

When professor Christine Van Broeckhoven came to a breakthrough in genetic research, this was mainly the result of the consultation of various archives, obviously combined with shared insights and persistent laboratory research. But without the files of the registry office, without the medical files of numerous mental healthcare patients, there would not have been a solid scientific story. All this was possible thanks to a unique combination of government databases, health data and a GP's hypothesis that Alzheimer's disease could be traced back to a family, to genetics. Excellent scientific work, and **a piece of good news I absolutely wanted to start with.**

This research would never have led to the same result if Professor Van Broeckhoven had not been able to look through archives, data collections, with the help of researchers trained in archive research and personal data management. One of those researchers came knocking on the Belgian Privacy Commission's door. He was familiar with privacy legislation and knew that it either requires explicit consent of anyone whose personal data are involved in a study, or, if this proves impossible or too difficult, the Privacy Commission's explicit prior authorisation.

Some municipal administrations were not so keen on opening up their registries to this kind of young researchers – at the time professor Van Broeckhoven did not have the reputation she has now. Administrations wanted to know whether they were authorised to open population registries to such research, and they wanted the Privacy Commission to tell them this.

Because of all sorts of legal battles, slow administrative procedures and an all too enthusiastic protection of other individuals' personal data, we as Privacy Commission failed – you have read correctly – failed to respond positively. **Bad news.** Fortunately, professor Van Broeckhoven and her team had drawn a clear map of the individuals whose DNA profiles had to be examined, and of their relatives. All individuals concerned gave their explicit consent to the study. The results were almost public when we, as Privacy Commission, finally also granted authorisation. But by then reality had long gotten the better of us.

This is an illustration of how difficult relationships sometimes are. How much researchers on the one hand and privacy authorities on the other get cold feet. And archive keepers, as owners of files, are often uncomfortable in between.

Nevertheless it is essential that the world of privacy protection and that of research, with archives as an essential component, set up a dialogue resulting in efficient and privacy-friendly cooperation.

But expectations may not be so good. **More bad news.** A new European data protection regulation is coming, including a terrible monster for archivists, at least that is what I fear: the right to be forgotten, *le droit à l'oubli*. What this means concretely is not just an enigma, but also a real nightmare. The right to be forgotten is said to imply in general that individuals have the right to erase documents or other elements from their personal life.

Yet there is more good news as well. The same European regulation has clearly created an exceptional position for scientific, statistical and historical research. It has explicitly

recognized the value and the social importance of keeping and processing personal data for these purposes, creating flexibility for scientific processing operations.

This is a clearer elaboration of the "obligation of restriction", the principle of proportionality, imposing the retention of personal data no longer than necessary for the achievement of the purposes the data were obtained for or further processed for, and in a form enabling identification of the data subject. Professional archiving is an absolutely legal implementation of this obligation of restriction.

It is important that this way of working can be further developed in the European regulation, since it is only a principle. Its elaboration still has to take place and I hope that you will rise to the occasion, with me at your side. Some of my privacy colleagues may blame me for that, **which is bad news.**

In my opinion, the European regulation supposes that privacy is superior to many other values and fundamental rights. But I beg to differ. As far as I'm concerned, the protection of privacy, of dignity, is an important fundamental right, but it is only a derivative of our universal right to a valuable existence in society. With the largest possible autonomy and freedom. To me that also means that I can develop my talents, that I can liberate myself from the limitations of our earthly fate. I know that research, science, and therefore also archives, contribute to that. I do not understand why, but I feel more human, more of a *homo universalis*, when I can read, discuss and enjoy how and why and by what this world was created as it really is. And in this quest of truth, reconstruction and reconciliation, I want my personal data and yours to be treated properly, respectfully.

Human rights activists will be at your side as well, because the right to privacy also implies (although this is sometimes forgotten) that individuals are granted the full right to know how others, organisations, governments, private institutions deal with their personal data. Based on current and future privacy law you have a right to know what others know, keep, process about you. You as archivists have the mission to collect, manage, structure these data and open them up to the public, to that individual citizen who wants to know what others have done with his personal data.

And we all know the most famous examples. Our German archivists and their colleagues from Middle Europe opened the Stasi files and other archives left by communist regimes, which deserves our attention. Especially if you consider how other, more post-fascist regimes, are unable to come to terms with their past. Archives are the treasury of democracy. Archives are a necessary condition to fully exercise fundamental rights, including the right to privacy protection.

I would like to conclude with some good news. Thanks to the experience we gained by working with professor Van Broeckhoven, Mr Karel Velle and with Mr Rudi Van Doorslaer of the Centre for historical research and documentation on War and contemporary Society, we, as a privacy authority, have made sure our windows and doors are wide open to a balanced vision and cooperation. Your willingness to discuss privacy-related aspects during your annual conference demonstrates that you are open to cooperation too. **And that is the very best news.**