of the American Medical Informatics Association, vol. 20, no. 1, pp. 16– 24, July 2012.

Motivation recap

- HRI sharing is beneficial to users and their social peers.
- Increasing number of users who share HRI in OSNs.
- People seek to maintain their privacy with respect to their perceived risks.
- People mitigate risks differently.

Research questions

1. What are the HRI sharing practices in OSNs?

2. How do OSN users perceive privacy risks associated with sharing HRI?

3. What risk-mitigating behaviours are adopted by OSN users in different risk levels.

Methodology: Online survey

Recruited 166 active OSN users through Amazon Mechanical Turk (MT).

Surveyed the following:

- Demographics and OSN usage.
- HRI sharing practices.
- Perceived privacy risks when sharing HRI with different users.
- Risk-mitigating behaviours at different risk levels.

Participant recruitment and survey execution

Recruited Amazon MT workers through CrowdFlower (required participants from the US that are 19 years of age and older with at least 1 active OSN account)

Posted a job with instructions and a link to the online survey web-site

To validate submissions, each participant was assigned with an alpha-numeric code at the end of survey

Participants used the assigned codes to submit the job (compensated with 1 USD upon submission)

Results and Discussion

HRI categorization

- We categorized different HRI examples into 8 groups.
- To triangulate our categorization, we performed a closed card sorting exercise with 11 participants.
- For almost all HRI examples, more than 65% of participants used similar categorization to ours.

"Our categorization was reasonable"

HRI categories	Examples
Healthy living	dietary and healthy eating, physical exercise, environmental hazards
Own Experience	experience with: previous surgeries, treatments and their side effects, symptoms
Useful found information	books, articles, websites
Mental and emotional health conditions	sad, stressed, happy, excited, depressed, mental disorder
Physical health conditions	sick, injured, not feeling good, in good shape
Medical health records	personal information and address, insurance related information, x-rays, reports.
Experience of somebody else	experience with: previous surgeries, treatments and their side effects, symptoms
HRI of people in your custody	parents, children, and others

Participant demographics

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Gender	49.4% 50.6%	Male Female
Age	All 59% 24.7% 8.4% 7.9%	19-70 (μ=30.4, σ=10, median=28) 19-29 30-39 40-49 50+
Completed education	25.3% 12.7% 39.8% 6.6% 10.2% 5.4%	high school post-secondary diploma undergraduate degree community college graduate degree other
Employment category	More than 18 different categories: IT (10.6%), Education (9%), Medical (7.9%), Banking (7.4%), and other categories including Student and Self-employed	

