

(Co-)Re-Designing the Participant Information Sheet

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1. Background

For any research study it is vital to be clear about the activity involved in order that appropriate consideration may be applied for working practice, safety, and to fully inform participants.

However, this assumes that information conveyed in a typical University approved document, would in turn it be read by participants whom would then supply the appropriate response to the researcher. This is not necessarily so.

This research is focussed on the development of a new methodology to empower and enable People with Learning disabilities (PWLD) and developers to meaningfully collaborate, rather than as a token evaluation gesture. A working arrangement has been established based upon collaborator involvement at all stages, not only 'when required', including design of the study structure (i.e. communication practices) and preliminary administration, such as a vital information source, the Participant Information sheet (PIS).

The collaborators in this study, (referred to as co-researchers) and the exercise represented here, are members of Communicate2u (C2U), a social enterprise working with People With Learning Disability (PWLD). C2U incorporate a diverse range of abilities and communication requirements and are involved in research and public governance issues of an otherwise marginalised user group.

2. Aim & Objectives

The aim of this exercse is to re-design a PIS to inform and engage co-researchers.

The objectives of this exercise are:

- To co-develop a PIS with PWLD
- To develop a co-designed symbols of research practice
- To produce a prototype PIS document

3. Participants - there are none

In the overall study and this exercise, there are no participants. Those based at C2U are co-researchers, engaged as an empowered provider of experiential knowledge. representing varied communication requirements such as those on the high functioning Autistic spectrum, mild to moderate learning disabilities and some restricted physical ability.

Considering the format and content provision to inform C2U, the standard PIS did not provide a suitable balance of research relevant information, suitable ethical acceptance for University governance purposes and communication of the activity at an appropriate level of complexity.

Therefore the PIS needed to be (co-)re-designed.

4. Methods

Inspired by the empowering techniques of Participatory Action Research (PAR) (Baum, 2006) and Experience Based Co-Design (EBCD) (Kings Fund, 2013), this exercise employed a series of co-design steps, key replicable requirements of collaboration and thematic analysis (Braun, 2006) to identify recommendations.

The key elements applied are:

- Performance of research song with whole group (reminder of research message)
- The group is organised by an experienced facilitator using inclusive communication
- An informal situation, planned to be non-academic
- Engagement with a creative task (research badge created) to signify activity importance
- Number of co-researchers in this exercise (n=4 to 6)
- Typical timeframe of 45 minutes to collaborate
- Activity based on capabilities of co-researchers (discussion, focus group, drama)
- Thematically analysed results to identify experience-led insights

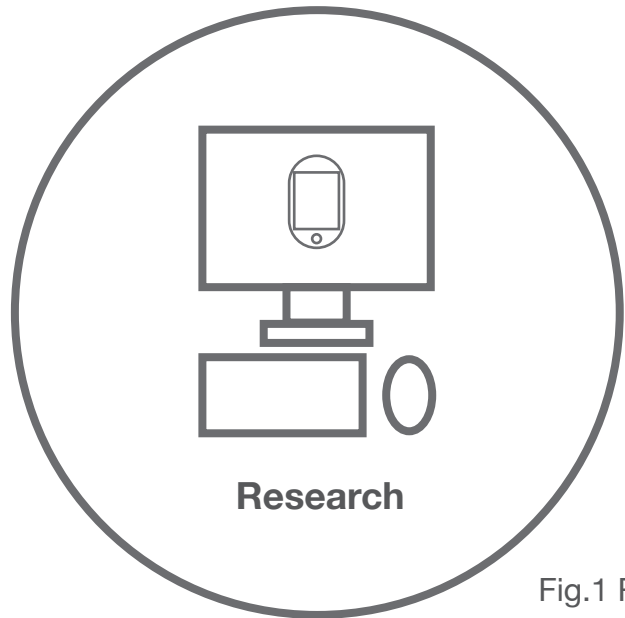


Fig.1 Research badge design

5. Results

The results from this gathering have been split into 2 themes linked by document format:

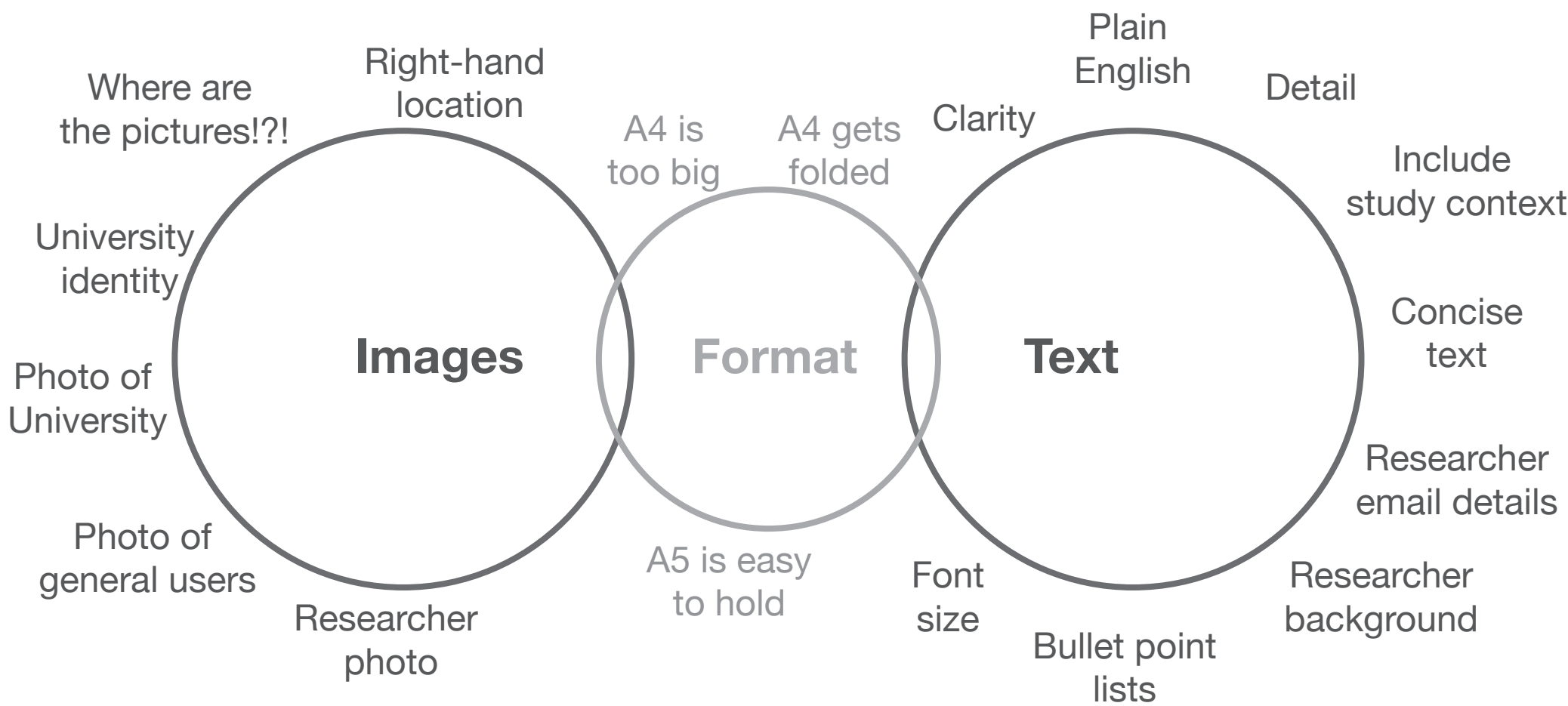


Fig.2 Thematic results

Key requirements for co-designed PIS:

- Clear, concise, well written information with detail
- Splitting information into sections improves readability
- Images can be quite sophisticated
- Images must locate with the text they are communicating
- Font size is important but relative to page size
- A5 size booklets are preferred and have greater credibility

