

# The retention of genetic family records

Guidance for clinical practice

July 2023

Produced by a working group of the British Society for Genetic Medicine

## About this report

*The retention of genetic family records* is the first report on this subject by the British Society for Genetic Medicine in liaison with the Joint Committee on Genomics in Medicine (comprising the Royal College of Physicians, Royal College of Pathologists and British Society for Genetic Medicine).

## Acknowledgements

This report was written by a working group of the British Society for Genetic Medicine in liaison with the Joint Committee on Genomics in Medicine. The members of the group were: John Dean, consultant in clinical genetics in NHS Grampian and honorary secretary of the British Society for Genetic Medicine; Alison Hall, senior humanities advisor, PHG Foundation, Cambridge, and former chair of the Ethics and Policy Committee of the British Society for Genetic Medicine; Joo Wook Ahn, lead bioinformatician for East Genomic Laboratory Hub, Cambridge University Hospitals NHS Foundation Trust, and former chair of the Science and Technology Committee of the Association for Clinical Genomic Science; and Anneke Lucassen, professor of genomic medicine and director of the Centre for Personalised Medicine, University of Oxford, chair of the Joint Committee on Genomics in Medicine and honorary consultant in clinical genetics.

We are grateful for comments from Gemma Chandratillake, William Newman, Tara Clancy, and the executive committees of the BSGM and JCGM, and the NHS England Clinical Reference Group in Clinical Genomics.

## Citation for this document

British Society for Genetic Medicine. *The retention of genetic family records*. London: BSGM, 2023.

Review date: 2028

## Copyright

All rights reserved. No part of this publication may be reproduced, distributed or transmitted in any form or by any means, including photocopying, recording, or other electronic or mechanical methods, without the written permission of the copyright owner.

Copyright © British Society for Genetic Medicine 2023

British Society for Genetic Medicine  
Royal Society of Biology  
1 Naoroji Street  
London WC1X 0GB  
[www.bsgm.org.uk](http://www.bsgm.org.uk)

Registered Charity No 1058821

# Contents

Purpose.....	4
Executive summary.....	5
Introduction .....	6
Existing recommendations.....	6
Current codes of practice for records management in the UK and their application to electronic records .....	7
Data protection legislation .....	7
The regulation of medical devices and medical software.....	9
Practical aspects of genetic family records and mainstream records of genetic information.....	9
The importance of family health and genetic information .....	10
Practical aspects of longer-term retention of electronic genetic family records .....	11
Recommendations for laboratory records and specimens.....	12
Conclusions .....	13
Recommendations .....	14
Glossary.....	16
References.....	17
Appendix:Table 1 – Examples of current record retention periods according to the different codes of practice.....	19

# Purpose

This report addresses the retention of genetic family information and genomic test data in health records. It is intended for health professionals, policy makers and those working in health systems. It describes recommendations for practice relating to the retention of genetic family records and medical records incorporating genetic or genomic information and makes some recommendations regarding future policy development. The content applies equally to paper and electronic records. This document is intended as a code of practice and implementation should comply with GDPR requirements.

# Executive summary

- A** Genetic family records are health records that document and describe the inherited disease history within a family. They capture genetic and health information about the family members and include medical histories, relevant clinical findings, clinical decisions and actions, investigation results, treatments, and information provided to individual family members.
- B** Genetic healthcare information which is relevant to an individual's healthcare should usually be part of the general health record accessible to all clinicians involved in caring for that individual.
- C** Genetic family records may contain sensitive information about relationships or future risks of disease, access to which should be restricted to genetic healthcare professionals or other healthcare professionals with genetics expertise.
- D** Genetic family records may contain important transgenerational information about health risks and should therefore be retained for a minimum of 30 years.
- E** Where the whole, or part, of the genetic family record is contained within the general health record, processes must be established to identify these sections of the record for longer (at least 30 years) retention. This is vital to ensure that they are not destroyed with the general health record 3–8 years after the death of, or last contact with the patient, or cessation of treatment of the patient, in accordance with current guidance for general health records.
- F** Clinical genomic laboratories should retain a copy of the final clinical laboratory report for at least 30 years, as this is considered part of the genetic family record.
- G** Other laboratory records of the genomic variants detected in a patient's sample and the supporting evidence for their detection and classification are 'working documents', which should be retained for at least 5 years.
- H** Healthcare providers hosting genomics laboratories must provide for the retention of final clinical laboratory reports for at least 30 years, and laboratory working documents for at least 5 years.
- I** Storage and interpretation of genomic variant information is a developing field and the data and other requirements for provision of a high-quality service in this area should be kept under regular review.