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	59%	19-29
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	8.4%	40-49
	7.9%	50+
Completed education	25.3%	high school
	12.7%	post-secondary diploma
	39.8%	undergraduate degree
	6.6%	community college
	10.2%	graduate degree
	5.4%	other
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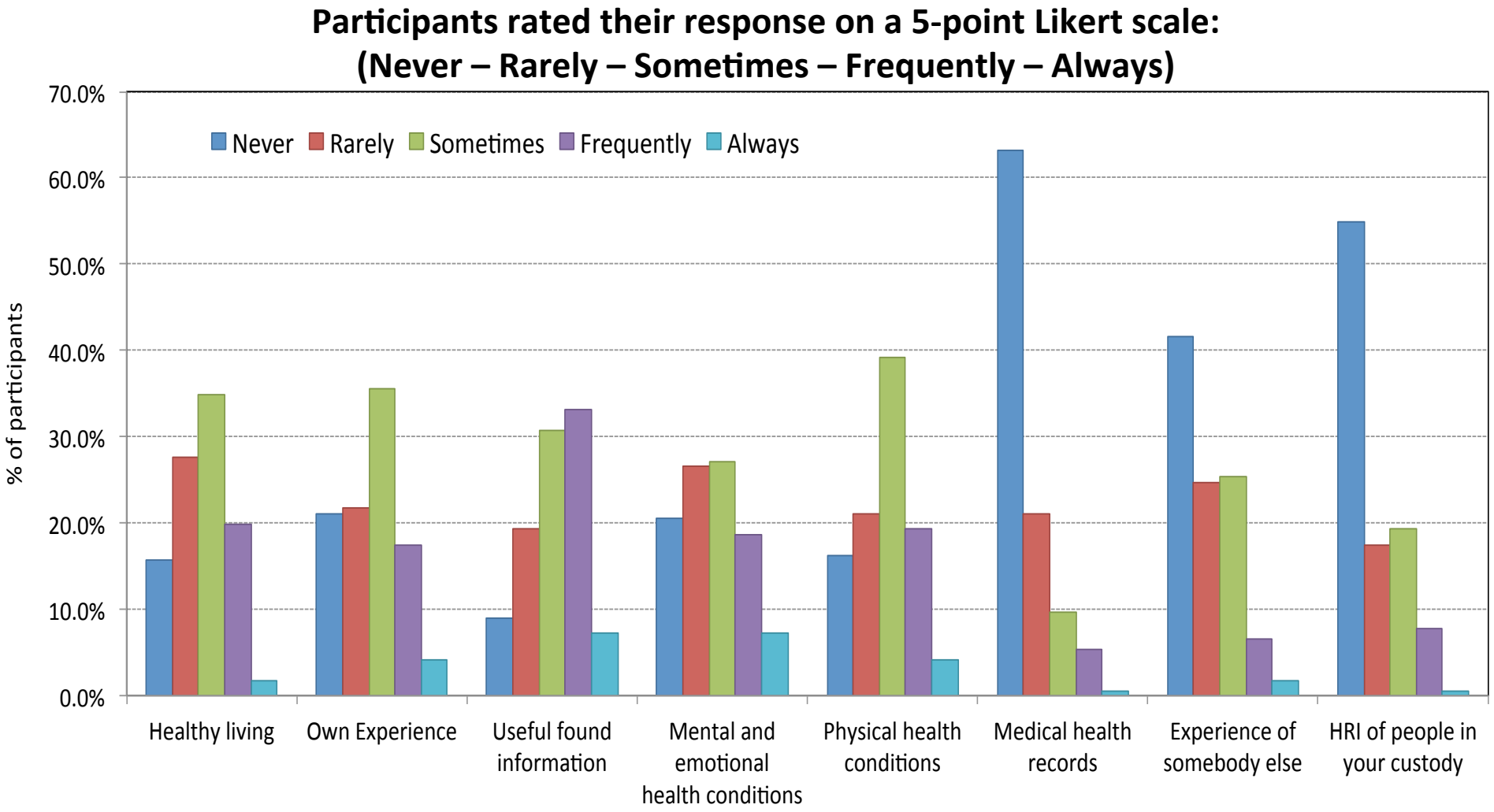
Participant demographics

- Is the sample representative?
- Can we generalize results?

OSN usage

- About 40% of participants had 1 OSN account.
- 140 participants (84.3%) logged into their OSN accounts on a daily basis.
- Majority of participants (96.4%) indicated having Facebook profiles.

How often do you share HRI in OSN?



