Patient and Provider Goals and the Using Patient-Generated Data in IBS and Weight Management

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Background

Patient-generated data is increasingly common in chronic disease management. Smartphone applications and wearable sensors help patients more easily collect health information. However, current commercial tools often do not effectively support patients and providers in collaboration surrounding these data.

Result

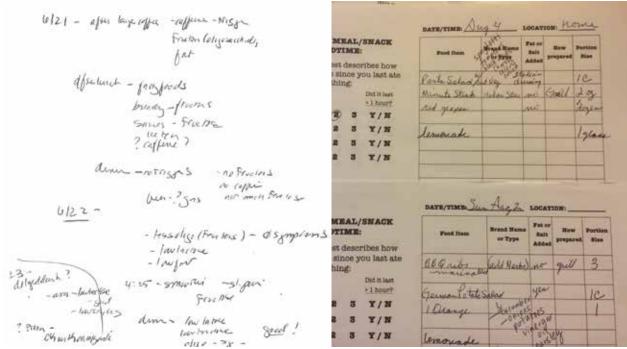
Self-explanation Artifact

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Method

- 211 patient survey
- 18 patient interviews
- 21 provider interviews

Inclusion Artifact





Data relevent for personal use might not be relevant to share

Lack of standard format creates barriers to interpretation

Structuring Artifact

Self-tracking data supports Patient-Provider collaboration in various forms and with various privacy needs

Difficult to curate data based on sharing goals and privacy needs



- Not enough time
- Questions about expertise and benefit offered

Compilation Artifact

Review of her food symptom journal that she brought with her today revealed that with worsening symptoms the patient's diet consisted more of high fat foods, FODMAP's and gluten. High-fat foods included foods such as steak, barbecue ribs. High FODMAP foods included onions, cucumber, and sugary foods. Gluten products included bagels. When this was compared to her diet when she was not having aggravated symptoms, patient also had evidence of some high-fat foods and gluten products but less FODMAP's. These high-fat foods included sausage and pork roast. High FODMAP foods included onions.

RELEVANT STUDIES: GES, 2012: Normal. 1 hour 53.4%, 2 hour 30.3%, 3 hours 5.6%, 4 hours not acquired.

UGIS/SBFT, 2012;

Normal appearance of the gastric mucosa and esophagus. Abnormal motility of the small bowel as described above. Multiple bowel loops were originally dilated which on subsequent images appear less dilated. 150 minutes post ingestion of oral contrast, there is still reflux of oral contrast into the duodenum and stomach. Abnormal motility is seen throughout the small bowel. In the proximal loops of the jejunum, on the real time imaging, to and fro motion was persistently noted.

EGD, 06/2012: retained bilious fluid and food, antral contractions present, dilated duodenum with some contractile activity; path: duodenum: patchy mildly active enteritis.



Need support to implement goals into next tracking process





Lack of sharing mechanism makes follow-up difficult

Implication

Designers

- Goal communication & implementation
- Data curation based on goals & privacy needs
- Goal oriented visualization & Summary

More Than Telemonitoring: Health Provider Use and Nonuse of Life-Log Data in Irritable Bowel Syndrome and Weight Management Chia-Fang Chung, Jonathan Cook, Elizabeth Bales, Jasmine Zia, Sean Munson Journal of Medical Internet Research

Health Practitioners

- Explicit conversations about intended use
- Efficient and effective verbal summary

Data may be reshared to other providers and beyond



Lack of mechanisms to integrate data from various sources

Researchers

- Provider and patient role in personal informatics models
- Privacy as a contexual integrity in boundary negotiating artifacts

Boundary Negotiating Artifacts in Personal Informatics: Patient-Provider Collaboration with Patient-Generated Data

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