THE QUANTIFIED SELF AND CLINICAL DECISION MAKING: UNDERSTANDING AND REDUCING CLINICAL DECISION BIAS AND ERRORS WHEN USING QUANTIFIED SELF Data

Final Report

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Background to this project

The working proposition informing this exploratory work is that the quality of decision making and judgments in clinical settings—specifically busy GP surgeries—may deteriorate with the introduction of Quantified Self Data. Previous work by Mr Peter West discussed the probabilities of incorrect or biased inference in data collected from embedded devices; the effect on decisions due to bias; and the effect of providing context with the datasets by providing relevant and/or irrelevant data.

The original aims of this project were to build on this work. Specifically,

1. To build a body of evidence at a larger and more diverse scale;
2. Inquire from health care, organizational, web science, and legal/ethical perspectives;
3. Gather evidence on the education/development needs of health care practitioners regarding decision making using quantified self data;
4. Link with industrial partners who can inform new products and services; and
5. Provide a set of data-based hypotheses to inform future grant proposals.

To this end we developed and applied a scenario-based role-play approach with GPs and hospital specialists in the US and UK, to elicit reflections on and insights about using patient self-logged data. We constructed two clinical scenarios from real-world data (these were published patient presentations), where there were a true diagnoses. We supplemented these scenarios with so-called "distractors"—self logged, patient provided data. In one case these data were of caffeine intake; in another, a month's log of resting pulse rates.

Our findings suggest that there is a moderate presence of bias when using self-logged data—in particular the use of the Representativeness Heuristic when making initial judgements. Additionally, we uncovered, multiple challenges and opportunities for the use of self-logged data in the differential diagnosis workflow, and identified capture, representational and interpretational challenges that are potentially preventing self-logged data from being effectively interpreted and applied by clinicians to derive a patient's prognosis and plan of care. We developed an understanding of these challenges, and outlined how members of the HCI community can potentially overcome them. Developing and testing approaches to overcome such challenges that would be useful to the HCI and product-development communities will inform future work.

Outcomes.

Research outcomes.
While our work was originally focused on the effects that self-logged, patient-provided data may have on clinical decision making, our results contribute to an understanding of the process of clinical decision making more generally. We have developed a model of clinical decision making when self-logged data are presented to clinicians, and have analyzed this model at a relatively fine level of granularity. Aside from model development, there are two major contributions of this work to date. We have contributed to the literature on the use of self-logged, patient-provided data. Our literature review surfaced 11 major themes.   We discovered that those themes are incomplete, and fail to inform HCI research. Further, our work, we argue, adds to knowledge about the roles that self-logged data play in the diagnoses process, and we inform HCI research on the potential to develop technologies where self-logged data would be useful to clinicians.

Research outputs.
1. Poster presentation at the Health Service Research Network symposium (Nottingham : 1-2 July 2015)
2. Conference paper presented at the Kings Fund Digital Health and Care Congress,(London : 16-17 June 2015) (Submission received 98:100 reviewer points)
   http://www.kingsfund.org.uk/sites/files/kf/media/Peter%20West%20and%20Richard%20Giordano.pdf
3. Paper submission to CHI 2016 (San Jose, CA : 7-12 May 2016)

Collaboration with External Stakeholders
Our collaborators gave us access to people, and would like to use our findings to inform professional development programmes for clinicians. One organization plans to discuss with us further collaboration that would inform future product development and evaluation. Our current plan is to work with two NHS institutions in the United Kingdom, and a large urban hospital in the United States.

Research impact.
Our research now affords a deeper understanding of
- how Quantified Self self-logged data would be used in practice,
- how these data are evaluated by working clinicians,
- barriers to interrogating these data during clinical visits, and
- factors that influence whether clinicians view such data as trustworthy.

More specifically, we identified opportunities how self-logged data could help with various phases of the diagnostic workflow process, including communication (of symptoms) with the patient, discovery of potential causes not yet considered, and refinement of hypotheses and treatment pathways. We discovered that the motivation for self-logging activities was also of critical importance to the diagnostic

process, by helping clinicians discover potential psychological disorders, or unspoken organic disorders. Finally, we identified reasons that clinicians distrusted self-logged data pertaining to accuracy of instruments, sampling methods, potentially missing data and patient activity or context, and identified potential ways that some of these issues might be addressed in the future.

These initial findings suggest that, although there may be a significant number of design challenges remaining, the use of self-logged data may eventually significantly improve clinicians' abilities to draw together evidence for clinical diagnosis. This, in turn, can result in faster, more accurate, and more complete diagnoses, which, in turn, improve patient outcomes, patient experience, and the efficient use of limited healthcare resources.