Proposals for Protocol Approval will be considered by school research ethics committees. Protocols are standard procedures which may be used in a variety of experiments

In order to be approved, a protocol will normally be well established in the relevant subject community. The protocol will also fulfil the following criteria:

1. The procedure is familiar (experientially) to participants;
2. Its risks are assessed and managed appropriately;
3. Research based on the procedure is already in the public domain published in reputable peer-reviewed journals;
4. Whenever it is replicated the procedure is conducted under the same circumstances, with similar kinds of participants;
5. The researcher(s) and/or supervisor(s) are experienced in using the procedure;
6. Participants are not members of vulnerable populations[[1]](#footnote-1)
7. The data is not “sensitive”.

In order to apply for protocol approval, please complete the attached form and forward it to your School Ethics Committee.

For full details of the protocol approval process please refer to the appropriate guidance notes.

|  |  |
| --- | --- |
| Proposer:  | Professor Wendy Keay-Bright |
| School: | Cardiff School of Art & Design |

BEFORE COMPLETING THIS FORM, PLEASE REFER TO THE NOTES ABOVE

|  |
| --- |
| **A – DETAILS OF PROTOCOL** |
| A1 Proposed title of protocol |
| CARIAD RESEARCH ETHICS PROTOCOL |
| A2 What is the purpose of this protocol? |
| The protocol will be used to enable members of the Centre for Applied Research in Inclusive Arts and Design [CARIAD] research group to actively involve stakeholders in their respective research projects. These stakeholders may include the friends, families and those responsible for the care of vulnerable people, as well as employees of partnering organisations, developers, consultants, decision and policy makers. CARIAD projects require balanced, empathetic and compassionate research methods that can be tailored to the specific needs, values, experiences and expressions of very particular groups of people. Whilst the protocol is not intended for direct use with vulnerable populations, it is designed to address the viewpoints of those people, who are often under-represented due to unequal power relationships and reduced means for communicating ideas. |
| A3 What procedure will the protocol encompass? |
| Procedures will encompass participatory design, co-design, co-creation, co-operative inquiry.The pioneering work of the CARIAD researchers is shaped by novel procedures that take people outside of their familiar areas of knowledge and routines. Each of these procedures is rigorously researched, carefully negotiated and collectively defined through consultation with stakeholders. In addition to more traditional methods, such as field observations, interviews and video analysis, the protocol procedures will include workshops, storytelling, the use of non-technical and technical artefacts and probes, as well prototyping and dramaturgical methods. |
| A4 Are these procedures well established in the subject community? | Yes |
| A5 If YES, please provide evidence |
| CARIAD researchers are responsible for undertaking a diverse range of applied research projects that draw on fields such as user-centered design, participatory design, graphic design, software engineering, health sciences, public policy, psychology, ethnography, anthropology, sociology, and communication studies. This diversity does not lend itself to a single theory or paradigm of study or approach to practice, however, the afore mentioned procedures have been well-documented, the publications below provide examples of these procedures where by the concern is to help diverse stakeholders communicate and commit to shared goals, strategies, and outcomes for example analyses, designs, and evaluations, as well as change objectives. 1. Druin, A., 1999. *The Role of Children in the Design Technology*.
2. Duysburgh, P., Slegers, K. and Jacobs, A., 2012, June. Interactive applications for children with hearing impairments: a process of inspiration, ideation, and conceptualization. In *Proceedings of the 11th International Conference on Interaction Design and Children* (pp. 240-243). ACM.
3. Ehn, P., 2008. Participation in design things. 92--101
4. Francis, P., Balbo, S. and Firth, L., 2009. Towards co-design with users who have autism spectrum disorders. *Universal Access in the Information Society*, *8*(3), pp.123-135.
5. Greenbaum, J. PD: A personal statement, CACM 1993. In Haraway, D. J. When Species Meet, 2008. Minneapolis and London: University of Minesota Press.
6. Hendriks, N., Huybrechts, L., Wilkinson, A. and Slegers, K., 2014, October. Challenges in doing participatory design with people with dementia. In *Proceedings of the 13th Participatory Design Conference: Short Papers, Industry Cases, Workshop Descriptions, Doctoral Consortium papers, and Keynote abstracts-Volume 2* (pp. 33-36). ACM.
7. Hendriks, N., Truyen, F. and Duval, E., 2013, September. Designing with dementia: Guidelines for participatory design together with persons with dementia. In *IFIP Conference on Human-Computer Interaction* (pp. 649-666). Springer, Berlin, Heidelberg.
8. Light, A. and Akama, Y., 2014, October. Structuring future social relations: the politics of care in participatory practice. In *Proceedings of the 13th Participatory Design Conference: Research Papers-Volume 1* (pp. 151-160). ACM.
9. Lindsay, S., Brittain, K., Jackson, D., Ladha, C., Ladha, K. and Olivier, P., 2012, May. Empathy, participatory design and people with dementia. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 521-530). ACM.
10. Lindsay, S., Jackson, D., Schofield, G. and Olivier, P., 2012, May. Engaging older people using participatory design. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 1199-1208). ACM.
11. Muller, M.J., 2003. Human-computer interaction: Development process. *Participatory Design: The Third Space in HCI*, pp.165-185.
12. Muller, M.J., Blomberg, J.L., Carter, K.A., Dykstra, E.A., Madsen, K.H. and Greenbaum, J., 1991, April. Participatory design in Britain and North America: responses to the “Scandinavian Challenge”. In *Proceedings of the SIGCHI conference on Human factors in computing systems* (pp. 389-392). ACM.
13. Simonsen, J. and Robertson, T., 2012. Participatory Design: an introduction. In *Routledge international handbook of participatory design* (pp. 21-38). Routledge.
14. Salvador, T. and Howells, K., 1998, April. Focus troupe: using drama to create common context for new product concept end-user evaluations. In *CHI 98 conference summary on Human factors in computing systems* (pp. 251-252). ACM.
15. Sato, S. and Salvador, T., 1999. Methods & tools: Playacting and focus troupes: theater techniques for creating quick, intense, immersive, and engaging focus group sessions. *interactions*, *6*(5), pp.35-41.
16. Sanders, E. B. -N. 1999. “Postdesign and Participatory Culture.” In Presented at the Proceedings of the International Conference “Useful and critical” – The Position of Research in Design. Helsinki: University of Art and Design.
17. Sanders, E. B. -N., and P. J. Stappers. 2008. “Co-Creation and the New Landscapes of Design.” CoDesign 4 (1): 5–18.
 |
| A6 If NO, please provide an explanation of why this is the case |
| Click here to enter text. |
| A7 How many projects carried out in your School in the last three years have used these procedures? | 6 |
| A8 Does the proposed protocol contain identical procedures to those used in these projects? | Yes |
| A9 If NO, what are the differences? |
| Click here to enter text. |

