Knowledge, care and the practices of self-monitoring

Kate Weiner and Ros Williams, UoS
Catherine Will, University of Sussex
Flis Henwood, University of Brighton
‘a medical revolution that promises to help us live longer, healthier lives’.

'30 billion funding gap in the next 5 years. The only way to deal with it through people taking more responsibility for health. The only way this will happen is through data'

Tim Kelsey, Director for patients and information, NHS England

It will soon be possible for patients to add their own data to the record. This might include blood pressure, peak flow, blood sugars and oxygen saturation measurements, and lifestyle information such as diet and exercise charts... **Patient-added data will need to be treated with care**. For example, it should not be assumed that patient-added data will be completely accurate in relation to self-monitoring, although over time the health professional will be able to gauge the accuracy of a particular patient’s data entry... health professionals could find themselves in a vulnerable position if they failed to act upon it and the patient came to harm. **Health professionals could also be held accountable if a patient came to harm if they relied on patient-added information without making their own clinical assessment and judgments.**

Royal College of General Practitioners (2010)
Scholarship on self-monitoring

Opening stances:
• Algorithmic selves
• Self-monitoring as obligation
• Political economy
• Participatory medicine

Focus on everyday data practices:
• Potentials for resistance
• Questioning data flows
Our reflections

• Empirical setting to date: Quantified Self and digital fitness.
• Our focus - Devices between clinic and home?
• More to say about
  - Knowledge negotiations & numbers 'in the wild'
  - Non-use, resistance and unexpected uses
  - Making technologies work in domestic spaces
  - Emotion and identity work
Aims

• *Tracking Ourselves?* - Explores how self-monitoring is accomplished, and what socio-technical networks are mobilised in doing so.

• Cases (?): Blood pressure, food intolerance/allergy, Body Mass Index (BMI)

• Cases of the domestication of clinical technologies (BP monitoring well established, squarely between clinic and consumer market)

• Started August 2016, 3 year project
Questions

- How is self-monitoring 'scripted' or shaped by professional, policy and commercial proponents?
- Why and how do people self-monitor? How far is this practice sustained over time?
- What do people do with self-monitoring data? How does this link with knowledge creation?
- Can self-monitoring be understood as a care practice? How might it link to questions about the responsibility for health?
Plans

Phase 1: Expert and industry shaping

*how expert/commercial proponents imagine self-monitoring practices and users*

- analysis of monitoring tech, commercial material, policy
- interviews - key commercial, expert and policy stakeholders
- observation of industry/professional meetings

Phase 2: Everyday practices

*how people self-monitor and what they do with self-monitoring data*

- interviews - people/households engaged in self-monitoring (show and tell)
- Photo elicitation interviews with subset - invited to take photos over 6-months

Phase 3: Beyond the household: wider networks of self-monitoring

*how actors and technologies beyond the household are involved in self-monitoring*

- interviews - actors involved in self-monitoring (charities, designers, clinicians?)
- analysis of relevant websites/texts
Tracking Ourselves is a research project concerned with exploring the everyday practices of people who undertake self-monitoring. We are interested in the social and cultural reasons for, and consequences of, our increasing engagement in self-monitoring for health, self-care and fitness.

This research is being funded by a Leverhulme Trust Research Project Grant, and is a collaborative project between the Universities of Sheffield, Sussex and Brighton.

http://www.tracking-ourselves.org

k.weiner@Sheffield.ac.uk
r.g.Williams@Sheffield.ac.uk