# Introduction

The creation of clear, accurate and secure clinical records is a key aspect of good medical practice, which was endorsed by the General Medical Council in 2011.<sup>1</sup> Clinical records include information about relevant clinical findings, decisions made, actions taken, information given to patients, investigations and treatments, and usually contain details of who is making the record and when. Clinical records pertain to an individual, but may be linked to other family members in a clinical genetic family record. A family tree or pedigree may link different individuals together. Such genetic family records are often vital to the correct interpretation of genomic variants, whose clinical significance may only become clear with knowledge of how the variant segregates with disease in the family, and the nature of and variability of associated disease.

The creation, maintenance, and destruction or archiving of general health records (the records life cycle) are the subject of different codes of practice in the four nations of the United Kingdom.<sup>2–4</sup> Family or genetic records are not covered in all of these.<sup>2</sup> With the advent of electronic health records creating different opportunities for storing and retaining genetic health records, the increasing importance of maintaining family genetic and health information, and regulatory changes (the Data Protection Act 2018,<sup>5</sup> the UK General Data Protection Regulation<sup>6</sup> and the EU General Data Protection Regulation<sup>7</sup>), it seems timely to revisit this area of clinical genetic practice.

## Existing recommendations

In 1998, the Clinical Genetics Committee of the Royal College of Physicians produced a report on retention of medical records, including clinical genetics records.<sup>8</sup> This report identified three categories of medical record relevant to clinical genetics practice:

- > individual primary or secondary care patient records where the patient has a diagnosed or suspected genetic disorder,
- > clinical genetics family records, and
- > laboratory records.

The report recommended that clinical genetic family records should be kept indefinitely because they contain information relevant to multiple generations of a family, including potential future generations. This includes diagnostic information about relatives (often confirmed from their individual records) to support management decisions in particular individuals who may have sketchy or incorrect information about the wider family history of a condition.

The report also recommended that the genetic family record should be kept separately from hospital notes, whether paper or electronic, while noting that other medical practitioners should be kept fully informed of their individual patient's risk/diagnosis. These medical practitioners would not usually have access to medical information about other members of the family, although a distillation of the evidence from these records might be contained within

an individual patient's assessment. This separation of the genetic family record was to protect the confidentiality of family members who might be under the care of a different clinician. The report noted that the drive towards electronic records may create difficulties for maintaining this separation.

The report did not make recommendations about retention periods for healthcare records from other specialties, apart from those of children who die, for which indefinite retention was also recommended.

## Current codes of practice for records management in the UK and their application to electronic records

There are three current codes of practice for records management in the UK. One applies to England and Wales,<sup>2</sup> the second to Northern Ireland,<sup>3</sup> and the third to Scotland.<sup>4</sup> The three codes have similarities and differences. For health records in general, the codes of practice state that minimum retention periods for various types of health record apply equally whether the record is paper-based or electronic and includes scanned paper records within the meaning of electronic health record. An exception is general practice (primary care) records which should be retained 'for the foreseeable future' if electronic, but only for 10 years after the patient's death if paper-based. In all three codes of practice, minimum retention periods are stipulated according to the category of record (adult, paediatric, obstetric etc). These periods begin when the record ceases to be operational. This is defined as the point of discharge from care (often taken as the last attendance of the patient at the healthcare provider), the time when the record is no longer required for current ongoing 'business', or the date of death of the patient. Table 1 (see Appendix) shows some of the minimum retention periods from the three codes of practice. At the ends of the retention periods, paper records may be destroyed, or reviewed for consideration of archiving. Some of the codes of practice suggest circumstances where archiving or continued retention might be appropriate, such as research participation, historical significance or possible genetic implications.<sup>3</sup>

