



Avoidance of DCO-cases

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Case 1: A patient, dies in a hospital shortly after diagnosis. The patient has not been informed about cancer registration.

In this case we assume that it should be possible to inform relatives of the patient.

If the doctor informs the relatives of the deceased patient about the cancer registration and they don't object to the registration of the data, it is possible to register data and to ask for more data.

If nobody was informed about cancer registration - neither the patient nor someone of his family - it is not possible to obtain additional information on a post-mortem case like this. In these cases the registry can only register the data it receives through matching with the FSO data (Cause of Death Statistics).

Who has to be informed?

The CRA only defines that the patient or his representative must be informed and by whom - nothing more.

All other questions in this context are questions "within the hospital" - and these questions are consequently to be answered by the hospital's legal service.

In other words, information on data that is (still) in the hospital (information that has not yet been reported to the registers) is governed by the law which is applicable to the respective hospital (this can be the Data Protection Act or cantonal laws or regulations). For questions concerning information or representation of cancer patients the same rules apply as apply elsewhere in the hospital (for information, representation). This is neither a matter for the registries nor for the NACR or the FOPH.

Case 2: A cancer registry becomes aware of a DCO-case through Article 10 CRO (Cause of Death Statistics), the cancer registry requests for data, no information date is found.

Case 3: A cancer registry becomes aware of a DCO-case through Article 11 CRO (Medical Statistics of Hospitals), the cancer registry requests for data, patient already died, no information date is found.

Case 4: A cancer registry becomes aware of a DCO-case through Article 12 CRO (screening programmes), the cancer registry requests for data, patient already died, no information date is found.

When the CR is informed about a case through the Cause of Death Statistics, the Medical Statistics of Hospitals or a screening programme and the patient already died, we anticipate that it is no longer possible to provide information to the family of the patient about cancer registration in terms of time (the person is no longer alive, finding relatives and informing them hardly seems realistic).

In general we assume that doctors, who are obliged to report, fulfil their duty to inform the patient. Meaning, we assume that these patient were informed, but the doctor forgot to report/didn't fulfil his reporting obligation. Therefore the cancer registry is allowed to ask for and register further data.

In view of the upcoming revision of the CRO, this interpretation seems justifiable to us.

Case 5: A cancer registry becomes aware of a DCO-case through Article 11 CRO (Medical Statistics of Hospitals), the cancer registry requests for data, patient is still alive, no information date available.

Case 6: A cancer registry becomes aware of a DCO-case through Article 12 CRO (screening programmes), the cancer registry requests for data, patient is still alive, no information date available.

In these two cases, the CR must try to find out the patient information date. In cantons that accept the exceptional regulation, the exceptional regulation, a temporary and provisionally limited measure until the end of 2021, can be applied:

- 1) The cancer registry has verified at least two unsuccessful requests for the date of the patient information from the person or organisation responsible for reporting;
- 2) 2) Six months have passed since the diagnosis date and no objection to the registration has been submitted.

Subsequently, the cancer registry can register data of cases 5 and 6 even without a known patient information date.

In cantons that do not apply the exceptional regulation, data concerning case 5 and 6 can only be registered in case of a known patient information date.