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Access to Deceased Records Policy

Summary

- *Prepared by* — Dr David Smith (Data Protection Officer)
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Introduction

GMC Guidance:

https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/confidentiality/managing-and-protecting-personal-information#paragraph-134

The records of deceased patients remain confidential. The duty of medical confidentiality extends beyond the death of a patient. The Corner Surgery (hereby referred to as "we", "us" or "the practice") will respect this.

The Information Tribunal in England and Wales has also held that a duty of confidence attaches to the medical records of the deceased under *section 41 of the Freedom of Information Act*.

Where the practice still holds the deceased's record, the practice is obliged to respond to a request under the *Access to Health Records Act 1990*.

In 2022, the GP Contract was updated such that if somebody wishes to make an Access to Health Records request for a deceased's record, this should be made to the last registered GP practice. That practice should, if required, request a copy of any physical record previously sent to Primary Care Support England (PCSE).

If the last registered GP practice is closed or not known, or the deceased was not registered with a GP practice at the time of death, the applicant will need to contact PCSE:

https://pcse.england.nhs.uk/services/medical-records/accessing-medical-records/access-to-medical-records-and-patient-details/access-to-health-records-ahr/

Access to such records, or disclosure of information from those records, is only permissible under certain strict circumstances. All such access or disclosures apply to the records of *individual patients* and the individual circumstances surrounding such a request for information.

Statutory Disclosures

There are circumstances in which the practice *must* disclose *relevant* information about a patient who has died. For example:

- When disclosure is mandated by law (e.g. Public Health England) or a court order
    - We do not need to redact third party references when disclosing the records under a court order
- To help a coroner, or other similar officer, with an inquest or fatal accident inquiry – sometimes the police approach GP surgeries requesting records on behalf of the coroner
    - We do not need to redact third party references when disclosing the records to the police for this purpose
- On death certificates
- When a person has a right of access to records under the *Access to Health Records Act 1990*, unless an exemption applies
- When disclosure is necessary to meet a *statutory* duty of candour.

There are circumstances when the practice *could* disclose *relevant* information about a patient who has died. For example:

- The disclosure is permitted or has been approved under a statutory process that sets aside the common law duty of confidentiality, unless we know the patient has objected
- When disclosure is justified in the public interest to protect others from a risk of death or serious harm
- For public health protection or improvement, in which case the information should be anonymised, unless that would defeat the purpose – we would expect such disclosures to be authorised under *regulation 3/5 of the Health Service (Control of Patient Information) Regulations 2002*
- When a parent asks for information about the circumstances and causes of a child's death
- When someone close to an adult patient asks for information about the circumstances of that patient's death, and we have no reason to believe the patient would have objected to such a disclosure
- When disclosure is necessary to meet a *professional* duty of candour
- When it is necessary to support the reporting or investigation of adverse incidents, or complaints, for local clinical audit, or for clinical outcome review programmes.

While there is no legal entitlement other than the limited circumstances covered under the Access to Health Records legislation, health professionals have always had discretion to disclose information to a deceased person's relatives or others when there is a clear justification. Disclosure in certain cases is likely to be what the deceased person would have wanted and may also be in the interests of justice.

'Disclosures in the absence of a statutory basis should be in the public interest, be proportionate, and judged on a case-by-case basis. The public good that would be served by disclosure must outweigh both the obligation of confidentiality owed to the deceased individual, any other individuals referenced in a record, and the overall importance placed in the health service providing a confidential service.' (Dept. of Health)

Consideration should be given as to whether such a request would be better directed to PCSE.

Before any disclosure of information, due consideration should be given to:

- Whether disclosing information is likely to cause distress to, or be of benefit to, the patient's partner or family
- Whether the disclosure will also disclose information about the patient's family or anyone else
- Whether the information is already public knowledge or can be anonymised or de-identified
- The purpose of the disclosure (if known, or volunteered)
- Whether the patient had objected to (or 'opted out') of uses of their confidential information whilst alive, such as a Type 1 or Type 2 opt-out, or their National Data Opt Out status was set to 'do not share'.

"Section 251" Approvals

Health Service (Control of Patient Information) Regulations 2002

Provision is made in these regulations for access to information about deceased patients. However, such requests must be justified, proportionate, and relevant. For research purposes, the research protocol and Research Ethics Committee approval must be viewed. Section 251 approvals are *permissive* – the practice is under no obligation to comply with any such request.

Consideration should be given as to whether such a request would be better directed to PCSE.

The General Data Protection Regulation (GDPR)

The GDPR only applies to information that relates to an identifiable living individual. Information relating to a deceased person does not constitute personal data and therefore, is not subject to the GDPR, as explained in *Recital 27*:

'*This regulation does not apply to the personal data of deceased persons. Member States may provide rules regarding the processing of personal data of deceased persons.'*

Access to Health Records Act

The *Access to Health Records Act 1990* only covers manual health records *made since 1 November 1991*. Access must also be given to information recorded before this date if this is necessary to make any later part of the records intelligible. The Act provides a small cohort of people with a statutory right of to apply for access to information contained within a deceased person's health record.

For deceased persons, applications are made under sections of the *Access to Health Records Act 1990* that have been retained. These sections provide the right of access to the health records of deceased individuals for:

(i) Their personal representative; and/or
(ii) Others having a claim under the estate of the deceased.

