**PCIG Consulting Template**

**ACCESS TO DECEASED PERSONS RECORDS**

**Version: 3.0**

**Date: 6 April 2021**

**This template is for use by Practices to Comply with the UK GDPR requirement to have a policy regarding processing of patient data. The template is Generic in design as PCIG Consulting have clients across the UK, local sharing arrangements and area specific sharing or processing will need to be added by the practice.**

**Change Control**

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| **Version** | **To** | **Change** | **Date** |
| **0** | **1** | **First Draft** | **13 August 2019** |
| **1** | **2** | **Updated in Review** | **1 May 2020** |
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[Practice Name]

**Access to Deceased Persons Records Policy**

**Document History**

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| Document Reference: | … |
| Document Purpose: | This policy sets out the [practice name] expectations for the Practice employees who manage access to records for the surgery. |
| Date Approved: | 6 April 2021 |
| Version Number: | 3.0 |
| Status: | FINAL |
| Next Revision Due: | April 2022 |
| Developed by: | Paul Couldrey – IG Consultant |
| Policy Sponsor: | Practice Manager |
| Target Audience: | This policy applies to any person directly employed, contracted, working on behalf of the Practice or volunteering with the Practice. |
| Associated Documents: | All Information Governance Policies and the Information Governance Toolkit, and Data Security and Protections Toolkit 2020 |

Access to a deceased persons information is not dealt with under GDPR or the Data Protection Act 2018, as these laws refer to data about living individuals.  As such any request for a deceased persons record is NOT a SAR as deceased persons are not covered by GDPR or any Data Protection law past or present.

The Access to Health Records Act (AHRA) 1990 provides certain individuals with a right of access to the health records of a deceased individual, interestingly the act only covers records created after 01/11/1991.

There are two distinct groups who have rights of access to information within the deceased’s record: –

1. personal representatives; (A personal representative is the executor or administrator of the deceased person’s estate.)  If your requestor is a personal representative move to the bottom of this email:-
2. and – anyone who may have a claim arising out of a patient’s death.

**A Personal Having a Claim arising from the death:-**

There is still an ethical obligation to respect a patient’s confidentiality beyond death, Individuals who may gain access to a deceased persons records are defined under Section 3(1)(f) of the Access to Health Records Act 1990 as, ‘the patient’s personal representative and any person who may have a claim arising out of the patient’s death’.  The BMA recently gave advise that in its opinion “BMA’s opinion that 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 any other person who may have a claim arising out of the patient’s death.”

Whilst after death you may have returned paper copies of records to PCSE, any access to electronic records should still be managed by the practice in accordance with AHRA, and NO FEE can be charged for providing copies.

You can refuse the request if in the view of your GP Section 5 below applies.

Cases where right of access may be partially excluded.

(1)          Access shall not be given under section 3(2) above to any part of a health record—

(a)which, in the opinion of the holder of the record, would disclose—

(i)            information likely to cause serious harm to the physical or mental health of any individual

(ii)           information identifies a third party without that person’s consent unless that person is a health professional who has cared for the patient

(iii)          Information that in life the patient asked to be kept confidential.

This includes the harm to the deceased persons and the requestor -so really, it’s up to the Dr to either uphold patient confidence after death based on the fact disclosure of the records would cause harm or release the data.  The GP should balance the benefit gained by disclosure to the requestor (such as family asking about cause of death or last illness) against the duty of confidence owed to the deceased, a good example might be if my son asked my GP about my hereditary Muscular Dystrophy after I died, if would be right to balance for disclosure as this is probably what I would have expected and wanted in life and be in the interest of my family.

I would check if requestor had a POA or is named a NOK in the first instance though.

If you believe the requestor has a claim arising from the  death - The basic rule is that you should release minimal information to satisfy the claim, and check that the Dr would be happy with the requestor receiving this data, and if this balances with the rights of confidence.

**Personal Representatives**

A personal representative is the executor or administrator of the deceased person’s estate.  A High Court judgment in 2020 held that a personal representative does not need to have a claim arising out of the death to access the deceased’s medical record and this right of access extends to all information within the record with limited exceptions (listed below.  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.

The legal rights of personal representatives to access the medical records of deceased patients are set out above. The legislation does not mean, however, that doctors are prevented from adopting an ethical approach to handling requests from personal representatives so that a balance can be achieved between the duty of confidentiality to the deceased and compliance with the legal duty to provide access.

In order to maintain patient confidentiality as far as possible, the BMA 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 which 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. 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 (as above).

**Redactions**

Information requested by personal representatives or others with a claim arising out of the death, should not be disclosed if:

* it identifies a third party without that person’s consent unless that person is a health professional who has cared for the patient; or
* in the opinion of the relevant health professional, it is likely to cause serious harm to a third party’s physical or mental health; or
* the patient gave it in the expectation that it would not be disclosed to the particular individual making the application; or
* it is the result of a particular examination or investigation which the patient consented to in the expectation that it would not subsequently be disclosed; or
* the record includes a note, made at the patient’s request, that the patient did not wish access to be given.