For electronic records, the record may be retained, archived, deleted or put beyond use. If the record is deleted or put beyond use, a metadata stub must be retained which shows that the record existed and has been deleted or put beyond use.<sup>2</sup> Although general adult health records have relatively short retention periods (6–8 years after last contact, or 3 years after death), certain categories of record have much longer retention periods in all three codes of practice, such as mental health records (20 years), obstetric records (25 years) and children's records (up to age 25, or to age 26 if treatment ceased at age 17). The Northern Ireland code notes that if a child's illness or death is possibly caused by an illness with genetic implications, then consideration should be given to longer retention. Both the Northern Ireland and Scottish codes of practice recommend 30 years retention for genetic records.

## Data protection legislation

All health records contain both personal data (identifiers, contact information) and health data (medical information about the patient's health, including medical history, treatments and investigations). Analysis of aggregated health data is necessary for a learning healthcare



environment and provides an evidence base for understanding disease causation and management. Appropriate management of digital records within healthcare promises more effective use of those data for public good. However, this increase in utility and accessibility needs to be balanced with concerns about data security, data breaches and exploitation. The revision of laws on data protection has implications for professional guidance in this area.

Current laws and best practice require those controlling and processing health data to perform a balancing exercise to weigh up the benefits of retaining data against the risks associated with continued retention. Key obligations are set out in the UK version<sup>6</sup> of the EU General Data Protection Regulation 2018 (GDPR)<sup>7</sup> and the Data Protection Act 2018 (DPA).<sup>5</sup>

These laws apply to personal data, namely data about an identifiable individual (UK GDPR Art. 4(1)). Much data that is used to support health and social care is personal data. These laws provide that data must be processed in ways that satisfy data protection principles (UK GDPR Art 5). These include that personal data shall be processed lawfully, fairly and transparently, and that they are 'adequate, relevant and limited to what is necessary in relation to the purposes for which they are processed' (Article 5(1)(c)). A further principle stipulates that data should be 'accurate, and where necessary, kept up to date' (Article 5(1)(d)). Data processing includes the generation, storage, use and retention of data.

Although these principles mirror obligations found in previous legislation (the Data Protection Directive and Data Protection Act 1998), the sanctions for breaching the new provisions are much more substantial than in the previous legislation. The GDPR (and UK GDPR) also goes further than previous legislation in that it introduces a new category of personal data – 'genetic data' (Article 4(13)). This refers to genetic data that can be linked to an individual.<sup>9</sup> Special rules and data processing safeguards attach to these 'genetic data'. However, it is also important to realise that not all genetic data derived from a person will be personal data. Given that most of our genome sequence is the same as that in any other human (some 99.9% of our genomes are identical) these special rules only apply to variations in our genetic code which can be related to an identified or identifiable person. Family members share a proportion of the variations in the genetic code – this is the principle behind commercial 'ancestry' genetic testing. This may affect the interpretation of the special rules. In addition, genetic data which is anonymised or aggregated for statistical or research purposes is excluded as it is no longer identifiable personal data.<sup>9</sup>

Therefore, there is a requirement for all those processing personal data including genetic data to consider when it is no longer 'necessary' for data to be retained. In the context of healthcare, where family health data and genetic or genomic data are used to guide patient management and treatment, our starting point is that the 'necessary' period of retention of data should be at least 30 years, to take account of the intergenerational impact of genetic inheritance.



