An Introduction to the Person-Centred Approach as an Attitude for Participatory Design

An Internet of Soft Things

Design School Kolding
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http://aninternetofsoftthings.com
• Context in my own making practice
• Aim – ethical participatory design research for the IoT
• Provocation (situation) – design knows nothing
• Proposition – the PCA as a continuation of UCD and HCD
• Framework – what is a PCA to design?
• Case study – IoSofT
• Impact – importance of the relationship
• Development of methodology and next steps
Composite materials, Friendship jewellery, and ensemble (with Speckled Computing)
Stille and HUG
Sensing Dance and Aeolia
“It was not until the tailor learnt to cut that the designer could ‘compose’ a costume.”

Electric Corset
MENTAL HEALTH RESEARCH IN THE UK:
MQ LANDSCAPE ANALYSIS 2015

1 IN 4 PEOPLE experience mental illness each year - nearly 15 million people

UK INVESTS
£115 million per year on mental health research

MENTAL HEALTH RESEARCH RECEIVES
5-5% of total UK health research spend

Amount spent on research per person affected:
CANCER £1,571
MENTAL ILLNESS £9.79

The total economic and social cost of mental health problems in England is estimated to be £105 BILLION.

FOR EVERY £1 SPENT by Government on mental health research, the general public donate £0.39. It's £3.75 for cancer.

www.joinmq.org

THE FIVE YEAR FORWARD VIEW FOR MENTAL HEALTH

A report from the Independent Mental Health Taskforce to the NHS in England
February 2016
"we are all applied behavioural psychologists"
The Internet of Things (IoT)
Aim: ethical participatory design research for the IoT

“Each of us is responsible for being aware of our own values and beliefs and being able to articulate their relevance”

(Proctor, 2014: 199)
Landscape of modalities of practice (philosophies of the person in the caring professions)

- Cognitive
- Behavioural
- Psychodynamic
- Social
- Disease and medical models
- Person-Centred Theory and Approach
DESIGN IN MENTAL HEALTH?

a literature review of design thinking in UK and European mental health

Sarah Kettleley & Rachel Lucas

CONTEXT

The current financial challenges faced by the National Health Service and the drive to improving mental health service provision have led to a need for innovative approaches to care that hold the potential to:

- improve service user experience
- respect the individual’s needs through collaborative endeavour
- redesign systems - positively impacting funding and resource teams
- inform service provision through the lived experience of service users, support networks, carers and staff

AIMS

The literature review aims to deliver a current picture of design thinking, methodology and practice being edited or explored within the field of mental health.

- 2010-2016: 51 or 61 based
- appropriate literature identified from outside these parameters eg, USA, Australia, used for future extended review

Our intention is to inform service users, providers, researchers and designers of:

- the benefits of diverse forms of engagement between service user and provider
- alternatives to staff and public patient involvement in core service quality management, and design research
- the philosophical frameworks underpinning research methodologies and service provision, or lack of them
- gaps in the literature and direction for future research, education and service development

There have been reviews of the design for mental health literature, but not the interactions between design and mental health, in doing so we support current NHS mandates citing quality of services.

FUTURE RESEARCH

This review suggests the following future research directions:

- Review of non-EU and Grey literature
- Digital tech developments designed for the person not the diagnosis
- Growing interest in evidence-based outcomes re: creative practice and mental health recovery
- Service design concepts brought to wellbeing services with a view to support replacement including NHS commissioning bodies

So for the findings from this literature review include:

- Design thinking practices such as Service and Participatory Design, currently lack an awareness of –
  - the larger mental health service provision landscape
  - range of mental health challenges faced by service users
  - the philosophical underpinnings of different services
  - the potential personal and ethical impact of working within this sector

- The following theoretical models can extend frameworks of design research to fully support studies within this sector
  - Behavioral
  - Relationship
  - Cognitive
  - Medical

ACKNOWLEDGEMENTS

The authors would like to thank Nottingham Trent University, Research Development Fund (UoA), Health Partnerships from SFU Library services, and the EPSRC ‘An Internet of Soft Things’ project (EP/L023601/1) for making this review possible.

METHODOLOGY

Search strategy:

- search terms developed around the separate domains of mental health and design
- rigorous key word search – developed a trial search for service selected databases
- identifying these in scope – highly iterative process, facilitated by the following key questions

Then the paper include description of each process or thinking, alongside consideration of mental health or wellbeing issues, or refer to design methodology or practice within mental health.

