Blocks and interferences: problems with the flow of blood pressure data

Presentation for OU workshop
‘What’s Big Health Data good for?’
Catherine Will and Kate Weiner
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)
Health tracking expectations
Data practices
They wanted, you know three readings a week [in antenatal clinic] or something and I said I just can’t do this, can I do it from home, but they said no. I said can I do it from my local GP and they said no, which was ridiculous because presumably they would trust a GP to like take a blood pressure ...

So I was a bit moany about this and so actually my partner brought the blood pressure monitor for me. And actually my blood pressure was high and then I agreed to take the higher dosage ... So I did use it frequently for the last 3 or 4 weeks of my pregnancy. And then it’s been in a drawer since.
Nora: I was a bit surprised because this is obviously a big change since 3 years ago, when they wouldn’t trust my readings at all. And also I would have thought the GP communicates with the consultant about my blood pressure but as he was asking I think maybe not. ...it does sound like he’s now trusting me yes to measure my blood pressure.

Kate: do you think he assumed you were taking your own blood pressure?

Nora: I don’t know, I don’t think so, I wouldn’t have told him that I have one. So I don’t think, he wouldn’t have assumed that I take my own blood pressure because there’s no reason for him to know that I would have one and I certainly didn’t wouldn’t have offered. So no I think he just means that, I think he just meant the GP. But that’s not very often is it?

Kate: You said ‘I certainly wouldn’t have offered’ in a very definite kind of way

Nora: Well yeah it’s just not very interesting
Alice and Mark

Kate: Yeah but have you ever offered them your, your own readings at the surgery?
Mark: I think I told them what I have done.
Alice: Yeah I’ve told them but they’ve never, they wouldn’t believe you would they, they’d want to do it for themselves.
Mark: Well they say about the, they’ll give you their own machines to use because of the calibrations
Alice: Yeah
Kate: So you might mention it but they wouldn’t write those figures down?
Alice: No they wouldn’t write the figures down.
Back to data?

- Add information never recorded, never ‘data’ at all?
- Lack of interest in the numbers? (Knorr Cetina 1999: ‘negative knowledge’) Monitor not track.
- Readings as information that is used up, consumed (Knorr Cetina 2010: ‘information knowledge’). Disposable data.
- Certainly potential for future use by companies – consumer profiling

New project ‘Knowledge, care and the practices of self-monitoring’ with Kate Weiner, Flis Henwood and Ros Williams, start Sept. Leverhulme Trust Research Project Grant