## The regulation of medical devices and medical software

A further area of legislation that may be engaged by genomic sequencing technologies is the regulation of hardware and software as medical devices. Ensuring that sequencing machines work as they should, that they generate robust and replicable results which, if necessary, can be used for post-marketing surveillance purposes by manufacturers and users, may impact the form, nature, and duration of data retention. This is particularly relevant when thinking about the intermediate outputs generated by clinical laboratories as part of the diagnostic process.

## Practical aspects of genetic family records and mainstream records of genetic information

In a paper-based genetic family record, documents relating to different members of a family may be stored together to facilitate treatment and management. Copies of key documents from the individual health records of family members are often kept (such as clinical letters or diagnostic information) to provide rapid access to information about the diagnosis in relatives, and about how the disease affects the family. The paper genetic family record can be stored separately from the general health record, with access restrictions to protect confidentiality.

Exactly the same genetic family record can be created as a standalone electronic genetic family record, separate from the individual patient electronic record, accessible only to genetic healthcare professionals. Identifying such a record for longer retention than the individual patient record is then straightforward.

When clinical records are electronic, it is also possible simply to link the individual patient records of family members and consider this to be the genetic family record. Each family member's individual record would also need to be linked to an additional electronic space to record information relevant for all family members, including sensitive information about family structure or individual relationships. This is often summarised as a family tree drawing. Relationship information is important for identification of others at risk, but may require similar access restrictions to those discussed earlier for the paper and standalone electronic genetic family record, to protect the confidentiality of other family members – some family members may not be aware of all aspects of the family history and relationships, including paternity or adoption.<sup>10</sup>

This creates a problem for retention of records policies. If, as recommended in this document, and as is covered by the codes of practice for Northern Ireland and Scotland, the retention period is longer for genetic family records than individual health records, then each family member's individual health record will need to be identified as being part of a genetic family record. Without being earmarked for longer retention, part of the genetic family record will be

lost when the family member's individual record is destroyed. Conversely, retaining the whole individual record could result in retention of medical information about the individual that is not relevant to the family genetic history, and this may contravene requirements in the Data Protection Act 2018 and the UK General Data Protection Regulation that processed personal data should be 'limited to what is necessary in relation to the purposes for which they are processed'. Smart electronic systems will be needed so that only relevant information is retained.

This problem also arises where genetic investigation and diagnosis has been undertaken by another specialty as part of the mainstreaming of genomic medicine, without input from genetic healthcare professionals. Letters or reports relevant to a genetic diagnosis will be created in an individual's electronic health record, which is not part of a genetic family record. These documents should be covered by the same retention period as genetic family records, so that the information is retained for relatives, should they seek health advice about their family history at a future date. Identifying and marking these documents for retention will require another process, such as text recognition software, or in the case of laboratory reports, the issuing laboratory could tag the document as 'genetic'.

## The importance of family health and genetic information

The need for retention of family medical information is becoming more important as genomic sequencing becomes more widespread. Knowledge of family medical information can be crucial to the interpretation of the pathogenicity of genomic variants. For example, in the current guidelines on variant interpretation<sup>11</sup> the use of the PS1 'de novo' criterion where one patient has the disease and there is no family history, or the PP1 co-segregation criterion requires knowledge of the medical health of relatives, and their genetic status with regard to the variant in question.

Assessment of clinical risk in an individual patient also sometimes depends on reported family history. Accuracy of individual patient reported family history during a particular episode of care may vary depending on the type of disease and the closeness of the relationship.<sup>12–15</sup> Patients may be less aware of the medical diagnosis of second degree or more distant relatives, than of first-degree relatives. This underpins the need for accurate clinical genetic records, particularly in relation to older family members (the younger family members seeking advice may be reluctant to trouble their older relative to obtain an accurate diagnosis, or that person's relevant individual health record may have been destroyed). This enables confirmation of the correct diagnosis, and this in turn requires long-term retention of the transgenerational genetic family records to facilitate accurate diagnosis, management and counselling for the younger generation.

