

Tracking Ourselves?

Caring for ourselves through everyday monitoring

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The Leverhulme Trust

Blood pressure monitoring - pilot interviews.

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. The project is funded by the Leverhulme Trust and shared between the Universities of Sheffield, Sussex and Brighton.

This document offers a brief summary of the pilot research that will be used to help shape *Tracking Ourselves?* Below, we outline the methods of the pilot research and provide a brief summary of some initial findings from the pilot work. We also provide details of conference papers that have disseminated these findings.

What did the pilot research involve?

The pilot research involved qualitative interviews with people who monitor their own blood pressure using a blood pressure monitor that they bought for themselves, or that they had borrowed or been given by a family member or friend. In other words, the devices were not provided by health care professionals e.g. GP or nurse.

The interviews were undertaken by Kate Weiner between May 2014 and July 2015. They focussed on: how people came to monitor their blood pressure and chose or acquired the monitor they use; how they monitor in practice including how often and where and why then; record keeping; people involved; anything else people track.

Interviews included a show and tell element - Kate asked participants to demonstrate their device and show and talk through the records they keep. When possible she also asked participants to show her where they undertake monitoring and where they store their monitors and records.



Do you ever measure your own blood pressure?

Do you own a blood pressure monitor?

Have you ever downloaded a blood pressure app?

I am looking for people who measure and keep track of their own blood pressure or who do this for someone else close to them. If you do this now or have done in the past, would you be willing to take part in an interview?

I am a researcher in the Department of Sociological Studies. I would like to know more about why and how people measure their own blood pressure and how people come to start (or stop) measuring.

Here are further details of the interviews:

- 27 semi-structured interviews with 31 people - including 4 couples.
- Participants: 17 women, 14 men, aged 27 to 82.
- Recruited through University of Sheffield volunteer list and snowball sample of retired people.
- Interviews undertaken in people's homes (10), Kate's office (7), interviewees' work place (8) and by Skype (2).

Observations about the findings to date

The place of numbers and data?

Record keeping was very varied - a handful of people used an app or compiled a spreadsheet, but often people record on paper - in a note book, in their diary, on scraps of paper and backs of envelopes - and some keep no records, just keeping an idea in their head. The specific numbers might not be memorable, as people might just remember whether their blood pressure was within limits or above a threshold.

This raises questions about what kind of projects people are fulfilling with monitoring, and we suggest that numbers are not always critical to these projects. Keeping an eye on something is different to ongoing engagement, tracking and building a cumulative picture. And if numbers are not critical to people's projects this raises further questions about the potential for data flows. There may be limited scope for data sharing - where data is not produced, or produced intermittently. Further, some interviewees were sceptical about whether their data would be accepted by or acceptable to clinicians.



A participant displays their various self-monitoring devices

DATE		BLOOD PRESSURE		PULSE RATE	CIRCUMSTANCES
DATE	TIME	SYSTOLIC	DIASTOLIC	PULSE RATE	
30/6	16:45	162	67	65	Saturday Rest time
8/2	10:15	149	64	66	Sunday after breakfast
17/2	23:50	143	61	63	Spring to bed
20/3					
25/5	16:30	150	60		Sunday Morning
17/6	20:30	158	63	66	Monday Night

A participant's blood pressure measurement log, with five sporadic data inputs across two years

Who and what is involved in monitoring?

Monitors might be used by one person, or seen as a household object, lent or shared with family, neighbours or colleagues. Members of personal networks may encourage monitoring, help with making purchasing decisions, or buy monitors as gifts and also help with using devices (setting up devices, interpreting reading) or undertake monitoring together.

Monitors may be kept in many locations within the home, sometimes they are placed near to hand, on table tops or nearby cupboards, in order to act as a reminder for use. At other times they are stored away in drawers, at the back of wardrobes or the bottom of a suitcase, which often indicated they were no longer in use - like a forgotten and unloved sandwich maker. Having a monitor does not mean using it.

What are people doing with monitoring?

These interviews suggest that blood pressure monitors may be used for many reasons:

- As a mood monitor - how am I feeling? They substantiate an embodied sense of feeling stressed or relaxed.
- Seeking reassurance at home for worries raised in the clinic. People may monitor as a reaction to doctor induced (white coat) high blood pressure or as a way to resist a diagnosis of hypertension (don't want to believe doctor's reading, take again at

home). This may lead to people monitoring only in the run up to or just after doctor's appointment to have alternative data and satisfy themselves about blood pressure readings.

- Ammunition to avoid further clinical intervention - related to the point above - people reported bringing in their own readings as a way to avoid further investigation. This may be because they do not want to trouble the health services or spend time getting to and hanging around waiting for appointments.
- As a technology of persuasion - people may be sceptical or resistant to doctor's readings but may be persuaded of hypertension by taking their own readings.
- Demonstrating care - people may give blood pressure monitors to loved ones or may monitor out of commitment to loved ones who express concern.
- Collaborating with clinicians – some people said that they were monitoring in response to an invitation or request from their GP or nurse. This meant keeping records to take into consultations
- Having fun - monitoring as a form of entertainment - 'having a go' on someone's machine - which might lead to more serious engagement subsequently.

Presentations:

1. K.Weiner & C Will (2016) Infrastructuring home blood pressure monitoring. *EASST/45 Joint Conference*, CCIB, Barcelona, 31 August - 3 September 2016.
2. C Will & K Weiner (2016) Blocks and interferences: problems with the flow of blood pressure data, *What's Big Health Data good for?* The Open University in London, 29 April 2016.
3. K Weiner & C Will (2015) Playing around with blood pressure monitors *BSA Medical Sociology Group 47th Annual Conference*, University of York, 9-11 September 2015.
4. K Weiner & C Will (2015) From knowledge to practice in self-monitoring: beyond narratives of responsabilisation and democratisation. *12th Conference of the European Sociological Association*, Czech Technical University, Prague, 25-28 August 2015
5. K Weiner & C Will (2015) The domestication of self-monitoring devices: beyond data practices? *Data Power Conference*, Cutlers Hall, Sheffield, 22-23 June 2015