



Research Briefing  
**Access to Health Records in  
Wales - a guide for constituents**

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Author: **Joseph Champion**  
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**National Assembly for Wales**  
Research Service

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Author: **Joseph Champion**

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## Contact Us

**Research Service**  
**National Assembly for Wales**  
**Tŷ Hywel**  
**Cardiff Bay**  
**Cardiff**  
**CF99 1NA**

 : 0300 200 7390

 : [Joseph.Champion@Assembly.Wales](mailto:Joseph.Champion@Assembly.Wales)

 : [Assembly.Wales/InBrief](http://Assembly.Wales/InBrief)

 : [@SeneddResearch](https://twitter.com/SeneddResearch)

 : [Assembly.Wales/Research](http://Assembly.Wales/Research)

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## Research Briefing

# **Access to Health Records in Wales - a guide for constituents**

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The following guide highlights who is entitled to claim access to health records, how applications are made, what records are potentially exempt and how any decisions can be challenged.

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# 01. Background

## The Data Protection Act 1998

The right to access personal health records derives from the **Data Protection Act 1998** (DPA). The DPA was passed in response to growing concerns around privacy of personal data and how that data is used and shared in the age of advanced telecommunications.

The DPA gives individuals (known as data subjects), or their authorised representative, the right to apply to see certain personal data held about them, including health records. These rights are known as “subject access rights”, and are contained in sections **7, 8** and **9** of the DPA.

The DPA also grants other rights, including the right to have information changed or challenged if an individual feels it is incorrect or if it is causing distress or damage to the data subject.

## What are health records?

The **Information Commissioner’s Office** (ICO) defines a ‘health record’ as a record which:

- consists of information relating to the physical or mental health or condition of an individual; and
- has been made by or on behalf of a health professional in connection with the care of that individual.

**Section 69 of the DPA** contains a full list of those that are considered ‘health professionals’; these include medical practitioners, dentists, nurses, clinical psychologists and a range of other clinicians and therapists.

There are different types of health records. The main ones are:

- General Practitioner (GP) records, these usually contain information about ongoing treatments, medications and conditions, allergies or reactions to medicines in the past, clinically relevant lifestyle information (like cigarette and alcohol consumption and weight etc) amongst other things.
- Hospital records, these contain information on; **hospital admissions and discharges**, scans or x-rays, test results, consultation notes and more; and

Opticians, dentists and other public and private healthcare providers will also keep records on the services and treatments they provide for individuals and are subject to the provisions of the DPA.

## Glossary of Terms

The following terms are used throughout this guide:

- data controller – a person who (either alone or jointly or in common with other persons) determines how any personal data are, or are to be, used. For the purposes of health records, data controllers are likely to be staff members of **Local Health Boards**, National Health Service (NHS) Trusts, GP practices or other primary care providers;
- data subject – an individual who has their personal data stored by a relevant organisation; and
- applicant – someone who has made a **subject access request** (SAR) to a relevant organisation. They may be applying for themselves or on someone else’s behalf.



## 02. Entitlement to access health records

### Individuals

Under the *DPA*, any **individual is entitled to be informed what personal data** of theirs a relevant organisation is holding. In this setting this applies to NHS bodies and affiliated organisations, as well as the private health sector and health professionals' private practice records. Individuals are also entitled to know who has received this data and what the data has been used for.

### Parents and guardians

Parents or guardians (parents) are not guaranteed the right to access their child's health records. Even if a child is too young to understand the implications of their rights to access personal data, data about them is still their property and does not belong to anyone else.

Parents can apply for their child's health records, but if the child is deemed mature enough to understand their rights, the child will need to provide permission for the data to be shared with their parents.

In general, children over the age of twelve are considered mature enough to understand their rights, and will need to give permission. However this age is not an established legal standard in England and Wales, as it is in Scotland, and each child's capacity will be assessed on an individual basis.

In most cases, the following will be considered before sharing a child's health records with their parents:

- the nature of the personal data requested;
- any relevant court orders relating to parental access or responsibility;
- any duty of confidence owed to the child;
- any consequences of allowing parents to access to the child's information, particularly if there have been allegations of abuse;
- any detriment to the child if the parents cannot access this information; and
- the views of the child on whether their parents should have access to the information.

### Relatives or advocates of a living person

The *DPA* does not prevent someone applying (the applicant) for access to the health records of another person (the data subject). However the applicant will have to prove that they have the permission of, or have **a level of Power of Attorney** over, the data subject in order to access the health records.