These factors require that genetic family records should be created which are accurate (through linkage to individual health records), and yet also preserve some confidentiality for relatives when an individual family member seeks medical advice about problems unrelated to the genetic family history. They require the genetic family record to be conserved across

generations. The creation of a genetic family record which is separate from the individual record allows a simple criterion like the last contact with a family member to determine the start of the retention period for the genetic record. It also collates all the relevant family information in one place, which should make risk assessment faster and more reliable for genetic health professionals, and improve the quality of care for the patient.

Two of the UK codes of practice already recommend retention of genetic records for 30 years, and this retention period is supported by recent research suggesting that the average human generation time is 26.9 years (23.2 for mothers and 30.7 for fathers).<sup>16</sup> We recommend that genetic family records as defined here should therefore be retained for at least 30 years to support transmission of genetic health information across the generations.

## Practical aspects of longer-term retention of electronic genetic family records

The advantages of well-designed electronic health records over paper records are well-recognised, and include aspects such as low storage space requirements, records which are always accessible and never lost, accessible at outreach clinics with appropriate data infrastructure without the need for transport of heavy paper, security, auditability, and their utility for health statistics, quality improvement and research. While paper records may be susceptible to fire, flood and other catastrophes, electronic records can and should be backed up elsewhere to mitigate against physical damage to one storage facility.

There are two main issues complicating the longer-term retention of electronic records. The first is the risk of 'bit rot' due to deterioration in storage media over time. This can be mitigated by keeping multiple copies of data in different locations. The second is software or operating system upgrades rendering existing digital information inaccessible. Emulation of the original software, preservation of an original host system, conversion of data to modern standard file formats, or routine migration of the data to the new system can all mitigate against this risk. Electronic records should therefore adhere to established data standards to facilitate interoperability between systems. As data standards may be updated over time, maintenance of records includes regular accessibility testing. For records where standards have yet to be established, a format that allows conversion to future standards should be adopted. These opportunities for robust longer-term storage of electronic genetic family records require planning and investment by the healthcare provider to protect against data loss and corruption. In designing such storage, consideration should also be given to reducing the carbon footprint of storing large volumes of data for prolonged periods.

# Recommendations for laboratory records and specimens

The Royal College of Pathologists published recommendations on the retention and storage of pathological records and specimens in 2015.<sup>17</sup> These recommended that DNA and RNA samples taken from patients in the investigation of a genetic disorder should be retained for a minimum of 30 years, that the final outputs of analysis and interpretation should be recorded in authorised reports also held for 30 years, and that machine outputs should be held for 5 years (one accreditation cycle plus a safety margin). For clarity, it should be noted that their remit was to ‘... make recommendations on minimum retention times for pathology records ... including those required for operational use, for education, teaching, training ... and against the possibility of future litigation, audit or allegations of scientific fraud ...’. They do not therefore consider data retention for future clinical utility such as reclassification of genomic variants. Laboratories should be aware of the increasing potential for reuse of genomic data. Such purposes and the retention period for data generated by research are out of scope for this document, pending outcomes of wider stakeholder debate with healthcare providers, patients, researchers and the public. For some undiagnosed patients, the rapid advances in technology may make it better to re-test a stored sample than to re-analyse data generated by older techniques.

Increasingly, clinical laboratories generate large volumes of data as part of diagnostic testing, exemplified by outputs of bioinformatics workflows (pipelines) required to process ‘primary data’ (basecalls) from next generation sequencing instruments into ‘secondary data’ (variants). Some of these outputs are considered working documents for the purposes of data retention: specifically, alignment and variant information in a standard data format (usually BAM/CRAM and VCF/gVCF).<sup>18</sup> These working documents should be retained for at least 5 years in accordance with Royal College of Pathologists guidance. Other intermediate outputs from bioinformatics workflows do not require long-term retention.

