Participatory eTextiles design with mental health care communities

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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*)

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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=YixEuzIOWfc