The politics of participation

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This document is the Accepted Version [AM]

Citation:

CRAIG, Claire, FISHER, Helen and SMITH, Sarah (2018). The politics of participation. In: Design4Health2018 Sheffield, Sheffield, UK, 4th September 2018-6th September 2018. (Unpublished) [Conference or Workshop Item]

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The politics of participation

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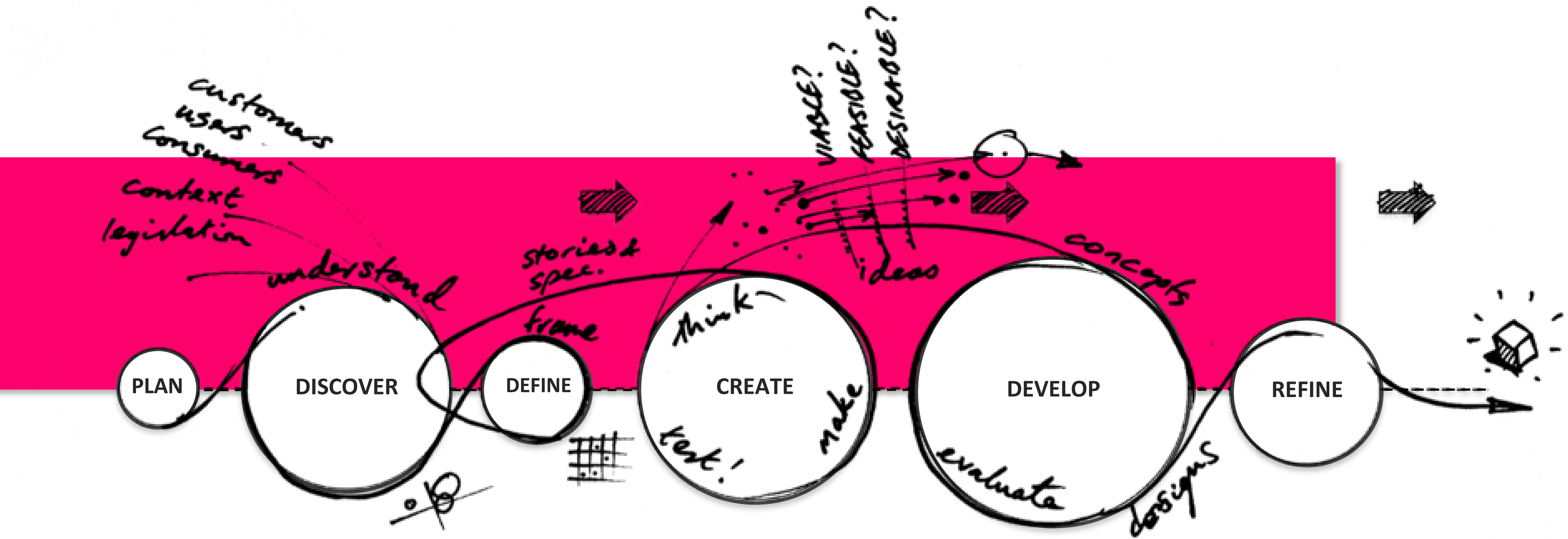
co-production and participatory design



PLAN

DISCOVER

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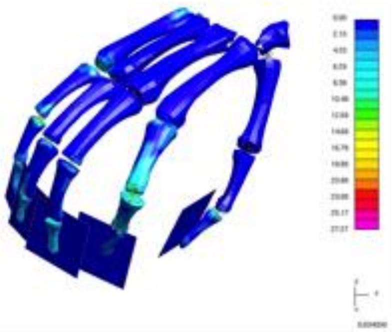
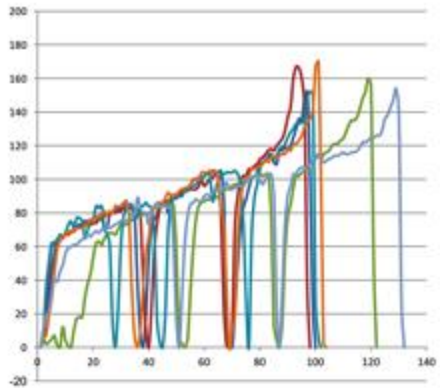
mnda
motor neurone disease
association

NHS
National Institute for
Health Research

More holistic product design





Designing better products

CROWN

Enabling us to understand the real questions

Improving the quality and design of bathroom furniture for older people

Project is funded by the EPSRC and supported Ideal Standard

‘If I’d known what I know now I wouldn’t have done it like that’

mi.sink

Bathroom sinks can be used for a wide variety of tasks by a diverse range of users of different age, size, shape and ability and might include children brushing their teeth or wheelchair users washing their hair.

mi.sink rotates around a central column and is height adjustable allowing for optimum and safe usability when undertaking a range of bathroom activities. Plumbing feeds and wastewater are discretely managed through the support column.