|  |
| --- |
| **B – POTENTIAL RISKS** |
| B1 What are the risks associated with the procedures (for both the participant and the researcher) and how will these risks be managed? |
| Risk1. Participants may lack the capacity, confidence or time to fully engage with the project in line with the vision of the research team.2. Danger to the researcher of ‘accusations’ by a carer concerning the infringements of human rights or loss of dignity of a person who lacks capacity3. Other researchers’ work is jeopardised by the poor ethical standards of inexperienced researchers.Mitigation1. A process of on-going consent or assent will be required from those representing their interests. This means that for each visit or interaction with the person, the research is explained in an acceptable and accessible way for all involved. The methodologies adopted for each project will address the need for fluidity, and will allow for responsivity and change management.2. Ensure the researcher is accompanied at **all times** with a carer or health professional and that all involved in the research activity are fully appraised of what is involved and that the activity has full approval of those who have a duty of care for the person who lacks consent.3. Research that involves direct contact with vulnerable people will only be undertaken under close supervision of a more senior researcher or health professional and never undertaken alone. |

|  |
| --- |
| **C – DETAILS OF INDIVIDUALS INVOLVED** |
| C1 Please provide details of academic staff qualified to supervise use of the protocol. You should include details of each individual’s experience in using the procedures and any relevant qualifications. |
| Professor Wendy Keay-Bright: Professor of Technology and Inclusion and Director of CARIAD. Wendy holds a PhD in Inclusive design and extensive research experience working with multi-disciplinary stakeholder groups including children and adults with learning difficulties. In her role as Design Director, Principal Investigator and Project Manager, she has been responsible for employing the above procedures in world-leading, externally funded research and development. The outputs of her inclusive methodologies have been software and print media, services and consultancy, the outcomes and impact have led to improved confidence, well-being and quality of life for diverse populations with disabilities. Professor Cathy Treadaway: Professor of Creative Practice, Cathy has been Principal Investigator on a major international interdisciplinary AHRC design research for dementia project. This collaborative research has investigated ways of designing to support the wellbeing of people with late stage dementia. Cathy has 15 years’ research experience of working with people using participatory and co-design methods as well as six years’ experience of working with people who lack capacity to give informed consent, including people living with advanced dementia. She has published extensively on her research involving people living with dementia. This work highlights the complex ethical considerations involved in researching with vulnerable people with memory loss, for whom ethics approval needs to be an on-going process of informed consent and for whom maintaining dignity and personhood is a research priority.Professor Gary Beauchamp: Director of Research and Professor of Education in the School of Education, with over 25 years’ experience in delivering high quality teaching in creative disciplines from primary to PhD level. His extensive applied research experience focuses on investigating the role technologies play in facilitating communication and creativity in the Welsh curriculum.Professor Andy Walters: In addition to his role as one of the founding members of [PDR’s User-Centric Design Group (UCD)](http://pdronline.info/en/consultancy/what-we-do/user-centric-design/), within CARIAD Andy explores new tools and techniques for designing with people, and the impact of such methodologies in the commercial domain, specifically though the development of rehabilitation products. |
| C2 Which groups of students do you envisage using this protocol eg what areas of study will they be involved in, will they require any particular qualifications or experience in order to use the protocol? |
| The protocol may include the work of Postgraduate students undertaking CARIAD Masters/MRes project and will include the work of CARIAD PhD students. |
| C3 Will there be any requirements placed on participants on whom this protocol will be used? NB If participant characteristics would require ethics approval then protocol approval will not be granted |
| It may be that some projects require NHS or other organisational or university ethics. These will be managed on a case-by-case basis. All named individuals authorised to supervise the protocol have experience in writing ethics applications that have been approved through external partners. |

|  |
| --- |
| **Research Ethics Committee use only** |
| Decision reached: | Protocol approved | x |
| Protocol approved in principle |  |
| Protocol not approved |  |
| Project rejected |  |
| Protocol reference number: 08\_1718\_E (WKB) |
| Name: Dr Stephen Thompson | Date: 16/05/2018 |
| Signature:C:\Users\sm16404\AppData\Local\Microsoft\Windows\Temporary Internet Files\Content.Outlook\B4LI4C32\S_Thompson.JPG |
| Details of any conditions upon which approval is dependant:This Ethics approval is valid until 16/05/2021. Should your project extend beyond this time an application for an extension to the approval will be required by CSAD REC.Please note, your project has been granted ethics protocol approval based on the information provided in your application. However, should this change at any point during your study or should you wish to engage participants to undertake further research then you are required to reapply to CSAD REC for ethics approval. |

1. NB: Projects in Professional Practice involving groups of children in a public place in school, with the permission of the school are exempted [↑](#footnote-ref-1)