### Relatives of a deceased person

The ***Access to Health Records Act 1990*** (AHRA) provides certain individuals with an unqualified right of access to the health records of a deceased individual. These individuals are defined under **section 3(1)(f)** of AHRA 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. Personal representatives do not need to give a reason for applying for access to a record, but do have to provide proof of their identity.

Individuals other than the personal representative have a legal right of access under AHRA, but only where they can establish a claim relating to a patient's death. The data controller is responsible for deciding if a legitimate claim exists.

## Clinical staff

Health records are kept so that professionals in the health service (including doctors, nurses and therapists) can administer the best care to individuals, based on the individuals past and current needs. Efforts to increase the availability of this information to the clinical staff who need it, when they need it, are taking place in England and Wales. The NHS in England has **Summary Care Records**, which contains basic data (such as a data subject's allergies or current medication) to help clinical staff deliver emergency treatment faster.

The NHS in Wales has developed an **Individual Health Record (IHR)** system. The IHR is a collection of **some basic data** about an individual's medical history. The IHR is used by medical staff (GPs and nurses) in a local **Out of Hours Service**, when a patient is presented for treatment.

Eventually, the IHR will be available to medical staff in other emergency and urgent health care settings in Wales. Any individual has the right to see a copy of their IHR, as well as to **opt-out** of, and **opt back in** to, the IHR system by contacting their GP practice.

Clinical staff will also have access, when appropriate, to a patient's hospital, GP and private healthcare records. The next section highlights how these records can be accessed by the data subject.

## Exemptions

The disclosure of health records for a living, or deceased, data subject can be restricted regardless of the rights of the applicant. This happens when the data controller deems the information may be liable to cause serious harm to the physical or mental health of the applicant or any other person. Data controllers can also restrict the release of data which may identify a third person, who has not consented to the release of that data.

A further exemption applies if the deceased data subject indicated that they did not wish their data to be disclosed, or the record contains data that the deceased person expected to remain confidential. This data would be withheld unless there was an overriding public interest in disclosing it.

## 03. Applying for access to health records

In most cases, the request for health records will need to be in writing (including email). There is no specific format that an applicant should adopt for their SAR, but **templates are available online**. **NHS Wales recommends that, where possible**, applicants bear in mind the following advice when writing their SAR:

- be specific; identify the exact information required from the data controller. Applicants should identify whether they are looking for the applicants own health record or the health record of another person. If possible staff names, the patient number/s, and details of the specific periods of time or treatments concerned, should be included;
- proof of identity; copies of the applicant's passport, driver's licence, or birth certificate together with other evidence which can confirm a place of residence, e.g. a utility bill, will need to be presented during the application process; and

- include contact details; this may be the correspondence address, telephone number and/or email address of the applicant. These will be used should the data controller need to contact the applicant to discuss the request.

Once the SAR is submitted, the data controller will contact the applicant, to advise them regarding the availability of the requested information and the fee applicable. Once the fee has been paid, the data controller should provide the health records to the applicant within 40 calendar days. The data controller is obligated to provide data that is readily intelligible to the applicant, by providing explanations of, for example, any abbreviations or medical terminology.

Data subjects also have a right to view their records at the relevant healthcare setting, without receiving a copy of them. The process for viewing records this way is the same as requesting copies of the records, but may incur a lower fee.

## Who to apply to

Depending on the circumstances of the applicant and the data they are seeking, the body that they apply to get their records from will vary. In most cases when details on a particular treatment is sought, then the health records manager of the **hospital** or the practice manager of the organisation (dentist or optician etc) that delivered the service should be contacted. The process is slightly different for accessing GP records, depending on the data subject's circumstances.

## Living data subjects

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When applying for the GP records of a living data subject, the **GP practice** where the data subject is currently registered should be contacted.

## Data subjects not registered with a GP

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The GP records of those who are not currently registered with a GP in the UK, (if they are overseas, in the armed forces or currently imprisoned for example) are held by the **NHS Wales Shared Services Partnership (SSP)**. Therefore to gain access to those records, applicants need to **contact the relevant local SSP office**.

## Deceased data subjects

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To access the health records of a deceased data subject, an applicant will have to have proof of their relationship to the deceased. Applicants will also have to provide any necessary consent or justification for their accessing of the data. NHS Wales also requests that applicants state the reason why they require the information.