VitrA

Guidelines for inclusive bathroom design that address older populations…

The Most Innovative Design for Ageing in the UK in 2017

UK OVER 50s HOUSING AWARDS 2017

Co-designing tools for engagement


Design/design thinking as the intervention

Authenticity of relationships

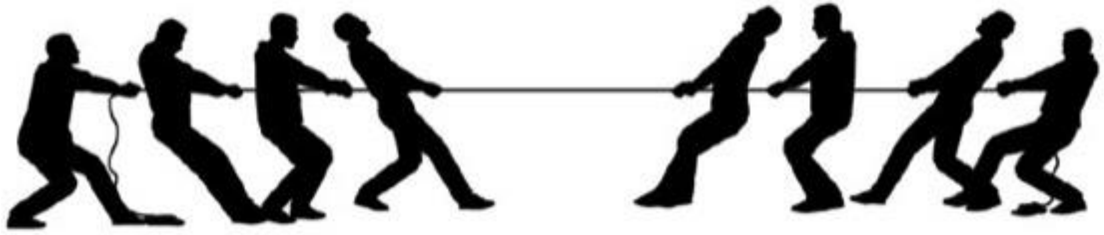
However co-design is predicated on a number of assumptions

Representativeness and representation?

I have to ask why are the people who are providing this content not usually the ones funded to present or at least co-present it? A 2 or 3 minute video clip of people looking happy and contributing is not the same as presenting the work for themselves and it suggests tokenism and exploitation. It also makes them appear as research subjects or participants not as co-contributors.

Kate Swaffer

ethics of authorship and ownership?



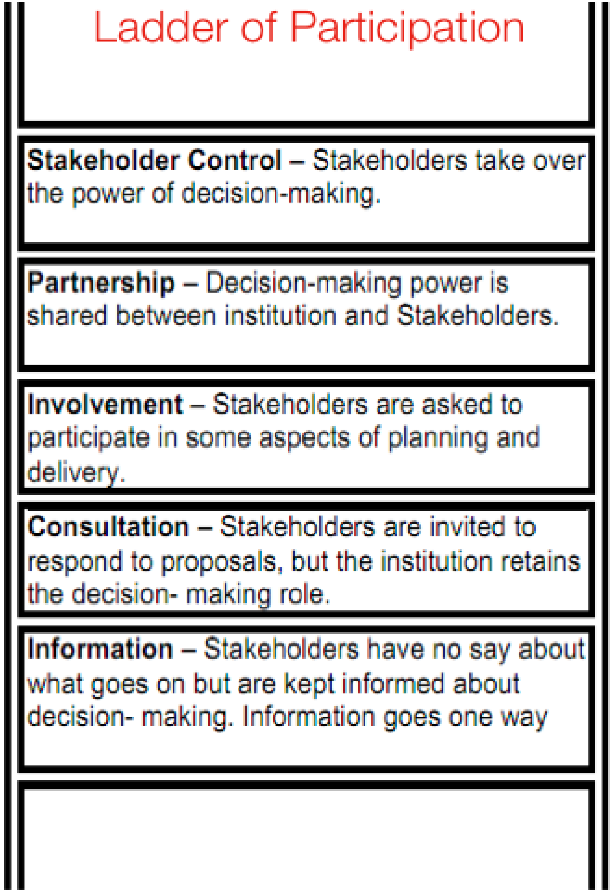
In December 2014, I came across one of my own poems on Twitter titled ‘Lost’ (2010, 2012) that appeared to be attributed to other authors, although I wish to state clearly in no way was it unethical in the research process or the way it was cited and in no way did this pilot study then published by Petrescu, MacFarlane, & Ranzijn (2014) breach any ethical protocols. The way the poem was published on Twitter was what caused me to notice it in the first place, which was as ‘‘‘Lost’’ (Petrescu & McNab)’, rather than as the author [me] who owned the creative copyright.

What are the broader socio-economic and cultural contexts in which the research operates?

GETTY IMA

Experiencing a sense of otherness:

Afterwards it was difficult: some people called me a 'grass' and a scab, others said I was 'la-de'-da' people felt betrayed because I had 'gone to the other side' It feels pretty lonely now. I don't think it will ever go back to how it was before'



Ladder of Participation

Stakeholder Control – Stakeholders take over the power of decision-making.

Partnership – Decision-making power is shared between institution and Stakeholders.

Involvement – Stakeholders are asked to participate in some aspects of planning and delivery.