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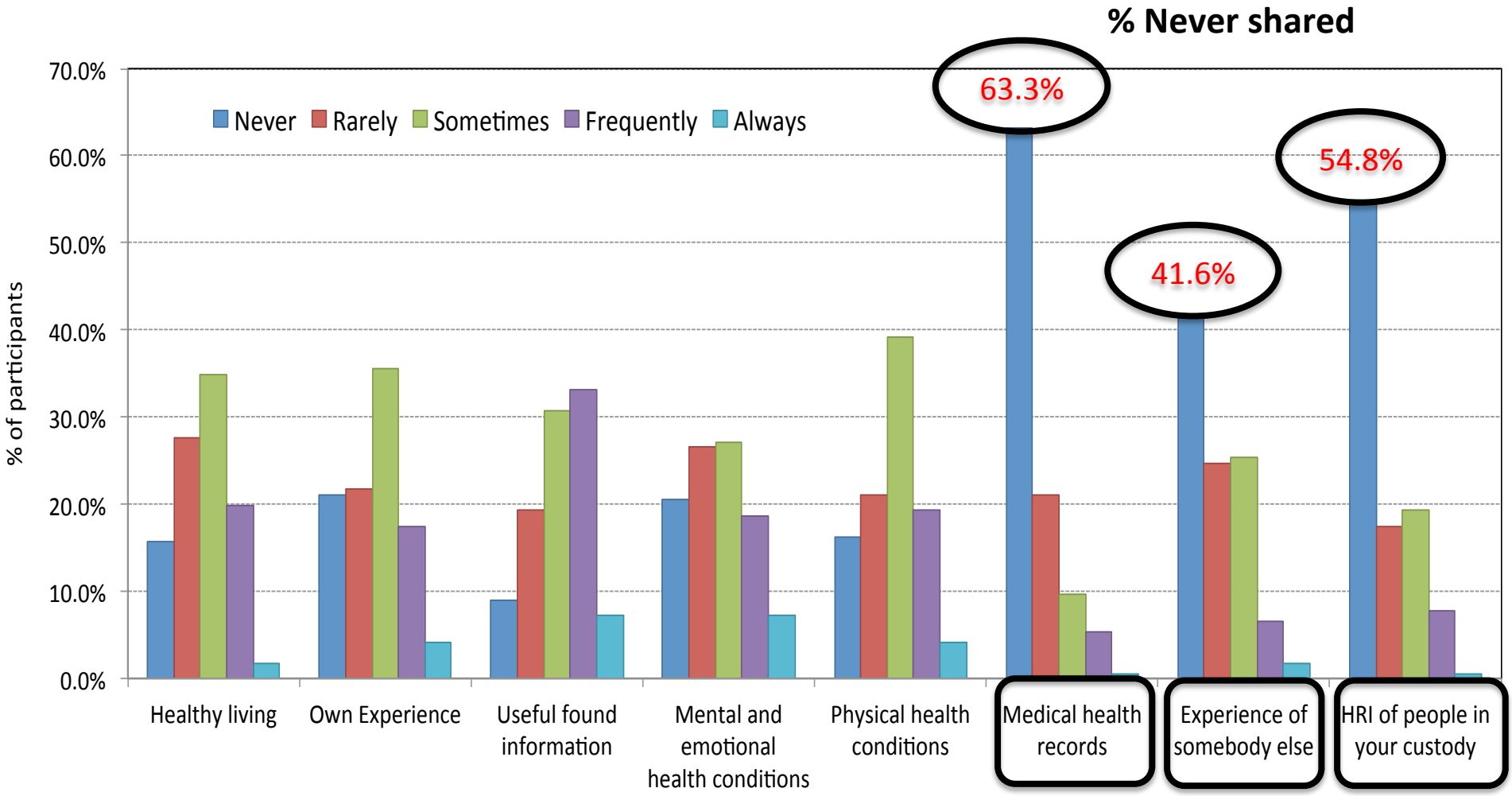

Why do you share HRI?

Participants selected all that applied from a list of common reasons.

Reasons for sharing HRI	Participants
Help others by sharing personal experience and knowledge	**66.9%**
Seek help or social support	**51.8%**
Get benefits by receiving useful feedback from on-line contacts	**48.2%**
Seek online interactions and make discussions	44.0%
Alleviate anxiety (sharing HRI makes me feel better and less stressed)	38.6%
Promote healthy living	37.3%
Other reasons	6.6%

For HRI that participants did not share

Reasons against sharing HRI	Participants
I have different people in my online contact list and I prefer not to share my HRI with all of them	**49.4%**
My HRI is personal and I do not share it with anyone	**43.4%**
I do not want to be treated as "the sick" person by my online contacts	39.2%
I do not want my online contacts to worry about me by receiving bad news about my health	34.9%
I do not want my online contacts to know about my HRI	34.9%
I prefer to share my HRI with my doctor	30.1%
I prefer to share my HRI offline	22.3%
My online contacts are not interested in my HRI	20.5%
Other reasons	4.8%

For HRI that participants did not share

Reasons against sharing HRI	Participants
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I prefer to share my HRI with my doctor	30.1%
I prefer to share my HRI offline	22.3%
My online contacts are not interested in my HRI	20.5%
Other reasons	4.8%

Might indicate privacy concerns

Key factors affecting perceived privacy risks

1. The recipient of information.
2. The HRI type and category.
3. The OSN where HRI is shared.
4. The health conditions of the individual at time of sharing.

How does each factor affect your perceived privacy risks?

(Responses varied on a 5-point Likert scale from "does not affect" to "strongly affects")

- More than 85% of participants indicated that all four factors affected their perceived privacy risks.
- HRI recipient and its type/category, *strongly affected* the perceived privacy risks of approximately 30% of all participants.