Full statutory explanation is below: -

*Deceased Patients’ Health Records*

*Access to deceased patients’ health records*

*33. The Access to Health Records Act 1990 (AHRA) 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, paragraphs 37 – 42 provide more detail.*

*34. There may be circumstances where individuals who do not have a statutory right of access under AHRA request access to a deceased patient’s record. Current legal advice is that the Courts would accept that confidentiality obligations owed by health professionals continue after death. The Department of Health, General Medical Council and other clinical professional bodies have long accepted that the duty of confidentiality continues beyond death and this is reflected in the guidance they produce.*

*35. In these circumstances the general rules that apply to the disclosure of confidential patient information should have effect to determine whether a disclosure is appropriate and lawful. Requests should be considered on a case-by-case basis and not simply rejected. Paragraphs 43 - 48 provide more detail on the considerations that apply where there is no statutory right of access.*

*36. There are also a range of public bodies that have lawful authority to require the disclosure of health information. These include the Courts, legally constituted Public Inquiries and various Regulators and Commissions e.g. the Audit Commission and the Care Quality Commission. 2 In these cases the common law obligation to confidentiality is overridden.*

*Access to Health Records Act 1990*

*37. The Access to Health Records Act (AHRA) 1990 provides certain individuals with a right of access to the health records of a deceased individual. These individuals are defined under Section 3(1)(f) of that Act as, ‘the patient’s personal representative and any person who may have a claim arising out of the patient’s death’. A personal representative is the executor or administrator of the deceased person’s estate.*

*38. 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.*

*39. There is less clarity regarding which individuals may have a claim arising out of the patient’s death. Whilst this is accepted to encompass those with a financial claim, determining who these individuals are and whether there are any other types of claim is not straightforward. 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.*

*40. 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. Personal representatives will also need to provide evidence of identity.*

*Applying for access under AHRA*

*41. A request for access should be made in writing to the record holder ensuring that it contains sufficient information to enable the correct records to be identified. Applicants may wish to specify particular dates or parts of records which they wish to access. This may help reduce the fee that is payable for copies provided. The request should also give details of the applicant’s right to access the records.*

*42. Once the data controller has the relevant information and fee, they should comply with the request promptly and within 21 days where the record has been added to in the last 40 days, and within 40 days otherwise.*

*Disclosure in the absence of a statutory basis*

*43. 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. Key issues for consideration include any preference expressed by the deceased prior to death, the distress or detriment that any living individual might suffer following the disclosure, and any loss of privacy that might result and the impact upon the reputation of the deceased. The views of surviving family and the length of time after death are also important considerations. The obligation of confidentiality to the deceased is likely to be less than that owed to living patients and will diminish over time.*

*44. Another important consideration is the extent of the disclosure. Disclosing a complete health record is likely to require a stronger justification than a partial disclosure of information abstracted from the record. If the point of interest is the latest clinical episode or cause of death, then disclosure, where this is judged appropriate, should be limited to the pertinent details.*

*45. This guidance is not intended to support or facilitate open access to the health records of the deceased. Individual(s) requesting access to deceased patient health information should be able to demonstrate a legitimate purpose, generally a strong public interest justification and in many cases a legitimate relationship with the deceased patient. On making a request for information, the requestor should be asked to provide authenticating details to prove their identity and their relationship with the deceased individual. They should also provide a reason for the request and where possible, specify the parts of the deceased health record they require.*

*46. Relatives, friends and carers may have a range of important reasons for requesting information about deceased patients. For example, helping a relative understand the cause of death and actions taken to ease suffering of the patient at the time may help aid the bereavement process, or providing living relatives with genetic information about a hereditary condition may improve health outcomes for the surviving relatives of the deceased.*

*47. In some cases the decision about disclosure may not be simple or straightforward and a senior lead on patient confidentiality, for example the organisation’s Caldicott Guardian or Information Governance lead, should be consulted. In the most complex cases it may be necessary to seek advice from lawyers.*

*48. A further range of issues and specific examples of circumstances where disclosure of information about deceased patients may be justifiable are considered in the ‘Frequently asked Questions’ provided in Appendix 2.*

*Fees for access to deceased patients’ health records*

*49. The fee structure under the AHRA is:*

*• Records held manually - where an applicant is permitted to view a record which is held manually and has been added to in the forty days preceding the application, access is free of charge.*

*• Records held wholly or partially on computer - where an applicant is permitted to view a record which is held wholly or partially on computer is free also • Hard copies of information - If an applicant wishes to obtain a copy of the record, they may be charged a fee.*

*50. Where health information is to be disclosed for the deceased in the absence of a statutory basis, any fees charged should be reasonable and proportionate to cover the cost of satisfying a request. It is recommended NHS organisations follow the fees structure established for the AHRA above.*

*Exemptions to disclosures of information relating to deceased patients*

*51. If the deceased person had indicated that they did not wish information to be disclosed, or the record contains information that the deceased person expected to remain confidential, then it should remain so unless there is an overriding public interest in disclosing.*

*52. In addition, the record holder has the right to deny or restrict access to the record if it is felt that:*

*• disclosure would cause serious harm to the physical or mental health of any other person;*

*• or would identify a third person, who has not consented to the release of that information.*