

Get involved!

EnCoRe also supports some PhD students who are working in the area of privacy and consent.

In her research, Patrizia, a PhD student at the [LSE](#), is interested in understanding how different parts of an organisation define the concept of data quality, given their differing data needs, and how a common understanding of data quality that emerges affects practice, and in particular how it is affected by privacy concerns.

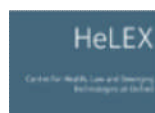
She is running various focus groups, the aim of which is to explore the different perspectives on data quality as this is affected by privacy concerns in organisations. The focus groups bring together the key stakeholders and managers involved in questions of data quality and privacy in a time-effective session (typically two hours).

As an example, in a recent focus group people working together discovered that, due to their different personal and academic backgrounds, when they referred to particular data quality dimensions they meant slightly different things. It was very beneficial for the participants to clarify definitions and perceptions of data quality during the workshop. Despite the fact that people work together and talk about the same issues every day, sometimes their backgrounds and experiences provide slightly different nuances to the same terms. These differences can lead to further issues that affect practices within an organisation.

Here is a recent quote from one of the organisations that benefited from the workshop:

"Yes we found [the data quality workshop] useful, thanks for coming. It certainly made us think and it taught us that we should not take things for granted."

Any organisation can take part in this research. Details about Patrizia's research project are available [here](#). For information and to take part, please write to p.bertini@lse.ac.uk.



International Data Sharing Conference

The conference focussed on the issues raised by international data sharing for medical research. It attracted 151 delegates from over 20 countries and was held at St. Hugh's College, Oxford, 20-22 September 2010.

Data sharing has had a significant effect on the way that medical and scientific research is carried out and raises a number of practical and implementation challenges, as well as broader questions about fairness, equity and justice. The conference created a space where people from many disciplines and countries could come to share ideas and their experiences of data sharing.

There was also a satellite ethics workshop run by Dr Paula Boddington in association with Procardis, and a "Patient-Centric Initiatives in Health and Biomedical Research" workshop organised in association with EnCoRe.

Contact

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Moreover, the impact of this conference has been to pilot a new way of running a conference within the genomics research field and also to stimulate thinking about data sharing. To carry on some of the thinking developed at the conference, there will be a special issue of Genome Medicine as well as a dedicated webpage for publications linked to the conference. EnCoRe participant HeLEX is also developing the [Oxford Statement on Data Sharing](#) to capture some of the ideas at the conference and help move the field forward.

Even if you weren't at the conference, you can get involved in some of the initiatives that were started

there and find out what happened, by visiting the conference [webpage](#), which contains [slides](#) and [podcasts](#) from the conference.

EnCoRe was involved in the conference because its second Case Study is being carried out in partnership with the Oxford Radcliffe Biobank ([ORB](#)). One result from this case study is the second EnCoRe technical architecture that will be released in early 2011.

2nd IEEE International Conference on Cloud Computing Technology and Science (CloudCom 2010)

This conference is the most prestigious international conference in cloud computing, and this year was held at Indianapolis, Indiana from 30 November-3 December 2010. Cloud computing has become a powerful emerging research area, and one in which privacy and security issues are of paramount importance and need to be addressed in order for the cloud model to reach its full potential.

As part of the conference, a one-day workshop on Cloud Privacy, Security, Risk and Trust was held, in order to focus on these issues and how to address them. This was chaired by EnCoRe researcher Siani Pearson, and presentations were given by Siani on privacy, security and trust issues arising from cloud computing and how some mechanisms (including some EnCoRe-related mechanisms) may be used to address these. Another presentation was given by EnCoRe researcher Michael Goldsmith on the inadequacies of current risk controls for the cloud.

To carry on some of the thinking developed at this workshop, a book on privacy and security for cloud computing is planned to be published by Springer.

Further details about the conference and workshop, including recordings of presentations and slides, may be obtained via the conference [website](#).



The EnCoRe team wish you a Merry Christmas and a joyful (and privacy-friendly) New Year!



EnCoRe Publications

"Privacy and Informed Consent in Online Interactions: Evidence from expert focus groups"
E. A. Whitley and N. Kanellopoulou (To appear in Proceedings of the International Conference on Information Systems, 2010, St Louis, Missouri.)

This paper draws on evidence from a series of expert focus groups done within the context of the EnCoRe project to question the function of "informed consent" in online transactions.

Informed consent and related concepts have a key role in much privacy research and are an integral part of much data protection legislation. Four expert groups, with participants from civil society organizations, data protection professionals, public sector organizations and small/medium sized enterprises (SMEs) took part in the focus groups. This paper reports on the results from the focus groups in terms of a) privacy policies, b) control over the use of personal data, c) consent as a response to regulatory requirements and d) the nature of informed consent.

The paper is available for download [here](#).

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