It is worth noting that retention of these working documents will require significant data storage infrastructure and that cloud-based solutions are likely to be optimal as per government public sector cloud first policy.<sup>19</sup>

As indicated above, the scope of this document does not include data retention for the purpose of future clinical utility; however, recent European Society of Human Genetics (ESHG) guidance is referenced here to initiate community discussion.<sup>20</sup> These guidelines state that local/population-based frequencies are a useful resource for variant prioritisation and should therefore be recomputed regularly; this is likely to require retention of VCF/gVCF files. They also recommend recording all classified variants in a database to provide a knowledge base (e.g. to aid classification of recurrent variants) and to enable variant reclassification on the basis of novel knowledge, both external (e.g. publications) and internal (e.g. recurrence within the database); variants should additionally be shared by submission to databases accessible by other laboratories and researchers.

# Conclusions

The retention and storage of genetic family records requires careful consideration. These records include genetic and health data about many members of a family, and are therefore multigenerational, storing family information across time. They include details about family relationships which will on occasion require additional safeguards for confidentiality to be protected. They are an irreplaceable resource for estimating genetic and clinical risk for younger family members, and, with suitable safeguards, offer a wealth of information for medical and genetic research.

A genetic family record should therefore have an independent existence from the health records of individual family members, although they may be linked. The retention period from the last contact with a family member should be long. Two of the codes of practice recommend 30 years, and although indefinite retention might be ideal, if there has been no patient contact for 30 years, it may be reasonable to review the record and consider whether archiving or destruction would be appropriate. In the context of healthcare, where genetic or genomic data are used to guide patient management and treatment, we recommend that genetic family records should be retained for at least 30 years, to take account of the intergenerational impact of genetic inheritance.

# Recommendations

- 1** Genetic family records in both paper and electronic form require additional protection and security compared with individual health records, to protect individual family members' confidentiality.
- 2** Where an electronic genetic family record is maintained separately from individual health records:
  - a) Access should be limited to genetic healthcare professionals or other clinicians with genetics expertise to protect sensitive relationship and risk information
  - b) Information relevant to the healthcare of an individual family member must be accessible to other clinicians through the individual health record, even if primarily stored in the genetic family record.
- 3** Where an electronic genetic family record is integrated into the hospital electronic records system, additional measures are recommended:
  - a) The genetic family record, which contains relationship and genetic risk information, should be protected by additional security
  - b) Access should be limited to genetic healthcare professionals or other clinicians with genetics expertise to protect sensitive relationship and risk information
  - c) The relevant parts of individual health records of family members (relevant clinical letters and investigation results) should be marked for longer retention as part of a genetic family record
  - d) Information relevant to the healthcare of an individual family member must be accessible to other clinicians through the individual health record, even if primarily stored in the genetic family record.
- 4** Genetic family records should be retained for a minimum of 30 years. The period of retention begins at the last date on which a family member made contact with the clinical genetics service, or the date of the last entry in the genetic family record, whichever is later. Consideration should be given to archiving at the end of the retention period.
- 5** Genetic information created as part of mainstreaming of genomic medicine should also be retained for a minimum of 30 years. Electronic records systems must be capable of marking the relevant parts of an individual health record for longer-term storage even when other parts of the record reach the end of their retention period and are scheduled for destruction or deletion.
- 6** Healthcare providers should develop a plan for digital preservation of electronic clinical genetic family records, and mainstream genetic information. This may

involve multiple storage locations, and operating processes to manage the effects of software and operating system upgrades. These might include emulation of previous software, regular updating of data files, or planned transfer to the newer system.

- 7** Clinical genomics laboratories generate large volumes of data as part of diagnostic testing. Outputs from next generation technologies and bioinformatics workflows are considered to be machine outputs and do not require long-term retention. However, records of the genetic variants detected and their supporting evidence should be retained in a standard data format (such as VCF and CRAM) by the laboratories for at least 5 years. The final clinical laboratory report for the patient forms part of their genetic record and should be retained for 30 years.
- 8** Consideration should be given to maintaining local variant databases and contributing to international variant databases to provide a knowledge base to improve interpretation of genomic variants in keeping with European guidance. Since this is a highly dynamic area, procedures and processes should be kept under regular review.