6. Output - booklet design

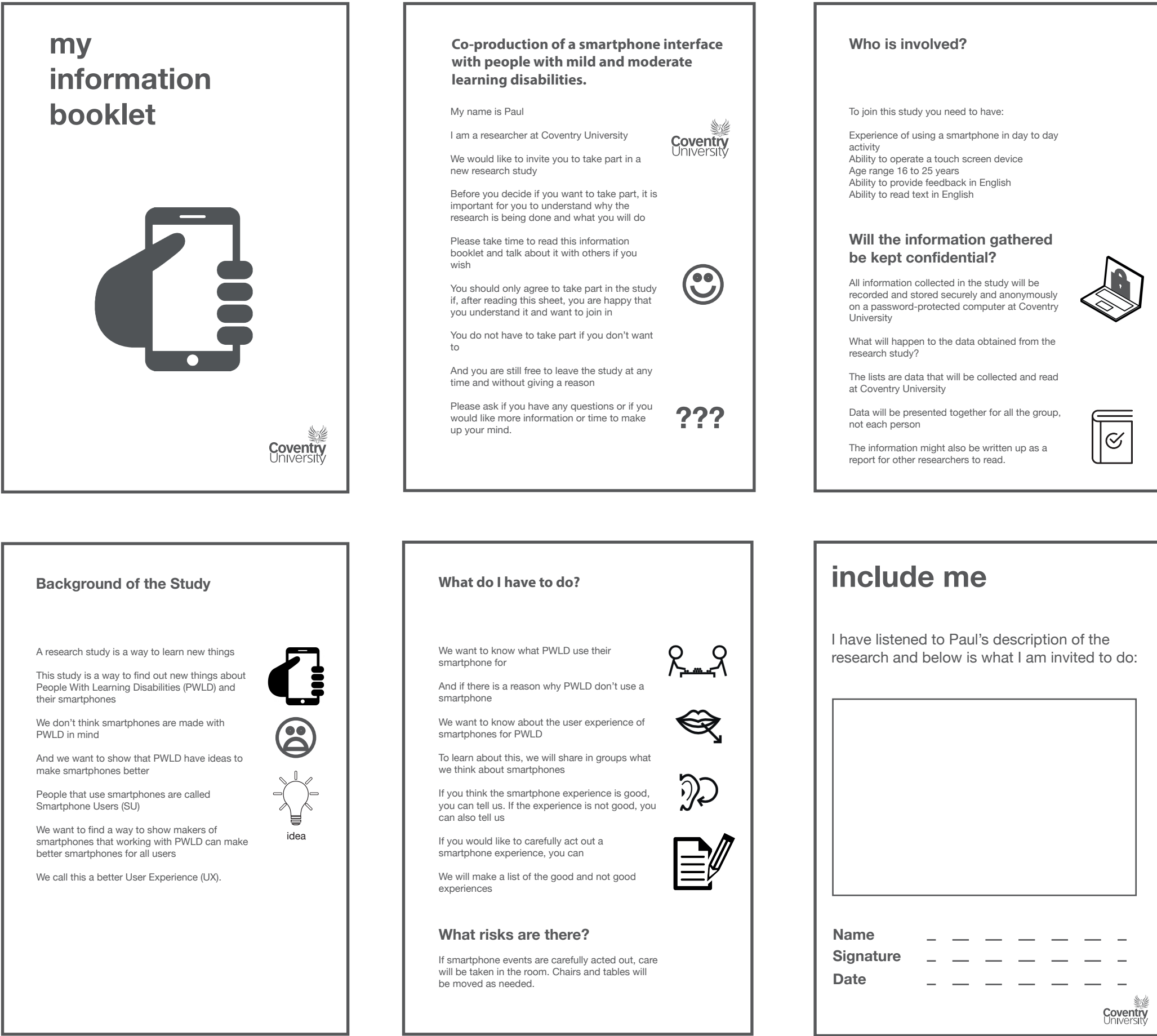


Fig. 3 A5 booklet layout

7. Conclusions

This group exercise was designed to learn ways to communicate meanings of sections of the PIS but not to pre-define the design and ask for agreement. As a result, the booklet design stems from the co-researcher's contributors. In summary:

- Informal atmosphere was more comfortable for co-researchers
- Co-researchers needed the freedom to participate intermittently
- Creatively collaboration in small groups provided focus
- Creative activity (badge designs) provided a mood of engagement
- Priority should be on clarity of images, with relative sophistication
- Flexible communication methods accounted for the group's needs
- The prescence of acquiescence bias may limit feedback from some co-researchers

References

Baum, F., MacDougall, C., and Smith, D. (2006) 'Participatory Action Research'. Journal of Epidemiology and Community Health 60 (10), 854-857
Braun, V. and Clarke, V. (2006) 'Using Thematic Analysis in Psychology'. Qualitative Research in Psychology 3 (2), 77-101
Experience Based Co-Design Toolkit, 2013. <https://www.kingsfund.org.uk/projects/ebcd>. Accessed 16022017.