- A grounded theory approach was taken to identify themes and sub-themes (Bryman 2013)
- immersion within the data (Munro 2006) allowed for specific area target interventions to be located
- A development of Sanders (2008) ‘Framework for Design Research’ integrated philosophical frameworks later used to inform the literature. Behavioral, cognitive, emotional and medical models

PAPERS LOCATED

1791 (171 in scope)

134 expert review

310

151

110

130

Full papers reviewed

71 further papers saved for future

So far the findings from this literature review include:

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  - Relationship
  - Cognitive
  - Medical

- Technological developments and design of assistive digital devices for mental health emerged as the largest category of papers
- User centred design effectively aids for a medical model and engage in design for a diagnostic label or disorder
- Increasing interest in participatory art, craft and creative practice in mental health research
- Language can be very challenging
Proposition – the PCA as a continuation of User and Human Centered Design (‘UCD’ and ‘HCD’)

<table>
<thead>
<tr>
<th></th>
<th>SERVICE DESIGN AS A SKILLED CONTRIBUTION</th>
<th>SERVICE DESIGN AS A PEOPLE CENTRED, CREATIVE AND SYSTEMATIC PROCESS</th>
<th>SERVICE DESIGN AS A PEOPLE CENTRED AND COLLABORATIVE MIND SET AND APPROACH</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Procurement</strong></td>
<td>Chosen for their skills (e.g. user studies and engagement, co-design, visual or creative skills)</td>
<td>Chosen for their process and organisational fit</td>
<td>Chosen for their approach to change and innovation</td>
</tr>
<tr>
<td><strong>Well defined and output oriented</strong></td>
<td>Oriented toward outputs; focused on developing/improving an offering</td>
<td>Open and exploratory; focused on developing/improving an offering</td>
<td>Open and exploratory; focused on learning a new way of doing things</td>
</tr>
<tr>
<td><strong>Contribution to NSD</strong></td>
<td>Initial stages of NSD (e.g. research and design activities)</td>
<td>All main NSD stages toward implementation</td>
<td>All main NSD stages toward staff independence</td>
</tr>
<tr>
<td><strong>Design outputs</strong></td>
<td>Distinct designed deliverables</td>
<td>Work in progress documents and prototypes</td>
<td>No definite deliverable</td>
</tr>
<tr>
<td><strong>Innovation outcomes</strong></td>
<td>Changes are informed by design contribution</td>
<td>Changes are led by design process</td>
<td>Change is enabled through learning</td>
</tr>
<tr>
<td><strong>Designers / Client relationship</strong></td>
<td>Separate processes with distinct roles</td>
<td>Collaborative processes led by designers</td>
<td>Integrated and emerging processes</td>
</tr>
</tbody>
</table>

Framework – what is the PCA to design?

BACP Ethical Framework

• Being trustworthy
• Autonomy
• Beneficence
• Non maleficence
• Justice
• Self respect
The Person-Centred Approach

• Trust in the individual
• Facilitative effect of therapeutic relationship
• Not a disease or medical model

“It is not that this approach gives power to the person; it never takes it away”

(Rogers 1978:289)
Not just rainbows and unicorns...

Facilitating a ‘Non-Judgmental’ Skills-Based Co-Designed Environment

Facilitator: Martha Glazzar

- We’ve done a series of workshops at Mind in Hackney. We talked about our issues, but made things.
- In the background, we’re thinking about how to bring life into the group.
- Critical constructive vs. unconditional positive regard.
- Guitar strap.
- Group agreement, smart technologies.
- Piolet mind.
- Unison not disjoint.
- Not much different, but more relaxed.

We had very deep group discussions.
An Internet of Soft Things

The An Internet of Soft Things project challenges how a radically connected world would be designed to benefit human wellbeing, and in particular, what types of experience can be instigated from smart textile interfaces.

Start Making Soft Things

The Project
Find out more about the project and the internet of soft things.

Toolkit
Get materials needed to run the electronic textile workshops from the project.

Blog
Check out what people involved in the project are making and doing.

Contact Us
If you want to find out more about the project, or just to get in touch, sign up here.

http://aninternetofsoftthings.com/
project structure

Smart textiles
CoI: Dr Amanda Briggs-Goode
RF: Dr Martha Glazzard
RF: Dr Tincuta Heinzel
Researcher: Karen Harrigan

Network technologies
CoI: Prof David Brown
Researcher: Dr Stephen Battersby
Researcher: Dr Matthew Bates
Researcher: Dr Evtim Peytchev

Project partners
Nic Roberts
Haley Berry
RF: Richard Kettley
RA: Rachel Lucas
PI: Dr Sarah Kettley
Nottinghamshire MIND Network

- Newark
- Lincoln
- Bassetlaw
- Grantham
- Nottingham
the mental health service network in the UK