# Glossary

**Genetic healthcare professionals** – healthcare professionals whose role is the care of families considered to be at risk of an inherited condition, and may include doctors, genetic counsellors, genetic nurses, clinical scientists and their administrative support staff.

**Genetic family record** – a health record which concerns a family, including the health of individual members and the results of investigations including genetic investigations.

**Individual health record** – a health record pertaining to a single individual, such as a hospital medical record.

**Genetic** and **genomic** are considered to have the same meaning in relation to records.

**Metadata** – data that provides information about other data, such as a record of where another file is stored, and what or whom it concerns.

**Primary analysis** – conversion of raw instrument signal data into sequence data consisting of nucleotide base calls, e.g. FASTQ files. Generally, the primary analysis takes place onboard the genomic sequencing instrument, for example the conversion of raw Binary Base Call (BCL) files on an Illumina sequencer to biological sequence data in the form of millions of short reads.<sup>21</sup>

**Secondary analysis** – alignment of the high-quality sequence reads against a reference genome (usually resulting in BAM files – see below) followed by detection of variants (usually resulting in VCF files).<sup>21</sup>

**FASTQ file** – a type of electronic file containing short segments of DNA base sequence and information about the quality of the sequence produced by a genomic sequencing instrument.

**BAM file** – binary alignment map file – a type of electronic file containing longer DNA sequence information generated by aligning the shorter sequence segments generated by the genomic sequencing instrument, and stored, for example, in a FASTQ file.

**CRAM file** – compressed reference-orientated alignment map – a type of electronic file containing longer DNA sequence information aligned to a reference sequence. It has similar uses to the BAM file.

**VCF file** – variant call format file – a type of electronic file containing information about all the DNA bases in an analysed sample which are different from the ‘normal’ reference sequence. Some these variants will have no effect on the function of genes, others may be pathological. A VCF file will also contain information about the quality of the sequencing data used to create the file and the sources of the reference sequence.

# References

- 1 General Medical Council. *Good Medical Practice*. GMC, 22 April 2013. <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/good-medical-practice>
- 2 NHSx. *Records Management Code of Practice 2021: A guide to the management of health and care records*. NHSx, 2021. <https://transform.england.nhs.uk/information-governance/guidance/records-management-code>
- 3 NI Department of Health. Good management, good records. <https://www.health-ni.gov.uk/topics/good-management-good-records>
- 4 Scottish Government Records Management. Health and Social Care Code of Practice (Scotland) 2020. <https://www.informationgovernance.scot.nhs.uk/rmcop2020/>
- 5 UK Data Protection Act 2018. <https://www.legislation.gov.uk/ukpga/2018/12/contents/enacted>
- 6 <https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/>
- 7 GDPR.EU. General Data Protection Regulation. <https://gdpr.eu/tag/gdpr/>
- 8 Royal College of Physicians. *Retention of medical records with particular reference to medical genetics*. London: RCP, 1998.
- 9 <https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/special-category-data/what-is-special-category-data/>
- 10 Royal College of Physicians, Royal College of Pathologists and British Society for Genetic Medicine. *Genetic testing in childhood. Guidance for clinical practice*. Report of the Joint Committee on Genomics in Medicine. London: RCP, RCPPath and BSGM, 2022. <https://www.rcp.ac.uk/projects/outputs/genetic-testing-childhood>
- 11 Richards S, Aziz N, Bale S *et al*. ACMG Laboratory Quality Assurance Committee. Standards and guidelines for the interpretation of sequence variants: a joint consensus recommendation of the American College of Medical Genetics and Genomics and the Association for Molecular Pathology. *Genet Med* 2015;17:405–24. doi: 10.1038/gim.2015.30. Epub 2015 Mar 5.
- 12 Professor Anneke Lucassen. ABC v St Georges: exercising judgment without fear. BioNews 1037, 2020. [https://www.bionews.org.uk/page\\_148351](https://www.bionews.org.uk/page_148351)
- 13 Ottman R, Barker-Cummings C, Leibson CL *et al*. Accuracy of family history information on epilepsy and other seizure disorders *Neurology* 2011;76:390-6. doi: 10.1212/WNL.0b013e3182088286.
- 14 Mai PL, Garceau AO, Graubard BI *et al*. Confirmation of family cancer history reported in a population-based survey. *J Natl Cancer Inst* 2011;103:788-97.
- 15 Augustinsson A, Ellberg C, Kristoffersson U, Borg A and Olsson H. Accuracy of self-reported family history of cancer, mutation status and tumor characteristics in patients with early onset breast cancer. *Acta Oncologica* 2018;57:595–603. doi:10.1080/0284186X.2017.1404635

