

# International Workshop on Post-Mortem Data Privacy

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## Summary

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The International Workshop on Post-Mortem Data Privacy was held in Paris on January 13th, 2017. It was organised by the COSTECH Research Unit of the University of Technology of Compiègne (UTC), and financed by the ENEID Research Project, in partnership with the Institute of Communication Sciences (ISCC) and the French national association of data protection officers (AFCDP). This document provides a quick summary of the discussions that were held during this workshop, and outlines proposals for further pluridisciplinary research in the field of post-mortem digital identity, privacy and law.

### The problem

There are more and more digital deaths. The Web is bound to become a graveyard sooner than later, with more profiles belonging to dead rather to live people. And as digital life becomes more and more intertwined with everyday “real life”, more and more personal data, some holding economic, social or even emotional value, are being orphaned by Internet users as they pass away. At the same time, new memorial practices are emerging on the web, especially on social networks. Mourners form communities around profiles that were either created by the deceased when they were alive, or created specially for the purpose of being a memorial by relatives and heirs. These new practices are often at odds with the terms of use of web services, if not with data protection and privacy law, as has been pointed out by research conducted by the ENEID Research Team.

Furthermore, web service providers, such as Facebook or Google, and data protection authorities, and also courts, are faced with an increase in complaints related to post-mortem personal data. They find themselves often legally ill-equipped to deal with such requests.

During the International Workshop on Post-Mortem Data Privacy, we looked from different angles, with jurists and social scientists, regulators and lawyers, at the intricacies of post-mortem personal data, which we defined as personal data<sup>1</sup> related to a deceased individual.

### Legal context

In the United States, the Uniform Fiduciary Access to Digital Assets Act (UFADAA) creates a harmonised framework regulating access to post-mortem personal data.

In Europe, however, the General Data Protection Regulation (GDPR), under recital 27, only applies to the personal data of living physical persons. But it does not preclude member states from adopting their own legislations regulating the use of post-mortem personal data. Such legislation is already in place in several member states, such as Bulgaria or France. Hungary is currently working on its own legislation, which should be adopted at the same time as the revision of its Privacy Act, in phase with the implementation of the GDPR.

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<sup>1</sup> We use the definition of personal data found in article 4 of the General Data Protection Regulation (2016/679/EU)

Each country having its own approach can lead to problems for web service providers, who need to have procedures in place that complies with each of them. Furthermore, the rules governing applicable law are different when it comes to personal data (related to a living person), or related to a dead person (post-mortem personal data). Yet discussions during the discussions, a path towards a solution may be found. First of all, both present regulators – from the French and the Hungarian data protection authority (DPA) – have stressed the need for a European discussion. It is thus likely that, in time, the Article 29 Working Party, soon to become the European Data Protection Board (EDPB), will issue an opinion on this topic, which can be used as a guideline by data controllers. But also, despite their differences, the French solution and the Hungarian solution to the problem have striking similarities despite having been developed independently from one another.

France's solution combines two elements: some of it is derived from case law, as was pointed out by Pierre-David Vignolle and Raphaël Dana's interventions, and some is based on a new provision, article 40-1, of the French Data Protection Act<sup>2</sup>, that was described in detail by Sophie Nerbonne of the French DPA. The combination of both legal sources create a situation where data subjects can define a will specifying the fate of their personal data after their death. If they decide not to do so, then their heirs, providing proof of their identity, may only ask for the digital profile of the deceased to be updated accordingly or to be deleted.

Hungary's solution will be based on a recommendation published recently by the Hungarian DPA, which was presented at the Workshop by its president, Attila Péterfalvi. Although the procedures it lays down are different, and many details also diverge, the general idea seems similar: either there is a will specifying what happens with post-mortem personal data, or heirs may only ask for the updating of profiles to take the death into account, or the deletion of processed personal data. Of course, even the latter rights will most likely be subject to specific rules and procedures, designated especially to ascertain the data subject's and to deal with conflicts between heirs on how to deal with post-mortem personal data.

These elements provide certain useful guidelines, even if, as pointed out by researchers of the ENEID Research Project, they do not give much room to evolutions on social media regarding the place and role of friends in the mourning process. Indeed, it is often the friends (or boyfriend/girlfriend) of the deceased who take on the task of maintaining memorials and updating their dead friend's profiles, which can of course lead to conflicts between friends and families.

### Philosophical questions

Beyond studying the social practices around digital mourning and making sense of complex rules governing post-mortem personal data, the International Workshop was an opportunity to show that there are many philosophical matters behind the technical aspects of post-mortem data privacy.

As shown by Lucien Castex, who used to take part in research conducted by the ENEID Research Team, post-mortem data privacy in France can be approached not only from the side of personal data legislation, but also succession and inheritance law, as well as contract law.

Edina Harbinja and Lilian Edwards also talked about how there is a question on whether post-mortem personal data should be seen as an asset linked to succession law, or as a value linked to the dignity of the law? The UFADAA, in the United States, clearly considers post-mortem personal data as assets, whereas Attila Péterfalvi mentioned the existence of a right of reverence in Hungary that can extend in some rare cases personal rights to after a data subject's death.

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2 Introduced by the Law for a Digital Republic (loi n° 2016-1321 du 7 octobre 2016 pour une République numérique)

Furthermore, do we protect the interests of the dead, assuming he or she had reasonable expectancies of post-mortem privacy in his or her life, that we have a duty to honour, especially in the frame of the trust relation between a web service provider and its users? Should, therefore, the autonomy of informational self-determination extend into death in the same way that economic autonomy is extended through freedom of testation? Or should post-mortem personal data be regulated in a way that serves the moral and economic interests of the living? And how does one take into account social or even collective interests, such as family memories, or the need to preserve historical archives? And should researchers be required to demonstrate a legitimate purpose before they can exploit post-mortem personal data for scientific research?

These questions were not answered during the International Workshop on Post-Mortem Data Privacy, but they were nonetheless discussed and may provide invaluable elements to be kept in mind for future research.

### Conclusion

The International Workshop on Post-Mortem Data Privacy showed that the topic goes further already complex technical and legal matters. A lot of social and even philosophical issues are raised that remain without definitive answers to this day. However, the International Workshop on Post-Mortem Data Privacy, of which the documents are published on this website, gave us the opportunity to share intellectual and legal tools we need to go further into the analysis of these complex issues.