Consultation – Stakeholders are invited to respond to proposals, but the institution retains the decision- making role.

Information – Stakeholders have no say about what goes on but are kept informed about decision- making. Information goes one way

When is co-design not co-design?

The principles

These are the Scottish Dementia Working Group research sub-group core principles for involving people with dementia in research.

Core principle
1

I never heard what happened

Principles:

- We want to be valued, and to be kept involved and informed.
- Good research gives you something after the end.
- There is a risk that people with dementia taking part in research can be "used" by researchers.
- Research should start from a place of seeking positive and lasting change in our lives, and in the lives of people with dementia in the future.
- It usually takes several years and more than one research project for positive and lasting change to happen.

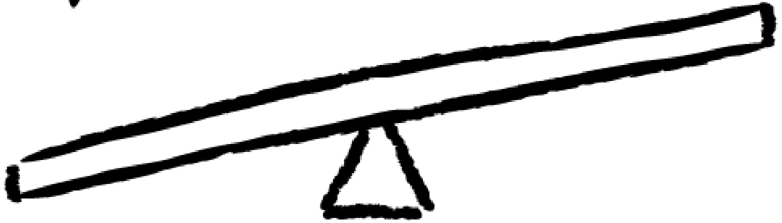
Core principle 2

Knowledge comes from all sorts of places

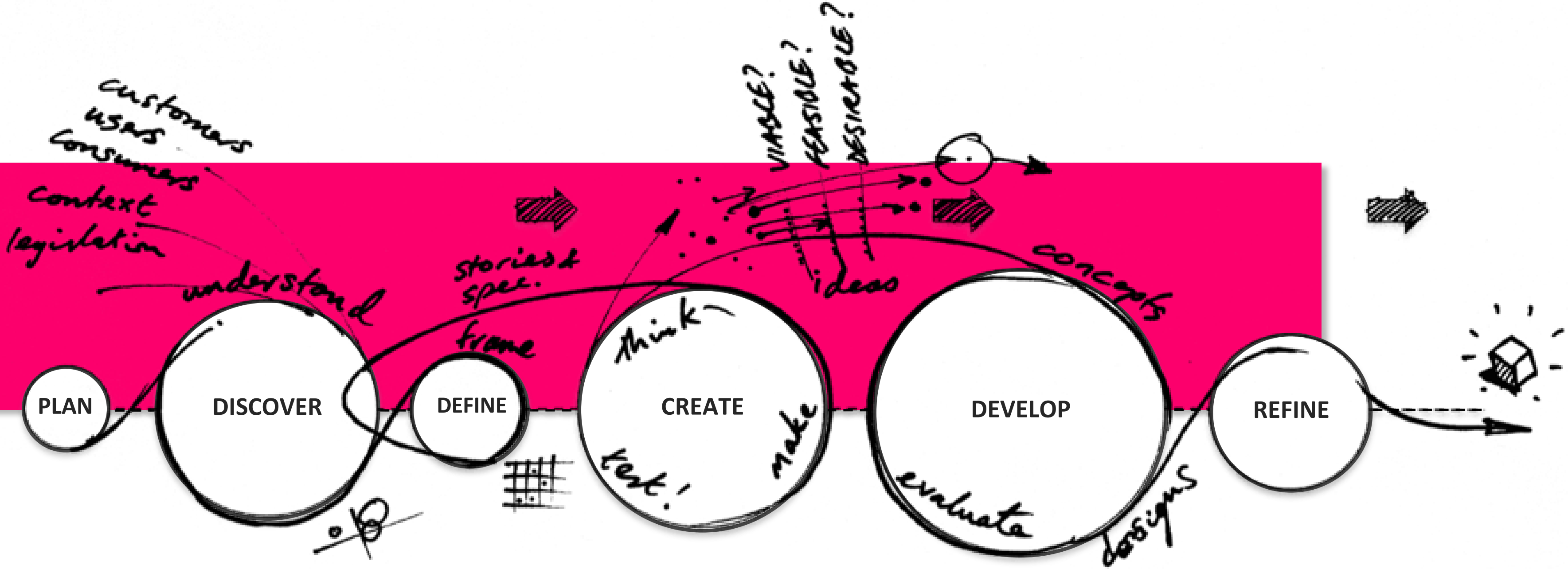
Principles:

- People with dementia experience it twenty-four hours a day, seven days a week.
- We are often involved in answering research questions, but we are not often asked about research priorities.
- Research priorities shouldn't just be set by researchers, but they shouldn't just be set by people with dementia either: we need to work together in influencing knowledge about dementia.
- People with dementia often have to be researchers themselves, for example finding out what support is best.

EPISTEMIC INJUSTICE



co-production and participatory design: a way forward: over to you



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Final reflections