• Mind is a charity (‘third sector’)
• Each venue is dependent on fundraising
• and is **not** a part of the NHS (although it can be commissioned by it):
  – which tends to be constrained by a political and financial emphasis on efficiency
  – and a culture of expertise
  – leading to time constrained therapies
  – and a reliance on medicalisation
• Mind represent a particular kind of community
• people may come of their own volition, or be referred
• they are members, not clients or patients
• they can access one to one therapies
• or attend groups
• they have very often been through the National Health Service and may have finished a course of CBT or drug treatment
• they may still be on medication
they may be experiencing any kind of mental health issue
and are frequently dealing with more than one
our co-research team turned out to include people living with:
  – psychosis
  – Korsakoff’s Syndrome
  – depression
  – anxiety
the nature of this group

- a pre-existing group
- maximum 7 participants; minimum 4
- includes the facilitators and researchers
- we are all co-researchers and group members
Phases - what we did

– **Group workshops – e-textiles**
  - Making small handheld reactive textile objects
  - Creation of personally significant outputs
  - Discussion of form and interface

– **Augmented domestic space – service design**
  - Interior scale smart textile interfaces and displays
  - Developed with invited textile artists
  - Bring together the handheld objects and the space
  - Co-design scenarios of use

– **Day trips – into the wild – future workshops**
  - Testing and developing scenarios in the urban environment
  - Identifying and reflecting on anxiety triggers and the IoT
Feeling creative? Want to learn/share skills? Interested in contributing to research that brings together textiles and electronics in a person-centred, therapeutic environment?

MIND and Nottingham Trent University are offering a 6-week course from Wednesday 12 November 2-5pm (and then every Wednesday) at the International Community Centre, Mansfield Road, Nottingham. There will be opportunities to develop this work further in a ‘smart’ flat and ‘in the wild’ in the future.

If you are interested, please contact MIND at
With the participants

• 1:1 relationships
• Be flexible in arrangements and expectations
  – Take account of physical settings
  – Support individuals
  – Be transparent and consistent
• Collect all data
• Use different formats to facilitate inclusion
Embodying the Ethical Framework

So how can you do this?

• Informed consent
• Group agreement
• Check and check out
• Our Starfish version of the ‘Recovery Star’
In the research team – building in reflection

- Debrief meetings crucial (and constitute data)
- Develop a spirit of person-centred supervision

...being aware of our own values and beliefs and being able to articulate their relevance....
...self-respect....
Impact – importance of the relationship

• it is hard to evidence the impact of this kind of work
• by definition we need to protect the identities of the people involved
• we can’t show you happy smiling faces
Bassetlaw workshop reflections
a film by Salamanda Tandem for IoSofT

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

With thanks to:
The Bassetlaw Mind Tuesday Art Group, staff
Chris, Elaine and Meg

Workshop planning:
Martha Glazzard, Richard Kettley, Rachel Lucas and Sarah Walker
your experience of these films

• some voices may be indistinct
• there are some long pauses
• the facilitators appear to lead or jump in
some positive impact

“During the sessions my concentration has been much higher

I have only left once for a cigarette – it would usually be much more frequent”

Chris
project outcomes

- new workshops for Mind clients
- new skills and training for Mind staff
- strong USP to support business case for new Nottingham city centre Mind venue
- reflections on a Person-Centred Approach to design
- New knowledge in joining smart textiles with the wider IoT
towards a person-centred approach to participatory design

<table>
<thead>
<tr>
<th>User centred</th>
<th>Person centred</th>
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</thead>
<tbody>
<tr>
<td>Identify the user first: health condition, demographic, etc</td>
<td>Get to know the person in front of you</td>
</tr>
<tr>
<td>Identify the problem or needs</td>
<td>Work to enable the person’s (or people’s) potential for growth</td>
</tr>
<tr>
<td>Don’t design for yourself</td>
<td>Be aware of yourself in the relationship (congruence)</td>
</tr>
<tr>
<td>Find out what people (behaviour) do or think (cognition)</td>
<td>Let people communicate and act; empathise with their experience</td>
</tr>
<tr>
<td>Design a solution or health intervention</td>
<td>Facilitate a context for sustainable change through reflection and generative action (entanglement)</td>
</tr>
<tr>
<td>Implicit or explicit expert model</td>
<td>strives to “develop an egalitarian partnership with a chosen community” *</td>
</tr>
</tbody>
</table>

*Orlowski et al 2015, p2*
Development of methodology and next steps

• Training and scaling up delivery of workshops
• Individual journeys (participants)
• Individual journeys (researchers)
• Developing the concept of participatory design
  – From recruitment through supervision and reflection to interpretation and presentation
Workshop training
Take away question

• In your practices, consider:
  – Is your approach one of instrumental or principled non-directivity?
  – How does this fit with the imperatives of ‘research’?
  – How does this impact on the role of the ‘expert’?

cf David Murphy
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http://aninternetofsoftthings.com
references

- Meg, Bassetlaw Mind member, 2015.