

European Commission Consultation on the Legal Framework for the Fundamental Right to Protection of Personal Data

EnCoRe Project Response

*Submitted by EnCoRe researcher Dr Nadja Kanellopoulou
HeLEX Centre, University of Oxford*

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A Call for Better Privacy Paradigms

This response stems from work that is undertaken by EnCoRe*, a large, interdisciplinary initiative with academic and industrial partners in the UK designed to address emerging needs for privacy and consent solutions in the management of personal data. EnCoRe stands for 'Ensuring Consent and Revocation' and aims to 'make giving consent as reliable and easy as turning on a tap and revoking that consent as reliable and easy as turning it off again'. EnCoRe project partners are committed to the development of regulatory mechanisms and technological solutions that afford and maintain better individual control in the management of personal data, or else, 'user-centric control'.

This view is in line with increasing scholarly and expert support that meaningful privacy protections can contribute to solving current challenges in the governance of data protection. In existing liberal society, where commitment to the values of personal freedom and individual development is paramount, the use of informational technologies grows hand in hand with unease regarding misuse of personal information. At present people have no effective ways to control how their personal data are used, including their deletion, if requested, from databases. Third party access practices make such even harder. Calls for better privacy paradigms and frameworks that afford individual control in the management of personal information emerge as an essential aspect of maintaining trust in increasingly sophisticated technological and informational environments. The ways in which these capabilities and environments are regulated and used pose a series of challenges for the ways in which effective protection of personal data can be perceived, conceptualised, implemented and achieved.

Current Challenges

These challenges can be grouped in two broad ways, firstly, as challenges for personal control in that individuals have very little power over how their personal information is used, especially once it has been passed to a third party; and secondly in that, regulators are currently ill-equipped to monitor and protect against breaches of privacy.

These challenges emerge in a background of great changes in the field of privacy and data protection. For example, in the field of medical research, as data sharing practices increasingly diversify and expand across national borders, the need for commonly-based standards and provisions for effective sharing is an ongoing source of concern, especially for those who advocate greater uniformity with common overarching legal instruments to protect privacy in Europe. On one hand, there is a dearth of legal frameworks, professional guidelines and stakeholder guidance setting standards in the application of privacy and data protections across several jurisdictions in EU and elsewhere. On the other hand, existing international guidelines and non-binding treaties helpfully provide a baseline for general principles in the application of privacy protections but are not the best way to regulate emerging areas undergoing major changes such as data sharing in medical research. Similarly, the importance of non-professional bodies that can adapt quickly to new circumstances and developments and contribute to setting standards for good practice needs more effective streamlining than what is currently available.

These issues altogether form a core body of concern for efficient and lawful data sharing across Europe. In the area of medical research more specifically - where EnCoRe collaborators have an ongoing interest - these general issues are further complemented by the absence of legal provisions regarding the differences between information rights derived from personal data and possible information rights derived from tissue samples, a gap that greatly impacts on the effectiveness of research protections through privacy norms.

In a background of diverse norms, national standards and application across jurisdictions, the doctrines that underlie current privacy and data protection frameworks as a basis for a more uniform protection across Europe remain unclear. Systematic theoretical perspectives and practical solutions in privacy relationships that take into account the interests of all parties involved are lacking, chiefly as regards the importance of individual control in the regulation of relationships between data controllers and processors, and data subjects. Recent developments in human rights jurisprudence (e.g. European Court of Human Rights) in the area of privacy could help influence the development of new data protection frameworks and perspectives. This

involves a growing body of work in support of the significance of guarantees of individual privacy and personal autonomy in informational environments.

Alongside understanding the challenges of data protection in a global environment and the significance of user-centric and intuitive frameworks, lays the importance of coordinated and effective oversight. The power that national oversight bodies - often described as 'lacking teeth' - are given for effective compliance to privacy norms is a quintessential part of current attempts to build powerful safeguards for data protection and privacy. An example in this direction are the recent consultations of the UK Ministry of Justice about the new powers of the UK Information Commissioner to impose fines for serious breaches of the Data Protection Principles (up to £500k), and the introduction of custodial sentences for knowing/reckless misuse of personal data. Both consultations are part of efforts to ensure better privacy compliance in data protection.

Emerging Notions and Future Action

Coordinated effort is needed across Europe to develop ways to enhance current data protection frameworks. As part of such steps, research is needed to clarify the relevant privacy doctrines involved; identify and build legal, regulatory and technological solutions; and promote synergies across different disciplines and sectors. This view supports a strong commitment towards defining the conceptual characteristics of privacy in informational society and its legal implications, and towards developing a more intuitive and functional understanding of privacy in the maintenance of personal identity in modern society. To achieve this, more interdisciplinary and empirical research is needed in the study of privacy and consent in order to develop and implement robust privacy protections and solutions. Current examples of interdisciplinary and empirical research on privacy in the UK are projects such as EnCoRe, PVNets, VOME.

Emerging work in this direction should provide novel and workable ways to better understand what individual 'control' in the management of personal data is and optimal means to build mechanisms and robust solutions that guarantee it. These involve synergy between academia, regulation, industry as a necessary part of clarifying conceptual and legal aspects of privacy and its implementation as well as developing practical ways to achieve better levels of privacy for all stakeholders involved in the use of informational technologies. Possible avenues in achieving these goals are new ways for *rethinking privacy*, *enhancing consent*, and *building user-centric revocation* mechanisms.

In pursuing such goals, a theoretical clarification is needed to explain how the protection of privacy is an essential part for the realisation of personal autonomy and identity maintenance in

information society. At the same time, there is a need to conceptualise consent and what it involves as a bi-directional process, and not just a communication exercise. Consent does not involve a mere giving away information or materials about oneself but instead a continuing obligation of respect and compliance to one's wishes for the life of the use of one's data, alongside existing obligations of fair and lawful processing.

A practical way to enhance individual control according to this framework is to build robust methods for the revocation of consent in the management of personal data. Revocation of consent has not been developed so far in the study of privacy and could become a new form of meaningful control of personal data. The possibilities for revocation should range from developing conceptual paradigms, building and implementing legal frameworks, to designing and putting into practice technological applications and solutions.

In this submission, while seeking to make giving consent to the use, storage and sharing of personal information 'as rigorous, reliable and easy as turning on a tap', and revoking that consent 'as rigorous, reliable and easy as turning that tap off' the EnCore project aims to stir more international debate on these issues, interdisciplinary work and scrupulous thought in building meaningful legal and practical mechanisms for better individual control in the use and management of personal data. Such work can contribute meaningfully to current international debate about the protection of personal data in this consultation, with the ultimate aim to help build new better paradigms and support individual confidence in the digital economy to the benefit of all.

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