- 16 Wang RJ, Al-Saffar SI, Rogers J, Hahn MW. Human generation times across the past 250000 years. *Sci Adv* 2023;9:eabm7047. doi: 10.1126/sciadv.abm7047.
- 17 Royal College of Pathologists. *The retention and storage of pathological records and specimens (5th edition)*. London: RCPATH, 2015.
- 18 BAM: <https://samtools.github.io/hts-specs/SAMv1.pdf>;  
CRAM: <https://samtools.github.io/hts-specs/CRAMv3.pdf>;  
VCF: <https://samtools.github.io/hts-specs/VCFv4.3.pdf>
- 19 <https://www.gov.uk/guidance/government-cloud-first-policy>;  
<https://www.gov.uk/government/publications/cloud-guide-for-the-public-sector/cloud-guide-for-the-public-sector>
- 20 Souche E, Beltran S, Brosens E *et al*. Recommendations for whole genome sequencing in diagnostics for rare diseases. *Eur J Hum Genet* 2022;30:1017–1021.
- 21 Pereira R, Oliveira J, and Sousa M. Bioinformatics and computational tools for next-generation sequencing analysis in clinical genetics. *J Clin Med* 2020;9:132.

# Appendix

**Table 1 – Examples of current record retention periods according to the different codes of practice**

Category of record	England and Wales	Northern Ireland	Scotland
<b>Adult health record, not otherwise defined</b>	8 years after last contact or death	8 years after conclusion of treatment or death	6 years after last entry or 3 years after death
<b>Child</b>	Up to 25 <sup>th</sup> birthday or 26 <sup>th</sup> if age 17 when treatment ended	Up to 25 <sup>th</sup> birthday or 26 <sup>th</sup> if age 17 when treatment ended, or 8 years after last entry, or 8 years after death if death occurred before age 18. If the illness or death could have relevance to adult conditions or have genetic implications, seek clinical advice about longer retention.	Up to 25 <sup>th</sup> birthday or 26 <sup>th</sup> if age 17 when treatment ended, or 3 years after death*
<b>Genetic</b>	No guidance	30 years from date of last attendance	30 years from date of last attendance
<b>Mental health</b>	20 years (10 years after death)	20 years after no further treatment considered necessary or 8 years after death*	20 years after last contact or 3 years after death*
<b>Obstetric</b>	25 years*	25 years after last entry or update or in the case of death, where the patient has been pregnant or given birth in the 12 months preceding their death the record should be kept for 25 years	25 years after birth of last child of until age 50, whichever is longer
<b>Pathology</b>	See HTA/RCPATH guidance	30 years, except coroner's post-mortem reports which, if added to the medical record, should be retained in line with the specialty	Subcategories apply – e.g. post-mortem records should be kept for 30 years
<b>Primary care</b>	10 years after death*, or 100 years if patient does not return to practice	10 years after death or after patient leaves the UK and EU, or indefinitely if electronic*	3 years after death, or 100 years if patient does not return to practice, or indefinitely if electronic*

\* additional subcategories apply



**British Society for Genetic Medicine**  
Royal Society of Biology  
1 Naoroji Street  
London WC1X 0GB  
[www.bsgm.org.uk](http://www.bsgm.org.uk)