Risk perceptions

Rate risk perception on a 5-point Likert scale:
(Very low – Acceptable – Moderate – High – Extreme)

HRI categories
Healthy living
Own Experience
Useful found information
Mental and emotional health conditions
Physical health conditions
Medical health records
Experience of somebody else
HRI of people in your custody

When sharing with:

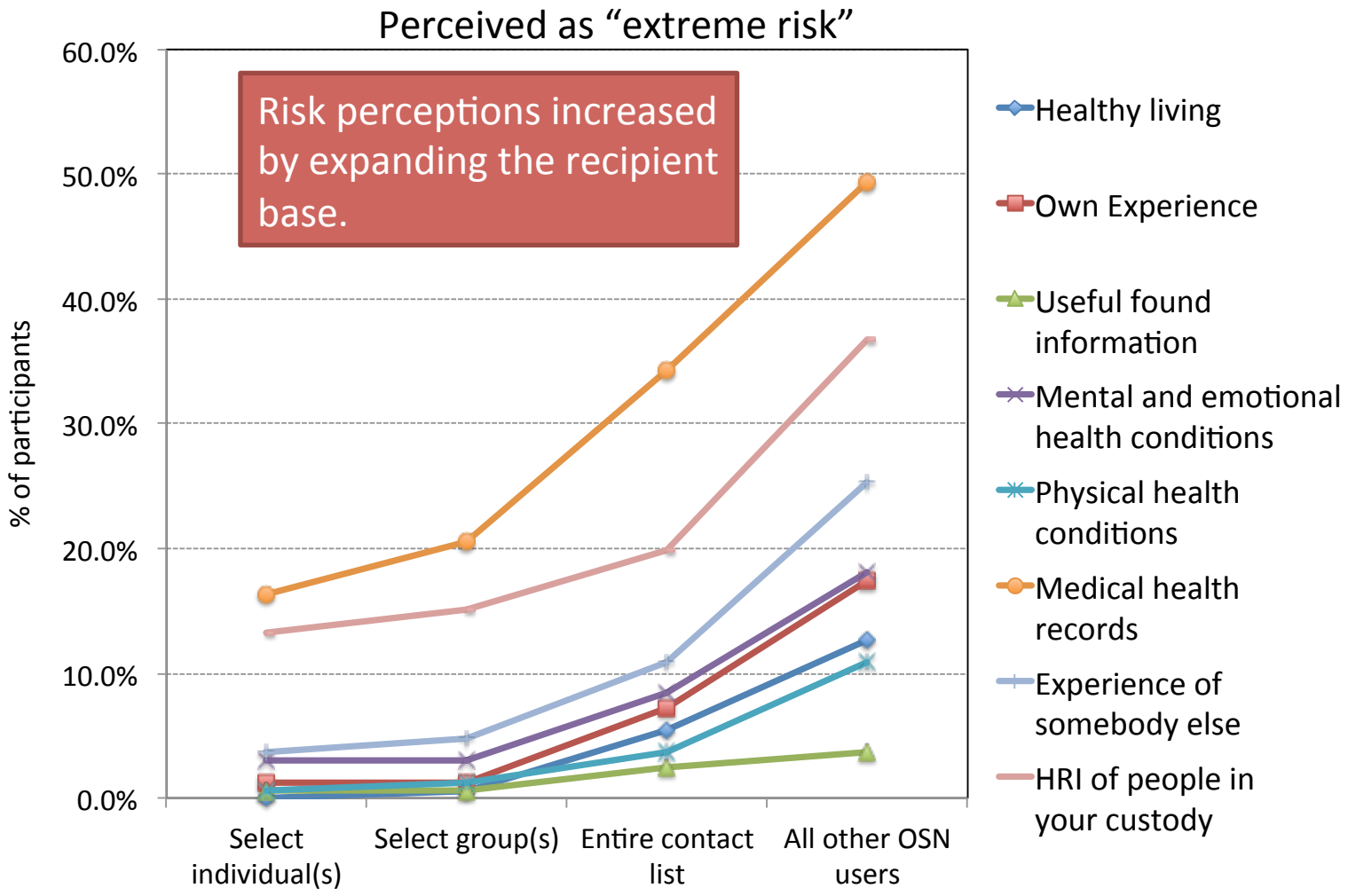
- Select individual(s)
- Select group(s)
- Entire contacts
- All other OSN users

Risk perceptions
(Sharing HRI among different user categories)

- Less concerned with "healthy living" and "useful found information".
  - No significant difference when sharing between "entire contacts" and "all other OSN users"

- Moreover, for "useful found information":
  - No significant difference when sharing between "select individual(s)" and "select group(s)"