As a result of *[AB v CD [2020] EWHC 691 (Fam)]* it is necessary to consider access requests by these two groups separately.

'The personal representative is the only person who has an unqualified right of access to a deceased patient's record and need give no reason for applying for access to a record. Individuals other than the personal representative have a legal right of access under the Act only where they can establish a claim arising from a patient's death.' (Dept of Health)

Personal Representatives

A *personal representative* is the person, or it may be more than one person, who is legally entitled to administer the estate of the person who has died. The term 'personal representatives', sometimes abbreviated to PR, is used because it includes both executors (for where there is a Will) and administrators (for where there is no Will, or the Will did not appoint executors). For most tasks involving dealing with an estate, the tasks that executors and administrators have to carry out are the same. Whenever we refer to personal representatives the content applies to both groups of people. Any references to executor or administrator mean the information applies only to that specific role. A person who is apparently next of kin is not automatically a personal representative.

Personal representatives do not need to provide a reason for seeking access to the record, although the record-holder must be able to establish that the requestor is indeed the personal representative. They must also provide evidence of their identity. To maintain patient confidentiality as far as possible, the British Medical Association advises that when personal representatives request access, it is appropriate to enquire why access is required and whether the request can be satisfied by providing access only to information that is relevant for the purpose. Ultimately, if the personal representative chooses not to provide a reason for access and insists on access to the full record, doctors must comply with these requests to comply with the law. A personal representative as the right to apply for access to the entire records dating from 1st November 1991, regardless of the purpose.

Others having a claim under the estate of the deceased

Those who do not have the status of personal representative but have a claim arising out of the death of the patient have a right of access only to information which is directly relevant to the claim. Under *section 5(4) of the Access to Health Records Act*, no information which is not directly relevant to a claim should be disclosed to a person who may have a claim arising out of the patient's death. Such an individual can only see records on a "need to know" basis.

The effect of this is that those requesting a deceased person's records should be asked to confirm the nature of the claim they say they may have arising out of the person's death. If the person requesting the records was not the deceased's spouse or parent (where the deceased was unmarried) and if they were not a dependant of the deceased, it is unlikely that they will have a claim arising out of the death. It is important to recognise that a Power of Attorney expires with the deceased. It is the executor that has control of the affairs of the deceased and a former Power of Attorney in the patient's life does not automatically have a valid claim.

Record holders must satisfy themselves as to the identity of applicants who should provide as much information to identify themselves as possible. Where an application is being made on the basis of a claim arising from the deceased's death, applicants must provide

evidence to support their claim. The decision as to whether a claim actually exists lies with the record holder. In cases where it is not clear whether a claim arises the record holder should seek legal advice.

Whether to a personal representative or someone else with a claim, access should not be given if:

- The appropriate health professional is of the view that this information is likely to cause serious harm to the physical or mental health of any individual; or
- The records contain information relating to or provided by an individual other than the patient or a health professional, who could be identified from that information (unless that individual has consented or can be anonymised); or
- The records contain a note made at the request of the patient before his/her death that he/she did not wish access to be given on application
    - If while still alive, the patient asks for information about his/her right to restrict access after death, this should be provided together with an opportunity to express this wish in the notes; or
- The holder is of the opinion that the deceased person gave information or underwent investigations with the expectation that the information would not be disclosed to the applicant.

We are not obliged to identify places where information has been removed where it is not obvious, or to offer explanations for any redaction. If we are asked why a record has been redacted, we can simply state that it has been done to remove third party information.

It is often advisable to contact a personal representative to seek their opinion(s) on whether such disclosure is appropriate, and to seek the permission of the person seeking the records to contact a personal representative. Whilst this is good practice, the consent of the personal representative is not always a requirement for disclosure.

Consulting With a Health Processional

Access to the health records of deceased patients is a complex matter outwith the *Data Protection Act/ General Data Protection Regulation 2018*. All applications should be passed to the Information Governance Lead, Dr David Smith, who will liaise with the other partners and administrative staff, as appropriate, in order to determine if and how to respond to the request.

Fees for Access to Deceased Patients' Health Records

The Access to Health Records Act was amended by the Data Protection Act 2018:

'3(4) No fee shall be required for giving access under subsection (2) above'

Accordingly, it is no longer possible to charge for access to medical records of deceased patients under the Access to Health Records Act.

Timescale for Responding Under the Access to Health Records Act

Once the surgery is satisfied that the person requesting the information is entitled to it, access must then be given within specified time limits.

Section 3(5) of the Access to Health Records Act contains the relevant provisions:

'(5) For the purposes of subsection (2) above the requisite period is—

(a) where the application relates to a record, or part of a record, none of which was made before the beginning of the period of 40 days immediately preceding the date of the application, the period of 21 days beginning with that date;

(b) in any other case, the period of 40 days beginning with that date.

(6) Where—

(a) an application under subsection (1) above does not contain sufficient information to enable the holder of the record to identify the patient or to satisfy himself that the applicant is entitled to make the application; and

(b) within the period of 14 days beginning with the date of the application, the holder of the record requests the applicant to furnish him with such further information as he may reasonably require for that purpose,

subsection (5) above shall have effect as if for any reference to that date there were substituted a reference to the date on which that further information is so furnished.'

Dr David Smith