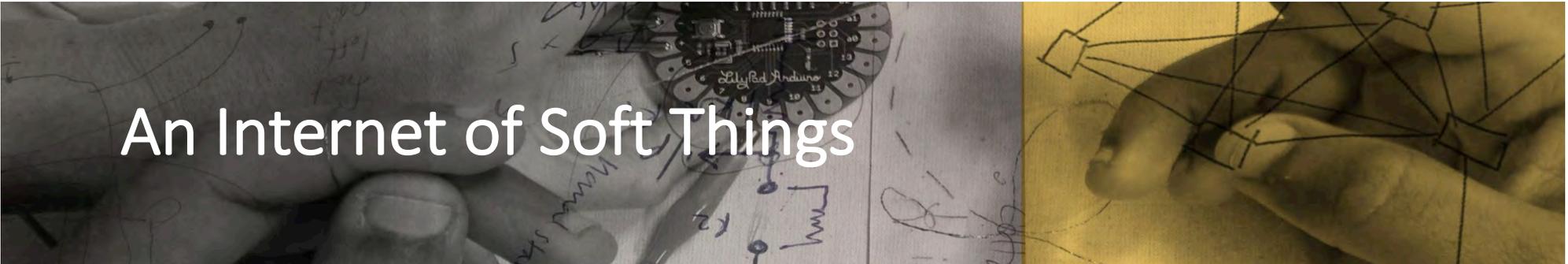# Participatory eTextiles design with mental health care communities

Sarah Kettley and Richard Kettley

An Internet of Soft Things

- This multidisciplinary project aims:

  - to develop a **person-centred** methodology for participatory design in the fields of eTextiles, Interaction Design and Service Design for the Internet of Things

  - to include **mental health** service users and providers in the developing public imaginary of these technologies.

http://aninternetofsoftthings.com/project/

What we are doing

- We have run a **series of workshops** at Mind, a third sector (charity) mental health care provider in the UK, where participants made hand held textile forms with soft circuits and light output

- One outcome of this is a **set of recommendations** for other design researchers who wish to develop their practice in the fields of mental health and wellbeing

Overview

- In this talk we will:

    - describe the **planning** of the workshop content

    - discuss **issues** around the Person-Centred Approach and skills-based learning

    - outline our **recommendations** for a participatory design research protocol for e-textiles work in mental health care environments

Planning of workshop content

- **Mental Health Awareness training** for whole team (delivered by Mind)

- **Planning included:**
  - skills teaching and practice
  - generation of ideas
  - person-centred, safe environment
  - variety of ways to self-report holistic experience
  - roles of researchers/facilitators/co-designers
  - informed consent
  - reflecting, being flexible

Issues around the Person-Centred Approach and skills-based learning

- **Non-judgemental**
  - when there is right and wrong way to do something: it will either work or not
  - if researcher/facilitator doesn't like the object the participant/co-researcher produces

- **Non-directive**
  - material, colour, design, function
  - separate process from content; **principled vs instrumental**

- **Roles of researchers/co-researchers** (who owns the process?)
  - autonomy
  - empathic attitude of researcher/facilitator
  - Achievement

- **Practice-led critical reflection**
  - role of researcher as facilitator/co-designer
  - reflection as data
  - reflection to inform ongoing design of research
  - working with non-verbal participants

Recommendations for a participatory design research protocol for e-textiles work in mental health care environments

- **Time**

- **Framing experience and expectations**

- **Relationships**

- **Power dynamics**

- **Data**

- **Co-production of narratives**

- **Debriefing and support**

- **Wider disciplinary and research expectations**

Recommendation: Time

- **Pace:**
  - pace within workshop *(3 hours including lunch)* and within series *(6 sessions)*
  - go at the pace of the participants *(difficult to plan)*
  - value achievement in different parts of the process
  - ideation and reflection - *eg 'what is light?'* – as well as skills
  - different types of thinking involved *(from STEM to STEAM)* so very engaging
  - overcoming physical as well as mental and emotional barriers

- **Resources:**
  - a lot of materials provided because of importance of choice and playfulness/risk
  - a lot of organisation before and after *(textiles and electronics and tracking/reflections)*
  - small things can make a big difference *(eg needle threaders and embroidery scissors)*

- **Timing:**
  - managing resources so they are not overwhelming *(tables, areas of room)*
  - risk of stress and disengagement