Risk perceptions



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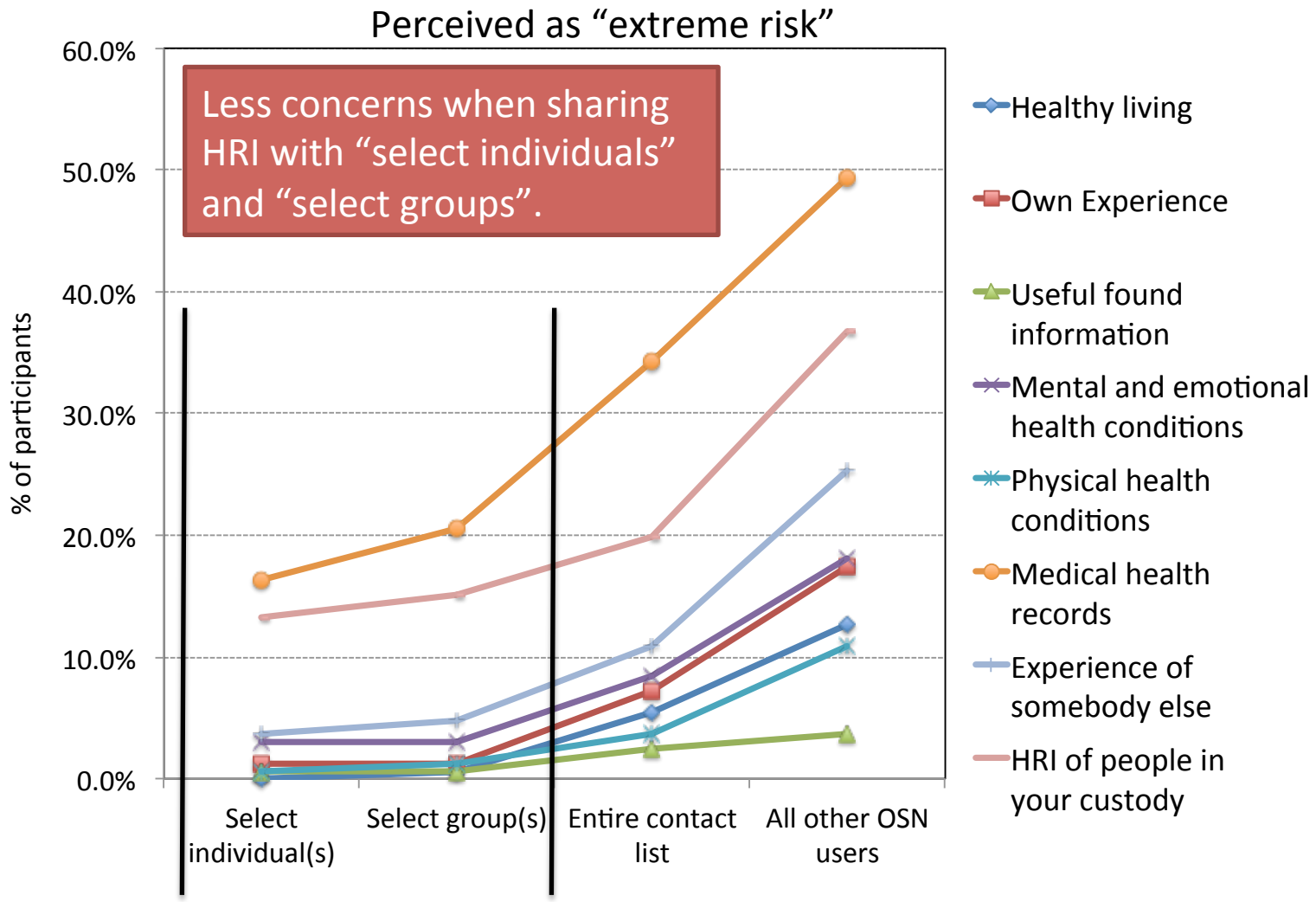

