

# You Don't Know What You Don't Know: Ethics and participant consent issues for eResearch users

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## ABSTRACT

This paper shares the experiences of researchers and research support teams to enable eResearch that is ethically sound, particularly with regard to the consent of research participants. A key goal of eResearch is to use compute and data intensive infrastructure and collaborative approaches supported by advanced ICTs (HPC, Cloud Storage, Collaborative tools and High Speed networks) to enable data sharing and re-use. This paper shares the practical challenges and solutions from the perspectives of researchers and research support teams at the University of Southern Queensland (USQ) and poses questions and suggestions on ethics dilemmas such as ensuring that research participants have consented to share the data collected on them with other researchers. A collaborative and consultative approach involving teams in the USQ Office of Research, the USQ Human Research Ethics Committee (HREC) Chair, the ICT Service Division and Library Services division resulted in successful outcomes for researchers.

## INTRODUCTION

This paper presents the experiences of enabling 'ethically compliant' eResearch approaches for two research projects being undertaken at the University of Southern Queensland (USQ). The two research projects shared similarities in that both use qualitative analyses of data collected via interviews and needed a central repository to store and share the data with research collaborators. Both projects also expressed the desire to improve the research outcomes and outputs by using eResearch services to collect, process, store, share and extend the uses of the research data and analyses for future research projects.

Both research projects had recently obtained USQ Human Research Ethics Committee (HREC) approval as they involved human participants. Australian university human research ethics committees are legislated by The National Health and Medical Research Council Act 1992 and informed by a series of guidelines including the National Statement on Ethical Conduct in Human Research [1] and Values and Ethics - Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research [2].

Following conversations with the USQ Office of Research it was identified that the research projects were faced with an ethics compliance dilemma that if the researcher was intending to share the research data with other researchers for their use in different projects, they required HREC approval to do so and also required the consent of their research participants. Furthermore, as the projects involved Children and Indigenous Australians there were added ethics issues that needed to be addressed prior to fully leveraging eResearch services [2, 3].

The paper now presents a brief background of each research project, the ethics compliance dilemmas faced by each project leader, the strategy used to address the ethics compliance issue and the outcomes. Reflections on the lessons learnt are then presented and a conclusion provided.

## EVERYDAY DIGITAL LIVES: CAPTURING AND STUDYING DIGITAL LITERACY NARRATIVES

This research project is a study of people's everyday digital literacies, that is, the practices in which we engage on a daily basis as we interact with technology. There has been a great deal of work around defining and measuring digital literacy, but less about how people themselves conceptualise and articulate their understanding of technology. Research has shown that so-called "digital nativity" varies widely across individuals, cultures and institutions [4, 5]. The project is collecting people's stories of their first encounter with a computer and their most recent uses of computers and digital devices. This entails digging into their memories of learning to read and write and learning to use computers. The research also explores the rules around using computers at home, at school and personally. It tries to find out how comfortable people feel with technology and what they do when things go wrong. Interviews will be undertaken on a wide range of participants about their experiences: from 14 and 15 year old schoolgirls in Brisbane to new university students and postgraduate students to academics involved in a digital research network at a regional university. The research attempts to build a picture of the trajectories of individual digital literacy within each person's social context.

The research project is conceived as playing a role in the development of digital literacies and skills. The research data (digital literacy narratives) are intended from the initial research conceptualisation to be archived and shared for community use, that is, both by other researchers and by the general public. The database will be developed to become a shared resource with open control, access, and use. In addition to general privacy issues, some of the research participants are children and special care needed to be taken to protect their privacy while allowing data to be re-used and re-purposed.

The original institutional ethics clearance application simply stated that all recordings would be placed in a database under Creative Commons – Attribution ShareAlike (CC BY-SA 4.0) license. While this proposal received ethics clearance, the fact that the researcher was working through the process with the USQ eResearch Analyst, meant that some ethics concerns were identified. In consultation with the Manager Research Integrity and Ethics and USQ eResearch Services, two amendments were made to the ethics approval:

1. The language of the consent form was changed to be and less technical and in plain language. Instead of simply detailing the license, a statement was inserted stating:

*"I understand that information gained during the study will be published in a public archive and that audio files will be linked to a photograph and a first name. The researcher has explained to me options for increasing my privacy by using a pseudonym and an alternative to a photograph.*

*I understand that the digital audio files will be placed in a public access archive under Creative Commons Licensing which means that other people will be able to listen to the stories and use sound clips from it."*

2. The location of stored files was changed from public sites (originally the narratives were to be stored on SoundCloud) to USQ and QRISCloud computers in order to ensure the security of publicly funded data.

Working closely with USQ eResearch services based in the Research and Innovation Division and closely aligned to the Office of Research facilitated immediate meetings with the Manager for Research Integrity and Ethics. This helped in identifying the issues and opportunities, amendment of the ethics approval and research participant consent form, prompt ethics clearance allowing a hasty commencement to the research data collection.

A key result for the project is that the data can now be fully re-used and shared, fieldwork is proceeding smoothly and there have been no issues around consent or data re-use.

