Disclosure of primary care records under the Access to Health Records Act 1990 (AHRA): Guidance

Audience: Primary Care Support England

July 2022

Updated guidance on the disclosure of primary care records under the Access to Health Records Act 1990. This guidance has been produced taking into consideration contemporary legal advice and complements the NHSE procedure for managing personal data requests.

1 There are two distinct categories of individuals who have rights of access to information held about a deceased patient in a primary care record:

- personal representatives; and
- anyone who may have a claim arising out of a patient's death.

2 NHS England will act as a record holder under the AHRA for primary care records only relating to deceased patients that were not registered with a GP practice at the time of death and the deceased patient's last registered GP practice has closed. In these limited circumstances, requests for access to these records are processed by Primary Care Support England (PCSE) on behalf of NHS England.

3 Where PCSE receives a request for access to records relating to a deceased patient who was registered with a GP practice at the time of death, Applicants will be referred to the practice at which the deceased individual was registered.

4 If the last GP practice is not known by the Applicant, NHSE will ask PCSE to undertake a GP registration history search, to enable NHSE to inform the Applicant. Where the practice no longer exists and the relevant primary care healthcare professional is not available, PCSE will process the request.

5 The Applicant should provide a signed authority for the application setting out whether they are the personal representative or, if not, state the basis under which their application is made e.g. they are the parent, sibling, etc. of the deceased and have a claim as a dependent under the Fatal Accidents Act 1976.

6 If a solicitor is acting on a requester's behalf, it is the solicitor's responsibility to verify that the requester is the legitimate personal representative of the deceased or has a legitimate claim arising from the patient's death. The record holder can accept the solicitor's statement that they have done the necessary checks, provided that they submit it to the record holder in writing by letter or email.

Requests from Personal Representatives

7 A personal representative, such as the person holding probate, can request access to a record under the Access to Health Records Act 1990.

8 Case law means that generally the information requested should be provided. The record holder should however take into account any wishes expressed by the deceased individual. For example, if they explicitly stated they do not want the personal representative to have access. In this circumstance, the record holder would usually respect the wishes made by the deceased individual, unless there was a valid reason not to.

9 Third party information must be removed as per section 13.

Requests from Applicants who may have a claim arising out of a patient's death

10 For requests from Applicants who may have a claim arising out of a patient's death, the Applicant should provide an outline of the nature of the claim.

11 PCSE will retrieve the relevant record and provide it to a clinician for them to identify the parts of the record to be disclosed in response to the application in accordance with section 5(4) of the Access to Health records 1990: *"…access shall not be given …to any part of the record which, in the opinion of the holder of the record, would disclose information which is not relevant to any claim which may arise out of the patient's death".*

12 The steps for collating the parts of the record to be disclosed are as follows:

i. identify information that is relevant to the claim based on the outline provided by the Applicant;

The starting position is that all records may be relevant to claim/potential claim investigations. Investigation of a claim will include the circumstances of the incident *and* an assessment of the impact of any harm which will inform the value of any potential compensation.

For the liability aspects of investigations, the records in or around the time of the patient's death and/or the incident which may have caused the death will be relevant.

For the parts of the investigation relating to the assessment of damages any records may be relevant to the claim. Records that *may* be relevant include patient's life choices (for example smoking or alcohol consumption) and their general medical history (for example weight, diabetes, previous illnesses or general physical condition). Whilst such records may not be relevant to the incident relating to a potential claim, they could be information that will assist the legal representatives to assess life expectancy and the potential damages.

For damages claims, unless the records meet the criteria set out in 13 or 16, the information should be disclosed;

ii. exclude or redact any information that is not relevant from the response;
iii. identify information for which any of the criteria listed in paragraph 13. apply, and exclude or redact the information from the response;
iv. identify information that relates to any of the conditions set out in paragraph 16 and, if present, assess whether the Applicant's outline of the claim includes a clear demonstration that this information is relevant to the claim. If there is no clear demonstration of relevance in the claim outline, exclude or redact the information from the response;
v. Include the remaining parts of the record in the response.

13 Information that meets any of the following criteria should be withheld or redacted:

i. where the note contains information likely to cause serious harm to the physical or mental health of any individual;
ii. information related to or provided by an individual other than the patient or a healthcare professional, who could be identified from that information e.g. children, family members, social workers;
iii. where a note specifically states that the record or a part of them should not be provided to the applicant (S4(3) of the FAA 1976);
iv. where information in the note was provided by the patient in the expectation that it would not be disclosed to the applicant or class of individuals including the applicant;
v. where information in the note was obtained as a result of any examination or investigation to which the patient consented in the expectation that the information would not be so disclosed.

14 Where there is any question as to whether the exceptions in paragraph 13 or 16 apply, advice must be taken from a qualified healthcare professional in accordance with section 7(2)(c) of the AHRA.

15 Where it is proposed some or all of the records requested should not be provided in accordance with the exceptions above, a broad outline of the time period covered by the records, and the reasons why the records are not being provided at this stage should be given to the requesting solicitor, so that further discussions can take place, if appropriate.

<u>Conditions requiring a clear demonstration of relevance by the applicant before disclosure is considered</u>

16 Conditions where the starting presumption is that, without clear demonstration of relevance, these will be redacted from records for deceased individuals requested in relation to a claim arising from the death.

i. Any form of sexually transmitted disease (STD), (unless the liability element of the claim relates to such a condition);
ii. Any termination of pregnancy (unless the liability element of the claim relates to such a condition);
iii. Any stillbirth (unless the liability element of the claim relates to such a condition);

iv. Any record relating to “protected information” under the terms of the Gender Recognition Act 2004 (unless the claim relates to this information and explicit consent has been given for the disclosure of the information);
v. Any record made before the Access to Health Records Act came into force (that is, any record made before 1 November 1991).

17 The Access to Health Records Act (AHRA) 1990 does not apply to record entries made before the 1st November 1991 when the Act came into force. This means that if access was granted to the record of a person whose date of birth was before the 1st November 1991, only the entries which were made after the 1st November 1991 are legally required to be shared. However, the record holder may decide to share records from before 1st November 1991 in line with the guidance set out above.

18 Due to the nature of the claims being considered, these should not be considered as inflexible categories – they are a starting point. If it is clear that the claim relates to, for example, the diagnosis and treatment of an STD, then that information should not be redacted from the notes provided – it is obviously relevant. However, if the claim relates to a failure to diagnose fractured neck of femur, for example, a diagnosis of an STD some years previously is unlikely to be relevant in the majority of cases.

19 It is important that sufficient information is provided at the time of the request to allow an assessment to be carried out. It is equally important that any concerns about inappropriate redactions are considered and the disclosure provided reviewed as soon as possible so as not to cause any undue delay in the management of the claim.

20 It is also important that if, on review, something is identified which is thought clearly not to be relevant, advice is sought from a Caldicott Guardian on the appropriateness of redaction before the records are provided.

21 If it appears that entries may be relevant to the claim, they should be provided.

22 The time the record holder has to respond is dependent on when the record was last amended:

- 21 calendar days, from the date of receiving the request, to either grant or refuse the request to the deceased person’s record. This is if there have been no entries, additions or amendments to the record in the 40 calendar days prior to the date of application.

- 40 calendar days, from the date of receiving the request, to either grant or refuse the request to the deceased person’s record, if there have been entries, additions or amendments to the record in the 40 calendar days prior to the date of application.

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