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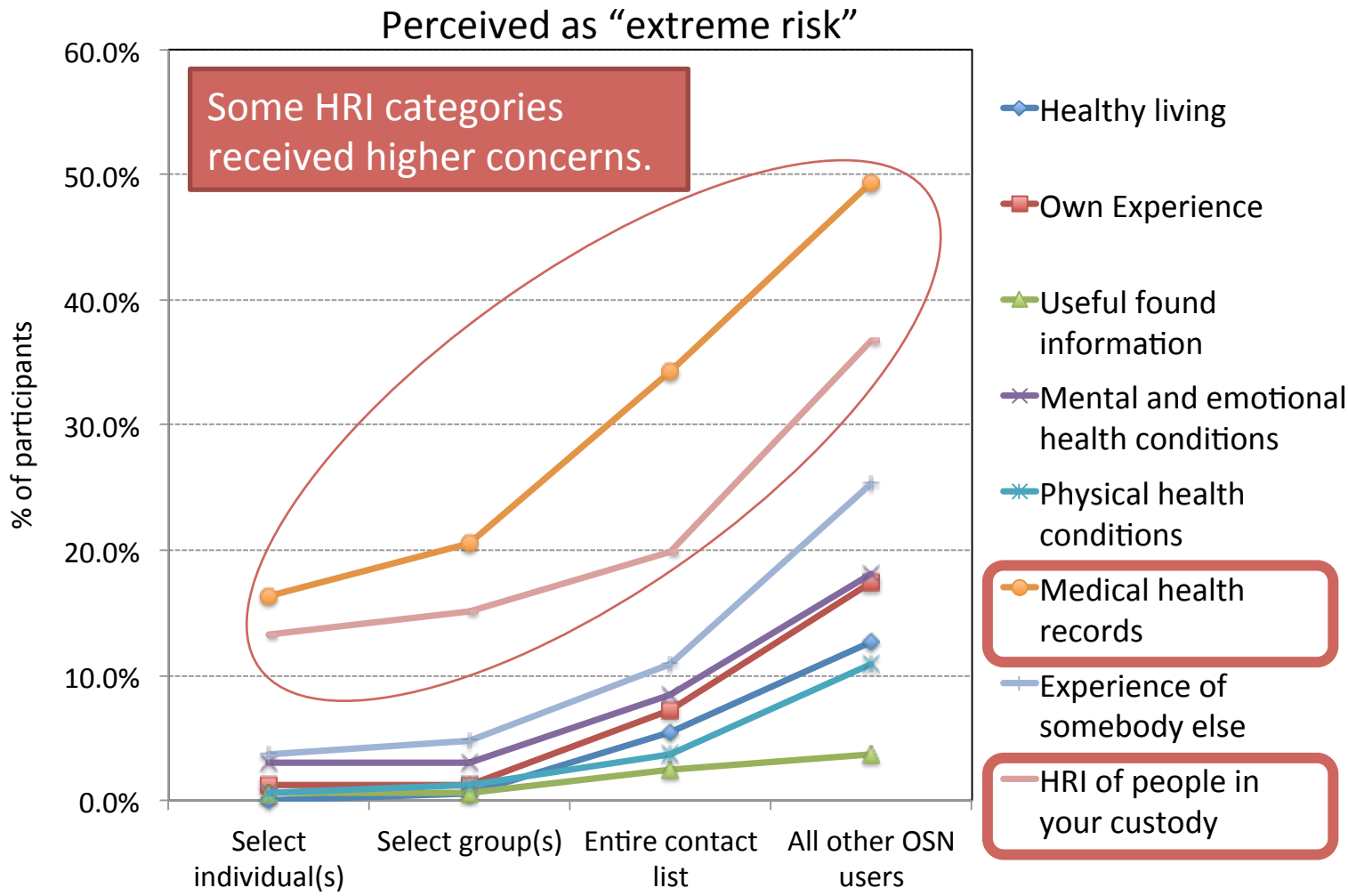

Behavioural responses at different risk levels (very low to extreme risks)

Participants selected all that applied from the following responses:

- Avoid risks by not sharing.
- Minimize risks by manipulating shared data.
- Minimize risks by filtering recipients.
- Minimize risks by changing OSN.
- Accept risks and share without any preemptive actions.

Behavioural responses

- Sharing profiles [1]:
  - Indifferent (always share)
  - Cautious (never share)
  - Self-revealing (use risk-mitigating techniques to share and get benefits)

- At acceptable risk level:
  - About 50% (self-revealing) minimized risks by manipulating shared data and/or filtering recipients.

Summary

Summary

Previous studies:

- Focused on niche user categories.
- Did not study active OSN users.

Our contributions:

- Quantified HRI sharing practices in OSNs.
- Highlighted key factors affecting privacy perceptions.
- Tried to build a solid ground for future studies.

Takeaways

- HRI sharing is a new application of OSNs.
- More concerns with sharing "medical health records" and "HRI of people in their custody".
- The recipient and the HRI category are the key factors affecting perceived privacy.
- Self-revealing users and risk-mitigating behaviours.

Future work

To capture users' risk perceptions and behavioural responses in more detail, we will:

- Create realistic scenarios for sharing HRI in OSNs.
- Place participants in the context of sharing HRI.
- Incorporate motivating factors (benefits).

Thank you!

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