Recommendation: Framing experience and expectations

- **Check-in; check-out**

- **Group agreement**

- Ongoing **informed consent** based on experience:
  - reflecting on process *(rather than product)*
  - building on trust in research(ers)
  - transparency: checking what's OK or not OK with each individual

- *Contrast to behavioural psychology which might seek to influence or persuade: in PCA people are inherently trustworthy and resourceful*

Recommendation: Roles & Relationships

- Researchers have **multiple roles**:
  - as ethical researcher
  - as experiential facilitator and/or co-designer
  - as participant

- Researchers have **relationships** with:
  - each other (the team)
  - the organisation/service and its representatives
  - the participants, especially their co-design partner

- Participants may have **varying levels of involvement** in the design process depending on:
  - their self-confidence/self-esteem
  - capacity for verbal and nonverbal communication
  - Dexterity and/or concentration levels
  - experience/awareness of design issues etc

- ***Importance of trustworthiness, empathic understanding and warm, valuing attitudes***

Recommendation: Power dynamics

- **Awareness of culture** (& funding) of sector (in UK):
  - Government (NHS) – 1st sector *(medical model)*
  - Private business – 2nd sector *(business model)*
  - **Charity/Community Interest Company/Social Enterprise – 3rd sector *(doing good)***

- **Presenting** yourselves and your project:
  - **Expert or non-expert**: level of detail on your institution, funding, backers *(need to know?)*
  - **Language**: academic/business/jargon may prohibit inclusivity and engagement in 3rd sector environment
  - **Beginnings and endings**: approachable, interested in the person, tea and cake!

Recommendation: Data

- **Anything that captures experience** *(including reflections)*
  - photographs
  - journals, blogs, notes and reflections
  - audio recordings of sessions, debriefings
  - meetings, informal chats

- **Disciplines might disagree** on attitudes to:
  - process/assessment/outcome
  - generative/evaluative research

- **Is your research perceived as:**
  - a service? *(eg Mental Health Awareness Week)*
  - or not a service? *(National Institute of Health Research)*

- *Making data available to future researchers (new Research Council directive in UK)*

Recommendation: Co-production of narratives

- **Co-design relationship:**
  - importance of consistency and sensitivity of researcher in this relationship for safety of participant
  - eliciting reflection and enabling feedback where participant finds this difficult

- **Interpersonal Process Recall (IPR):**
  - reviewing video playback to pause and recall what wasn't said at the time, to explore thoughts and feelings

- **Film-making:**
  - involving individuals in film-making process and showing their experience in their own words at their own pace

Recommendation: Debriefing and support

- **Self-care** for the researchers

- **Informal debriefing** or more formalised supervision

- Encourage self-discovery of **non-cognitive responses and reflections**

- **Own your own stuff**

- *Importance of right environment: trustworthiness, empathic understanding and warm, valuing attitudes*

Recommendation: Wider disciplinary and research expectations

- Whatever the discipline, **bring it back to mental health**
  - Impact
  - contribution

- Prioritise **safety of participants**
  - work with existing staff/support and train whole team in mental health awareness
  - work to ethical code/framework eg BACP *(include psychotherapist on team?)*
  - transparency and trust
  - active listening and valuing

- Process itself (of making/doing) is **understood and assumed to be therapeutic**
  - it is valued regardless of proving benefit of a product

- Evaluate the **workshop design not the product**

An Internet of Soft Things Team

- Sarah Kettley, PI *(Design Research)*

- Amanda Briggs-Goode, Co-I *(Textiles)*

- David Brown, Co-I *(Computer Science)*

- Matthew Bates *(Computer Science)*

- Steven Battersby *(Computer Science)*

- **Martha Glazzard** *(Textiles)*

- Tincuta Heinzel *(Textiles)*

- Isabel Jones *(Film-maker)*

- **Richard Kettley** *(Psychotherapy)*

- Rachel Lucas *(Psychotherapy)*

- Anna Sadkowska *(Service Design)*

- **Sarah Walker** *(Interdisciplinary PhD student)*

Contact: richard.kettley@ntu.ac.uk

Website: http://aninternetofsoftthings.com/project/

Bassetlaw workshop reflections
a film by Salamanda Tandem for IoSofT

Director/researcher: Isabel Jones
Film/photography: Geoffrey Fielding

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https://www.youtube.com/watch?v=YixEuzl0Wfc