11 Dealing with deceased study participants

In a few cases, the trustee is informed that study participants have died during or after the study. The TTP assumes that the death of a study participant does not result in any changes and that no additional measures need to be taken. Any withdrawals by relatives of the deceased are implemented in the same way as during the participant's lifetime. Is this correct and legally permissible?

The applicability of the GDPR to the information of a person ends with the death of that person.[38] Recital 27 of the GDPR explicitly states:

> *"This Regulation does not apply to the personal data of deceased persons. Member States may provide for rules regarding the processing of personal data of deceased persons."*

The opening clause contained in the second sentence was only used in Germany, as far as can be seen, for the area-specific data protection law in accordance with § 35 SGB I in conjunction with Sections 67–120 SGB X. Section 35 para. 5 SGB I stipulates that the processing of social data is permissible if the provisions of Chapter 2 of SGB X are observed. In addition, however, the processing of the data is always permissible if no legitimate interests of the

38 *Karg*, in: Simitis/Hornung/Spiecker gen. Döhmann, Datenschutzrecht, DSGVO Art. 4 Nr. 1 Rn. 39.

deceased or his/her relatives are impaired by the processing. Social data are personal data which are processed by a body mentioned in §§ 35 SGB I with regard to its duties under the SGB (§ 67 para. 2 s. 1 SGB X).

The bodies mentioned in § 35 SGB I essentially include health insurance funds and associations of GKV-accredited physicians, but not health care providers, hospitals and research institutions. Only in the exceptional case that a research institution conducts research for a body named in § 35 SGB I and receives social data for this purpose, could the applicability of §§ 67–120 SGB X be considered according to § 35 Para. 5 SGB I.

As a rule, however, the basic rule will remain that the applicability of data protection law ends with the death of a person. However, this does not mean that all legal protection is no longer applicable upon death. In the context of the constitutionally guaranteed fundamental rights, one would no longer speak of a right to informational self-determination, but of a right to post-mortem personal rights. According to German constitutional law, the protection of post-mortem personal rights is based on the protection of human dignity, which extends beyond death. However, this protection does not extend to the general freedom of action under Article 2 para. 1 GG, which can only be exercised by the living.[39]

In its judgment of 12 July 2018, the Federal High Court (Bundesgerichtshof—BGH) ruled that, in the event of the death of the account holder of a social network, the contract of use is in principle transferred to the account holder's heirs in accordance with Section 1922 BGB.[40] Access to the user account and the communication contents contained therein are not opposed by the deceased's post-mortem personal rights, telecommunications secrecy or data protection law. However, the BGH left open the question as to whether a relative or heir may also assert data subjects' rights under data protection law. In the opinion expressed here, this is not the case. Only the data subject is entitled to data subject rights. Art. 4 No. 1 first half sentence GDPR defines the data subject as the identified person to which the data relate. They therefore constitute highly individual rights. The BGH concludes an authorisation to the access to a Facebook account by heirs not on basis of concerning rights after the GDPR, but alone from the fact that contracts, which a deceased had concluded, pass on to the heirs and the latter thus themselves become contracting partners. Aspects of data protection law are only examined by the BGH to the extent that it is established that data protection law does not preclude access by heirs.[41]

The BGH stated that in the event of an encroachment on the immaterial components of the post-mortem personal right, the closest relatives of the deceased

39 *Karg*, in: Simitis/Hornung/Spiecker gen. Döhmann, Datenschutzrecht, DSGVO Art. 4 Nr. 1 Rn. 39.
40 ECLI:DE:BGH:2018:120718UIIIZR183.17.0.
41 ECLI:DE:BGH:2018:120718UIIIZR183.17.0, Rn. 64.

may assert defensive rights in the form of injunctive relief and revocation claims.[42] However, if data continues to be processed for purposes for which the deceased had given his effective consent during his lifetime, no averting interference with post-mortem personal rights can be foreseen.

From a legal perspective it is therefore not mandatory to grant a right of withdrawal to the relatives. However, there should be no major obstacles to such a procedure.

42 ECLI:DE:BGH:2018:120718UIIIZR183.17.0, Rn. 53; BGH Urt. v. 6.12.2005 — VI ZR 265/04, BeckRS 2006, 808.