When a patient dies in Wales, their GP health record is stored by the SSP. Therefore the **relevant local office** of SSP will need to be contacted. If a deceased data subject's hospital, or other, records are sought then the organisation responsible for creating that record should be contacted.

## The cost of accessing health records

The cost of accessing health records can vary, depending on the type of health records requested, for example, electronic only records will be lower. However, at the time of publication, the maximum fee chargeable is £50.

## Minimum lengths of retention of hospital records

Different health records are kept for different lengths of time. The minimum retention periods are set out in Annex D of the Department for Health's **Records Management: NHS Code of Practice**. In general the guidance indicates that:

- GP records should be kept for ten years after the death, or the leaving of the European Union, of the data subject;
- hospital records are usually kept for eight years after the conclusion of treatment or the death of the data subject. Exceptions apply, for example maternity records are kept for twenty five years after the birth of the last child;
- the records of children and young people should be kept until their 25<sup>th</sup> birthday or 26<sup>th</sup> birthday if the young person was 17 at the conclusion of treatment. The records should be kept for 8 years in the event of the young person's death; and
- records relating to the treatment of data subjects considered **mentally disordered** should be kept for twenty years after the last entry on the record. The records must also be kept for eight years after the subject's death if they died while in the care of a medical organisation.

While these are recommended lengths of retention, there are exceptions and organisations have the flexibility to set their own retention periods. As a result some records may be held for longer, but not shorter, periods of time.

## 04. Changing health records

An applicant may consider the health records they see or receive as incorrect. If so they have a right, **under section 14 of the DPA**, to have that information rectified, blocked, erased or destroyed. In most cases, health records would be rectified, with a note clarifying what the applicant feels is and is not correct. The Department for Health's **Guidance for Access to Health Records Requests** (PDF 182KB), explains the process:

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*If a patient feels that information recorded on their health record is incorrect, they should first make an informal approach to the health professional [or body] concerned to discuss the situation in an attempt to have the records amended. Where both parties agree that information is factually inaccurate it should be amended to clearly display the correction whilst ensuring that the original information is still legible. An explanation for the correction should also be added.*

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The original information should be kept legible, as the information is considered essential to understand past clinical decisions and to enable any audit of the quality of care provided.

### Making a complaint in relation to health records

If a patient has met informally or discussed their concerns with the data controller and is not happy with the result, they can make a complaint through the **NHS Wales complaints procedure**, the **equivalent English system** or the **complaints procedure of the private healthcare provider** who delivered the service.

The complaint can be made under **Section 10 of the DPA**. Section 10 grants the right to data subjects to prevent processing (the use of information) likely to cause them damage or distress. NHS



Wales should respond to a complaint made under Section 10 within 21 days. Their response should either accept the need for them to change the record, or to justify their decision not to.

To make a complaint against health services provided by NHS Wales, the complainant should contact the relevant **Local Health Board (LHB) or NHS Trust**. If there is a concern about services that are delivered by a GP, dentist, pharmacist or optician the responsible practice should be contacted.

If the complainant does not want to go to the practice, then the LHB can be asked to investigate instead. The complainant can also go to their **local Community Health Council (CHC)**, who will provide free, confidential and impartial help through their **Complaints Advocacy Service**.

In cases where there is disagreement on the accuracy of a record, it is recommended that the data controller include a statement from the data subject in the record. This statement would set out the data subject's view on the content.

If the applicant feels they have been inappropriately or unlawfully denied access to their health records, they can go to the **Information Commissioner's Office (ICO)**, which can investigate the claim further. If an applicant is denied an independent review by the ICO, or is unhappy with the way a complaint has been handled by the LHB, NHS Trust or other healthcare provider, they can complain to the **Public Services Ombudsman**. The Ombudsman is independent of the Welsh Government and the NHS. There is no charge for the service. The Ombudsman will not normally become involved unless you have already complained officially and are still unhappy.

Alternatively an applicant may apply to the courts to have their requests under the DPA upheld, although qualified advice is recommended before pursuing this option.

## 05.Key Sources

- Citizens Advice, **NHS patients' rights in Wales**
- Department of Health, **Guidance for Access to Health Records Requests** (PDF 182KB)
- Information Commissioner's Office, **Find out how to request your personal information**
- Information Commissioner's Office, **Subject Access Code of Practice** (PDF 897KB)
- National Health Services Wales, **Your Information, Your Rights**