

Perceiving Patient Privacy in the Context of Heart-Failure Telemonitoring:

*Adapting the Contextual Integrity
Framework to Gauge Patients' Privacy
Perspectives*



Martin French
Concordia University

Heather Patterson
Intel Labs

Westin (Harris-Equifax)

The “Medical Privacy Concern Index” (1993)

- Used questions like:
 - “It concerns me that my medical information is being seen today by many organizations beyond those that I go to for health care services”
 - Do you agree somewhat with this statement?
 - Do you disagree somewhat with this statement?



Westin (Harris-Equifax)

The “Medical Privacy Concern Index” (1993)

- Used questions like:
 - “It concerns me that my medical information is being seen today by many organizations beyond those that I go to for health care services”
 - Agree Strongly
 - Agree Somewhat
 - Disagree Somewhat
 - Disagree Strongly
 - Not Sure

- Derived categories like:
 - High (13%)
 - Medium (45%)
 - Low (42%)



Source: Kumaraguru and Cranor 2005

CI Analytic Framework Applied to Telemonitoring

- How comfortable are you with your doctor getting regular updates about your weight?



CI Analytic Framework Applied to Telemonitoring

- How comfortable are you with your insurance company getting regular updates about your weight?



CI Analytic Framework Applied to Telemonitoring

- How comfortable are you with your doctor getting regular updates about your alcohol and tobacco use?



CI Analytic Framework Applied to Telemonitoring

Methods: Conceptualization

- 1) the different **types** of health information transferred via telemonitoring
- 2) the different potential **recipients** of each type of data produced by telemonitoring interventions, and
- 3) the different **transmission principles**, which we operationalized in terms of granularity, associated with various data flows.

CI Analytic Framework Applied to Telemonitoring

Methods: Conceptualization

- 1) Key information types: WEIGHT, MOOD, BLOOD PRESSURE, PHYSICAL ACTIVITY LEVEL, PHYSICAL ACTIVITY TYPE, and GEOSPATIAL LOCATION;
- 2) Key information recipients: DOCTORS AND NURSES, TECHNOLOGY RESEARCHERS, PUBLIC HEALTH PROFESSIONALS, and HEALTH INSURANCE COMPANIES.
- 3) Key degrees of granularity: EVERY HOUR, EVERY SIX HOURS, EVERY TWELVE HOURS, EVERY DAY, EVERY WEEK, EVERY MONTH.

--inspired by fractional factorial experiment designs: 48 questions

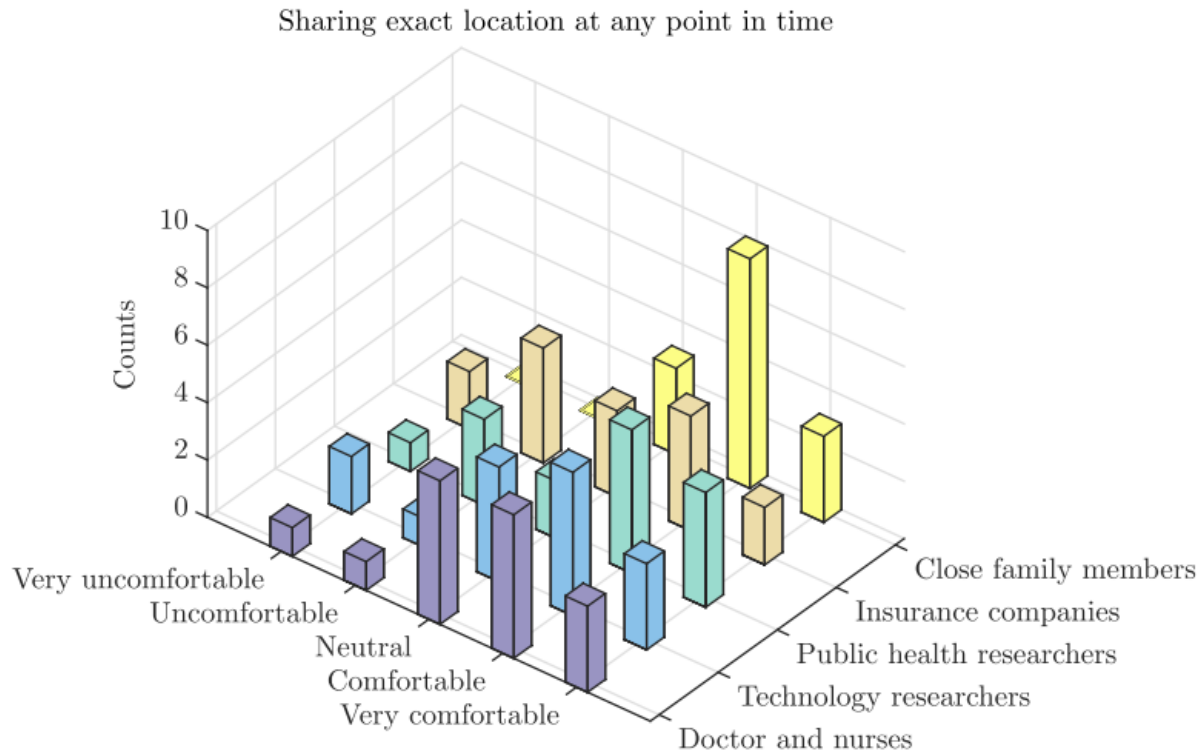
CI Analytic Framework Applied to Telemonitoring

Methods: Pilot test with CHF patients (35 Qs)

1. How comfortable do you feel with <u>doctors and nurses who treat your heart failure</u> getting regular updates about your weight	1= Very Uncomfortable 2= Uncomfortable 3= Neutral 4= Comfortable 5= Very Comfortable
2. How comfortable do you feel with <u>doctors and nurses who treat your heart failure</u> getting regular updates about your mood at any point in time (Example: depressed or anxious)	1= Very Uncomfortable 2= Uncomfortable 3= Neutral 4= Comfortable 5= Very Comfortable
3. How comfortable do you feel with <u>doctors and nurses who treat your heart failure</u> getting regular updates about how physically active you are (Example: very active, not at all active)	1= Very Uncomfortable 2= Uncomfortable 3= Neutral 4= Comfortable 5= Very Comfortable
4. How comfortable do you feel with <u>doctors and nurses who treat your heart failure</u> getting regular updates about your sexual activities?	1= Very Uncomfortable 2= Uncomfortable 3= Neutral 4= Comfortable 5= Very Comfortable

CI Analytic Framework Applied to Telemonitoring

Methods: Pilot test with CHF patients (N=15)



CI Analytic Framework Applied to Telemonitoring

Conclusions

- Learning about how CHF patients feel about the contextual integrity of their health information is difficult
 - Post-surgery
 - On heavy medications
 - In pain and discomfort
 - Other things on their minds...
- How should health care systems care for the CI of their patients' information?
 - Technical solutions
 - What 'more-than-technical' solutions ought to be in the mix?
 - Information Counselors/Advocates/Ombudspeople?

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References

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