A key lesson learnt was that early engagement with eResearch services can potentially save research projects time-costly revisions. The Research Integrity and Ethics team are partners not opponents of research projects. Even with their focus on the requirements of traditional subjects-based research with its emphasis on de-identification of participants and removal of data context, they were able to support other kinds of research that requires context and individual detail to provide meaning. The benefits of eResearch are not limited to the use of High Performance Computing but include facilitating the creation of secure and useful solutions for data storage and re-use.

## **WORLD HERITAGE AND ENVIRONMENT**

The project conducts research on the Great Barrier Reef aesthetics, social value and management; heritage tourism, World Heritage and Indigenous values.

In this project a key concern resulted from the nature of the research, which involves human relationships with the environment that draws on both anthropological and historical sources. The data and analysis is qualitative, including interviews, archival documents, still and moving photographic images, books. The researchers in the project continue to seek a way to enhance the research impact using eResearch services ethically and with research integrity given that not all the research data is available for sharing and not all can be copied. The research project is faced with challenges of sharing 'data' from historical and human sources, as the researcher does not create the 'data'. Ownership may belong to many different individuals and institutions. However, the ordering and selection of those materials is an integral part of this type of research. It is also important to note that the 'data' collected in this type of research project relevant to continuing research. The 'data' is never 'finished' and therefore simply available to others.

Consultations with USQ eResearch services and a plan to review research and integrity mechanisms to facilitated data sharing and re-using is being considered in order to comply with relevant ethical guidelines and principles [3]. This

research is still in the early stages and exploring the best use of eResearch services including the collaborative use of qualitative research software on a NeCTAR VM and QRIScloud platform.

The eResearch approach undertaken for the research projects entailed: aligning administrative and technical components with ethics approval; implementing data storage on Cloudstorplus and QRIScloud to facilitate research team collaboration and sharing of the research data and allow for wide re-use and re-purpose of the data; and use of Quadrant, a collaborative research project management software and SeeVogh for video collaboration as listed on QCIF (Queensland Cyber Infrastructure Foundation) catalogue of services [6] which extend the USQ ICT services[7].

## CONCLUSION

Collaborative efforts are beneficial as solutions may be shared by research that may have encountered similar problems along their research journeys. Innovation functions most effectively with strong institutional support and the skills that different research professionals can bring to the table. Collaboration, especially early collaboration and sharing of ideas, between different teams can be very fruitful even if sometimes team members seem to be speaking different languages.

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## ABOUT THE AUTHOR(S)

**Dr Jenny Ostini** is a Postdoctoral Research Fellow (Digital Futures and Personalised Learning) with the Digital Futures Collaborative Research Network, hosted by the Australian Digital Futures Institute at the University of Southern Queensland. She is a qualitative social scientist with expertise in narrative analysis, critical discourse analysis, content analysis, interviewing and ethnography. Prior to joining USQ, Jenny worked at the Queensland Council of Social Service. She first worked in low-income consumer advocacy around water and energy efficiency and then on developing online content to help build the capacity of social sector to manage change. This included developing a website to host digital content such as podcasts, videos and digital archives and then creating that content. She also worked at the University of Queensland's Healthy Communities Research Centre as a qualitative social scientist engaged in evaluating community health interventions. Jenny is interested in the production, consumption, use, and transformation of knowledge, and social change in a digital environment. Her current research project is collecting and studying digital literacy narratives to examine how people get, and share knowledge in a digital world. She is also a fan of the Oxford comma. <http://www.usq.edu.au/digital-crn/meet-crn/jenny>.

**Dr Francis Gacenga** is the QCIF eResearch Analyst at the USQ. He has 15 years' experience in IT service management as a researcher and practitioner. Francis has worked in government agencies in IT service strategy, design, transition, operation and continual service improvement. He offers a service oriented approach to eResearch service delivery beginning with an understanding of the researchers requirements and offering a suite of cloud compute, storage and collaboration tools, platforms and infrastructure as services that enable data-driven, collaborative research that fosters an interdisciplinary research culture. He conducts research at USQ and has presented research at international conferences and published articles in academic and industry journals. He has worked internationally in information systems development, support, training and management as a systems administrator and computer programmer at the local and state government level and as a lecturer and tutor at the tertiary level. In 2002 the Institute for the Management of Information Systems (IMIS) UK awarded him a gold medal. His research interests include IT service management, eResearch, ITIL, service science, performance measurement, content analysis and design science. He has served as a reviewer in a number of international information systems journals and conferences.

**Dr Eliza Whiteside** is currently the Manager, Research Integrity and Ethics in the Office of Research at USQ. She has been a researcher and/or a lecturer for almost 20 years in Australia and the UK. She publishes in the biomedical sciences and public health research fields and regularly presents her research at International and Australian conferences. Eliza has been the recipient of numerous research and teaching awards and in late 2013, her commitment to research and community engagement in science was rewarded with a Queensland Young Tall Poppy Award. Eliza is a reviewer for several Australian and international journals and also contributes to popular media communications (television, radio, print and online) as an expert speaker for medical research.